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Exploring parents' and teachers' experience of a novel programme: SAFE with Schools [SwiS] – a systemic attachment-based approach for caregivers of autistic children

by

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Author's Declaration

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Abstract

Tara Jane Vassallo

Exploring parents' and teachers' experience of a novel programme: SAFE with Schools [SwiS] – a systemic attachment-based approach for caregivers of autistic children

This research explored the experience of thirty-two parents and teachers of autistic children, from nine schools in the southwest of England participating in a novel systemic attachment-based programme SAFE with Schools (SwiS). Designed as a competency-based framework with a non-blaming approach using established techniques and activities drawn from systemic family therapy, the SwiS programme was employed to engage parents and teachers experiencing autism-related difficulties. The aim was to explore their experience of SwiS and in turn how these caregivers made meaning of autism through the systemic attachment-focus of SwiS, what it revealed about the nature of the parent-teacher-child system, and whether strengthening parent-teacher relationships and providing techniques to support problem-solving might create a more cohesive system around the child and be experienced as helpful for all concerned.

A blended interpretative methodological approach was employed to explore themes and meanings from data gathered from a variety of sources. These included interviews, reflective journals, focus groups and meetings, as well as observations during field work and researcher-participant interactions.

In the initial phase parents revealed that they were living with fear, isolation, blame and distress related to autism. They also felt the need to abandon traditional parenting to meet the needs of their child. Teachers reported the need to maintain a professional façade, wanting to make a difference for autistic children, but also experiencing fear of judgement. Subsequently, their experience of SwiS revealed as central that positive changes in their relationships were triggered by the impact of the systemic aspects of the SwiS programme. Themes emerged that captured this impact. Time spent together was found to be helpful and there was an improved shared understanding alongside recognition of barriers including bureaucracy, lack of time and professional and domestic pressures. The systemic activities initiated positive change in understanding and collaboration between teachers and parents, and also understanding of the child. Reflection and the ability to slow down and consider challenges collaboratively improved and this allowed for more effective problem solving. Teachers

varied in their engagement and meanings associated with autism and length of service was a factor suggesting that meanings and practices around autism were changing over time. In general, participants experienced systemic ideas and activities as a positive alternative approach to challenges, providing a framework to '*loosen*' established patterns of thinking and relational responses to autism and autism-related problems.

Key findings and recommendations suggest that considering autism systemically, using an attachment-based approach, may be supportive of parent-teacher relations and help improve problem-solving for caregivers of autistic children in mainstream education. This research highlights the need for new thinking in terms of responses to autism in the home/school context and offers a novel framework from which to move forward.

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Figures and illustrations

Glossary of Terms

ASC	Autistic spectrum condition (wider community adopted title - nonclinical)
ASD	Autistic Spectrum disorder (clinical title)
DSM-V	Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition
EAL	English as an Additional Language
EHCP	Education health and care plan
ICD-10	The International Classification of Diseases 10th Edition – Classification of Mental and Behavioural Disorders
PSHE	Personal Social Health and Economic (name of national curriculum lesson)
P-T	Parent-teacher
SAFE	Systemic Autism-related Family Enabling
SEN	Special educational needs
SENCO	Special educational needs co-ordinator
SEND	Special educational needs and/or disabilities
SFT	Systemic Family Therapy
SPD	SwiS Programme Day
SwiS	SAFE with Schools

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Introduction

An overview of the research as a guide to engaging with this thesis

Aims of this study in brief

The main aims of this research are to explore the relationships, communications, and experiences of *parents* and *teachers* as the core system of caregivers and educators to an autistic child in *mainstream* education, who took part in a systemic attachment-based programme *SAFE with Schools* [SwiS]. The key focus was to better understand how parents and teachers made meaning of autism and find out if creating a more cohesive system around these children would be helpful for these main caregivers and the children themselves. Formulated largely from established therapeutic tools and activities, drawn from systemic family therapy and attachment theory, the SwiS programme was employed as the principal structure to engage parents and teachers experiencing interactional and/or autism-related challenges as well as difficulties working together. The systemic attachment-based framework of SwiS sought to strengthen relationships between caregivers around the child, and support problem-solving, both with each other and with the child they shared care of.

Introducing the SwiS research in two-parts

It is important to note that this research is not an evaluation of the SwiS programme. Rather, it is an exploration and reflection of how parents and teachers experience systemic ideas as useful or helpful in the context of autism, particularly to learn more about caregiver constructions of autism, home-school/parent-teacher relations, and how these influence the system around the child.

To understand experience, one must also understand the initial positions of participants. From this, any change from further and ongoing experience can be

identified. Therefore, this research contained two distinct stages: an *exploration stage* and an *intervention stage*. Prior to the introduction of the core SwiS programme, an exploration stage was conducted with participants to understand their initial positions in terms of constructions of autism, the needs of children, the processes of home-school communication and where parents and teachers *were* in their relationships. Initial position key themes are discussed in the analysis of caregiver experience within the exploration stage analysis and findings in *Chapter 7* and further supported in the related peer-reviewed paper in *Appendix G* (Vassallo, Dallos & Mckenzie, 2020). The *exploration stage* was followed by the *intervention stage* where parents and teachers took part in the SwiS programme, the analysis and findings of which are explored in *Chapter* 8

Introducing SwiS and the need for a programme of support

The need to research a programme to support parents and teachers was conceptualised from a blend of my own experience and my work with families of autistic children, having observed and experienced over many years, successful and problematic communication and relationships between parents and school staff and the proliferating impact this could have on all concerned. A critical observation was that early or initial communication between parents and teachers was frequently *crisis activated*, triggered by something having *gone wrong* at school. This appeared to have unfortunate consequences, for example promoting a sense of blame from both parents and teachers of the other, anxiety about sending or receiving the child to the school setting, and in some cases a developing pattern of mutual suspicion between home and school contexts.

Often caregivers can become stuck in these negative thinking and patterns of interaction, therefore SwiS was designed to create opportunity for parents and teachers step back from this, to work together to avoid such crisis-activated interaction, using

established therapeutic tools and activities from systemic practice as an adaptive framework to support this process *(Chapter* 4 *and Appendix D Part-2).* However, it was recognised in the development of SwiS that these interactions and communications between parents and school staff were also shaped by wider systems of understanding and discourses about autism, (*for example, medical vs socially constructed models and the influence of political discourses*). It became apparent from my own observations and experiences, there were multiple, complex, competing, and often contradictory discourses operating around autism, influencing parents' and teachers' attitudes, beliefs and responses, not just toward the child, but also toward each other.   In addition, it was recognised that theories, knowledge and understanding about autism had shifted (*for example the loosening of thinking around deficit concepts such as a lack of theory of mind*), with increasing information and attention on stakeholder-led theory (Milton, Heasman & Sheppard, 2018), autistic perspectives and culture (Singer, 2016; Williams, 1996b), coupled with major shifts in diagnostic classifications (*for example, the removal of Asperger's Syndrome from DSM-5 as a specific diagnosis*) (American Psychiatric Association, 2013). However, my experience had also showed me that parents' and teachers' own knowledge, expectations, and understandings did not always reflect this contemporary shift in complementary or compatible ways. For instance, if parents were more informed than teachers about social models of autism (Vassallo, Dallos & Mckenzie, 2020), and teachers retained a medicalised view of diagnosis as a way of understanding the child, or vice versa, this potentially placed parents and teachers in a highly confusing and antagonistic space, drawing on different and often opposing discourses when facing difficulty. Importantly, if a lack of shared understanding was the basis of their initial interaction, then arguably this could set the foundation for a difficult partnership going forward.

Introducing the demographic

It is important to note that this research and the discussions throughout maintain a systemic focus on the relationships *between* parents and teachers and children diagnosed as autistic *without* an accompanying intellectual or learning disability. This is a key distinction to hold in mind, as this type of diagnosis *(autism without a learning disability)* accompanies a majority of the 70% of diagnosed autistic children who attend mainstream education in the UK (Department for Education, 2021; Mandy *et al.*, 2016).

Although this group of children are required to walk the same educational pathway as their non-autistic peers in mainstream schooling, there is no escaping the rich and varied differences that exist between them in terms of their experiences, perceptual contrast, and consequently in their contributions, needs, and outcomes. Therefore, teachers and parents need to make sense of the competing and often contested discourses, such as autism's unknown aetiology, and assumptions about core characteristics, whilst navigating the heterogeneous nature of autism relevant to their child, that naturally accompanies such diversity. This is important when considering the influence of discourses on these relationships, as different discourses available to teachers and parents come to shape their relationships and ultimately impact their perceptions of ability and difference within their children.

Introduction to positionality and theoretical framework

Therefore, throughout this research, I have largely departed from discussions of conventional models of autism, particularly autism as a *disability* wherever possible, instead, bringing to this research further ontological questions and explorations about autism largely as a *difference*, influenced to some extent by both social constructionist (O'Reilly & Lester, 2017) and critical realist ideas (Kourti, 2021). Along the way, I also intend to explore how the complexities of autism with its varied meanings and understandings impact family relationships and professional practice, and are embedded

within culture. The influence of the parent-teacher and wider systemic relations in my own life led me to draw on a *bioecological systems* perspective (Bronfenbrenner, 1986), as both a theoretical systemic framework, a *tool* with which to explore *how* differences in understanding and meaning come to influence parent-teacher relationships, and help explain the parent-teacher experience of autism, ultimately shaping interactions with one another.

Whilst I expand on my positionality in more detail in *Chapter 2* , it is important to state from the outset that this research is grounded in my own lived experience. I am a parent to young person, who has a diagnosis of autism, I am also an educator with a focus on autism, and a long-standing advocate for autistic people and their families within my community. Therefore, it is essential to make clear my interest and connection in this area, which is embedded and reflected upon throughout the thesis, as this experience has informed my theoretical approach and was central to the creation of SwiS.

The thesis framework in brief

This thesis sits within the discipline of education but is substantially informed by psychological scholarship. This is reflective of my personal position together with the SwiS core philosophy of attachment-based systemic family therapy, and its target audience of parents, teachers, researchers, and practitioners. It is impossible to separate the two disciplines of education and psychology, as both play pivotal roles in the lives of autistic people, their families, friends, and those within their system.

To make meaning of this area of study, context is critical. Therefore, attention must be paid as to *why* such a programme and focus are necessary in the first place. Contributions to the autism context and the difficulties experienced by the autistic community are many and complex, and the underpinning factors that feed into and shape it cannot be ignored (*I refer to wider issues such as health inequalities explored*

in Appendix A). However, to include everything that is contextually relevant to the autistic experience is beyond the scope of this thesis. Therefore, I have included a series of appendices, to support points and provide background and additional information for the reader, offering a deeper level of engagement with my thesis should it be needed.

Organised into nine chapters, not including this introduction, *Chapter 1* aims to provide the necessary context, framing the *why* of the research and offering a rationale for such a line of inquiry. By reflecting on the evolving opinions and positions of the autistic community, the current state of the autism landscape, and outcomes for this group, *Chapter 1* offers a little historical context of autism, and a view of autistic experience, informed by the insights and perspectives of autistic people, which are held in mind throughout. It also provides an overview of the inequities and poor outcomes experienced by autistic children, young people and their immediate system (*parents and teachers*), across education, health and social care domains in the UK. This is to share with the reader a picture of the scale of inequity, explore the influence of diagnosis, and highlight the importance of working systemically. *Chapter 2* presents my positionality within the research in more detail and outlines the inspirational roots of this study. I share some autobiographical insights, including my own thoughts and experiences of autism, as well as ideas about how autism is perceived and shaped across domains of society and its value within different cultures. *Chapter 3* focuses on constructions and discourses that shape understanding and ideas of autism, drawing on Bronfenbrenner's bioecological systems theory (Bronfenbrenner, 1995a) as an underpinning framework. *Chapter 4* explores theories and explanations of autism from an attachment-based, systemic family therapeutic perspective, which has contributed to the development of SwiS, introducing the original SAFE programme from which SwiS evolved. *Chapter 5* provides an overview of the extant literature of parent-teacher/home-school intervention

programmes for autism, where parents and teachers genuinely work together as a team, highlighting the gap in the research that has helped to shape this study. *Chapter 6* presents my research questions and methodological approach as well as my extensive, ongoing, ethical considerations and responsibilities for this research, justifying why I selected the approach I did. *Chapter* 7 presents my analysis and findings from the exploration stage of my research, offering insight into the initial positions of participants and parent-teacher relations. *Chapter 8* presents an interpretative and observational analysis of the intervention stage of the research and participants' experience of the SwiS programme, exploring how parents and teachers construct meanings of autism through engagement with SwiS. *Chapter 9* discusses my findings in response to my research questions, together with the study's strengths and limitations, implications for future research and practice, and my concluding thoughts.

Definitions, language, discourses, and meanings

Defining what constitutes the *autism community* is important, and for this research refers to those who have been diagnosed autistic, have a working diagnosis of autism, or identify as autistic but are either waiting for assessment or have not pursued a diagnosis. The *wider autism community* refers to those closely connected to the autism community, such as family, friends, and advocates.

Understanding *how* autism is talked about, the debates around language that shape discourses and meanings of autism, influencing how parents and teachers communicate and interact and how their meanings and understandings of autism are accepted and differ both with one another and their children, are also important considerations when exploring what supports and what gets in the way of effective communication between them.

For context, it is necessary to overview key positions on language that influence meaning and perspective, shaping attitudes and approaches to autism. Throughout this

thesis, the language used favours the dominant *identity first* language, i.e. *autistic child, *autistic person, *autistic adult, *is autistic, *autist *(a previously pejorative term, but one increasingly owned and used by autistic people)* as opposed to the now less preferred *person first* language, i.e. *child with autism, *person with autism, *person on the autism spectrum, *has autism.

The terms *neurodiversity, *neurodiverse, *neurodivergent and *neurodivergence are also used, terms that were originally coined to identify the *movement* highlighting the oppression of the autistic population (Singer, 2016). However, it is important to state that I recognise the term neurodiversity has become a broader term for an increasingly varied range of perspectives and conditions and is no longer used to exclusively signal autism. Indeed arguably, the term *neurodiversity* perhaps should encompass *everyone.* That said, where these terms are used, they will refer to or include autism unless otherwise indicated.

Currently the terms neurodiverse and neurodivergent are often used interchangeably, but in fact have very distinct meanings. Neurodivergent refers to the individual, whereas neurodiverse, refers to a population. For example, a family can be neurodiverse, consisting of different neurotypes, whereas an individual within the family cannot; it does not make sense. They can however be neurodivergent, that is, a person whose neuro-style diverges from the dominant neurotype (*or neurotypical*) within the group. There exists a counter argument for not using these terms at all, in that everyone is different, the global population is neurodiverse and everyone within it neurodivergent, no one is in fact *neurotypical*, so it could be argued, neither of these terms make sense. However, these are the current terms adopted by autistic people, and used within their own neuro-affirming discourses, applying them comfortably and frequently to reflect the more overt and qualitative distinctions that characterise autism, for example, in communication differences and sensorial experience. Therefore, for the

purposes of this research, I will respect these descriptors that belong to the significant population who have been labelled *autistic* and use them throughout. I will also include the terms *neurotypical, neuronormative, predominant neurotype* and more frequently, *non-autistic,* to describe individuals and populations without an autism diagnosis. A caveat to this is that I acknowledge these antonymic terms are also potentially very broad, particularly the term *non-autistic*, which may encompass a variety of individuals with other experiences, perspectives, conditions, as well as potential differences and disabilities unrelated to autism. However, the use of such terms is to draw attention to those children with a diagnosis of autism and provide differentiation within discussion.

The choice of language within this research has been carefully considered and is a deliberate approach. Person-first language usually accompanies more medicalised pathologising references to autism, and identity-first language is concomitant with social, cultural, neuro-affirming difference models. I undertook much consultation with autistic children, young people, and adults, both prior to and throughout the research process and, although I received a spread of preferences in terms of language from the autism community, the majority preference was for identity first speech.

This orientation toward identity first language within the autism community, wider autism community and the literature is increasingly recognised as a move toward destigmatising autism and establishing a neuro-affirming discourse (Anderson-Chavarria, 2022; Gernsbacher, 2017; Kapp *et al.*, 2013; Silberman, 2015; Vivanti, 2020). This preference for identity-first language is particularly strong from the cohort of autistic individuals who can self-advocate, as well as from autistic allies such as parents and carers. However, this is not a universal preference, and at this moment in time, the autism community still differs in its language choice. Therefore, I have chosen to reflect this within my writing, favouring identity first language, but also using terms appropriate for, and relevant to, the discussion at hand. At some point in the

future, the decision on language may develop toward consensus, rendering the written style of this research in need of updating. I recognise this at the outset, that the language preferences and accompanying discourses of the autistic community, like so many other communities, are constantly evolving, and I understand the need to be prepared to adapt my response to that evolution. However, at the time of writing, the key message I received from consultation with the autistic community was *not to allow the politics of language and terminology to prevent the important conversations from taking place*. My own current position on language, is to respectfully adopt *whatever is preferable to the person I am communicating with*. For myself, and members of the autism community and wider autism community who kindly helped me with this and other aspects of the study, the focus is *the research* and the messages and learning that come from it.

That said, language, and the resulting discourses surrounding autism, are important topics as they evolve from different domains and perspectives, shaping our understanding, meaning, attitudes and ultimately the treatment of autistic people. For example, by exploring the construction of parent and teacher narratives and the way in which discourses develop, we can better understand the diverse sources parents and teachers draw from (*such as medical or clinical practice, research, psychology, and the wider autism community [as defined above], as well as the world of family therapy and systemic philosophy, which crosses all these perspectives*). This reminds us how relevant language is and provides insight into how parents and teachers build their understanding of autism and shape their narratives, which in turn offers clues as to how *difficult* or *mis- communication* occurs, as these sources are often in contradiction with each other. Therefore, it is important to hold in mind that the way language influences narrative and autism discourse is central to this research.

What is clear about conversations of autism is that there is no single meaning, and currently no single language which exists to adequately convey that meaning. Meanings of autism, constructed in the narratives of parents and teachers are inevitably as varied as the children they care for, potentially making communication challenging in the face of such complexity. Whilst the debate about language will undoubtedly continue, the resolution of which, requiring an undertaking far beyond the scope of this thesis (*being an altogether different study*), I would emphasise from the outset, it is the voices of autistic people that need to be better heard, and that the autistic community should lead on decisions of official use of language, identity, as well as other decisions about them, decisions that once made should be respected by all.

"Nihil de nobis, sine nobis - Nothing about us, without us"

Chapter 1

Setting out the autism landscape as a rationale for study

> **'It takes a village to raise a child'**
>
> *(Ancient proverb)*

1.1 *A systemic beginning: Autism Case-1*

This ancient proverb was never truer, than when applied to raising autistic children. Reflecting on Leo Kanner's autism '*Case-1*' of Donald Triplett, living in a time when the word *autism* was largely unknown, formal diagnosis brand new, and before *autism intervention* was even thought of, we see what happens when *the village* rallies (Donvan & Zucker, 2016). Psychiatrist Eugen Bleuler is credited with coining the word *autism*, in his work with schizophrenia (*a word which he is also credited with creating)* (Evans, 2013); however, it was the work of Leo Kanner, who in the 1940s set down the foundations for what would be an ongoing evolution of autism (Evans, 2013; Milton, 2012a). Donald Triplett was certainly not the first person to display key characteristics of what is now termed autism. Autism has always been with us (Frith, 1989; Williams, 1996a). However, Donald was the first person to be officially *labelled* as such (Donvan & Zucker, 2010).

Said to have certain savant skills, extraordinary abilities or '*islands of genius'* (Treffert, 2009), Donald was fascinated by numbers and music. It was purported he could calculate complex number problems and had perfect pitch (Donvan & Zucker, 2016, pp.40). He was also seen by Kanner to possess some of the more familiar characteristics associated with medicalised views of autism, reflected in the diagnostic criteria we see today within both the DSM-V (American Psychiatric Association, 2013) and ICD-10 (World Health Organization, 1992) clinical diagnostic manuals for mental disorders, which have gone on to become the basis of the medicalised diagnosis of

autism and are also part of popular discourses about autism we still encounter today. Clinical descriptors such as '*deficits in social-emotional reciprocity*', difficulty with '*developing, maintaining and understanding relationships*' and '*deficits in nonverbal communication*' (American Psychiatric Association, 2013), as well as a preference for a set of *restricted interests*, were all attributed to Donald in a way that, for a time, overshadowed all the competencies and talents he possessed (Donvan & Zucker, 2010).

That said, although Donald developed differently from most children, he did eventually find his place in the world, not least due to the tireless efforts of his parents to support him and their fortunate position of having means enough to ensure he had adequate resources to sustain him. At the time of writing, Donald still lives happily, a seasoned global traveller, a competent driver and an avid golfer, valued and respected for his strengths and talents by the community of Forest, Mississippi, where he grew up (Donvan & Zucker, 2010). Instead of regarding Donald as *tragic* or *broken*, a problem to be *managed* through the segregated institutional system of the time (*a system designed only to meet basic human needs enough to alleviate social conscience),* the community of Forest, Mississippi ensured more for Donald by embracing him and autism in all its rich diversity as part of the fabric of their society, before they really knew what *autism* was and before society had taught them a *value-negative* response to the label. Crucially, the *village* or *system* around Donald replaced pity with ambition for him. The result is a life well lived.

1.2 *The unacceptable state of the current autism landscape*

The current level of inequity experienced by autistic people (*as a considered population*) in the UK, across most of life's domains, including education, health and social care, underpins the motivation and rationale for this study. For many, such inequity means *a life well lived* is not a reality and, for most, Donald's experience is far removed from theirs. The National Autistic Society [NAS] offer a conservative

estimate of more than 1% of the UK population being diagnosed autistic (National Autistic Society, 2018). This suggests autism is a significant part of the lives of more than three million people every day, with more than 100,000 of this number represented by children. Factor in educational connection, the addition of teachers and peers, and that number of connections to autism grows exponentially. However, 2020 figures actually place the prevalence of autism much higher, in excess of 2% nationally and exceeding 3% in Northern Ireland specifically (McConkey, 2020). Even more recently, a Lancet review of underdiagnosis places these figures higher again with 2.94% (1 in 34) of 10-14 year olds having a diagnosis (O'Nions *et al.*, 2023). So for a significant proportion of the UK population, autism is an intimate part of everyday life. Even these are conservative figures, and do not take into consideration the vast numbers of undiagnosed autistic adults, or those children and young people for whom diagnosis is either not necessary, or a lengthy waiting game, a delay often experienced in years, not months (British Medical Association, 2019). In the United States of America [USA], statistics are similar where, at the time of writing, 1 in 36 children (approximately 2.7%) is formally diagnosed autistic (Centers for Disease Control and Prevention, 2023; Christensen *et al.*, 2016), with numbers estimated higher when including those awaiting diagnosis and those who for other reasons do not pursue one. The World Health Organization (2021) suggests a global figure of 1 in 160 on average; however, they also acknowledge the prevalence of autism in low to middle-income countries is largely unknown. Cultural barriers in some countries where autism is simply not recognised at all, also contribute to the global lowering of this figure (World Health Organization, 2021). However, a more recent systematic review by Zeidan *et al.* (2022), has revised this figure to 1 in 153 globally.

Within the UK, the autism community constitutes a significant minority group, making the following outcomes difficult to accept. For all the reasons set out below,

supported, expanded and reflected upon in *Appendix A*, generally, autistic people fit the criteria as an oppressed and othered population (Milton, 2016b), with unnecessary early death (Hirvikoski *et al.*, 2016) the final and all too common consequence of a cascade and compound set of acknowledged inequities (Sharpe *et al.*, 2019b), that start in early childhood and persist throughout the lifespan (Westminster Commission on Autism, 2016). Autistic people are nine times more likely to die by suicide than the general population, have limited access to health care, be chronically lonely and unemployed, (having the lowest employment statistics of any work-able '*disability*' group) (Autistica, 2021), have poor educational outcomes (All Party Parliamentary Group on Autism, 2019; Ambitious About Autism, 2018b), be excluded educationally and socially (Ambitious About Autism, 2018d), which together results in life expectancy of an autistic person being cut short by up to 30 years (Hirvikoski *et al.*, 2016). As many of these factors are entirely preventable, it is abhorrent to consider that autism has become a life limiting condition, with an additional financial cost in excess of £32 billion per year in the UK alone, largely due to *'society's systemic failure to accommodate autistic people'* (Bottema-Beutel *et al.*, 2021).

1.2.1   *The inequity of fitting in*

Observing this landscape for autistic people, we see it is one of compound injustice and disadvantage from early on in their lives. General societal expectation still places the emphasis on autistic people to *fit in*. This is demonstrated, for example, in education, where the focus of social conformity for all children results in the propensity to socially *upskill* autistic people; for children this is often presented as *social skills training* (Robinson, Bond & Oldfield, 2018), but more often experienced by the autistic child as a lesson in *masking*, the hiding of the authentic self.

1.2.1.1 *Masking*

Masking is something we all do to some extent as a form of *social lubricant,* suppressing or hiding elements of ourselves when adapting to various social situations (Miller, Rees & Pearson, 2021). However, in autism, the demand is amplified with the person often using all available cognitive and emotional resource to disguise their differences, simply to be accepted. For example, to inhibit natural inclinations to move their body or talk in certain ways.

Autistic people often describe masking as exhausting, leaving the person with little in the way of internal emotional and cognitive resources for the function of the situation, such as learning in school or ironically engaging in the social situation they are masking for, which goes some way to explaining the association of masking and mental health difficulties in autism (Chapman *et al.*, 2022). Masking is often *encouraged* to help autistic people have more successful communication with non-autistic people; for the autistic person to adopt the non-autistic perspective and be more like them. It is rarely, if ever, the other way round, where understanding and acceptance of the autistic perspective from non-autistic others is encouraged.

1.2.1.2 *Fitting in is a one-way street.*

Sadly, in my experience, both as parent and practitioner, the limited efforts to move toward reciprocal communication and understanding, particularly in education (*for example supporting non-autistic children to understand an autistic perspective*), are rarely *truly* reciprocal or based on current knowledge and understanding of autism, and are too often littered with misconceptions and stereotypes. This is not surprising given there remains a chronic lack of access to appropriate education and information about autism across allied services, within schools, or during teacher training (Humphrey & Symes, 2013). Therefore, how can we expect teachers or other educators be able to communicate to non-autistic children the importance of the individual autistic

perspective and what that might mean for a person, and how for example, elements of autistic experience might be shared by other children such as an enjoyment or dislike of certain sensory experience or a deep passion and interest in a particular subject. Instead, in the absence of broader understanding and only a label to draw on, children are often viewed and singled out as *wholly* different, pathologised, missing opportunities to share in similarities with their peers as well as finding mutual value in their differences.

Information about autism within education is often rooted in behaviourist approaches, supporting increasingly authoritarian behavioural management and discipline agendas (Armstrong, 2018; Reay, 2022). Behavioural approaches to classroom management often accompany the curriculum and subject specifics within teacher training programmes which contain little else. For example, the opportunity for teachers to learn about attachment and *their* influence in terms of systemic practice is rare, if not entirely absent, with attachment often understood by teachers only in simplistic terms of *secure* and *insecure,* as a direct measure of *good* or *bad* parenting, contributing to the parental blame culture and overlooking ideas within attachment theory that, for example, views all *behaviour (a common 'complaint' about autistic children)* as attempts at adaption (Crittenden, 2006).

Instead, what may occur in practice, is that *accepted wisdom* or folk knowledge about autism is *passed down* from practitioner to practitioner, often perpetuating misconceptions and outdated practice, as opposed to reviewing and updating knowledge individually. Despite research and understanding of autism advancing significantly in the past decade, this still has not resulted in improved training for new teachers in the UK (All Party Parliamentary Group on Autism, 2019). This potentially increases dependence on longer-serving teachers for their knowledge, who are more likely to have gained their understanding and experience of autism, embedded with historical behavioural approaches and created for *compliance* purposes. When applying such

hand-me-down knowledge to the question of the *inequity of fitting in* and moving from a *one-way street* to a more reciprocal understanding of autism, this raises questions as to whether practitioner understanding of autism (*given the chronic lack of practitioner training and enduring poor outcomes for these children*) is sufficient to ensure any attempts at reciprocal *upskilling* of non-autistic peers about autism, does not instead perpetuate marginalisation and misunderstanding.

To illustrate this, I offer the following vignette.

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Vignette 1 – Classroom visit

During a classroom visit, an autistic child was experiencing a *meltdown* (leading to shutdown) and was laid, distressed, on the floor. The teacher communicated to the visitor how incredibly proud she was of her class, having *taught* the other children in the class to be *undisturbed* by the child's *behaviour* (a misunderstanding of autistic distress), by ignoring what was happening and waiting for the child to calm down on their own. The visitor watched, albeit briefly, as children continued about their scholarly activity, avoiding or even stepping over this child, and indeed remaining focussed on what they were doing, before the visitor could stand it no longer, gently siting themselves on the floor alongside the child, almost, but not quite touching, but being reassuringly present and calm. As the visitor sat there, reflecting on the teacher's obvious pride in how she had *managed* the *behaviour* of this child, their own emotions were almost as uncontainable as the distressed child's. However, looking around the class, the teacher was right, it was indeed true, the class of students *had learned* not to be *bothered* by this child. Their education had remained uninterrupted, and their learning had continued unimpeded. That said, after this child and the visitor had connected for a few minutes, and together identified the source of his distress, which was that he had been denied access to the toilet post-recess and had wet himself a little (*I won't go into what this says about the inadequacy of practitioner training and understanding of interoceptive signalling here*), the visitor questioned *what* exactly the teacher had modelled and instilled in her class. Was it resilience and focus? Or had she taught the next generation of future adults who would grow up alongside their neurodivergent peers, to show zero empathy and simply *step over* a person lying on the ground in distress? Was the real lesson here that autistic people are *less than human,* and if so, *this is how you treat them?* In general, children are naturally empathic, and their automatic response to distress is to want to help and offer comfort (Decety, Michalska & Akitsuki, 2008). However, if they are denied this natural response, and are instead *taught* by their significant adults and authority figures that distress is to be ignored, how likely is it that they will perpetuate this attitude going forward into adulthood? And if so, where does it stop?

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Figure 1 Classroom visit vignette.

In this example, it was clear the teacher had developed strong ideas for navigating difficulties in the classroom, she had gained through educational agendas of behaviour management based on behaviourist principles. In addition, it highlights the dehumanising effects of diagnosis, and entrenched discourses that influence and perpetuate such responses. In general, autism interventions within education are focussed on changing the *autistic child,* so autistic children can learn to a non-autistic educational framework and make friends with non-autistic children by *masking* their individual autistic characteristics. *Evidence-based* interventions, often focus on helping the child to *fit in* and are revealed by their approach, such as helping the child with communication and interaction, cultural training, and more often used in schools, *resilience* training and *exposure* techniques, to help autistic children *overcome* difficulties such as environmental sensitivities, to remove resulting *avoidant behaviour*, a common safety strategy employed by autistic children (Lilley, 2015; Schmidt *et al.*, 2013; Sutton, Webster & Westerveld, 2019). However, in adopting this approach, we undermine the very foundation of inclusion, by failing to teach non-autistic children the value of a different perspective, and how to connect with it in a meaningful way. Statutory educational support mechanisms, such as Education Health and Care Plans (EHCPs), which are not generally framed as competency-oriented documents, are littered with such goals, aimed at altering, or at the very least *masking*, autistic characteristics. It is also seen in practitioner language and is another sign of oppression. For example, the term *reasonable adjustment*, refers to *allowances* made by the non-autistic community, for autistic differences, where the autistic perspective is *accommodated*, instead of embraced and accepted as part of our humanity and the rich fabric of our ongoing societal development.

Some responsibility for the perpetuation of such attitudes also sits within autism research, in focusses such as *changing the autistic child* so they might enjoy meaningful

relationships (Rowley *et al.*, 2012), because differences in communication and presentation are deemed to be the problem, rather than a lack of understanding of the autistic perspective (Roberts & Simpson, 2016). The message is clear, *the authentic autistic self is not welcome,* a message that has been adopted by society, reflected throughout all these inequities, widening the *belonging*, *inclusion,* and *opportunity* gap. Society still serves the predominant neurotype, almost without consideration of the neurodivergent minority. Therefore, isolation and marginalisation are more the norm for autistic people, ensuring the social *annexing* of this community is continued, generation after generation, with little incentive for society to understand differences and even meet them halfway; an attitude illustrated in *Figure 1,* a situation that sadly is not unusual. From the perspective of the non-autistic social majority, such responses maintain the constructed *meaning of autism* as being a *problem*. This is a consequence of an embedded and medicalised social discourse, that considers autism a disability, as opposed to a socially inclusive narrative that considers it a *difference*.

When talking to non-autistic people about autism, I often use the somewhat simplistic *'geographical strangers'* analogy. I ask: *If Autism was a different country, and those that came from that country spoke Autistic, meaning we struggled to understand each other, and they had customs, preferences, and behaviours somewhat different from our own, upon meeting, would we think of them, or ourselves, as disabled, because these differences between us made communication tricky?* The answer that always comes back is a resounding *'No. Of course not!'.* Instead, suggestions of *learning a little about the other person's culture* and *sharing our own with them*, taking time to *understand the language*, and showing *patience* as they try to grasp ours are common, as is the shift in perspective when the realisation occurs that communication with autistic people is indeed a *two-way street*.

Milton (2012b) describes this as the *double empathy problem*, a mismatch in communication between two different social actors, rather than a deficit just in one. Unfortunately, without more widespread *realisation* such new thinking will not occur, and autistic people will continue to be set apart as *not one of us*, depriving society of so much colour, richness, and talent.

1.3 *The 'village' effect: the importance of the system*

When we reflect on the experience of Donald Triplett, autism's Case-1, the benefits of applying a systemic approach were evident then, more than 70 years ago. When a person's environment does not *disable* them by determining their value by what they cannot do, but rather by what they can, everyone's lives improve, not just the autistic person, but also those within their system, *their village.* Yet contrary to Donald's experience, and despite the government's own more recent evidence of the benefits of a systemic approach seen in child protection (Munro, 2011) and the development of co-production, autism has now escalated into one of the most negatively impactful developmental differences within modern society, particularly in terms of marginalisation, inequitable life chances and, as previously highlighted and discussed in *Appendix A,* the high and increasing human and financial costs. In light of these escalating costs, seemingly without improvement to the life outcomes of autistic people despite such enormous investment, it seems ludicrous that little has been done to address the question of *why this is*? (Westminster Commission on Autism, 2016).

For many who are autistic, and often for those who love, support, and care for them, such marginalisation and poor life outcomes are an unnecessary and direct consequence of being neurodivergent. This says more about our attitude to *difference* as a society, than about autistic people themselves, particularly as the challenges experienced are more often socially constructed than rooted within the person. At the 2018 Autistica conference in London, keynote speaker, renowned neuroscientist and

autism researcher Professor Francesca Happé recounted a quote she had heard from a colleague, which had stuck with her, and which indeed stuck with me. She said: *'pure autism never comes to clinic'* (Happe, 2018). This, she explained, made a point on two levels. Firstly, autism rarely, if ever, occurs in isolation. Therefore, there are often co-occurring (*medically defined as co- or multimorbid*) conditions experienced by the person, often resulting in further labelling and/or clinical intervention. Secondly, and I believe most crucially, she explained this quote could be understood in terms of *who are the individual core characteristics of autism actually problematic for?* As a person whose position and direction of research is to some extent influenced by social constructionist principles, this latter interpretation is critical; the neurodivergent aspect of autism, the part that means the person experiences the world differently, is not in itself problematic. It is not problematic for the autistic person, and it is not problematic for anyone else. However, once the autistic person engages with the environment, an environment constructed for the non-autistic mind and body, and that environment then layers on demands, based on non-autistic expectations, whilst wholly rejecting autistic ones, it creates the condition where the autistic person starts to experience socially constructed difficulty and distress. It is not being autistic that is distressing them, it is having to navigate the neuronormative world and deliver on neuronormative expectations and rules, with a mind, body and set of sensorial and perceptual preferences, that are at odds with, and denied by, a neuronormative environment and culture. This distress proliferates to caregivers, such as parents and teachers, who themselves are influenced by, and must navigate, a *muddled* and often *contradictory* set of discourses about autism, fuelled by medical diagnoses, which tell you nothing about a person, but which go on to shape and influence how children are responded to, *Figure 1* being a case in point.

Diagnosis is often where difficulties are perpetuated and exacerbated by the action of diagnostic *mental condition* labels within the medical manuals, which are all inherently negative (*as neither the DSM nor ICD texts are competency-oriented*). By listing differences as deficits, they construct a deficit discourse, which if widely adopted contributes to the autistic person becoming *othered*, reinforcing the idea that *different=less,* where societally, we then behave accordingly. If we want to change the narrative around autism, we should consider it more systemically, restoring a *village approach* toward people, and easing autism and diagnosis from the grip of such negativity. Moreover, we should *formulate* on an individual basis, a person's strengths and differences as well as their support needs, as was afforded to Donald; an approach Leo Kanner took *tentative* steps towards in the 1930s, but sadly did not persist with.

> *Formulation in autism - early foundations….*
> *It was at Yankton [late 1920s] that Kanner noticed, and rejected, an institutional penchant for pigeonholing patients by syndrome. He hated this. Too much emphasis was put on figuring out what label to stick on each patient, he concluded, and not enough time was spent listening to the patients themselves. Kanner developed his own style of writing up an individual's medical history. Instead of usual dry compendium of dates and previous illnesses, he presented his patients' histories in full sentences, with well-developed paragraphs and telling details taken from his personal observation. This would become a hallmark of his work: to appreciate the actual stories of his patients, and to use that understanding as the key to diagnosing and treating them."*
>
> (Donvan & Zucker, 2016, pp.27)

Despite Kanner's initial attitude of unpacking the individual stories of each autistic person, neither formulation nor a systemic approach to autism developed widely. In fact over time, attitudes moved in quite the opposite direction, to one where (*as the label 'autism' suggests*), any identified difference was assumed to reside within the self, a problem with the person. This problematising approach has proliferated across our culture, ensuring autism is viewed negatively, with systemic contributions from the wider environment and others external to the autistic person rarely reflected upon as

being linked to, or causal for, any distress response or resulting marginalisation of autistic people.

1.3.2   *Society's dangerous need for 'sameness'*

Such *problematising* attitudes to autism were evident in early attempts at autism intervention, such as Ole Ivar Lovass's use of Applied Behavioural Analysis [ABA] programmes, as autism *therapy*, which at that time, had an agenda of *training out* what were considered autistic *traits* and *behaviours*, to make the person *appear* indistinguishable from their non-autistic peers (Lovaas, 1987; Lovaas *et al.*, 1973). Historically, and indeed currently, society is not overly tolerant of those who present differently, preferring everyone to *fit in*. Interestingly, such a demand for *sameness* required from more general society, is an irony for the autistic community that is difficult to overlook.

The human rejection of difference and requirement to *fit in* is of course not new, or unique to autism. One can draw parallels with the cruelty of colonial thinking of the 20th century where a history of other assimilation policies on measures of race and culture resulted in atrocities such as the stolen generations of Greenlander (Archibald, 2006), Torres Strait Islander, and Indigenous Australian children (Schaffer, 2006), the cultural insights of whom I briefly discuss in 2.3.2. Whilst such overt assimilationist practices are rare these days, they are still present in more insidious forms and often appear in our everyday society without us even noticing as again they are embedded within autism discourses. For example, within educational agendas, they might be presented as *supported learning* or *social skills training*, designed to suppress difference and ensure all children work to an identical framework underpinned by homogeneous targeting and performance expectations. Unfortunately for autistic children, there is no escaping the undertone of assimilation within educational practice that clearly would prefer the eradication of some autistic characteristics whilst overlooking the value of

others. Like Indigenous survivors, there remains a generation of autistic people who still carry the embodied scars of being subjected to such *interventions of change* (Leaf *et al.*, 2021) and, without a societal attitudinal shift, a similar risk remains to the generations who follow them.

1.3.3   *The protection of the village: society matters*

With all we have learned about autism through recent history, and despite it being one of the most common *developmental diagnoses* in children, autism remains one of the least (*properly*) understood and, for many, the least supported (All Party Parliamentary Group on Autism, 2019; Westminster Commission on Autism, 2016). This is evidenced by the poor outcomes for autistic people locally, nationally, and globally, despite the increased research and understanding of neurodivergence (All Party Parliamentary Group on Autism, 2019).

However, turning our thoughts back to Case-1, for Donald Triplett, this was not his eventual experience. So why was this? After his parents summarily removed him from the institution where they were initially advised to leave him and brought him home, Donald's life changed. His parents and his community either resisted, or were initially unaware, of the more pathologising features of diagnosis, which were (*and sadly still are)* central to the medical profession's view of autistic people. Donald attended school, gained employment, had hobbies, and his *village*, his community, the system around him, supported him in this, resulting in a good life (Donvan & Zucker, 2016). As I reflect on this, I cannot help but wonder why, if we got it so right in the beginning, what went wrong, and *what would happen if we viewed autism more systemically and returned to the village approach?*

Unfortunately, this question is without a simple answer, and herein lies the dilemma. When oppression is as overt and entrenched as it is with autistic people, it becomes normalised, making change difficult, particularly when marginalisation, powerlessness and inequities impinging on every domain of life are the general way of things for a community (Milton, 2016b). Additionally, to *officially* be called autistic, one must still be given a *medical diagnosis*, which anchors autism in pathology. Any clinical diagnosis is powerful and, by nature, carries a deficit discourse. Therefore, autism diagnosis is firmly embedded within that deficit discourse, where it has been for many decades, made by the type and level of practitioner that as individuals we have all been conditioned to trust and not question.

From a parent-carer perspective, this can position them as powerless in the face of a medically based diagnosis of *disability* in their child, identified by a *doctor* or more likely a multidisciplinary team (*all generally medical*) who agree with each other that a child is *disabled* or *deficient*. For parents in particular, to challenge this requires strength, knowledge and a lot of courage, to somehow throw off the weight of this clinical power and, on top, resist any inevitable questioning of their parenting skills, a perpetual *go-to* discourse of *we blame the parents* within practitioner conversations of autism (Clements, 2021). Considering autism systemically within the child's context, formulating on the individual, shifting the focus toward a profile of ability and assumed competence, whilst acknowledging and responding to what is more challenging for a person, particularly looking more widely at the systemic influence of environment and asking oneself *'what am I doing to contribute to this situation'* is something that is not easy to do. Particularly when society in general is geared toward accepting clinical labelling as a guide to tell them what is *wrong* with the *person*, where to site *blame* for

this, and moreover have a prescription or formula for what to *do* with them, with exclusion being a frequent outcome.

We see this for example within education, where mismatched agendas between families and schools (*operating under performative pressure according to the political demands of the wider or 'macro' system*) compete, making access to the right support difficult and largely focussed on needs that will support the educational agenda, rather than those of the child and family context (Done, 2022). For parents and teachers (*the key members of an autistic child's immediate or 'micro'- system),* this makes working together very difficult, resulting in parents often being shut out (Lilley, 2015) and teachers operating in silos with their own agenda for the child, or worse, parents and teachers operating in opposition, often whilst apportioning blame to the other.

Such is the experience of many children, families and teachers today (Hornby, 2011; Vassallo, Dallos & Mckenzie, 2020). Despite the emphasis on co-production to encourage collaboration and help bridge the home-school divide, directives found within the Children & Families Act (GOV.UK, 2014b), the SEND Code of Practice (GOV.UK, 2015) and the new SEND reforms (Department for Education, 2023), educational institutions still wield the majority of power and decision making in terms of children's education, decisions that, due to educational policy, are more often made with *performance targets* in mind than children (*how to maximise educational attainment and a high Ofsted rating, with ever shrinking resources*). This pressure on schools does not favour the inclusion agenda generally, which requires flexibility and innovative approaches, making it resource heavy within such a rigid and financially inflexible educational framework (Armstrong, 2018; Lilley, 2015). This is particularly true for autism, where the needs of children often remain unmet, and teacher knowledge of autism is scant (Vassallo, 2023, p.203). This situation also does little to foster healthy parent-teacher relations, because school priorities such as attendance and

academic success may not be parental priories, who instead often favour social connection, emotional wellbeing and belonging over academic achievement (Petrina, Carter & Stephenson, 2015). Therefore, keeping parents of autistic children at arm's length can be seen as vital by those responsible for balancing finances, limiting pressure on schools by avoiding engagement with those with such competing priorities.

However, the trade-off is increased pressure on teachers, who must then interact (*or not*) with parents, with less resource, less knowledge, and less support. This disconnected approach is inherent across our education system, and the daily reality of it is stressful and unproductive for everyone involved, as evidenced by the continued poor educational outcomes for children, and the difficulties experienced by both their parents and teachers, emanating from poor relations (All Party Parliamentary Group on Autism, 2019; Ofsted, 2021; Westminster Commission on Autism, 2016). Therefore, it prompts the important following questions: *would outcomes for the child improve, simply by approaching autism more systemically, by uniting the key members of the child's system?* In turn, *would that system be mutually supportive of those within it?* If so, *how would this be experienced by those key members of the system?* And *what effect could this have on the child?* These are the questions that have shaped my interest and seeded my research in this area, having glimpsed, just for a short while, a similar *village effect* on my own family.

Chapter 2

Author's positionality and meanings of autism: some autobiographical insights.

2.1 <u>Introduction</u>

This chapter sets out my positionality in more detail and offers some autobiographical insights that have influenced my journey to this point. I explore my own experience of the many perceptions of autism across professional and multicultural domains and discuss the different meanings of autism based on my life and exploration within Australian and UK contexts.

2.2 <u>Positionality and my influence</u>

My personal experience of autism makes it particularly important I acknowledge my role and interest in this subject from the outset, and how my connections with autism have inspired and helped to shape this research.

Autism, in terms of how it has been defined, experienced, and interpreted by myself, my family, and our interaction with the social world, is a welcome part of my everyday existence, present across multiple dimensions of my life. However, it is not the most important thing. It is just one story in a compendium of stories to tell about my family and more specifically, my son. To elaborate, at point of writing, I have had the privilege of spending twenty years as mum to an amazing young man who I love beyond words and of whom I am immensely proud. He is a loving, caring, intelligent, independent person, interested in and adept at so many things. He also happens to be diagnosed as autistic, a label to some extent he identifies with, but is not defined by. My life with him has taught me so much and continues to do so. It has enabled me to better understand and appreciate the full value and joy of an entirely different view of the world, to slow my thinking and embrace the world revealed by such a perspective.

It has also offered a level of reconcilement and sense-making of my own difficult early experiences, growing up as a *different* child, differences my interaction with the world constructed as *'bad'*, that I previously internalised as deep character flaws, forever holding me back and rendering me worthless. Such reflection has illuminated and to some extent validated my lifelong sensitivity to injustice as being *reasonable*, reigniting my courage to *call it out* where I find it, and hold true to a core imperative *not to avoid* what is difficult, to always try to *do the right thing*. These are just a few of the many *learnings* from a life with my son which have had an influence on my positionality.

I must also acknowledge my career, which has helped shape this research. As an educator, as well as an advocate for others who have (*or care for someone who has*) a perspective of the world that does not fit with normative constructions, it is difficult to live and work so closely with people and not be affected by the shared experience. Therefore, to preserve the integrity and authenticity of this research, I would like to present my interest in this subject from the outset and acknowledge the effect my personal lived experience and interpretation may have on hermeneutic process within my findings, something I expand upon in 6.3.5. Whilst great care and effort have been taken to be reflexive about the influence of my own life events within this project, it is impossible, and would indeed be detrimental to the research, to try to remove all trace of my own experience from being reflected within it.

Interpreting and writing about another's truth is a multi-layered and complex process. During the retelling of lived experiences, people construct their stories, and these disclosures naturally undergo a primary interpretation by the owner, as they begin to make meaning of them and think about how to convey this meaning to another. However, any such experiential account is then subject to secondary interpretation by the listener (Smith, Flowers & Larkin, 2009). This is particularly salient when personal identification with a participant's story is in play. It is impossible to ignore the

mutuality that helps to bring forth another person's truth and drawing on and reciprocating with one's own shared experience is a natural part of that process. As I am privileged to share a common position with both my parent and teacher participants, in terms of contextual understanding and empathy for their experience, this *sharing* has been very much a part of this research. That affinity with others not only engenders trust but, particularly for parents, offers a small sense of belonging, one that says *you are not alone*, something many autistic people and their families often have little experience of.

This is particularly important to reflect upon, and will be throughout this research journey, as my life with, and immersion in, the world of autism underpins my motivation and purpose to carry out this study. For me there is no greater motivator than your own child, to inspire you to understand, support, and endeavour to have a positive influence on something that is such an intrinsic, essential, and remarkable part of who they are.

2.3 *Autobiographical inspiration for the study*

Most research catalysed by personal experience has embedded somewhere within it evidence of the author's story. Reflecting on mine, I can clearly trace the inspiration for this study back to 2005 and our family move from rural England to Australia, with my husband and then two-year-old son.

Having been in a new country less than eighteen months, immersed in a world evolving at odds with what social norms told me to expect of motherhood and what my child and my family life should look like, my son's diagnosis of autism arrived. He was approaching just four years old.

I say *arrived* because it came without struggle. Within three months of our first visit to the GP with some questions about my son's development *(questions prompted by my ideas of 'expected developmental norms', compared with what I was seeing in my*

son), we were quickly swept up in a robust, but highly medicalised diagnostic process. As a family, we underwent a multidisciplinary assessment, led by a clinical psychologist, supported by a speech and language pathologist, occupational therapist, and paediatrician. Assessment took a few weeks and to its credit was not entirely restricted to my son. The assessment included family interview to understand our personal context, assess parenting style, review attachment, and gather a family history. They then assessed my son (*including our shared interactions*) across multiple domains, at home, at school, and in public (*for example, going to the park, eating out, shopping and so on),* before the *team* convened to *diagnose* my child *autistic,* followed up with an array of support offered to us. I highlight this because, not only did this happen in the context of our initial ignorance about autism, as we were picked up and carried along in a *whirlwind* of largely biomedical professional input, but also because it was a departure from the experience of most of the families of autistic children in the UK I have since consulted with. Within their stories, diagnosis is more often a protracted, hard-fought business, frequently taking years (All Party Parliamentary Group on Autism, 2019), with little robust assessment or accompanying support before, during, or after, leaving families exhausted and depleted and often wondering what the point of it all was, given so little help follows.

Whilst we as a family were initially derailed somewhat at the departure from our expected path of parenthood, adapting to our *new normal* in a new country turned out to be an easier transition than we were led to believe and had come to anticipate. Initially, diagnosis was a positive experience for us as parents, as it not only offered both my husband and myself information about autism, information that had not previously been on our radar, but as parents, it lent an interesting insight into each of our own *unique* histories and perspectives of the world, perspectives we had always considered *normal*, as indeed for us they were, but on reflection and closer scrutiny, were perhaps not as

typical as we had thought - a discovery not entirely unusual within neurodivergent

families. After a challenging pre-diagnosis start to life in a new country in relation to

our son's development, a swift formal diagnosis meant we quickly found support,

guidance, and community, and settled into life with a system that held us, an experience

I initially assumed everyone had.

2.3.1 *Personal, professional, and public knowledge and understanding of autism.*

My attitude and opinion, like my knowledge and understanding of autism, has

evolved over time and most importantly to note continues to do so, as it is shaped by my

experiences, interactions, and learning, and by the decisions I have made along the way.

Although *a 'life with autism'* is something I have in common with other parents, I find

in many ways I have also walked a different path to most of the families with whom I

now interact and support. I have had the good fortune to traverse other countries and

cultures and gain just a small insight into the attitudes of others toward

neurodivergence. That exploration has deepened my questioning, as the range of

responses to autism I have witnessed has been vast; from openness and embracement to

prejudice and fear, and everything in between.

This is perhaps reflective of the diverse nature, *not* of what autism *is*, as it is

different to each person, but rather what it *means* to different people, and how its

meaning can be influenced according to the societal and political inclination of the

moment. Compared to the '*dark ages*' of the 1980s and 90s, where autism was less

known in more generalised society, autism is now in flux. Medically, it confers the

disease model; however, changes within diagnostic manuals also mean autism is now an

umbrella term incorporating multiple '*neurodevelopmental disorders*' (Sauer *et al.*,

2021), adding to the complexity and confusion of how autism is recognised, understood

and diagnosed.

Few people, if any, will say they have not of heard of autism, largely due to extensive awareness campaigns, and introduced legislation, such as the introduction of the Autism Act in 2009 (GOV.UK, 2009), but also due to the increased appearance of autistic characters in the media. However, awareness and legislation do not necessarily translate to more general understanding. Therefore, since the turn of the century, *awareness* campaigning has changed to *acceptance* campaigning, a decision the autistic community hoped would organically lead to better understanding and treatment of autistic people, embracing them *as they are*, with all their strengths and differences, particularly when complemented by increased representation in mainstream entertainment, literature, and other means of social communication. Whilst public awareness, and knowledge has improved to some extent on what it was thirty-to-forty years ago, to the non-autistic population, the *meaning* of autism and the predominantly medicalised discourse that accompanies it has not changed all that much. This is reflected in the unimproved life outcomes explored in 1.2*,* entrenched public perception and stereotypes that persist despite education, awareness campaigns, and inclusion agendas, and the point that autism is still classified as a neurodevelopmental/mental *disorder*, a label that tells you nothing about the person.

2.3.1.1   Practitioner understandings

Within the autistic community, people generally understand autism as being a different perspective of the world, that there are as many personal experiences and interpretations of autism as there are individuals given the label. They also understand their experience of the world (*the construct of their autism*) is influenced by their ecology (Bronfenbrenner, 1995a). For example, the impact of interrelations with their environment, culture, and social influences, might hold negative or indeed positive views of autism, shaping how a person is perceived and what opportunities are afforded to them, or stories constructed *about* them, as illustrated by Donald Triplett's

experience. However, this is not necessarily understood or accounted for within professional services, where autism is still officially a pathology, as opposed to individual characteristics representing degrees of difference from a narrow definition of expected *norms*.

The aetiology of autism remains unknown but is '*likely multifactorial'* (Sauer *et al.*, 2021), meaning genetic and non-genetic factors influence the expression and constellation of differences, from person to person. Such unknowns mean the nature of making a diagnosis is not only complex and ill-defined, but also highly subjective, varying from clinician to clinician (Hayes *et al.*, 2022). That said, the biomedical discourse has attempted (*fairly successfully*) to objectify and reify autism into something definitive, a set of *symptoms*, *traits*, and *deficits,* a pathology to be applied homogenously to vast numbers of heterogeneous people. This is despite the label itself telling you very little about the individual person, there being no single way to *be* autistic (Williams, 1996a, p.vii), any more than, it could be argued, there is no single way to be neurotypical.

2.3.1.2   *Slow change of public and educational understanding of autism*

Whilst there are many reasons for a *glacial pace* shift in understanding and acceptance of autism from a societal perspective, this level of ambiguity from professional spheres may be a contributing factor. There are just too many unanswered questions about autism. Autism is unpredictable, context dependent, and too varied from person to person, as it confers a unique experience on each individual. Without a *one size fits all* in terms of approach and understanding of the autistic perspective, to non-autistic people what is *not* known about autism might seem overwhelming and too disparate to fully comprehend or begin to engage with.

Humans are hardwired to fear the unknown, and when presented with it, will seek clarity and information, or otherwise reject it. Ambiguity is uncomfortable (Raub,

2022; Trautmann, Vieider & Wakker, 2008), and such a lack of understanding and clarity that exists publicly and professionally about autism may drive what Robinson and Goodey (2018) describe as *'inclusion phobia'* with fear of the unknown at its root (Croll & Moses, 2000; Shevlin, Winter & Flynn, 2013). In my observations over time, this resistance to inclusion of autistic people, which often begins in schools, has contributed to the continued *othering* of this community, as social attitudes remain largely reticent to embrace this diverse demographic of humans.

The current education system illuminates this for us, where inclusion ideologies directly conflict with performative policy. For example, a child's right to *an education*, *play* and *recreation*, jars with the right to deny them admission to a school on the basis of cost to, or impact on, other students (Robinson & Goodey, 2018), a contradiction within a system that on the surface espouses creativity and uniqueness (*as long as they are not 'too creative' or 'too unique'*) (Robinson & Aronica, 2016). This is a system where all is well as long as students stay within the prescriptive framework of the curriculum, meeting *school's* expectations of behaviour, presentation, and of course a demonstrable specific profile of subject abilities to achieve a standardised set of GCSEs that a *school's* success (*not the child's*) can be measured on (Ball, 2004; Shukry, 2017). In reality, this is a framework that actually leaves little room for uniqueness or difference to be accommodated, let alone accepted and valued (Hornby, 2015), which is where autistic differences begin to be problematised and rejected.

2.3.2   *A 21st century cultural shift in meaning?*

That said, increased societal awareness and resistance to ongoing injustice and exclusion has strengthened the voice of the autistic community, resulting in the growth of the neurodiversity movement (Singer, 2016). Historical and continued oppression of the autistic population together with the ground swell of other movements and minority groups, particularly conversations on gender diversity and identity construction (Castro-

Peraza *et al.*, 2019; Thorne *et al.*, 2019), have provided a *boost* to shift the social narrative toward a more open and receptive position. This has helped create conditions to empower many members of this community to take ownership of the autism label and the discourses surrounding it, in an attempt to control and more accurately demonstrate the spread of representations. Whilst this is positive it could also be argued it does little to mitigate the *'them'* and *'us'* culture.

The yesteryear use of the word autistic as a slur, is largely (*thankfully*) disappearing, along with other words used to disparage sections of society. For many within the autistic community (*more often those without an intellectual disability or co-occurring condition*), being diagnosed autistic is an essential part of their identity. However, one cannot escape the way the meaning and perceptions of autism shifts, depending on context, which is more frequently shaped, not by the needs of the individual, but by the current political climate and resulting policy agendas (Shukry, 2017). For example, too often we see social policy decisions, particularly in relation to education and health, dictate what support is available, making cuts to provision for the most vulnerable, particularly in times of economic stress, suggesting the meaning of autism to policy-makers is one of *lesser value*, and therefore an acceptable population to be top of the list to disadvantage. This is reflected in the perpetual poor outcomes for autistic people, often with catastrophic effects (All Party Parliamentary Group on Autism, 2019; National Autistic Society, 2017; Ofsted, 2021; Westminster Commission on Autism, 2016) and something I elaborate on in 2.3.2.7.1.

2.3.2.1   *Acknowledging the 'less-talked-about' face of autism.*

I freely admit, for a very brief time when my son was first diagnosed, I was fearful of the word *autism,* as I had only a basic understanding of what it signalled, based on culturally transmitted information derived from a medicalised perspective and representations in the media, which at the time were rare. To me autism suggested an

inability to communicate, learning disability and all the implications and outcomes associated with that. This was fear largely born of my own ignorance, and perhaps a British enculturation of a label that told us autism is a *personal tragedy* (Ravet, 2011; Runswick-Cole, Mallett & Timimi, 2016). However, what I saw in my child was not what I *thought* I knew about autism – this was simply *not* my experience. The perception of tragedy was *never* a part of our family's life. We were blessed with a happy, healthy, loving, fiercely independent, immensely intelligent little boy, therefore this word, *'autism'* immediately created a contradiction in my thinking, throwing the meaning of it, for me, into chaos. Yes, our situation was *different,* but it was far from *tragic.*

However, it must be acknowledged that for a proportion of the autism community, both autistic individuals and their families, it can be perceived that way. For some, their experience of autism is not a positive one. They may be living with extreme difficulty (*dare I say the word 'suffering'*), and co-occurring conditions, finding life intensely challenging, and therefore may indeed feel their autism (*or for parents, their child's autism*), is tragic. Whilst the more recent positive voice of autistic self-advocates and/or their families should be amplified and heard, I am also acutely aware, having learned much from other individuals '*with autism'* who do not feel such positivity, this is not representative of all who have a diagnosis of autism. When extolling the positives of autism and autistic culture, of which there are many, we should take care not to diminish the very real difficulties experienced by what is still a significant proportion of the autistic community. For many autistic individuals and their families, they live with the type of autism that is far less researched and explored (Bessette Gorlin *et al.*, 2016), the type that renders an individual unable to understand, or be understood by the rest of society, where the world they inhabit is cut-off from everyone and everyone else is cut off from them, where self-harm or harm to others is a

constant risk, and where access to the simple enjoyment of everyday life is severely limited.

Whilst this population is *not* the subject of this particular research, it would be irresponsible and disrespectful to fail to acknowledge their very real and ever-present struggles, struggles that are not entirely socially constructed, but that according to autistic people themselves, result from material differences in minds and bodies that are *not* created entirely equal (Singer, 2016, p.13).

For myself, as my learning developed and I was exposed to and engaged with diverse cultural responsivity to autism, I was able to better understand and appreciate the light and shade within the vast array of autistic experience. For my own family experience, being able to move away from the deficit-laden label and embrace the extraordinariness being autistic afforded my son was important, and largely made possible by the positive influence of our system, setting our direction of travel for the future.

2.3.2.2   Culture shocks

My own first experience of societal response to autism initially felt largely positive. As I expand on in 2.3.2.6, in general, the mainstream cultural attitudes toward autism I experienced whilst living in Australia seemed quite forward thinking and well intentioned, particularly in terms of learning *with* the person and not allowing attitudes to be misled by a medicalised label. On the face of it, acceptance was the norm, as was having high expectations of autistic children in mainstream education, where ability, particularly *niche* ability, was acknowledged, freely nurtured, and more often capitalised on. Positive interventions to support autistic children in their development were also more the norm, particularly around the mechanics of speech and communication development if needed, access to social interaction through extended

play, and the education of parents to the autistic perspective, something we were glad to receive.

However, as I reflect on those early days, when the diagnosis of autism was new to us as a family, the peripheral inclination and direction toward more behaviourally based interventions were always there within the education system and wider service provision. This was promoted as supporting children and their families to access, and thrive in, the *real world*, but all too often were really vehicles for obtaining compliance from the child. As the world is not built for the autistic perspective, further reflection raises questions about the depth of acceptance I *believed* we were experiencing. Was the approach from the school *really* all about accepting us as we were, as my son was, learning from us, valuing the diversity and colour he brought, whilst teaching him skills that would be taught to any child during childhood development? Was it as genuine as that or was it my Western culture's veiled need to *integrate* us, a *deviant family*, into society, where no one noticed our collective differences? This question remains unanswered even today, although as time moves on and my global experience of attitudes towards difference in general deepens, I would probably argue more for the latter.

However, at the time, it did not feel so insidious, and my son's experience was, and for him remains, a largely positive one, as does mine. Indeed, the warmth and inclusion from our community seeded the very idea for this research. Nevertheless, reflecting on the social world's attitude toward autism over the years, I cannot completely lose the gnawing feeling that *timing* played a huge part in this good experience, leaving me to wonder if our initial *Donald-esque* experience would have continued had we stayed. Would my son, and us as a family, have continued to experience the same level of inclusion and value as Donald Triplett (*Case-1*) did? Although I hope it would have, within the warmth and kindness of the community we

found, I strongly suspect, had we remained in Australia, the wider, macrosystemic pressure for conformity and the commodification of children *(particularly in education where they are deemed as 'value-positive' or 'value-negative', depending on whether they are cheap or expensive to teach and offer a return on investment)* (Ball, 2004; Shukry, 2017) would have increased in line with the typical expectations attached to development, just as it did here in the UK on our return. As my son matured, moved toward adulthood, he would no longer be young enough to be forgiven his social *differences*. The clues *were* there in Australia, I just did not clearly see them at the time. In one *parent-practitioner* interaction, I remember being *emotionally slapped* by his speech and language therapist, who, when my son was still just four years of age, pointed out that his '*eccentricities*' as she called them or, as I prefer to think of them, his '*natural wonder and response to the world*' (*something to this day I love and find fascinating)*, would not be so *cute* or regarded so well by society when he was twenty, and as a parent I would be failing him if I did not *prepare* him for this, and help him '*overcome*' these *differences* whilst he was still young enough to '*change*'. Her words of '*he won't stand a chance*' and '*what happens when you are no longer around*' pierced my soul. As a mother, this was a *heart in my boots* moment, I was paralysed with fear; an embodied experience I will never forget, as the feelings of panic for the future, and guilt for being a *poor parent* and not *preparing him for the world*, were summarily *instilled* within me in an instant by this one conversation. I was *frightened into action*, reacting with 'Right! I should follow the programme and the advice of experts, because really, '*what did I know*'?'

The truth was, at that point, the answer was not very much. I knew something of the medicalised *presentations* of autism, enough for me to have raised my concerns with the GP in the first place, but not much beyond that, and this conversation ensured I felt the weight of my ignorance. My own instincts as a mother were suddenly undermined.

They felt instantly less valuable, less meaningful, as clearly the only way I could properly parent my child was to *listen to the professional experts* and *do what they say*, to *'intervene'* in a radical way, which was frightening as a parent with so little knowledge. I remember her words '*while he's still young enough to change'* and the urgency with which she said them. But I did not want to change him. Of course, I wanted him to learn. Yes. But to fundamentally change him? No. The looming start date of Kindy (Australian kindergarten) was already enough of a change for me; and whilst it could be argued, the very idea of wider schooling forces us as parents to accept change in our children to some extent, to '*give them up'* to be shaped into what is acceptable in society, where too often conformity is valued over knowledge and skills, what was being proposed here was more than shaping - this professional advice was no less than a complete *'remould'*. This did not sit easily with me, and blindly following instruction without question in any situation has never been my strong point - a trait that probably goes some way to explaining my own difficulties with education. Therefore, despite the professional weight of diagnosis that said my child was deficient, and the installation of parental guilt because my rejection of that limitation might leave him ill-prepared for life, I knew I needed to educate myself, not just about autism, but about my son and what autism meant to him. I needed to understand his perspective of the world – and to do it fast. My natural questioning nature meant I was not ready to completely abandon my ideas of motherhood quite yet. I knew my son in all his potential, and whilst he was certainly different from other children in his communication, expression and preferences, I was sure these qualities did not need eradicating. In so many ways he was exceptional, and I wanted to explore ways to develop them, therefore I needed more information.

2.3.2.3   A different culture

Being new to the autistic perspective as a white Western family living in a culturally diverse country, it was evident to me there *must* be other approaches and ideas about autism that might also illuminate the question of whether we were simply being *integrated*, that my own cultural habitus would not reveal. The more I explored, the more I encountered increasingly different responses to autism. In a tangential conversation with our family doctor, he explained, within his Sri Lankan context my son would be considered a *'deep thinker'*, not in any way deficient.

At the time I remember wanting to explore this comment further. *Could my child be a great thinker, a dreamer, a philosopher? Was this what he was born to do?* I would not class myself as fatalistic in any way, but occasionally life nudges you and makes you pause. *Was that a clue? Did I miss it?* Sadly, like many things about Westernised parenting, time to reflect and explore *with* your child is often limited by other pressures. The meandering flow of growth and change in childhood, have now been *timetabled* and relabelled as *milestones*, things to be met and mastered. This is something the *good-parenting* discourse forces you to closely monitor, to ensure your child achieves them; a series of challenges, boxes to *check*, urging you and your child more quickly onto the next. *Tick. Tick. Tick*. This is amplified if your child is developing differently to expected *norms*, as there is an immediate social pressure to *correct* any divergence, an urgency and impetus toward *early intervention*, to help get them '*back on track'* (*whatever that is*), or at least somewhere close. There is no time to explore whether their natural inclination and original trajectory would actually be better. No. They must meet the same milestones everyone else does, the cookie-cutter child, otherwise they will be forever disadvantaged and cast into the commodified *negative-value* box by society, and in particular by education (Ball, 2004). For parents,

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the urgency for this is a powerful force that sweeps you along, and for a time, I admit with some enduring regret, we were powerless in its current.

2.3.2.4   *Indigenous culture*

My curiosity for *another view* led me briefly to explore Indigenous Australian culture, as I was fortunate to have connection to this community both socially and through my studies, albeit somewhat limited. My brief experience and interactions with Australia's First Nation people and their stories and history, revealed mixed attitudes toward, and experience of, neurodivergence.

For some within this community, ideas and meanings of autism were more organic in nature. Their mindset was one of acceptance, and their response to children with a different perspective was the epitome of Donald's *'village'*; because for the Indigenous Australians I met*,* the raising of any child, was *'everybody's business'* (Bailey & Arciuli, 2020). This accepting attitude is reflected in the nearest word antipodean cultures have for autism, that the Indigenous Australian community now share with New Zealand Māori culture; '*Takiwātanga'*, meaning '*in his/her/my own time and space'* (Te Pou o te Whakaaro Nui, 2019; Tupou *et al.*, 2021).

However, in my early observations of and interactions with families of autistic Indigenous children, one of the first things I noticed was there appeared to be an *attachment* gulf between the child and their caregivers, which momentarily gave me cause for concern. The children were allowed to *dance to their own tune,* but without parental connection it seemed. Reflecting on this, I was of course viewing attachment from my own perspective and what that looks like. I had considered how attachment might *look* different cross-culturally, but I felt somehow that fundamental features such as protection from danger, seeking safety, comfort, as well as organisation of feelings and mutuality, would be universal. However, from a cultural perspective, I could not be sure whether this *gulf* I thought I saw, was autism related, whether this would be any

different if the child had been typically developing, or indeed if this pattern would change over time. These children were allowed to *be alone with themselves* wherever and whenever they wanted. There was an absolute acceptance of the child to inhabit their own world, but without it seemed, any concerted effort from parents to join them there. To my Western internalised model of parenting and attachment, this initially felt alien and lonely, like an abandonment of the child, left isolated to wander further and further away. Of course, I was completely wrong. What I came to understand about these few autistic Indigenous Australian children, who were unencumbered by Western demand, was that they were in fact simply engaging with their community's cultural *ways of being*, and as a result, seemed less anxious or stressed (*something that cannot be said of autistic children in Western culture*), and were often very self-sufficient, appearing not to experience the *demand anxiety* I saw from most autistic children I knew, my own son included. Therefore comfort-seeking, for example, looked different, perhaps less frequent, as the children felt inherently safe wherever they were. They were not only surrounded by *actual* safety from an extended secure-base (Vassallo, Dallos & Stancer, 2023), but more importantly, an internalised *knowing* that if comfort was needed, it was found *immediately*, available *everywhere*, from *everyone.* Parents and extended family were relaxed, but simultaneously present, and everyone *seemed* to understand the child, and be happy to meet that child's needs collectively. If the parents were not available in that moment, there was a whole *village* available to *bridge* the attachment needs of the child, a parallel I would later draw between parents and teachers.

This of course was a snapshot in time, and what the world held for these young people once grown, both within and outside the boundaries of their community, one cannot foresee. But on speaking to Elders, and community members, I soon understood everyone would care for this person according to their *'lore'*, which is rooted in kinship

and a mutual sharing or obligation to each other, a non-negotiable in collectivist Indigenous Australian culture. It was enlightening to watch these young children *at home* in their wonderings and imaginings that a different view of the world afforded them, one they were permitted to explore, completely unencumbered.

2.3.2.5 *When 'this' meets West*

It must be acknowledged the accepting values I experienced within Indigenous Australian culture as well as other cultures, were not necessarily representative of all Indigenous communities across Australia. Reflecting on my more regionalised experience of Indigenous community when positioned in contrast to the wider Western ideas of autism I was seeking an alternative to, I must accept, as an outsider, I possibly experienced a slightly idealised view of the community approach to autism I witnessed from Indigenous Australians. Nevertheless, idealised or not, my interactions with Australia's First Nation people did offer a glimpse, just for a moment, of how things *could* be for autistic children in society.

Further research of wider Indigenous Australian communities did indeed reveal their experiences of autism were not always so positive. Some families and communities report significant marginalisation and isolation due to the differences in their children (Lilley, Sedgwick & Pellicano, 2020). In a scoping review made subsequent to my own community interactions, Bailey and Arciuli (2020) found that autistic Indigenous Australians and their families were some of the most marginalised people in the country. However, from my own earlier observations, these negative experiences appeared less pronounced when observed within the authentic context of Indigenous Australian culture, only becoming more evident the closer their links were with Western society, where *its* version of child development with its timescales and milestones overshadowed more traditional *ways of being*. I observed the support and high expectations I accepted as positive within my Western context created confusion

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and conflict, and could sometimes be interpreted by Indigenous Australians as interference and a suggestion their children were broken and needed fixing. Consequently, communities coexisting within, or close to, Western society, often had Western influences and ideals of child development thrust onto a very different culture that were neither wanted, nor in many cases, needed.

In terms of autism diagnoses, it is suggested that prevalence rates should be the same as for Indigenous Australians as non-Indigenous Australians; however, they are significantly lower (Bailey & Arciuli, 2020). A low diagnosis rate in this population might be explained in multiple ways. As described above, for those communities more distant from Western influence, there may simply be no imperative for *medical diagnosis*. The community takes care of its own - until death - rendering our Western labelling meaningless.

However, for those more closely connected to Western life and influence, there may be more significant cultural barriers, as Indigenous Australians are also often reluctant to take on deficit labels (Bailey & Arciuli, 2020; Jalla, 2016). Whilst this is fine for Indigenous Australians who remain separate from Western influence, for those who do not this resistance can further disconnect these communities from systems such as education or healthcare, systems they have come to rely upon.

There is no word for disability in Indigenous Australian language (Jalla, 2016) because disability is talked about in an inclusive way, in terms of what the community needs to know about an individual to ensure their needs are met. For example, the community might acknowledge difficulties experienced by a member, in terms such as '*Grandfather does not hear the same*' or '*we speak so everyone can hear*' rather than give Grandfather a deficit label of '*deaf*', and they would adjust their behaviour toward Grandfather accordingly, to ensure he could '*hear*' in other ways. This difference in approach between Western individualist and Indigenous Australian collectivist culture

is perhaps a perfect storm for *exclusion* (*as opposed to inclusion*) as there is already an existing general lack of understanding, acceptance, and respect from white Western society for the diversity of Indigenous Australians and their *ways of being*, without the introduction of further diversity such as autism. The Western approach to autism could learn much from Indigenous culture, as our medical paradigm, signalling autistic characteristics as *deficit*, simply does not fit with Indigenous Australian ideas of *giving a person what they need to participate in their community,* an established, inclusive and effective *village* approach to difference; an approach that, in an albeit more *diluted* form, ironically seemed to be working for us.

2.3.2.6   *A different path – a part of a system*

Receiving a diagnosis of autism is generally a '*watershed'* moment for any parent and every family will react to it differently, depending on what autism means to them, the discourse they engage in, and the circumstances behind their personal journey. What *is* universal, is that receipt of a diagnosis signals change (Vassallo, 2016). Whether that change is expected or not, whether the diagnosis comes as a shock or is welcomed (*perhaps after a long period of fighting for recognition that their child is developing on a different trajectory*), change is inevitable.

It was that *change* that was recognised and acknowledged when my son was diagnosed, and a menu of services, support, and education offered to us, his parents, as well as to our wider system, including our son's school.

At that time in Australia, understanding of autism was no more advanced than it was in the UK. However, what did differ, was how autism was approached. As I alluded to in 2.3.2.2, at that point in time, acceptance and understanding for the most part, felt the norm in our small corner of Australia, and our general experience of social attitudes within our immediate community, was that the value of all people, regardless of their neurology, was not just recognised, but prized. I recall musing that the

colloquial Australian maxim of '*everyone deserves a fair go*' was perhaps not just words after all, and maybe Donald Horne's 1964 pop-sociological *'lucky country'* scathe might, for us, have been misplaced. A pivotal difference for us as a family was, at the point of diagnosis, we were immediately scaffolded by several important things, a solid parental education about autism, (*initially medicalised, but quickly turning toward the autistic perspective*), expertise in educational and therapeutic approaches for everyone to learn *how* to best support our son according to his strengths and preferences, and a relationship with our system, our *village*, who united and in many ways helped us to raise our son for a few precious years.

The attitude of the system was one of evolution, learning about, and reflecting my son's unique perspective of the world, and providing balance in terms of respect for his preferences and importantly appropriate exposure to theirs. *Evolution* meant it was certainly not perfect but, for the most part, *living together successfully* was key. We still experienced some exposure to, and pressure from, services engaged with during those early years, whose approaches were rooted in more behaviourally based theory, to try to teach him *the way of the neurotypical*. However, this soon settled instead into learning through his play preferences, spending large parts of the day bouncing together on the trampoline, making extraordinary creations with Lego (*thank goodness I've always loved Lego*), or using his hyperlexic talents to explore and develop understanding of the world through books and his love of reading. To us and his school, he was perfect as he was, and he remained fully included in the general learning of all children, whilst being taught in ways that suited him, allowing him to stay true to his authentic self. This was in contrast to our subsequent return to the UK a few years later, which saw a rapid shift away from teaching him in the way he could learn, making his own choices about how he engaged with the world and the reciprocity of that with others, to the one-way street of simply *fitting in,* something I elaborate on in *2.3.2.7*. To

this day I still wrestle with the injustice of the missing element to that. Teaching any child about the world is indeed important (*what are parents and teachers for if not to provide love, safety, education, and the foundations for life*). However, *inclusion* requires reciprocity, meeting autistic people halfway, for others to understand the autistic perspective so autistic people are not (*recounted in Figure 1*) *stepped over* in the classroom by their peers, so they can feel they belong, to reflect the systemic approach of Indigenous culture which asks, *'what do we need to know about this person so they may fully participate'*. This was my son's initial experience of growing up in Australia and neither he, nor we, felt any such injustice at the time. Growing up *down under* is something he still reflects on with great fondness even today, although he does not necessarily articulate exactly *why* it was good, he just *knows* it was and feels warm about it, a legacy, I believe, of the effect our *village* had on him.

2.3.2.6.1 *The support of the village*

Reflecting on receiving my son's diagnosis in Australia, I remember our small family unit took full advantage of the array of support options and education that accompanied it, a very different experience to most UK parents who receive little if any post-diagnostic support (McKenzie *et al.*, 2021). Parent education, support services (*social and professional*), an autism parent network, and an array of educational options, were all available (Valentine, 2010), and we grabbed what information we could with both hands as we were desperate to know more. The positive open attitude of the Australian education system, the school and its teachers, unencumbered by targets, tests, or a closed-door approach, enabled bi-directional communication between us and our son's school to flow easily, maintained by respect and transparency on both sides.

Being English, our understanding and experience of education meant this level of openness from the school was a bit of a surprise. Their willingness to work closely

with us as the experts on our child, as well as with external specialists, who were helping our son to *learn how to learn* in his own way, through play, social connection, and the education of his parents, made such a difference to our daily lives; our surprise soon faded and we embraced it, particularly as the school soon became hungry for further knowledge about autism too as, like us, they had very little experience or training and were keen to understand and know more. Early *bumps* along the way were quickly resolved and our relationship settled into one of genuine partnership.

Our *village* had started to evolve around us, almost without us noticing, the effects of which have remained with us to this day. With a very few exceptions, attitudes from my son's teachers, our community and wider society were accepting, embracing and respectful. Seeing only my son's talents and abilities, valuing his unique character and characteristics, and supportive of things he found challenging, we remained free from any obvious prejudice and avoided any significant isolation during those critical post-diagnostic years. Indeed, we became integral to, and fully included within our community, and the little negativity toward autism we did experience was minimal, peripheral and soon passed. Communication triangulated naturally between our newly redefined constructed *family unit*, which included our social network and the school and saw our son flourish beyond all initial expectations.

2.3.2.7   *The reality crash*

Our return to the UK was an awakening. The free and open communication, access to support services and general autism awareness we were used to, were all absent. Understanding, acceptance, and appreciation of all the positives neurodivergence brings were also missing from most people's radar. Here autism meant something else. Autism equalled *problem,* and we soon became the typical autism family who had to *do battle* every day for the most basic of support from school, or health services, where need outpaced available funding, and attitudes to autism were

still firmly anchored to the medicalised deficit model (Vassallo, 2016). The meaning of autism in the UK was still largely one of tragedy and disability, and the response to it was ineffective. This was reflected in the focus on labels to make value judgements, the associated negative language used to describe autistic people, the resistance to parental input across education, health, and care domains, and how services were organised, prioritised and commissioned. If autism was suspected, an absence of pre-diagnostic support meant families had no information or help for difficulties, as this was (*incorrectly*) communicated as being contingent on diagnosis, particularly in schools.

This steer towards diagnosis has seen an increase in already long wait times for assessment, stretch into years, something that at time of writing has not improved, despite yet another a government strategy to tackle it (GOV.UK, 2021). The dearth of post-diagnostic support (McKenzie *et al.*, 2021), lack of professional training across education, health, and care services (Shevlin, Winter & Flynn, 2013) and focus on crisis-led *band-aid* services offering families avoidant strategies to manage problems, such as *respite* (Autistica, 2017; British Medical Association, 2019) reinforces a lack of joined up thinking or adoption of a critically systemic approach to autism.

2.3.2.7.1 *Autism as value-negative*

It was the Covid-19 pandemic which brought into sharp relief how the lives of autistic and disabled people more generally are really valued within UK socio-political culture. Nothing reveals the true nature of government beliefs and attitudes more quickly than when it is plunged into crisis. One of the first challenges I faced at the start of the pandemic was in my voluntary and community capacity as an autism advocate. Supporting a national response from wider autism and learning disability advocates and organisations across the country, we were mobilised to challenge medical action, where *do not resuscitate* (DNR) orders were attached to otherwise healthy autistic and learning disabled people in the face of a shortage of respirators and medical

intervention (Scorer, 2020). In the midst of the chaos that was lockdown, a national

campaign was launched in response to desperate calls from families of autistic young

adults, fearful their children were identified as *collateral* under these orders, orders that

were not applied to their health-equivalent non-autistic peers, but were applied for no

other reason than in response to a label which says your life is worth less than others,

you are devalued because you are deemed different or disabled (NHS England, 2020;

Scorer, 2020), an example of labelling being a matter of life and death (Runswick-Cole,

2016).

2.3.2.7.2 System? What system?

Reflecting on this experience and our time in Australia, there remains a clear and

demonstrable difference in cultural response to autism. Our return to the UK meant a

shift in meaning toward autism, which in turn meant approaching autism from a

systemic perspective (*where family, school, and services worked together for the*

betterment of the child, rather than budgets or performance targets, where inclusion

was a genuine goal), was suddenly about as far from everyday practice as one could get.

A lack of joined up thinking proliferated beyond the classroom, where support of

autistic children meant allied services operated in silos and where communication

between school, primary services and parents was scant. Families had been protesting

for years *(and still are)* that accessibility and support for autistic children are

inconsistent, often ineffective and, if sought, are frequently pursued without

consultation and co-construction with others in the system, including parents. This is

supported and evidenced in the recent national SEND review from Ofsted, where co-

production was cited as being generally '*weak*' (Ofsted, 2021) and the subsequent

SEND reforms identifying the current system as being unfit for purpose (Department

for Education, 2022a; Department for Education, 2023). In my own family's

experience, and in those of many others, educational support was, and still is, often

delivered with more than a *hint* of how grateful families should be, given they have brought this *problem* to the school's door. Parental suggestion for, or challenge to, practice was not received as collegial, nor was it respected as coming from a place of experience and knowledge. Instead, it was more often interpreted as *interfering*, or worse, *part of the problem* (Vassallo, Dallos & Mckenzie, 2020).

Whilst the needs and difficulties faced by families and schools raising and educating autistic children were similar on both sides of the world, this reluctant and intransigent approach to inclusion of autistic children and their subsequent outcomes, as well as the impact on their parents and teachers, contrasted so starkly with my own early experience, it immediately illuminated the focus of this research of how different things could (*and should*) be: raising an autistic child was not a solitary journey, but a wholly collaborative one, as my Indigenous friends explained, raising a child was '*everybody's business'* and therefore one which would be most successful if approached systemically.

Needless to say, my own autism journey started in earnest on the day of my son's diagnosis, and although I have walked a different path to most mothers, made many, *many* mistakes, and learned so much, I have travelled side by side with him ever since. It has been, and continues to be, a wonderful education and a privilege to be a part of such an amazing life.

Chapter 3

Constructs of autism: Merging the personal and the theoretical.

3.1 <u>Introduction</u>

This chapter explores some of the relevant theories and associated discourses underpinning debates, controversies and mismatches in understandings of autism, providing a backdrop to my research. I will explore the medical-social model debate, and touch on social constructionist and critical realist perspectives that contribute to the '*muddle*' of ideas and discourses that not only shape the thinking and beliefs about autism for parents and teachers, but also influence their responses to each other as well as the child they share care of. Primarily I will draw on insights from Bronfenbrenner's bioecological systems theory as an underpinning theoretical framework to demonstrate the importance and power of the system around the child, from the micro- to macrosystemic and its wider socio-political influence, to illustrate why we need to think more systemically.

3.2 <u>Constructions of autism</u>

3.2.1 <u>*My personal view and construction of autism*</u>

My perspective of autism at this moment in time and stage of my learning is reflective of the complex and multifarious nature of those given the autism label, shaped by my interactions with the wider autism community. My position accepts that divergences in areas such as cognitive style, communication, sensorial sensitivity and preference exist, and combine to *lightly* connect to ideas such as Mingers' (2014) *'explanatory mechanisms'* where autism would be *dynamic* according to systemic influence and context, rather than a set of *'universal laws'* that say *'this is true about autism and all autistic people'*, ideas found in more medicalised constructions. Hobbs

(2015) describes this in her review of Mingers' approach, as a *'mission to conjoin systems thinking and critical realism in order to foster dialogue and debate'* (p.175). Applying this to autism, this is exactly my aim, to bring about connection, dialogue and thinking about autism that is flexible and not fixed between those who operate within the very system being discussed.

Although my construction of autism prefers to *formulate* rather than make generalisations, I also accept the label offers a degree of personal identity construction for autistic people and can be a functional *signpost* for non-autistic perceptions and social narrative about this population. Therefore, whilst I acknowledge the tensions surrounding the autism label and the implications for individuals depending on the meaning attached to it by others, I do not wholly reject it, or the concept of neurodivergence in terms of recognising degrees of experiential difference between autistic and non-autistic people (Singer, 2016). I accept both, and openly sit with uncertainty in my thinking and continued learning in terms of the current reality of systemic challenge (*and the potential for their resolution*) that exists for autistic people and their wider community.

3.2.2 *Critical realism and social construction: constructing a 'realism' view of autism.*

This perspective has led me to adopt a more integrative position from which to consider the meaning of autism, particularly across educational and familial contexts. To explain, my epistemological stance on autism, although influenced by social constructionist ideas, it is not completely determined by them, as my position is more of a broad alliance of views that also has a foot in the camp of critical realism.

Critical realism is not one unified theory, set of beliefs or methodology. As Archer *et al.* (2016) describe it, critical realism is an *'alternative paradigm'* that is more like a set of

family resemblances in which there are various commonalities that exist between the members of a family, but these commonalities overlap and crisscross in different ways. There is not one common feature that defines a family, instead, it is a heterogeneous assemblage of elements drawn from a relatively common "genetic" pool. Critical realism is a philosophical well from which Marxists, Bourdieusians, Habermasians, Latourians, and even poststructuralists have drawn. The reason for this is simple. Critical realism is not an empirical program; it is not a methodology; it is not even truly a theory, because it explains nothing. It is, rather, a meta-theoretical position: a reflexive philosophical stance concerned with providing a philosophically informed account of science and social science which can in turn inform our empirical investigations. (Archer *et al.*, 2016)

For me, this description also reflects the heterogeneous nature of autism and more closely reflects my position and current thinking about it. Ontologically, critical realism acknowledges the reality of things that exist (*some people are autistic*). Yet epistemologically, knowledge is subjective, and indirectly linked to that reality, according to our perception or representation of it *(we know autism exists because autistic people socialise, present and communicate differently to cultural norms, which through continuous interaction with our social world has shaped our expectations and perceptions of 'how people are')*. We acknowledge *things* in the world exist, however, our knowledge of social reality is more subjective, may have multiple meanings, and be based on interpretative *(and in the case of autism)* perhaps more socially constructed views. This is closer to the core of my belief that there *are* people in the world who do indeed *diverge* from the *neuro-normative* (*another social construct*), who each have a different experience of the world, but whose *'difficulties'* are reified by responses and expectations of those norms from others, resulting in socially constructed labels and categories (*able versus dis-able*) (Davies, 2016). This means when considering an autistic person, one might recognise the autistic perspective as a general *experience of being*. However, the multiple perspectives that may be attached to it, being constructed by that experience and interaction with the world, which are individually meaningful, but mediated by context, means that everyone's *experience of being* is unique. For example, if you take a thousand people who identify as autistic, you may indeed

uncover a thousand meanings and a thousand different viewpoints. Therefore, regardless of label, should we not simply *'get to know the real person'*?

This sits in contrast with my experience of services, particularly education and wider health and social care practice, where constructions of autism and the resulting attributions about autistic people made by non-autistic people are still rooted in deterministic deficit perspectives that explain little about who a person is, what they can do, with a tendency to *lump all autistic people together* (Sauer *et al.*, 2021).

Within these areas of professional practice, the deficit view of autism, highlighting a set of *'symptoms'* or *behavioural presentations* determined as *inappropriate* or *maladaptive*, being set against social norms, has over time helped socially construct and maintain the deficit discourse that still shapes how we think and talk about autistic people, influencing the development of stereotypes and expectations *(autistic children cannot make eye contact, are more visually oriented, prefer routine).* Although ideas about autism have more recently shown signs of exploring a *difference* paradigm of autism, as with any entrenched idea, moving away from stereotypes and deficit characterisations (Mac Carthaigh, 2020), means change is slow to permeate all professional practice and there remains a *deficit discourse* legacy.

As we engage with these discourses and social constructions, they embed within us, influencing our thinking, and consequently our responses to the person, rather than encouraging us to develop genuine knowledge of them. Socially constructed ideas of autism and their emerging discourses not only have the potential to short-cut thinking and shape culture but, from a systemic perspective, have the potential to directly influence practice and in turn the person. For example, if the meaning of autism to a teacher is one rooted in such stereotypes as inflexibility, literality, visual preference, communication deficit, and an inability to form friendships, then that meaning might be generalised, influencing how they approach *all autistic children;* assuming all autistic

children need a visual timetable, require social skills training, or *prefer* being alone and so on.

From a systemic perspective*,* as a key member of a child's system, how the teacher views autism influences their treatment of the child, which may be at odds with the child's other main systemic influence, their parents. Bronfenbrenner's bioecological systems theory (Bronfenbrenner, 1995a), illustrates this for us, highlighting the power of systemic influence around the child in terms of how social context shapes their development, as well as the function and wellbeing of those within their microsystem who interact together. If parents and teachers hold different beliefs and attitudes about autism, they may respond differently to the child, resulting in relational conflict between them and confusion and distress in the child, exacerbated by their opposing beliefs.

My life as part of the autistic community, has *repositioned* me somewhat in my worldview, and continues to do so as my learning evolves. Adopting a blended perspective, encompassing social constructionism and a critical realist social ontology, is perhaps an unusual one, and may even appear anomalous in its conflation. However, this philosophical orientation is appropriate, given the flexibility in approach it affords this systemic exploration with caregivers of autistic children. It separates social-construction and the importance of social context, from more extreme anti-realist ideas of the social world and autism within that (Elder-Vass, 2012). This makes it an appropriate lens through which to view the perspectives of parents and teachers of children who have nuanced and diverse needs, characteristics, and experiences of the world. Similar to the label of autism, critical realism *'explains nothing'* (Archer *et al.*, 2016), ergo everything is open to new thinking, interpretation, and consideration, whilst allowing for people to be '*active in constructing their own world'* whilst recognising they are also*, 'constrained and shaped by structures that have real effects'* (Craig &

Bigby, 2015, p.311). Engaging in a philosophical position that was anything less flexible and responsive when contemplating concepts, complexities, and the heterogeneity of autism would be to do the wider autistic community, and this research, a disservice.

3.2.3 *Social and medical models of autism*

In terms of how we view autism, many parents, families, and teachers of autistic children, as well as autistic people themselves, would disagree with the medical deficit model and associated discourse accompanying diagnosis, suggesting autistic children *cannot* communicate effectively, or that there is something maladaptive about their child's passions or areas of interest, pathologised by diagnostic labelling (American Psychiatric Association, 2013; World Health Organization, 1992). However, they also experience a dilemma in the need and directives from school to seek a medical diagnosis in order to access support. This is where those who *know* these children and young people intimately, would argue the *difficulties* experienced, are not necessarily generated by any deficit within the child, but rather fit the social model; *dis-abled* by barriers to inclusion within society, rather than *impairment* in the self. For example, within education, families report challenges are often a direct result of having to navigate a system that struggles to accommodate diversity, champions homogeneity and has little or no understanding of perceptual, sensorial and experiential differences; in essence, a system not designed for their children (Howlin, 1998).

This is particularly evident in mainstream schools where inclusion is predicated on supporting autistic children to *'fit in'* and manage with the existing framework, rather than creating an environment of universal access. For example, the term *reasonable adjustment* suggests '*we will offer some concessions to make it easier for you to access our environment, but we will not change it to be universally accessible*'. Such *concessions* then reflect how autism is perceived, tending toward the formulaic,

fitting children to the available educational approaches, as opposed to creating

approaches based on what the children need (Shevlin, Winter & Flynn, 2013). This

means the standard *trotting out* of visual timetables, ear defenders, fidget toys and

sensory rooms (*in my experience, often near empty large cupboards, frequently

resembling cells and more likely used for punitive [isolation] purposes than therapeutic

support)* as a potential *one-size-fits-all* for difficulties, together with the ever-present

social skills training, learning to be like everyone else. These *interventions* for autistic

children are still written into a high proportion of EHCPs, despite a growing knowledge

base that suggests interventions such as social-skills training leads to the suppression of

self-authenticity and increased *masking*, which is strongly linked to poor mental-health

outcomes, and an increased risk of suicide (Beardon, 2019; Chapman *et al.*, 2022;

Miller, Rees & Pearson, 2021). Therefore, arguably we need to step away from such

deficit views of autism, and instead *formulate* about an individual, recognising their

unique profile of innate abilities, skills, traits, strengths, differences and limitations that

will vary across their development as these intersect with external and systemic

influences, contexts and processes over time. This view of a person's development,

connects with Bronfenbrenner's bioecological systems process-person-context-time

[PPCT] model of development (Bronfenbrenner & Evans, 2000), discussed in 3.3.1.

Many autistic children, young people, and adults support this argument too, that

although they experience the world in a significantly different way than non-autistic

people, they are not deficient, just different. However, they are then disadvantaged by

their environment and the psychosocial expectations and norms from a non-autistic

dominant culture holding a narrowly defined view of *'normality'* sitting in opposition to

their particular perceptual preferences (Vassallo, Dallos & Mckenzie, 2020). They

experience pressure from the neuronormative social world that through the wider

'normative gaze' oppresses children to *conform* to a particular way of things, which

leaves them disadvantaged, excluded, or *dis-abled* if they do not. Autistic people will

tell you they try, but the expectation is for them to do all the work. Navigating a

neuronormative world for a neurodivergent person is exhausting, leaving little resource

for anything else.

3.2.4 *Converging constructions*

It should be recognised that, despite the desire within the autistic community to

move away from the medicalised discourses that pathologise difference, pragmatically

there is difficulty as well as advantage when applying a social paradigm *exclusively* to

constructions of autism.

The contradiction that exists between social and medical models is well

understood (Dyson, 2001). Therefore, adopting a more integrative stance is arguably

more sensible (Ravet, 2011), as reflecting on *both* medical and social models, rather

than the binary *one or the other* position, offers a more balanced view, as both models

have their strengths and limitations. For example, on one hand, medical labelling can

invoke assumptions and deterministic thinking and low expectations, marginalising by

highlighting differences as deficits within the person, increasing for example the

totalising risk, where the danger is the child becomes seen as *'the problem'*. On the

other, medical diagnosis allows for recognition of difference, identifying and meeting of

need and improving outcomes. The contrast provided by the social model that sites

deficits away from the person and *within the environment* is a helpful counterpoint;

however, cultural change is glacially slow and such models can negate people's lived

and embodied experiences (Owens, 2015).

The minimisation or dismissal of genuine difficulties (*2.3.2.1*) experienced by

autistic people and their families often occur within social models of autism, where

viewing autism through a purely *asset* lens, can make autistic children and families feel

further marginalised, as if they are *making a fuss over nothing*. In addition, by locating

problems as being entirely externally derived, one can place the autistic person and their caregiver in a position of hopelessness, where their agency is stymied, given they can do little to change the environment or society *in the moment* to ameliorate a presenting difficulty. Indeed, whilst the social constructionist perspective offers multiple and competing ways to understand ideas of autism, anti-realism extremes of social construction might seek to negate the existence of autism altogether (Runswick-Cole, Mallett & Timimi, 2016). This approach is particularly damaging for autistic people (Milton, 2016a) as it can undermine feelings of identity, identity that has more recently been adopted by a large proportion of the autistic community, having begun a powerful movement to shift attitudes toward a neuro-affirming view of autism (Singer, 2016) without the need to undermine the concept of neurodiversity completely, something the purist social constructionist might indeed argue for.

Additionally, approaching autism from a purely social perspective can also have practical implications within the existing real-world medicalised landscape, the autistic community must currently still navigate. We see this with the provision of adequate support, both in terms of education support and governmental funding for it, where help is often only accessed by subscribing to the medical model and acceding to a pathologising label.

Although there is an attitudinal shift beginning within autism discourses, particularly toward acceptance, in reality, ideology always outpaces action and change. Therefore, until the rest of society *catches up* and the equity of life chances for autistic people gain parity with those of non-autistic people, the uncomfortable truth is that the medicalised label remains something of a *safety net*. The removal of the label completely might, within the current landscape, undermine what little redress, power, or compensation the autistic community has to balance the inequities they experience and

damage any progress the autistic community has made in terms of identity construction and label ownership.

Whilst ideally differences experienced and expressed by the autistic community would be understood, accepted and fully embedded within society as being '*everyday'*, for instance just as being left-handed is nowadays (*let's face it, we once used to burn lefthanders at the stake*), this is not the current reality for autistic people or for those that love and care for them, and at the current rate of change will most likely, like left-handedness, take many years to even begin to resolve (*just as left-handedness is still not fully accepted within some cultures*). Therefore, while we try to find the *elusive-inclusive* societal ideal, we perhaps in the meantime need to consider an integrative position, the *space between* the medical and social polarities (Ravet, 2011), which is more accepting of the current *messiness* of things and allows us to connect with autistic people in a multi-dimensional way that avoids dismissing or pathologising perceptual and experiential differences, whilst still allowing us to flexibly, dynamically, and sensitively respond to, and respectfully capture, the diversity of the whole person, reflected upon in *Appendix B* and the shifting perceptions of autism.

3.3 *Bronfenbrenner: drawing on bioecological systems theory as an underpinning framework - the influence of the system around the child.*

An approach that avoids the simplistic contradictions inherent in a social vs medical dichotomy is Bronfenbrenner's bioecological systems theory (BEST) of human development (*Figure 2 Bronfenbrenner's nested systems*). It offers a view of the complex relational elements and pressures that are more broadly at play in a child's life, impacting their experience and ultimately their developmental trajectory and outcomes. In relation to autistic children and educational inclusion, Bronfenbrenner allows us to look beyond the influence of parents and teachers residing in the child's microsystem

and consider the effect of macrosystemic action, such as policy decisions which have the potential to influence context for the child and everyone involved.

Although investigating, critiquing and unpacking the function (*or indeed dysfunction)* of educational and political policy for the inclusion of autistic children is not one of the aims of this research, its contribution in both its current and historical forms, in terms of outcomes for this community, is important, as part of the system of influence across multiple systemic levels, as denoted in Bronfenbrenner's 'person, process, context, time' [PPCT] model within BEST (Bronfenbrenner, 1995a).
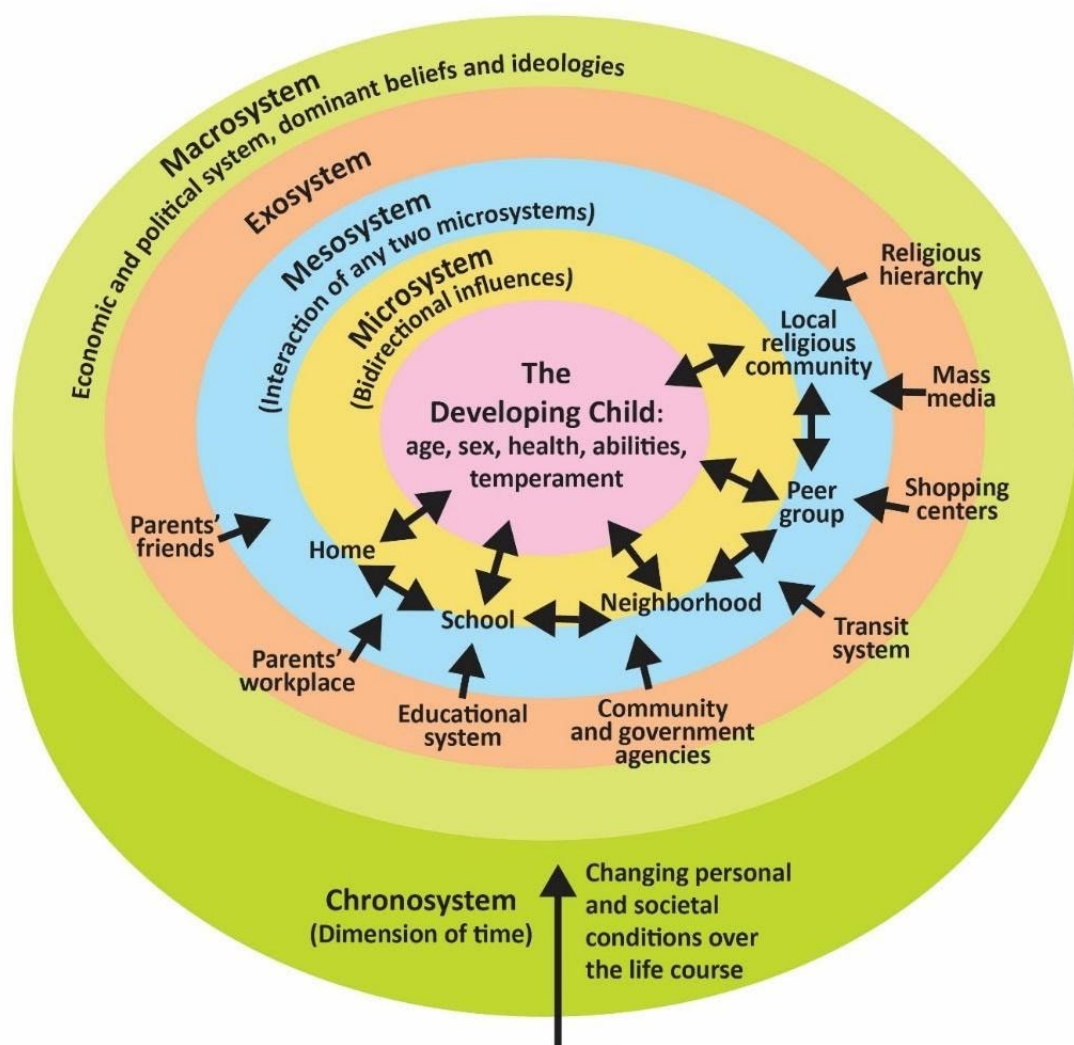
(Schull et al., 2021, p.59)

(Image by Ian Joslin licensed under CC BY 4.0)

Figure 2 Bronfenbrenner's nested systems

3.3.1 _Person process context time model [PPCT]_

Bronfenbrenner posits, when studying child development, we must look beyond just the child, and consider their ecology, their immediate and distal environments, and social contexts that influence the child's outcome and ultimate developmental trajectory.

He explores this in his later theoretical work, highlighting _transactional processes_ as being highly influential in human development (Bronfenbrenner, 1986; Bronfenbrenner, 1995a). By extending his original bioecological systems theory, Bronfenbrenner considers the complex layers of interdependent influences as well as bi- and multi-directional interactions that occur regularly and endure over _time_ (chronosystem), across a child's multiple environments or _contexts_, as being key to development, something he describes as '_proximal processes'_. Proximal processes are the repeated interactions between the child and significant others, usually found in domains such as study, problem-solving, skill acquisition, and group or lone play (Bronfenbrenner, 1995a, p.620). However, Bronfenbrenner does not exclude the unique contribution of the individual, the _person_, in terms of the innate biological traits, temperament and personal characteristics that each human brings to interactions across the course of their development, acknowledging each person is '_an active agent in, and on, its environment'_ (Bronfenbrenner, 1995a, p.634). Critically, he also makes the point that broad developmental outcomes in childhood that are shaped by _proximal processes_ with significant others across _contexts_, later become the very _innate_ personal biopsychological characteristics that are considered _agentic contributions_ as we get older, which raises the question, _are we really socially constructed after all?_

Bronfenbrenner also highlights the intersectionality of influence _on_ and _from_ the wider system around the child, particularly from mesosystemic relations, for example, the bi-directional interaction between the child's microsystem of parents and teachers, and the downward pressure of macrosystem influence such as educational policy, its

aims, expectations, and demands, and how these can proliferate like ripples on a pond, exerting their force and influence on systemic interaction (*particularly salient for teachers*), affecting how that system responds not only to the child, but also to others within the system (Bronfenbrenner, 1986) *(for example, choosing between including the child and meeting their needs or excluding in order to meet educational targets).* This is particularly important, as the child not only has a direct relationship with those within their close system, such as parents and teachers, but the child also has a relationship *with the relationship* between members of their system, such as how parents and teachers are together (O'Toole, 2016; Vassallo, 2023). It is this very influence from these close members of the child's system that this research is predicated on. Bronfenbrenner's bioecological systems theory provides a basic theoretical framework to explore this, by helping to conceptualise and explain the bi- and multidirectional influence between the child and their immediate and wider system, all acting on one another, to influence the trajectory of child development, based on this dynamic function (Milton, 2013).

3.3.2   *Macro-to-microsystemic influence: the ripple effect of policy decisions*

We can see how far the exchange of interactions reaches across the system, when we apply them, for example, to educational policy decisions such as funding cuts or process changes. Although these are made at a macro level, they directly influence at a micro or individual level, governing what type of support a child receives, or indeed whether they receive support at all. We can observe these systemic effects as they ripple across the system, impacting not only schools and teachers, but also the individual child and their family; examples of this cascade of influence on support, caregivers and children are offered in *Appendix C.*

3.3.3 *Why the home-school relationship matters.*

As explored in the examples in *Appendix C,* changes, even small ones, can have systemic effects which can be difficult for some autistic children to accommodate without significant support, requiring additional input and reassurance from both the parent-home context and the teacher-school context, as both are involved as part of the child's microsystem. If the child is not able to accommodate the change, this can lead to a state of anxiety and be reflected in their presentation at home or in school, or both. Anxiety (*one of the most common presenting difficulties in autistic children*) might make separating from the parent difficult or manifest in being unable to attend school (Adams, Simpson & Keen, 2018). Anxiety can also create conditions for withdrawal or more overt behavioural communication throughout the school day, as the child reveals their anxiety or frustration in the classroom, undermining the child's learning experience and making the teaching experience more demanding for the teacher, adding to their load or even diminishing their job satisfaction (Saloviita & Pakarinen, 2021). If the teacher is not aware of the home situation, or the parent is not aware of what is happening at school, neither can properly understand and support the child, as half the information is missing.

Effectively managing such nuanced situations to meet the needs of autistic children, or indeed any child, requires deeper knowledge of the child across contexts, underpinned by effective communication between home and school. Therefore, strengthening the immediate system around the child, particularly the relationship between parents and teachers, so each can support the other and each understands the other's context, providing the foundation to problem-solve together, may be protective against minor events becoming major difficulties (O'Toole, 2016; O'Toole, Kiely & McGillicuddy, 2019). As exampled in the following three sub-sections, an effective

parent-teacher relationship is essential to properly support autistic children in the current educational landscape.

3.3.3.1   *The importance of the child-teacher relationship*

For autistic children more generally, multiple transitions across the day, co-occurring anxiety, social isolation, bullying, and the sensorial challenge that comes from navigating a neurotypical environment, are all known common challenges that autistic children experience (Maiano *et al.*, 2016; McKinlay *et al.*, 2022). These can combine, undermining feelings of security, of school being a '*safe-haven'*, instead making it feel a hostile place to be.

For a child, having stability in the form of a secure relationship and connection to their teacher is important to stave off negative feelings and alleviate school related anxiety, anxiety that can impact across all domains (Caplan *et al.*, 2016; Losh *et al.*, 2022). As I explain in *Chapter 4* the teacher is integral to and completes the *circle of security* (Marvin *et al.*, 2002) as the child transitions from one secure-base (*home*) to the next (*school*) and from one safe pair of hands (*parent*) to another (*teacher*) and of course back again. In general, parents are constant, making attachment and security at home more comforting and a preferred place to be, offering that *safe-haven* all children need as they explore the world and gain experience.

Teachers, on the other hand, change frequently in primary education and the child must establish a new relationship each year. This is one of the most difficult transitions autistic children make; a process that if managed sensitively can be positive, but can also derail a child's school experience if it goes wrong (Losh *et al.*, 2022). Therefore, for example, a teacher deciding to leave halfway through a year might have significant impact on an autistic child, as this level of change could set off a cascade of difficulty, disrupting the stability and attachment they may have developed. This could have the potential to undermine a child's progress and derail their relationship with

school and learning, leading to behavioural distress in school, or even being unable to attend, increasing difficulties in the classroom, at home, or both, adding to the load of teachers and/or parents.

Whilst this scenario is again hypothetical, it is not in fact unusual and is borne out when we consider underpinning factors such as the aforementioned teacher attrition levels (McLean, Worth & Faulkner-Ellis, 2023) and school absence and exclusion rates for autistic children (Ambitious About Autism, 2018d), illustrating how decisions at one level might cascade and intersect at other levels, impacting the entire system around a child. It also highlights the importance of close parent-teacher relationships that may not only provide bi-directional information to support the child in the classroom, but also a parent-teacher relational element that is mutually supportive. If teachers have more information *(information that parents hold),* then shared knowledge about the child can make supporting the child easier. If teachers can better support the child, this will likely increase feelings of efficacy. Feelings of efficacy increase feelings of satisfaction in their role, reducing the chance teachers will leave (Perryman & Calvert, 2020; Price & McCallum, 2015)

3.3.3.2   *Autism in the classroom: a chance to make a difference or a drain on resource?*

In an ideal world, having autistic students could offer a school and its teachers an opportunity to be inclusive, a professional challenge and a chance to make a significant difference in the lives of children and their families, who face multiple disadvantages. However, depending on the *meaning* of autism (*and therefore the meaning of the child*) within school culture and personal experience of the teacher, it might also signal to both a resource drain and reputational threat. For a headteacher the meaning of autism might elicit pound-signs and present an economic concern or signal a potential threat to performance data and a good Ofsted report (Ball, 2004; Done, 2022;

Gómez-Marí, Sanz-Cervera & Tárraga-Mínguez, 2022; Shukry, 2017). Performance pressure within school culture changes the meaning of autism to teachers, creating bias generated by labels within an inclusion framework (*such as it is*) in target-driven mainstream education. It can create internal conflict in teachers, between being child-centred and meeting needs, and succumbing to performative pressures of doing just enough to '*tick the right boxes*' (Perryman & Calvert, 2020) to keep their jobs. Therefore, when you turn a service (*education*) into a business and hang careers and livelihoods from a school's Ofsted score, a score dependent on homogenous arbitrary measures such as GCSEs and SATs results being attained by your students, you immediately highlight any child that might cause that target to *drift* as being a *problem*.

As the years proceed toward tests and exams and the pressure on schools and teachers to *get results* increases, autistic students are often viewed as an unsustainable drain on resource and a risk to the school's performance indicators (Ball, 2004; Shukry, 2017). Therefore, the temptation to sacrifice their progress or even reject them altogether can become too great, demonstrated in the high levels of '*off-rolling*' and *exclusion*s which, despite efforts to bring numbers down, are still equivalent to levels a decade ago (Long & Danechi, 2019). In their '*We Need An Education*' report Ambitious About Autism (2018b) showed, although overall exclusions in schools had increased by 3.7% between 2012 and 2016, exclusions for autistic students had risen by almost 60% during the same time period. Provisional estimations show that trend to be continuing upward, notwithstanding the shift in pattern due to the Covid-19 interruption where, at the time of writing, adjusted figures are still being processed. However, reports suggest access to education for autistic children suffered significant collateral damage during the pandemic, as educational focus turned to meeting the needs of the majority *value-positive* students, suspending statutory responsibility and even forcibly delaying the return of autistic students after schools had reopened and non-autistic

students had been welcomed back (Crane *et al.*, 2021; Genova, Arora & Botticello, 2021; National Autistic Society, 2020).

Low levels of teacher confidence to teach autistic students and a lack of comprehensive and ongoing training compound this, increasing the likelihood of exclusion, either within the classroom environment, or from the school altogether. In their report '*The Autism Act, 10 Years On'*, the All Party Parliamentary Group on Autism (2019) identified less than 50% of teachers felt they had the requisite skills and training to meet the inclusion agenda and teach autistic children properly. This figure has not improved since the reforms of 2014 when 60% of teachers said the same thing when polled (Ambitious About Autism, 2014). This not only puts a strain on teachers operating in conditions that increase their own anxiety, but highlights an enduring gap in professional development, teacher knowledge, and investment, which not only impacts their autistic students, but has systemic ramifications for the other children in their charge.

Again, the power of the parent-teacher relationship to work together to resolve problems takes centre stage here. It is shown that when parents are involved in their children's education, outcomes for the child both academically and socially are improved (Đurišić & Bunijevac, 2017; Goldrich Eskow *et al.*, 2018; Hornby, 2011), a result welcomed by parents, desired by teachers and essential for schools wanting to retain or improve their status in a *performance-based target-focussed* education system.

3.3.3.3   *Teachers as role-models and 'bridging' attachment figures*

What a teacher *does* is highly influential on all children, as a child's main teacher is a key member of their microsystem (Bronfenbrenner, 1979). Primary school teachers can spend more than half of a child's waking hours with them. They are not just educators, but also role models, and even *bridging* attachment figures (Verschueren & Koomen, 2012). As such, children take their lead from their teachers' actions and

seek comfort from them. By demonstrating exclusion, rather than embracing a child's differences as valuable part of the whole classroom community, the teacher has the potential to influence the behaviour of other children toward their autistic peers, and so perpetuate, or correct, societal misunderstanding about, and behaviour toward, autism across the next generation. Students who share a classroom with autistic children and see them being rejected from within by adults, perhaps by their removal to a corridor with a teaching assistant, by being seated on a separate desk away from others in the shared learning space, from derogatory *comments* made toward them, or as seen in *Figure 1* simply ignored and stepped over, go on to assume this is what you *do* with autistic people, and that it is *okay*. When this happens, opportunity for non-autistic students to connect with their autistic peers (*and vice versa*) is immediately limited and limited further still if this response to an autistic child by their peers is then extended to the playground. This type of adult modelling reinforces *othering* behaviours by children, signalling to them, it is acceptable to exclude on the basis of difference.

As discussed in *1.2.1.2,* currently there are few (*if any*) measures in schools designed to enrich social attitudes of *'all'* children and ensure the autistic perspective is more widely understood and accepted, whilst at the same time giving autistic students similar opportunities themselves, to learn about and understand others. Instead of educating on *difference* to help autistic and non-autistic children understand and accept and value one another, redressing the power imbalance, autistic children are encouraged to change and *fit in,* to be more like the non-autistic majority. School reports and parent-teacher meetings are peppered with suggestions that *'[child] brings it on themselves', 'they just will not fit in'.* This maintains the message that because autistic people are different, they are '*wrong*' and therefore must make all the concessions. They must adjust and be more like their non-autistic peers, as their authentic selves are less valuable. To the non-autistic population, it highlights this person is *not one of us*.

Again, the home-school/parent-teacher relationship is crucial here, as inclusive classrooms are not always popular with *all parents*, who may feel their *typical* child is in some way disadvantaged by it (Sira, Maine & McNeil, 2018). Children are not born prejudiced; it is learned along with resulting behavioural discrimination largely from significant adults and surrounding culture. Children internalise negative emotions and responses that they witness adults attaching to a group, and in turn may go on to make similar associations (Marks, 1997). However, exposure to significant adults who do not hold these views can be protective against developing such exclusionary social attitudes (Sira, Maine & McNeil, 2018). Therefore, a strong relationship with the parents, not only of the autistic child, but of other parents, is essential in order to share knowledge and engage in any problem-solving needed to ensure the classroom culture reflects inclusivity and that everyone is comfortable with that. This is important as these young people will grow up to be adult peers, employers, future community leaders and so on (Albuquerque, Pinto & Ferrari, 2019; Bhargava & Narumanchi, 2011). Therefore, teaching and modelling genuine inclusion and acceptance in school is paramount for a societal shift in attitudes to occur, to improve the likelihood of autistic children going on to meet their potential, or at the very least finding a place of belonging in the world.

3.3.4 *Theoretical Perspective & framework*

The theoretical perspective could be described as the standpoint from which one views the world, guiding thinking, which ultimately influences the structure of research. I am by nature a systemic thinker, which steers me to toward the ecology of a context, focussing on the interconnected nature of the social world and its infinite complexity. My thinking about the social world reflects that complexity in its flexibility, consideration of multiple perspectives, and interconnectedness of relationships, as in the case of this research. I accept that nothing happens in a vacuum, that as a society we all influence and are influenced by each other, from an individual micro level, through

family systems, to broader contexts of collectives or groups that make up our wider social world. As complex beings, I accept our actions, experiences, and reactions are not entirely independent, but partially determined by the multi-layered and far-reaching influences of our own close and more distant systemic influences.

To best illustrate this, Bronfenbrenner's bioecological systems theory [BEST], (Bronfenbrenner, 1977; Bronfenbrenner, 1995a; Vélez-Agosto *et al.*, 2017) provides the theoretical lens through which the power and influence of such complex systemic relationships can be viewed, not just in the study of autistic experience, but also those who interact together around the child, particularly within the child's immediate microsystem. Using the principles of attachment narrative (Vetere & Dallos, 2008), a core tenet of the SwiS approach, the experiences of my participants were explored, and their interactions better understood systemically.

The underpinning rationale for this choice of theoretical perspective, is that BEST suggests the family unit, however it is defined, is inextricably linked psychologically, emotionally and physically, and that the system has a profound influence on the thoughts, feelings and behaviours of its constituent members (Bronfenbrenner, 1991; Cridland et al. 2014; Dallos & Draper, 2010; Kerr, 2000). This provides an explanation for why a systemic approach can be a positive one for autistic children, as it sets aside any preconceived ideas that accompany the label, allowing us to look at the context in which the child is situated and all its influences, rather than just looking at '*the autism*'. BEST allows us to explore the interconnections between system members and interaction feedback loops that influence and maintain communication and behaviour between those system members. Just like the reflexivity and integration of my philosophical position, BEST allows for a dynamic, multi-faceted, complex but flexible view to unpack relationships and view the power of central and peripheral interactions that directly, as well as indirectly, influence the child.

Attachment narrative complements this, uniting family systems and attachment theories with ideas of narrative development to offer an integrated approach to systems of thought for exploring and interpreting the experiences of parents and teachers, their constructions of autism, formulating their experience and disclosures to interpret and make sense of them within a systemic framework (Vetere & Dallos, 2008).

Small changes in the parents' or teachers' response to the child, can have implications not just for the child, but also for each other. Interactions at home, impact subsequent child behaviour and interaction at school, and vice versa. Attitudes about school from home, influence the child and their feelings of safety toward that setting, also vice versa. In effect, home and school *'encircle'* the child, creating their main system, and the triadic processes and interactions between those within that system, influence the child, as well as each other. It is for this reason this research has widened the definition of the core members of the *'family system'* to include not only the child and their parents, but also their teachers *(residing in the child's microsystem)* (Bronfenbrenner, 1991). This allows the consideration of the effect those system members have on one another and ultimately on the child. The justification for defining the system in this way is based on the high degree of contact and measure of influence both parents and teachers have on the child, particularly during primary school years, the age focus of this study.

3.4   *Why we need to think systemically*

3.4.1   *The value of and impact on the system*

In consideration of the sometimes-competing priorities between parents and teachers and the poor outcomes for autistic students, it is perhaps important and significant that both parents and teachers report an overlap, in terms of the core difficulties they experience raising and educating their child. Both parents and teachers cite communication and *'behavioural'* difficulties as key stressors underpinning

problems they experience across many domains of family life and professional practice, but with differing effects (Vassallo, Dallos & Mckenzie, 2020).

3.4.1.1 *Parents*

For parents, socially, the behavioural differences in their children, fuelled by a lack of understanding about, and negative responses to autism by the general population, contribute to relationship tensions, exclusion from social activity, the evaporation of friendships and even loss of family support (Krakovich *et al.*, 2016).

On a practical level, lost productivity and resulting financial strain are commonplace (Hurley-Hanson, Giannantonio & Griffiths, 2020), as parents learn they have to drive the fight for even basic support for their child, in many cases exchanging *career for carer*, quickly learning that compared to other conditions support for autism is scant, and what is available is hard-fought, particularly to gain any level of equity in education and life chances for their child (Ganz, 2007). Cognitively, expectations for the future are often replaced with fear, as parents are kept awake by thoughts of what will happen to their child when they are no longer around to advocate for them (Silberman, 2015, p.14; Vassallo, 2016). This coalesces to ensure parents of autistic children experience greater psychological distress and anxiety than parents of neurotypical children or even parents of children with other disabilities, feeding depression and mental health problems in over 50% of parents (McKenzie *et al.*, 2019; Myers, Mackintosh & Goin-Kochel, 2009).

What is striking in all of this is that each domain of life negatively impacted is underpinned by parents operating in isolation, exacerbated by a lack of systemic support, because the normal system around the child *(and by default around the parent),* has shrunk.

3.4.1.2   Teachers

As school makes up a significant part of an autistic child's system, its value and importance cannot be overstated in terms of its effect on child outcomes. Just as with typically developing children, what happens to an autistic child at school has the power to be transformative, the difference between their success and failure (Ambitious About Autism, 2018c), making the child's teacher a pivotal part of their system. Yet in mainstream education, teacher attrition rates have soared and school exclusions for autistic children are unacceptably high, further shrinking the child's system, undermining the consistency and developmental benefit that a positive school life brings (Ambitious About Autism, 2014).

The level of exclusions for autistic students has burgeoned disproportionately (Ambitious About Autism, 2018d; Ambitious About Autism, 2018b), possibly as a result of conflicting priorities within the mainstream education system, where careers are determined by academic outcomes being the primary measure of success, whilst additional pressure on schools to provide a fully inclusive education for students with SEND is ever present. However, inclusion is expected to be provided in the face of increasing austerity and budgetary cutbacks and delivered by teachers who feel they lack the requisite skill-set to do so (Ambitious About Autism, 2018c; Roberts & Simpson, 2016). As touched on in *3.3.3.2,* inclusion training is woefully inadequate for teachers, and what is provided is often out of date and ineffective. Until recently, learning about SEN in general could be avoided almost entirely in degree courses for newly qualified teacher (NQT) status, an obvious gap, given that 15-20% of pupils on-roll at any one time have some level of SEN, with autism accounting for almost one third of statutory education health and care plans (EHCP) (Department for Education, 2018; Nash & Norwich, 2010). In my ongoing discussions with teachers, the availability of inclusion training for other types of SEN (*e.g. EAL, mobility, medical and*

sensory impairment etc.) has improved slightly in terms of resources and professional development; however, the two main areas of difficulty that persist in the classroom that teachers feel are most problematic are communication and overt (*challenging*) behaviours. Both continue to receive little or no attention in terms of specific teacher training and wider support in mainstream education, yet both are absolutely central to autism. Teachers report class disruption as responsible for increasing their stress and diminishing their feelings of self-efficacy and professional competence to manage such situations, resulting in burnout (Hastings & Bham, 2003; Maslach, 1976; Pas *et al.*, 2010). This is partly due to a greater teaching load and increased pressure for improved academic results, and partly because the push for inclusive education has meant that every teacher now needs to be a SEN teacher, an unrealistic expectation without the requisite training and effective support at their disposal (Ruble & Dalrymple, 2002).

In an educational landscape where teachers must constantly defend their professional reputations in the face of increased classroom diversity and often performance related pay, where a poor Ofsted report can be career-ending for a Headteacher, and success for a school is measured in SATS or GCSE results, then as a consequence the desire to remove anything that might impede either of those measures becomes an obvious *'quick-fix'* and may explain the rise in exclusions and off-rolling for autistic pupils. The cost of autism, both human and financial, continues to rise (Ganz, 2007) with little alteration to the status quo.

3.5 *Introducing SwiS as a novel framework for exploring autism-related difficulties.*

Considered from the medical model, early autism research has had a strong focus on understanding its aetiology, which meant experimentation on children with a diagnosis, was not uncommon (Alpern, 1967; Hermelin, 1970; Saini *et al.*, 2015); for example, aforementioned intervention forerunners such as Ole Ivar Lovaas researched

techniques such as Applied Behavioural Analysis (ABA) (*1.3.2*), developing

behavioural models of intervention to *train out* autistic traits (Lovaas, 1977; Lovaas,

1987). For Lovaas and others in his field, their aim at that time was not so much to

'teach' or *'upskill'* autistic children as modern ABA-based techniques purport to do

today by teaching latent concepts *(for example, joint attention, something generally

innate in typically developing children)*, but to alter the presentation and functioning of

autistic children, so they '*learned to appear'* indistinguishable from their non-autistic

peers by *'masking'* their autism. Respect for, and understanding of, the autistic

perspective and the benefits of neurodiversity to wider society was not understood, as

autism at that time, was considered a devastating lifelong disability to be feared and

eradicated. Therefore, the legacy of interventions meant a general focus on *changing

the child*. These early crude and ethically dubious beginnings of autism intervention

and research have thankfully begun to give way to greater understanding of it,

witnessing the beginning of a shift from scientist-led research to a more shared *scientist-

stakeholder* approach. Research to understand the autistic perspective, to share

understanding of why perceptual and experiential differences occur, is more often being

undertaken in conjunction with autistic people and their families. This rightly keeps

them, at the centre of any exploration, reflecting their maxim *"nihil de nobis, sine nobis

- nothing about us without us",* a phrase adopted by, and fundamental to, the autistic

community.

However, interventions are often still largely targeted at *changing* autistic

children. Many are designed for the school context, delivered in the classroom and are

fairly well established, as are interventions designed for the home context, delivered by

parents. What is missing however, are approaches that do not aim to fundamentally

change the child, but instead accept the child and their view of the world as they are,

and instead, act on, and support the *system* around the child to find more holistic

solutions to difficulties (*which often occur as a result of their rejection*), by supporting making room for and respecting autistic differences, so *everyone has what they need to participate*, something more reflective of genuine inclusion.

A gap in the literature exists, in terms of such programmes of support, in particular those that operate systemically across both home and school contexts. The novel approach of SwiS to help address this gap sits central to this research. SwiS as a systemic, attachment-based programme utilises a family therapeutic framework and established techniques and ideas from systemic family therapy to help parent-teacher caregivers explore relationships and challenges related to autism in a safe and supported way. It aims to understand how as caregivers around the child they make meaning of autism and encourages the development of positive communication and problem-solving between them. This study will explore parents' and teachers' participation in SwiS as a novel approach to parent-teacher interaction, to understand their constructions of autism and whether SwiS is experienced as helpful.

Developing and maintaining a positive home-school alliance is not an easy task as there is often a mismatch in goals, beliefs and understandings between parents and teachers. Conflicting views become more important when difficulties arising at school or home, occur as a result of problems within the other context, or as an interaction of the two. The differing views, priorities and approaches of caregivers be confusing for the child, which can create tensions between parents and teachers, who then position each other as part of the problem instead of part of the solution (Hornby, 2011, pp.19). Poor parenting is often cited by schools and teachers as the reason for perceived behavioural challenges from autistic children, and equally parents cite teacher and school response to their child and inadequate levels of support as being responsible for their child's poor educational outcomes and the behavioural distress their child displays once back in the safety of their home.

There are evidenced-based interventions to support autistic children but because autism is generally thought of intrapsychically, as a biological condition of the individual's mind, rather than as a result of systemic influence, their focus tends toward treatment of the child, locating problems with *them*. However, if taken in isolation, as discussed in *1.3,* the more common presenting features, characteristics and preferences of autism are rarely problematic for the person with them. Indeed possessing atypical behavioural expression and unique cognitive and linguistic styles are not in themselves detrimental to the autistic person or to anyone else as Francesca Happe's maxim of *'pure autism never comes to clinic'* (Happe, 2018) suggests. It is only when these characteristics are rejected by wider society, demanding they change, and societal value and acceptance made contingent on change occurring, that style and expression become pathologised. However, instead of trying to *'change'* an autistic person or constrain them by non-autistic norms and experiences, what if we explored the world from a different viewpoint – the autistic person's viewpoint? Would a collaborative home-school problem-solving approach improve caregiver understanding of the child's viewpoint? If so, how would caregiver-child interactions be made different by that increased knowledge? From a systemic perspective, could a deeper understanding of each other's contexts be perceived as mutually supportive for parents and teachers improving confidence and feelings of efficacy, reducing stress on both? It was hypothesised that improved synchrony and positive communication between caregivers might reduce conflict, increasing consistency and predictability across contexts for the child, making the home-school transition more comfortable. If so, might cross-context consistency for children result in increased opportunity for targeted teaching/learning? Would this approach '*impact the impact'* of perceived autism-related pressures on everyone within the system? These are some of the questions this research explores with the parents and teachers within this study.

Chapter 4

The SAFE with Schools [SwiS] programme: its evolution and theoretical background

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4.1 Introduction

In this chapter I will describe the SAFE with Schools (SwiS) programme, a systemic attachment-based framework designed to support parents and teachers of autistic children explore difficulties and improve their relationship through more effective problem-solving. The chapter will explore how SwiS evolved, its theoretical background and present the programme in a manualised format in Part-2 of *Appendix D.*

4.2 Systemic Autism-related Family Enabling: introducing the SAFE programme.

SwiS evolved from the intervention programme Systemic Autism-related Family Enabling (SAFE) (McKenzie *et al.*, 2020; McKenzie *et al.*, 2019; Mckenzie *et al.*, 2017). SAFE was initially created as a package of support for families of children given a diagnosis of autism. It was designed in collaboration with autistic children, young people and their families, together with a small team of clinical and developmental psychologists and family therapists. The programme was piloted at a university in the Southwest of England.

4.2.1 The original SAFE approach

SAFE is a manualised approach offering a package of support to families, incorporating the core principles of Attachment Narrative Therapy (ANT), (Dallos, 2023) and based on established Systemic Family Therapy techniques. It uses playful, family-led activities informed by attachment and narrative theory (McKenzie *et al.*, 2020), drawing on multi-family therapy (Asen & Scholz, 2010), the work of Marvin *et al.* (2002) - the Circle of Security, together with the *'known strengths and preferences*

of autistic people' (Stancer, 2023). It is designed to be delivered within the first year of diagnosis, although it could also support families during the protracted pre-diagnostic wait, or adapted to support other challenges, such as eating disorders, ADHD and anxiety. SAFE's array of activities aim to complement the autistic perspective, in conjunction with therapist expertise, to *unstick* families from negative patterns of thinking and interaction around ideas of autism, aiding problem-solving and improving familial communication (McKenzie *et al.*, 2019). Many of the core elements of SAFE that focus on the multi-layered dynamics within family systems are distilled into the SwiS programme. These are described in more detail throughout this chapter.

SAFE for families consists of a minimum of five therapeutic sessions, combining individual family therapy sessions and multi-family therapy sessions delivered over a sixteen-week period (McKenzie *et al.*, 2019). The individualised family therapy allows families time to *slow down* and *step back*, to look at problems differently, such as tracking patterns of interactions, modelling and role-play. These activities are designed to involve the whole family, as a core assumption of systemic family therapy is that problems often exist as a result of relationships *between* people, rather than sited *within* a single person (Dallos, 2023). SAFE gives families an opportunity to shift thinking away from the dominating autism discourse often accompanying the medicalised view of autism diagnosis, which is often the only view families have been exposed to. For parents, this medical perspective can create a *totalising* view of their child *(discussed later in this chapter)*, an *autism-saturated* narrative locating difficulties solely within the child, creating beliefs in parents that this is a fixed state, that difficulties are there *because of the autism*, and therefore there is nothing they can do to change their situation.

The SAFE multi-family therapy sessions provide an additional dimension for support, a forum for collaboration and shared experience so families feel less alone. As

isolation is common where there is a diagnosis of autism in the family (Woodgate, Ateah & Secco, 2008), engaging in peer support and shared experience is important, as this is known to be helpful across many areas of difficulty (Altiere & Von Kluge, 2009). Within these sessions families have a chance to share difficulties and successes and become consultants to one another, in an environment fostering reciprocal support and knowledge exchange, together with a sense of community and belonging.

4.2.2   *Development of SAFE*

SAFE's development was in response to an emerging and recurring local pattern of need, identified in families of children given a diagnosis of autism, and the national recommendations for better-quality support, care and services for the autistic community (McKenzie *et al.*, 2021). Further investigation of this phenomenon showed that difficulties and concerns locally reflected the national picture where pre- and post-diagnostic support for families was at best limited (*usually to the offer of 'parenting' classes which most families found unhelpful and patronising*), but more often was non-existent in the UK (Crane *et al.*, 2018; Crane *et al.*, 2016; Rutherford *et al.*, 2016). Families reported having to *do battle*, sometimes enduring years of delays in the wake of inadequate services, just to receive some acknowledgement of, and explanation for, their child's distress and unique developmental trajectory (O'Reilly *et al.*, 2017; Rutherford *et al.*, 2016; Vassallo, 2016). However, a common factor across families was, and is, that once they received a diagnosis for their child, they were left with no more information of how to support their child than they had before, except now their child had a label, suggesting a complex and nuanced set of needs that parents were left no offer of help of how to meet. This post-diagnostic lack of support often left parents feeling ill-equipped and frightened for the future. Research suggests this was not unusual, as 94% of parents experience this worry (Wallace, Parr & Hardy, 2013). However, this is often accompanied a downward spiral of stress and challenge, as their

child experiences increased difficulties, in the face of diminishing support (Vassallo, 2016). A point of writing, recent years have seen an overall worsening picture for inclusion nationally, with yet another set of SEND policy reforms on the way (Department for Education, 2022a) to try to *fix* the broken system designed to help children, but struggling under scrutiny, as well as the legacy from the Covid-19 pandemic, further reinforcing the dispensability of autistic life embedded within the system (Scorer, 2020).

More locally, parents describe feeling increasingly excluded and under pressure for their children to adhere to social norms, particularly in school, but also in familial or wider social situations, compounding over time, leaving children excluded for their autistic perspective, and parents criticised and judged as *incompetent*, with little or no help available for those who ask for it (Dallos, Grey & Stancer, 2022; Denman *et al.*, 2016; Vassallo, 2016; Woodgate, Ateah & Secco, 2008). SAFE was designed to help bridge the post-diagnostic support gap.

4.2.3 *Current position of SAFE: Definitive clinical trial*

Positive results from the primary outcome measures of SAFE resulted in support for a wider NHS definitive clinical trial to be undertaken and currently progress is being made towards that aim. This is particularly salient, as post-diagnostic support and family services in autism are still acknowledged to be largely inadequate and often absent across many local authorities in the UK (Department for Education, 2022a; Department for Education, 2023; Westminster Commission on Autism, 2016), where the current 2023 educational discourse in terms of inclusion remains one of systemic and nationwide failings (Done & Knowler, 2023).

4.3 *Overlap of difficulties: repeated family stories*

Despite the uniqueness of every autistic person and their family, certain broad and common difficulties are often seen within autism research, such as navigating communication differences, environmental challenges, emotional distress, and levels of poor mental health (Stancer, 2023, p.139). These are frequent in both children and parents, relationally connected to experiences of exclusion, rejection, isolation, and blame, particularly from those external to the core family. Similar challenges were found across many of the families within the SAFE programme. However, more specifically (*and emerging early in the SAFE research*) repeating themes of family isolation and challenges around transitions, especially to-and-from school, were revealed (McKenzie *et al.*, 2020). Family stories of difficult relationships with educational settings, often accompanied by perceptions of parental blame for a child's autistic presentation in the classroom, were common and repetitious (Dallos, Grey & Stancer, 2022; Vassallo, Dallos & Mckenzie, 2020). These experiences were apparently typical for UK families which in contrast to our Australian experience as a family returning to England, *we* had also begun to encounter.

4.4 *Contribution to development: The evolution from SAFE to SwiS.*

SwiS evolved from a blend of research findings from the SAFE programme (McKenzie *et al.*, 2020; Mckenzie *et al.*, 2017) and my own *contrasting* experiences of education as a parent of an autistic child as detailed in *Chapter 1 -and Chapter 2* .

Being active within the local autism community, voluntary and educational sectors in the UK, an opportunity at the university as a visiting lecturer in autism introduced me to the founders of the SAFE programme, where I became involved with the research during its early phase and took an active role in SAFE's development. As a special education practitioner, with a psychological background, and most importantly being part of a neurodivergent family and the parent of an autistic child, I brought to the

SAFE research an authenticity and unique insight that broadened SAFE systemically, by introducing a wider community perspective that was invaluable to the eventual development of SwiS. As systems theory is applicable beyond the confines of the family, I was able to highlight the link to ecological systems theory and the influence of school. This contribution enabled me to play a central role in the development of both SAFE and SwiS, where for SAFE I initially consulted as a parent/family representative, offering community support and liaison to the families, providing a familiar *link* within the research, as someone who could share in their experience. I then further deepened my research involvement, undertaking the full therapeutic training with the SAFE programme therapists to support my wider roles as researcher, PPI (*patient and public involvement)* representative and co-applicant on the SAFE research bid, where the project undertook its aforementioned NHS feasibility trial (McKenzie *et al.*, 2019).

4.4.1 *SAFE pilot and feasibility study outcomes: the element of SAFE for families that illuminated SwiS.*

A key outcome from both the local pilot study and wider NHS feasibility trial of SAFE was that it was helpful to families on dimensions of improving communication, family functioning and overall wellbeing, reducing feelings of familial stress and isolation (McKenzie *et al.*, 2021). However, as I helped extract these finding from the narratives from participating families, I also observed that families were experiencing much broader systemic difficulties and needed support, particularly when navigating the education system, highlighting the needs of their children were at odds with educational expectations, which connected strongly with my own contrasting experiences of navigating the education system, first positively in Australia, then less so in the UK. This pattern of negative experience for families was enduring. The *battle perception* to obtain meaningful and appropriate support for their children (*something I had also*

explored in my earlier research) (Vassallo, 2016) was still very much a key issue for parents and a source of considerable distress (Yates, Keville & Ludlow, 2023).

Some of the source of this distress is often attributed to the limited understanding of, and response to, the autistic perspective within education, as this often results in misunderstanding and exclusion for autistic children and means many families are often in disagreement with schools and teachers (Brede *et al.*, 2017). For the SAFE families, the consequences of such a lack of understanding, together with unmet needs, school demands and subsequent punitive actions on their children, cascaded to distress to the wider family.

My role in extracting these findings within the SAFE research, placing them alongside a broader systemic stance, together with research from a community and insider perspective, led to the development of SwiS (Vassallo, 2016). Within the wider research, relationships between parents and teachers were also reported as being at best strained, often in conflict or non-existent, with general communication between school and home following a similar theme (McKinlay *et al.*, 2022). Parents reported feelings of being *in the dark* as to what was happening to their children when they crossed the school threshold, and then having to *pick up the pieces* when their children came home upset and anxious after the school day, often distressed as a consequence of the day's events (Vassallo, 2023). This *detached-from-school* experience was happening within families, despite previous educational reforms (GOV.UK, 2010; GOV.UK, 2014b; GOV.UK, 2015) directing schools to co-produce all educational decisions in partnership with parents and families, ensuring the voice, views and needs of children were heard and responded to at every juncture of their educational journey (GOV.UK, 2015). There was no resistance to this from parents; all were hungry for increased connection to their child's school.

4.4.1.1 Inclusion stress and the isolation of teachers from families

Working in the education sector myself, as a university lecturer and researcher in child development and education (*with an autism specialism*), I was beginning to see a pattern of increased teacher stress in response to inclusion pressures, central to the reforms at the time, that *'every teacher is a teacher of SEN'* (NASUWT: National Association of Schoolmasters/Union of Women Teachers, 2016). Teachers were (*and to-date still are*) leaving the profession at a rate of approximately a third within five years of qualifying and over 40% leaving within ten years of qualifying, taking a wealth of experience, expertise and intellectual property with them (Department for Education, 2019; Department for Education, 2022b; Worth, 2018). If *inclusion pressure* is a factor in teacher attrition, then research to understand and offer remediation of this is critical.

The idea of *inclusion stress* is supported by literature suggests teachers' perceived self-efficacy ratings of how to manage and support autistic students is directly linked to levels of stress and burnout (Boujut *et al.*, 2017; Hagaman & Casey, 2018). In a study by Ravet (2018), both graduate and student teachers described autistic students as '*unapproachable*' and teaching them as '*terrifying*'. Teachers often report feeling overwhelmed by their students and a *disconnect* from the students' families, creating feelings of resentment, judgement and bias. These attitudes towards families of autistic children and other students labelled as having *special educational needs*, who have different communication and perceptual preferences and overt behavioural presentations, are significantly entrenched within the teaching domain and serve to exacerbate tensions in relationships between home-school contexts (Dickson *et al.*, 2018), where those immediately around the child are not working together optimally, or indeed in some cases, at all. In their longitudinal study, Ravet (2018) identifies the importance of increasing opportunities for teachers to work systemically, in *partnership* with parents to resolve this, as currently many teachers simply do not want to teach

these students, as (*due to implementation of inclusion policy preceding adequate teacher training*) teachers feel ill-equipped to do so.

The focus on targets and school performance (Hall, 2023, p.76) is recognised to be at the expense of teacher training (Ravet, 2018). Hence teachers are not prepared for the increasingly diverse cohort of children they now receive and go on to educate. Such a back-to-front approach to inclusion arguably contributes to the poor outcomes for autistic people and needs addressing, but also raises other questions about the unsustainable myopic focus of '*performance targets*' and the '*business of education*' under a neo-liberal political gaze (Hallett & Hallett, 2023). The ramifications of this impact our most vulnerable children in terms of exclusionary practices (Done & Knowler, 2023) and miss the value and opportunity that comes from having a broader vision of diversity.

This lack of '*joined up*' systemic practice in UK schools, sitting in contrast to my own experience of inclusion in Australia a decade prior, provided additional inspiration for the SwiS intervention and shaped the framework for its development and how we might effect positive change for autistic children, despite inclusion challenges.

4.5 *SAFE and SwiS: a shared theoretical base*

The SAFE and SwiS programmes incorporate a combination of theories, ideas, and understandings of child development and the nature of autism in terms of its individual perspective. Both programmes draw on principles and techniques from, systemic family therapy (SFT) and attachment narrative therapy (ANT), incorporating attachment theory to facilitate those around the child in communication and problem-solving together (Dallos, 2006). Both frameworks support a competency- and strengths-based approach recognising that with support, solutions to problems tend to emerge from within family systems, from individuals and caregivers (*parents and wider family members*) and, in the case of SwiS, extending the child's '*system*' to include

teachers (Vassallo, 2023). SwiS supports those wider family systems to build on those

strengths and family dynamics, developing strategies to improve problem-solving,

making management of everyday challenges easier.

4.5.1 _Systemic family therapy and autism_

As with SAFE, SFT is central to SwiS. A well-established and recognised

psychotherapeutic approach, SFT is used to help support those in close relationships, to

explore and express difficult emotions in challenging situations and find solutions to

problems (Dallos & Vetere, 2021). It is suitable for adults and children, and used to

support other conditions such as ADHD and Anorexia (Dallos & Draper, 2010;

McKenzie _et al._, 2019). SFT is particularly helpful with difficulties involving adult-

child dynamics and has been shown to help families in many areas, including school-

related problems (Carr, 2014).

4.5.2 _Unique contribution to knowledge and the need for a systemic approach_

However, the application of SFT as an intervention to support autism-related

difficulties specifically, is an under-researched area. Although there is some evidence

that SFT can be beneficial to autistic children and families (Monteiro, 2016), as

explored in _5.7.1,_ a Cochrane library systematic review found few studies have

investigated the efficacy of this approach, and none where a randomised controlled trial

was employed to provide a more robust methodological design (Spain _et al._, 2017). To

the best of my knowledge, the feasibility study for SAFE was first to do this (McKenzie

_et al._, 2020; McKenzie _et al._, 2019; Mckenzie _et al._, 2017) and the SwiS study the first

to explore a systemic approach within schools (Vassallo, 2023).

This dearth of research in the use of SFT to support the difficulties associated

with autism is a surprise, given the political agenda around autism and associated

statutory recommendations which highlight the value of systemic practice with families

for all children with specific educational needs. Indeed, as discussed in *5.1,* systemic practice is the foundation of co-production, which is now a priority within policy, which at the time of writing sits within the 2014 Children and Families Act (GOV.UK, 2014b) and its operational guidelines that forms the 2015 SEND Code of Practice (GOV.UK, 2015), and centrally embedded within the new SEND reforms (Department for Education, 2022a)

4.5.3   *Attachment Theory and SwiS*

The Bowlby-Ainsworth theory of attachment (Ainsworth, 1973; Ainsworth & Bowlby, 1991; Bowlby, 1958; Bowlby, 1969), which draws on psychological, ethological, bio-evolutionary, systemic, and object-relational understanding of human development (Dallos, 2023), and resulted in a partnership of almost half a century and the development of theory that is still a cornerstone of child development and relational theories today, is central to both SAFE and SwiS programmes. Adopting a broad perspective, SwiS considers the idea of attachment situations in terms of the child's transitions between school and home and the exploration challenges such transitions present, as well as the influence of parents' and teachers' own attachment needs, considering the influence of both caregivers' attachment styles on the child they share care of.

Ideas about attachment have historically been thought of in terms of secure and insecure (*anxious avoidant/dismissive, anxious ambivalent/preoccupied, fearful/disorganised subtypes*), with secure attachment being considered as positive, and insecure types of attachment considered less positive, unhealthy, or harmful, particularly when considering relationship formation in children. Many parents' experiences of attachment theory applied to their children have been understood in terms of a *value judgement* on their parenting from practitioners or clinicians (Vassallo, 2023, p.206), where they feel blamed, and as a result find discussions around

attachment difficult, with many actively resisting entering into any conversation about it at all (Vassallo, Dallos & Stancer, 2023). Therefore, a more sophisticated model (the *dynamic maturation model* or DMM) was drawn on. The DMM approaches attachment from a developmental perspective which considers all forms of attachment responses as attempts at adaptation (Crittenden *et al.*, 2014), where current ideas of attachment can be explained in terms of '*activating strategies*', '*deactivating strategies,* or a mix of both, as opposed to simply secure and insecure (Dallos & Vetere, 2021). This was designed to help dispel some of the misconceptions about attachment that might be held by caregivers.

Fundamentally, attachment can be considered as two interdependent processes, that of exploration, but also of safety and comfort seeking. It is a survival mechanism that results in a child seeking protection and reassurance from their caregiver with whom they have an enduring tie, in response to external danger or threat (Dallos, 2004; Teague *et al.*, 2017). The need for attachment is considered an innate drive, a biologically programmed need, found not only in humans, but also in other species. As Harry F. Harlow found in his series of classic primate experiments during the 1950s and 60s (*where he transformed our understanding of the primacy of the caregiver attachment relationship*), the power of physical contact and comfort appears to surpass even our drive for food and water (Harlow & Zimmermann, 1959). Arguably, this is because the comfort of the *cuddly* figure signals at a higher evolutionary level the availability of wider protection from danger, not just the supply of food.

4.5.3.1 Attachment theory and the secure-base: parents and teachers as attachment figures

All children need to feel safe in order to confidently go out into the world, to explore and interact with it, and acquire the necessary knowledge and experience that ultimately shapes them as people (Vassallo, Dallos & Stancer, 2023). Autistic children

are no exception. However, their perception, understanding and experience of the world might influence their experience of safety during explorations, which may differ from that of non-autistic children. For example, within the sensory world, stimuli that an autistic child finds disconcerting, a non-autistic child might be impervious to or vice-versa. Equally, what a non-autistic child finds exciting and stimulating, an autistic child might find overwhelming or frightening.

For all children, having a secure-base (*a safe-haven in whatever form or representation that takes*) from which to explore is critical in the exploration process, as such ventures may present significant attachment situations in terms of separation from the contact comfort and emotional security provided by the primary caregiver and the secure-base (Marvin *et al.*, 2002).

In nursery and school-aged children, this attachment situation is one that occurs regularly and, for some children, can be a difficult experience, as they are often without access to an attachment figure during the day (Vassallo, 2023). Autistic children in particular, can find this separation challenging for a number of reasons (Stoner *et al.*, 2007). For example the separation from the safe-haven of home into a world of unpredictability (*which can be sensorially challenging*), the responses of others where there is little knowledge of, and adjustment for, their autistic perspective (*compared to that of their primary caregiver who understands and responds to their needs*), and the environmental and sensorial onslaught of the school setting (*compared to the predictable and controllable space of home*) (Goodall, 2015) can all accumulate to undermine children's feelings of safety and security throughout the school day, until able to return to their *secure-base* and enduring attachment figures (McKinlay *et al.*, 2022). However, even this transition can present a further challenge, as children can become *overwhelmed* with relief at going home, *anxious* about what they are bringing home from school in terms of admonition, or *fearful* in anticipation of the demand to do

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it all over again the next day (McDougal & Efstratopoulou, 2020; Vassallo, Dallos & Stancer, 2023). Such cyclical and perpetual transitions can raise anxiety in children, to the point where they begin to resist going to school, employing avoidant or delaying tactics. This can be for a variety of reasons, not least of which is having to navigate new situations without the comfort of their main attachment figure to provide the emotional support and safety during exploration endeavours. Therefore, the value and utility of access to an attachment figure in school to provide a continued secure-base or safe-haven is an important consideration.

4.5.3.2   *The influence of teachers as attachment figures*

Although knowledge of attachment theory has been shown to enhance teaching roles, teacher training largely focuses on subject related matters and behaviour management (Kearns & Hart, 2017). Teachers are, however, often the most influential adults in children's lives after their parents. Therefore, it is understandable that during long periods away from home (*the school day*), children might look to them to fill the attachment void, particularly in terms of comfort and emotional regulation, as the child's relationship with their teacher is not only shaped by their attachment to their parent but also contributes to their generalised attachment schema. Although it might be argued that the school context is not particularly conducive to the elements that facilitate attachment (*such as longevity of relationship [as teachers change annually at best], a different level of emotional investment from teachers compared with parents, and shared attention with many other children, limiting 'exclusive' time*), emotionally responsive and receptive teachers, who provide a continuing secure-base or a safe-haven at school and who invest time providing comfort and care to anxious children, might be considered temporary or *bridging* attachment figures (Verschueren & Koomen, 2012). Indeed, if their parents need to work long hours, it is conceivable some children might spend more of their *waking* time with their teacher, than with their parents. Therefore,

just as we acknowledge the impact of parents' own attachment needs in caregiving situations, the need for love, respect, and approval (Vassallo, 2023, p.219), it is imprudent to ignore the influence of teachers' own attachment needs and the impact these might have on children in their care.

Cassidy (2016, p.15) clearly identifies '*time spent caregiving*' as being highly influential on a child's attachment hierarchy. Therefore, if considered systemically, this elevates teachers as important figures in attachment terms, and immediately places them in a *de facto* attachment and caregiving partnership with parents and a part of the child's generalised attachment schema, making the parent-teacher relationship all the more important in terms of working together to meet the child's needs.

However, access to emotionally receptive teachers providing secure attachment responsivity is not always possible, therefore seeking an attachment figure at school could be problematic for children, as fundamental differences exist between home and school systems and environments in terms of how attachment needs are communicated and subsequently met. At school, teacher time and resource are limited, as they may have more than thirty children in their charge at any one time. Therefore, if a child feels unsettled, is hurt, or in need of comfort, they must navigate serious competition from other children for the teacher's care and attention. Consequently, children learn that teachers are often much less available to them than their parents, which can influence children's behaviour according to their principal attachment style (Vassallo, Dallos & Stancer, 2023) as they generalise and extend their internal working model of attachment. For instance, children who have developed secure attachment styles might be confident enough to tolerate the lack of availability from teachers and instead be able to wait their turn, or even manage their emotional needs until they get home, where they know those needs will be met. Whereas, children who display anxious-avoidant or '*de-activating*' patterns of attachment, are most at risk of going unnoticed, *appearing* to

manage without the attention, but are in fact more likely to become withdrawn (Kennedy & Kennedy, 2004). However, children with anxious-ambivalent or '*hyper-activating*' attachment styles using activating strategies (Dallos & Vetere, 2021) are more likely to find a lack of timely responding difficult to cope with, and so may display more extreme attachment strategies in terms of externalising and escalation of behaviour and emotional dysregulation. The danger here, is they become viewed as problematic or disruptive, as their presentation and distress increases and they oscillate between accessing and resisting comfort. This distress may then continue at home, as the child struggles to settle and recover from what has upset them at school.

4.5.3.3   *Teacher attachment needs*

Teachers, like parents, have their own attachment styles, which might be in contrast to those of the parents and therefore different to what the child they care for is used to. This means children must potentially navigate two contrasting attachment responses in order to have their emotional needs met, which can be confusing and unsettling for them. For example, if the '*hyper-activated*' child is met with preoccupied strategies from the teacher but not rejected by them, the child might feel emotionally understood but prone to escalations. If the teacher is more dismissing, the child might feel rejected and misunderstood. This can serve to escalate the child's response, which can result in the child becoming unable to manage emotionally, descending into a meltdown or shutdown situation (Kulig & Saj, 2021).

Being a teacher, and caring for the development of children, does not automatically guarantee a secure attachment style or that teachers will engage secure strategies with the children in their care. Interestingly, in a number of studies, teacher attachment orientations have been found to be less likely to be secure and more likely to be avoidant or preoccupied. Acer and Akgun (2010) found that, within a cohort of 91 trainee teachers, only 11 showed secure patterns of attachment. This was supported by

a further study where Kepalaitė (2012) found only 13 of 145 teachers demonstrated secure strategies. Both studies showed a propensity for avoidant attachment styles, with teachers more likely to employ dismissing strategies. In a study by Morris-Rothschild and Brassard (2006), teachers with anxious, avoidant or preoccupied attachment patterns found they adopted class management strategies that were less efficacious than teachers with secure styles. They were more likely to avoid, withdraw, capitulate or dominate in challenging '*pupil-teacher*' situations and overall had less-positive relationships with their students than their secure colleagues.

This was explored further in a study of student-teacher relations and teacher attachment perspectives, observed from an adult attachment model (Riley, 2009). Teacher-student relations were examined from an *identity perspective*, where the activation of teacher attachment behaviours in response to class behaviour management issues saw a power-shift, where teacher responses became those of *'care-seekers'* as well as *'care-givers'*. To explain, it is accepted that teachers hold a significant '*caregiver*' role, having considerable responsibility toward their more vulnerable charges. They have authority and power in the domain of the classroom and children may look to teachers for safety, comfort, and security while at school, developing an attachment to them. In response to this, many teachers admit to developing strong ties to the children in their care, acknowledging emotional bonds with their *class* helping them connect to their students *as a whole*, a connection that enables them to instil, and share in, the joy of learning (Hargreaves, 1998). However, as Riley (2009) observes, this is an interesting relationship, as the teacher also has a *care-seeking* attachment relationship with their class of children. In terms of professional identity, having a class of students provides a sense of comfort and safety for teachers, as they *need* students to consider themselves teachers in the first place. A teacher's identity is to some extent dependent on this relationship, a position not always held by students, who can be

independent and self-directed learners without the need for a teacher. This suggests learners hold a unique power in this dynamic, placing teachers in a *care-seeking* (as well as *care-giving*) attachment position, keeping them anchored to their class, who *as a whole*, provide the context to satisfy and reinforce the teacher's sense of professional identity. A teachers' identity is also maintained by their employment status, which in the UK context contains a dependency on meeting performance targets, targets that are comprised of a majority of their students passing standardised tests. Children, such as autistic students, whose different thinking and learning perspectives might pose a threat to the equilibrium of such a rigid educational dynamic and so distract or *emotionally separate* the teacher from their attachment object (*the rest of the class of students who by passing standardised tests help the teacher reach their performance targets, reinforcing their identity*), may induce an anger response, or a desire to distance (*avoid*) themselves from the *threat* of the *difficult* child. If the teacher is inclined toward an anxious, avoidant attachment orientation and responds accordingly, this may result in these children being educated *separately* from their peers, in corridors, alone in *pastoral* spaces, anywhere away from the teacher, as the teacher seeks to avoid challenging interactions, preferring the comfort of the more compliant *group*. Such exclusionary practices are commonplace for autistic children in mainstream education (Done & Knowler, 2023; McKinlay *et al.*, 2022).

Interestingly, even before Bowlby's (1969) theory of attachment was published, Wright and Sherman (1963) began to identify elements of *teacher type* which spoke of the influences from parents and former teachers in shaping the *type* of teacher a person became. In this extract we can see embedded within it an attachment narrative element, including a suggestion that family stories or scripts, a central element within family therapy (Byng-Hall, 1985; Byng-Hall, 1998), extend to the multi-generational context

of teacher-student relations, suggesting teachers feel a familial connection with their children, influencing their subsequent responding.

> *We propose that for one type of loving teacher her behavior is a means of keeping the love of the earliest mother image she remembers. She remembers that her mother was loving in the first stage and that giving in was rewarded with love in the second. She identifies with the loving supportive mother by repeating and thus preserving this valued image. This dependency is satisfying to her, for what is most important is the love that she had and which she now keeps by embodying it in her own behavior.*
>
> *There is another type of loving teacher – one who was deprived of the rewards of love in childhood. She succumbed to her mother's demands out of the fear of punishment rather than the prospect of reward. This teacher's behavior is guided by her desire to make up for her loss. In contrast to the first kind of loving teacher, she loves her pupils not only in order to be loved by them, but also to gain the vicarious restitutional gratification of providing children with the love which was once deprived her.* (Wright & Sherman, 1963, p.71)

Observing interactions and experiences for autistic children and their parent and teacher caregivers through an attachment lens sits central to the SwiS programme, both as an underpinning philosophy and as the theoretical base supporting the systemic focus of SwiS. It is also embedded within its range of activities and programme content, and the facilitation of parent and teacher caregivers to work together to access the *entire* knowledge of the child's daily experience and share and learn from that systemically to better meet the child's needs. SwiS draws from ideas and precepts of how people interact, particularly between children and their main caregivers, to understand the interdependent relational processes taking place, and the impact of these on the child, as well as on, and between, caregivers themselves (Vassallo, Dallos & Mckenzie, 2020).

4.5.4   *Contribution from the Attachment Narrative Approach*

Contributions from Attachment Narrative Therapy [ANT] support the attachment element of SwiS and provide an additional helpful feature to the framework. Similar to attachment theory, ANT has an ecological approach in terms of understanding that the family are inextricably linked to, and influenced by, a variety of contexts, including their immediate family, their school, and their culture, that all

impact on a family, on multiple levels (Dallos, 2023). ANT also foregrounds the importance and influence of triadic relational processes that look beyond the relationship the child has with each of their parents, to the relationship the child has with their parents' relationship (Karamat Ali & Dallos, 2023), which in the case of this research considers the influence of the parent-teacher relationship itself and the child's position within that dynamic.

Narrative approaches seek to understand how people make meaning from their lives through the stories they construct and tell (McAdams, 2005). Broadly, it is important to understand that human beings are natural storytellers and story seekers. Our memories and experiences coalesce into stories, which, when shared, communicate *us* to *others*; in sociocultural terms, it tells people *who we are*. We understand this even before we learn language, to help us make sense of the world, in terms of what to do, how to behave, and what to expect. According to Dallos (2004) and McAdams (1993), our early attachment patterns, shaped by family interaction, drive the formation and coherence of our individual narrative stories that we develop for all sorts of contexts within our lives. Narratives make up and aid our participation in the social world, forming and influencing our culture and shaping our identity (Kauschke, van der Beek & Kamp-Becker, 2016). In our *constructions* with others, we develop shared narratives that provide the context for social interaction, helping us recognise the *familiar*, and find *connection*. We see this in similar or culturally *safe* narratives, such as connection around hobbies, careers, education and sport. When new relationships are formed, they offer a narrative thread that seeks compatibility through a shared construct, helping us bond and make meaning together, but might equally be abandoned if no commonality is found.

4.5.4.1 Developing shared beliefs, and attachment-based narratives

In the everyday world of children, they not only construct their own narratives but are subject to many shared ones from their adult system with whom they form *attachments* (Dallos, 2004). Shared narratives found in family traditions reveal *'the sort of family we are'*, influencing how a family functions, how they communicate, construe, and respond to one another, overlapping with their attachment patterns. For example, family conflict might be addressed through high levels of emotional discussion or argument. The narrative may be one of '*hyper-activating*' or emotionally charged strategies when faced with difficulty, similar to what we see in resistant/ambivalent attachment patterns. On the other hand, a family that finds resolving conflict too confronting, might develop a narrative of side-stepping such interactions, *closing down* around problems, preferring to *let it lie*, avoiding attempts to find resolution, reflective of avoidant attachment patterns. Alternatively, a family's narrative might be one of collective responsibility, where *family meetings* might be employed to discuss and resolve conflict, where everyone is heard in a safe, warm, and measured environment. Family narratives might also follow patterns where authority roles are upheld, with decisions deferred to a hierarchy, where once made are less likely to be challenged. How families construct their narratives and construe each other within their family units impacts the development of the child's own story and how that child makes sense of their wider world and responds within it.

4.5.4.2 Problem saturation and totalising

As with any family, there is diversity in the sorts of narrative used within families of autistic children. For some, more recent accepting and inclusive ideas and constructs about autism have helped them to feel emancipated in their narrative approach to autism (Tan, 2018). By throwing off conventions, stereotypes, cultural discourses, and beliefs about autistic people that seek to oppress and pathologise

differences, they have instead embraced the autistic perspective, the sense of identity and freedom to explore autistic culture that diagnosis brings (Riccio *et al.*, 2021; Russell & Norwich, 2012). For others, the opposite is true, where conversations have become *problem-saturated* with discourses dominated by the belief that *autism* is the reason for all their problems and that *nothing can be done* to improve their situation (Dallos, 2001). In these cases, the diagnosis is restrictive, becoming an insurmountable problem that permeates every domain of life, leading to a sense of *totalising* (McKenzie & Dallos, 2016) that the person, together with the difficulties experienced within the family, are all *autism* and therefore '*the problem*', limiting their ability to see and act beyond the negative and totalising discourse to the positives of an autistic worldview.

4.5.4.2.1 *Internal narratives influencing representations of autism*

Internal narratives are possibly the earliest and most influential on us, because as children we incorporate early memory and experience which are essential to connection with others, particularly primary caregivers. This helps create internal models or representations of what relationships look like and what to expect, in reference to ourselves (Bretherton, 1990). If as children our narratives (*the combination of early memory and experience*) of primary caregivers are positive models of acceptance and love, then our internal model or representation of the relationship is formed as being one of safety and security. If an internal representation is formed from rejection or fear experience for instance, a very different narrative develops, suggesting part of the world is a dangerous place (Dallos & Vetere, 2021).

This is further complicated by the narrative of *being in a family* that is held by the parent. If their internal model of received care is less positive, this may impact the narrative they form with their child. Their own *stories* of being parented and family functioning, the narratives of their experience, can influence their expectations and

responses to their own children, highlighting how representations of parent-child relationships are inextricably linked to attachment formation (Bretherton, 2009)

Beyond the context of the nuclear family, children are also subject to shared narratives in the context of school with their peers and their teachers. For example, teachers establish learning and behaviour narratives shared by their class, which provide clear expectations of how children should respond in that setting, such as attending to the teacher, completing their work as asked, putting their hand up to speak, and so on. These narrative constructs make up the '*story of school*' for children, which governs their behaviour in that specific context, but not in others; for instance, it is less likely a child would raise their hand to speak when at home. Our constructions or *narratives* help us develop working models of how things are, and we internalise these to help us make sense of our world as we navigate its differing contexts (McAdams, 2005).

In terms of representations of autism, as caregivers, internal models of it may differ. For parents, their '*story of autism*' might be new, and based only on one experience of it, that of their own child (Weusten, 2011). Depending on their experience and system of support, they might come to develop a positive narrative of autism, that autism is a part of their child, makes them unique, and perhaps exceptionally good at certain things (Thompson & McFerran, 2015). On the other hand, they may face problems, be unsupported in their family or community, making difficulties more pronounced, becoming *problem-focused* and constructing the aforementioned *problem-saturated* narrative of autism (McKenzie & Dallos, 2016).

For educators, it may be slightly different but, depending on experience, a teacher's internal model of autism may be formed from a narrative of the first autistic child they taught or indeed from an amalgam of several experiences (Bolourian *et al.*, 2022). Often educators will communicate they have taught a child '*with autism*' and therefore feel they '*know about autism*'. Their narrative, formed from prior experience,

has helped develop an internal model of autistic children and will elicit certain ideas, expectations and responses, based on that experience (Jury *et al.*, 2021). This can result in assumptions and influence how children are treated, whether they are included or excluded in the class. This can also set an expectation of *problems* from the teacher, creating a mismatch in understanding and communication between the teacher, child and parents, particularly if the parent view of autism is positive but the teacher's prior experience was challenging and the context's (*school*) response to autism is negative.

4.5.4.2.2 Totalising in school

Drawing broadly from research in eating disorders (Dallos, 2004), we can see how not only parental ideas about autism can become *problem-saturated*, but also those of teachers, where school conversations about autism-related difficulties can come to dominate the thinking of the school staff and their view of the child, narrowing their *field of vision* in terms of possible solutions in the classroom. This could lead to a *totalising* approach for teachers, making autism a negative, insurmountable problem, causing them to become *stuck* in patterns of thinking and interaction that pathologise the child, siting any difficulties firmly within that child, that they are the *problem*. This might in turn influence the teacher's internalised view of the child. Even when attempting to view them as a unique individual, with a unique set of characteristics (Vassallo, Dallos & Mckenzie, 2020), their thoughts and conversations may still be directed towards, and dominated by, problems related to '*the autism*', particularly if negative discourses combined with performance pressures are in play. This has the potential to overshadow abilities, lead to low expectations, and exclude exceptions, times where ideas and connections with the child were *positive*, shutting down potential discussions of resolutions to difficulties that might be available to them.

Where problem-saturation occurs, where the mode of pathologising is present, it is difficult to move away from ideas that promote any response to the child as being

other than shrouded in '*the autism*', as if a disease or monster had consumed them. We can see from this how the emerging preference for *identity-first* language (*discussed in the Introduction*) from the autistic community might be helpful and preferable for some. The word *autistic* signals a way of *being*, a facet of identity, as opposed to the description of *having autism,* which conveys *weight* in its appendage, being something you carry, a burden, a disease, like *having cancer.* Therefore, a child '*having autism'* is all-consuming; it is *sentencing*, and such a perspective makes it impossible for it *not* to dominate thinking. The ANT principles used in SwiS seek to address this (Dallos & Vetere, 2014). They provide the space for caregivers to *slow down* their thinking and *step back* from problems, to reframe their narrative around the child where things are *always* going wrong and are problematic *because of the autism*.

4.5.4.3   *Attachment narrative principles within SwiS*

ANT also seeks to help resolve some of the emotional, behavioural, and relational difficulties relating to long-term impact of early childhood anxiety, trauma, or disrupted attachment. In relation to autism, autistic children typically experience high levels of anxiety, with school-based anxiety particularly common in autistic children attending mainstream school (Adams, Simpson & Keen, 2020; Ashburner, Ziviani & Rodger, 2010). This might be for a variety of reasons: the unpredictability of the school environment, sensorial overload, unmet needs, lack of understanding of the autistic perspective impacting how others respond to the child, bullying, exclusion, and so on. These can all coalesce to make attending mainstream school a difficult experience for autistic children.

Using a systemic approach, engaging parents and teachers around the child so problems may be addressed, the SwiS programme format *loosely* incorporates ANT's four phases toward shared problem-solving; co-creating a secure-base (*where parents and teachers come together in a safe non-hierarchical space, secure in the anticipation*

that both are there to support the child), engaging in the exploration process (*sharing what they know about autism, knowledge and stories of the child and how and how to support them*), intervening, trying new or alternative things*, (moving towards problem-solving together*), and maintaining (*having developed the relationship, to continue the format of communication and problem-solving*). The detail of this, explored in the core SwiS research, is set out in *Appendix D, Part-2*.

4.6 *Summarising the SwiS framework*

Designed by the SAFE research team, which includes myself, the inaugural SwiS research was carried out by me as principal investigator, with collaboration from the wider SAFE research team on introductory sessions. Like SAFE, SwiS is a positively geared programme, to be delivered in a multi-systemic group setting, centring on developing and strengthening genuinely meaningful and open relationships between parents and teachers. It helps caregivers to build on successes with their child, and recognise what they are already doing well, both as individuals and as a team. The drawing together of autism understanding with novel ideas and established therapeutic techniques and activities from attachment theory and systemic family therapy to support parents and teachers across the home-school context is, to the best of my knowledge, unique to SwiS (McKenzie *et al.*, 2020; McKenzie *et al.*, 2021; Smock & Turns, 2016). These established systemic techniques and activities are specifically tailored to help parents and teachers develop an understanding of autism unique to their individual child using a guiding framework. They can be used individually, as caregivers together, and with the child whose care they share. The programme, set out in detail in *Appendix D. Part-2* is designed to support ongoing communication between parents, teachers, and their children, enabling them to explore difficulties in a non-blaming way, facilitating the parent-teacher relationship to improve problem-solving *around* the child. It is

important to stress that the programme is designed to promote a continuing format of

interaction between the home-school caregiving system (Vassallo, 2023, p.201).

Chapter 5

Exploring the research landscape of UK approaches and programmes for parents and teachers of autistic children

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Part One

5.1   Introduction: defining the research field.

This chapter and its accompanying *Appendix E* provide an overview of the research landscape within the UK of approaches and programmes for parents and teachers of autistic children attending mainstream education, using a systemic family therapeutic framework.

I begin in part one by reflecting on the importance of *systemic practice* and *parent-teacher relations*, both in the context of autism and more widely, by reviewing both current and historical literature supporting this. Systemic practice is established as a cornerstone of educational co-production with families *(a UK educational directive)* (GOV.UK, 2015, p.61); however, a systemic approach to education is still reflected more in policy (Department for Education, 2022a) than in practice within schools, with UK co-production (*and ergo systemic parent-teacher relations*) more recently evaluated and described as *'weak'* (Ofsted, 2021)*.

Part two of the chapter will then turn to an overview of the extant literature of programmes that support *systemic practice* and *parent-teacher relations* using an *attachment-based family therapy* approach. This section of the chapter identifies a dearth of research in this specific area, which, given the recognised benefit of such partnerships and policy expectations, highlights both the gap in research and the original contribution provided by the SwiS programme and this study. In a further significant widening of the criteria, containing only parent-teacher partnership working as a

criteria, a small number of eligible parent-teacher partnership studies are included and explored in more detail within *Appendix E*

5.2 Systemic parent-teacher relations in context

The benefits of *positive relationships* are extensive and well understood in many areas of life including parent-teacher relationships. Good communication between parents and teachers and the home-school partnership is recognised globally as essential in promoting positive child outcomes (Department for Education Employment and Workplace Relations, 2017; Hornby, 2011; Kaplan, 1950; United States Department of Education, 2013). This is particularly evident when parents and teachers engage in shared goal-setting and problem-solving (Benson, Karlof & Siperstein, 2008; Sheridan, 1997; Syriopoulou-Delli, Cassimos & Polychronopoulou, 2016; Zablotsky, Boswell & Smith, 2012).

Whilst research to support the benefits to children of good parent-teacher relations has grown within the social science and educational literatures in recent years (Hornby, 2011; Sheridan, 1997; Sheridan & Wheeler, 2017; Zablotsky, Boswell & Smith, 2012), it must be acknowledged that not only is the development and maintenance of such relationships inherently problematic under the current education system, it also has a difficult past.

When Kaplan (1950) first made his observations about the benefit of positive parent-teacher relations on child outcomes, he also identified misunderstanding *(poor communication)* or limited knowledge of the other's context as underpinning tensions that limit mutual engagement and joint participation in the child's education. Across recent educational history, a perception of *difficulty with parents* has remained an ongoing narrative within education, impeding improvements to the parent-teacher relationship and perpetuating the parent-blame discourse (Colker, 2015; Hornby, 2011; Hughes, Wikeley & Nash, 1994). The persistence of such a blame culture positioning

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practitioners-vs-parents, together with repeated changes to educational policy and cuts to resource, do little to improve this (Clements, 2021). Seventy years after Kaplan made his observations, although positive parent-teacher relationships are more commonplace for typically developing students, for children with special educational needs and/or disabilities, and particularly those with a diagnosis of autism attending mainstream education, little has changed, as parent-teacher partnerships are still not as embedded in everyday practice or valued by education services as they should be (Department for Education, 2022a). Indeed, families of autistic children are more likely to feel dissatisfied by communication from teaching staff, remaining isolated from, and at odds with, the school system (Zablotsky, Boswell & Smith, 2012).

5.3 *Global importance of parents-teachers partnerships*

Whilst it is well understood within educational and child development domains that children whose parents take an active role in their education generally do better than those whose parents are uninvolved (Borgonovi & Montt, 2012; Clark, 1983; Epstein, 1983; Epstein, 1987; Epstein & Dauber, 1991; O'Toole, Kiely & McGillicuddy, 2019), for many families the extent of this varies considerably.

5.3.1 *Parent-teacher relations in typical and autistic families*

In my experience, for families of neurotypical children following an *expected* educational trajectory, taking an active role in their child's education may not necessarily translate to developing a strong partnership with their child's teacher, with parents and teachers often having only a *light touch* in terms of communication with one another. The two may not meet beyond brief parent evenings or school events, nor in many cases do they feel they need to, because if all is well with their child's schooling, their interactions will likely tend towards being mutually positive, with parents and teachers more often aligned in their shared educational goals.

For many typically developing children and their families, this arrangement works well and is sufficient to ensure a successful educational experience for the child. Most children are able to follow the curriculum, have implicit knowledge and understanding of what is expected of them both in school and beyond in terms of homework, behaviour, and extracurricular activity, and can execute these expectations with positive results (Epstein & Dauber, 1991; Hill & Taylor, 2004). Peripheral parental involvement in reading, writing, and other educational activities such as homework, sport, and special projects, augments and scaffolds the child's learning and is perceived by the school as *'good parental engagement'*. For parents and teachers of typically developing children, this *lighter touch* in terms of home-school relations is often sufficient for their children to succeed in school.

Achieving a successful outcome from such a light touch is less likely for parents and teachers of autistic children in mainstream education (Elsworth, 2003). The demands of school life, which are often incompatible with the needs of autistic children, together with the lack of support in mainstream education in the UK (Department for Education, 2021; Department for Education, 2023; GOV.UK, 2021), means that extra attention (*and, by default, resource*) is needed to facilitate a positive educational experience and outcome, not just for the child but for those within their child's microsystem engaging in mesosystemic relations (O'Toole, 2016; Vélez-Agosto *et al.*, 2017) .

Similarly to typically developing children, the benefits to autistic children of an active parent-teacher collaboration and the development of a sincere relationship between home and school contexts rooted in shared goals are suggested to be protective factors for them across multiple dimensions, including academic achievement, social success, and prosocial behaviour (Azad *et al.*, 2018; Hill & Taylor, 2004; Hornby, 2011; Hornby, 2015; Kim *et al.*, 2013). Systemic practice in terms of parents and

teachers working together in partnership around the child is considered to be so important that UK SEND law and practice recommendations (*in the form of co-production*) have evolved to support and encourage these partnerships, promoting and protecting the rights of parents and children to be involved at every level of decision making around the child's education (Department for Education, 2023; GOV.UK, 2014b; GOV.UK, 2015). Yet in mainstream schools across the UK, many parents of autistic students are *not* involved in their child's education in any meaningful way (Ofsted, 2021). Whilst it might be possible to *get by* for the child who can follow the prescriptive educational programme*,* for those following a different developmental trajectory, a lack of systemic connection places them at a distinct disadvantage, supporting conditions (*reflecting Kaplan's observations*) of poor or miscommunication between members of their microsystem to become embedded and parents to remain on the outside (Kent, du Boulay & Cukurova, 2022).

5.3.2 *Politically constructed barriers to parental involvement in education*

One reason for a lack of involvement from parents is because the centralisation and commodification of education and performative culture within our schools has, over recent years, slowly transformed how we *do* education (Ball, 2004; Ball, 2003; Bilton, Jackson & Hymer, 2018; Connolly *et al.*, 2022). Increasingly, schools are moving away from being integral community spaces, performing a community function. Instead, schools are more frequently big business and according to McNamara *et al.* (2000, p.475) operate in a free marketplace, where their *clients* – the parents, and their *product* – the children - now carry a *value*, where children, or rather their standardised-tested outputs, are exchanged for reward (*i.e. a good Ofsted rating*). These values then carry judgements, which are placed on children in terms of *positive-value* (will perform in standardised testing and present little challenge to school life, and therefore *cost less*) or *negative value* (has special educational needs, requires a different approach to learning,

does not fit with standardised testing therefore may impact performance data, drain resource, and therefore *cost more*) placing pressure on school priorities, resulting in *management* of these children rather than the *development* of them, or their rejection from joining the school in the first place. As Ball (2004) describes

> *many headteachers seem ready to admit, the best way to improve your school and thrive in the performative culture is to change your intake.* (p.10)

Children are currently subject to an educational culture where their value is measured by academic attainment, which exists as a prerequisite to good employment and productivity, upon which their value as a citizen is measured, something Hallett and Hallett (2023, p.367) alarmingly suggest has a *'strange echo'* of the former USSR education system.

For schools, target-driven agendas are frequently antagonistic to inclusion agendas, which are often at best tokenistic in the face of performative imperatives embedded across mainstream education (Glazzard, 2014). This is compounded when parents of autistic children favour their child's social, cultural, and emotional development over academic goals. All of this means it is often safer and easier to keep such parents at *arm's length* (Kent, du Boulay & Cukurova, 2022), as attempting collaboration where schools and parents have such divergent priorities and views of children is unlikely to go well.

5.3.3   *Parental barriers to engagement*

From a parental perspective, these are very real barriers to active involvement (Elsworth, 2003). Describing a late 20th century educational shift in focus (Curry & Adams, 2014) in response to the *'professionalisation'* of teaching, Mary Henry (1996, p.15) describes the systematic separation of home and school, and the *'walling out'* of family and wider community. Such barriers to educational participation are often further impacted by a multitude of factors, undermining any *resistance* parents might be

able to exert to this type of exclusion, with everything from a lack of social and cultural capital, poverty, social disadvantage, resource limitations inhibiting initiation of engagement, to power imbalances, and activation of parents' own negative school experiences (Bourdieu, 1986; Christenson & Sheridan, 2001; Hill & Taylor, 2004; Hornby, 2011; Hornby & Lafaele, 2011; O'Toole, Kiely & McGillicuddy, 2019; Vassallo, 2023; Voltz, 1994). These all serve to impede parental involvement, undermining feelings of efficacy and agency.

Despite the evidence supporting the benefits of a positive and active parent-teacher relationship, research suggests that genuine partnership working between them falls far short of the rhetoric of it (Hornby & Lafaele, 2011). To date, there remains a paucity of authentic partnership practice and coproduction between school and home contexts within the UK education system (Azad *et al.*, 2018; Boddison & Soan, 2021; Hornby, 2011; Ofsted, 2021), enacted only when necessary to tick the right regulatory boxes, resulting in inauthentic relations.

This problem was identified by Christenson and Sheridan (2001) more than two decades ago, where for many reasons good parent-teacher partnerships, although much talked about, are less frequently applied, encouraged or nurtured. Again, this is particularly noticeable for the seventy percent of autistic students educated in mainstream schools, where an absence of systemic practice sees schools resist the home-school relationship and the welcoming of parents as co-educators, limiting opportunities for each to come together to form a connection (Azad *et al.*, 2018; Kent, du Boulay & Cukurova, 2022; Miretzky, 2004). Therefore, efforts to go beyond theoretical understanding, to find ways to improve this in practice, deserve greater attention.

5.3.4   *The benefits and risks of working and not working together.*

Much of the literature examining interventions with a focus on parent-teacher partnerships centres on *typically developing* children and targets specific demographics or *at-risk* groups. These range from wider societal problems such as poverty and other social disadvantage to engaging in gang behaviour, developing substance abuse habits and general conduct problems (Fosco *et al.*, 2013; Kratochwill *et al.*, 2009; Stormshak & Dishion, 2009; Stormshak, Fosco & Dishion, 2010; Webster-Stratton, Reid & Hammond, 2001; Webster-Stratton, Reid & Hammond, 2004). By increasing communication, problem-solving and goal setting behaviours in a consultative collaborative style between parents and teachers, such as is found for example in the Conjoint Behavioural Consultation [CBC] approach (Sheridan, 1997; Sheridan *et al.*, 2001) discussed further in *Appendix E,* studies have found the parent-teacher relationship to be somewhat protective against these wider existential threats (*particularly gang related behaviour and substance abuse*). They have reported positive results on child outcomes by avoiding or limiting involvement in such activity ultimately reducing the negative consequences associated with this type of behaviour (Fosco *et al.*, 2013; Kratochwill *et al.*, 2009; Mortier *et al.*, 2009; Sheridan *et al.*, 2017; Stormshak & Dishion, 2009; Stormshak, Fosco & Dishion, 2010; Webster-Stratton, Reid & Hammond, 2001; Webster-Stratton, Reid & Hammond, 2004). Further examples include reductions to externalising oppositional behaviours of children both at home and in the classroom, as seen in both the FAST and Head-Start models (Kratochwill *et al.*, 2009; Webster-Stratton, Reid & Hammond, 2004) and increased pupil engagement as demonstrated in the UPS model (Mortier *et al.*, 2009).

Although the benefits to children of a strong home-school/parent-teacher relationship are well understood, for example where parents and teachers meet regularly (*something more likely to occur in primary school than secondary*) and communicate

well on outcome measures such as academic progress, social success, and the reduction of anxiety and distress (Hornby, 2015; Josilowski, 2019; Josilowski & Morris, 2019), simply *knowing* this is not it seems enough to establish the context for it to happen and for positive parent-teacher relations to thrive as a matter of course.

This situation is not unique to the UK, with frameworks and reviews from across the global North identifying and focusing on the quality of home-school partnerships as *what* is needed, without identifying *how* to get there (Department for Education Employment and Workplace Relations, 2017; Goodall & Vorhaus, 2011; United States Department of Education, 2013). Despite its introduction into law, sustained change in the UK educational context has not happened, with partnerships remaining largely underdeveloped (Kent, du Boulay & Cukurova, 2022), and coproduction *'tokenistic'* (Arnstein, 1969). Even with the stimulus of deliberate action to drive them forward, such as direct training, education, or participation in programmes of interventions designed to facilitate and maintain a positive connection, school commitment to parental partnership is difficult to maintain, with parent-teacher communication often the first thing to be compromised when faced with multiple competing priorities, something I discuss in my review of *Achievement for All* in *Appendix E*. There are many reasons for such a lack of sustained adoption of collaborative action between schools and families. One may be the pressure on resources of schools, teachers and parents, limiting the opportunity for partnership working to become established (Stephenson *et al.*, 2021). Historical difficulties in terms of educational culture and home-school conflict, which keep parents and teachers separate and maintains an entrenched lack of enthusiasm for closer bonds, could provide an alternative explanation (Epstein, 2005; Lasater, 2016). A lack of teacher training and professional development investment offers a further explanation, as teacher training in how to communicate and develop partnerships with parents is at best limited and more often non-existent (Azad

et al., 2018; Broomhead, 2013; Forlin & Hopewell, 2006; Lasater, 2016; Mann & Gilmore, 2021; Murray *et al.*, 2011); the knowledge exists, but as this is not communicated to teachers, the practice does not. A more alarming and, from a family perspective, common explanation is that schools simply do not want children with complex needs in their settings, as schools perceive these children as hard work and believe them to represent a threat to school outcomes (Armstrong, 2018). This makes *selectivity* more likely and certainly more attractive (Ball, 2004); therefore encouraging '*deviant families'* into the school community and developing a good relationship with them is counterproductive to this aim.

Equally educational programmes for parents do not extend to helping them navigate the education system or communicate effectively with teachers (Azad *et al.*, 2018; Murray *et al.*, 2011). This is critical, as research also suggests education and training has a direct influence particularly on teacher attitudes and consequently the treatment of children. In their systematic review of co-production training for teachers, Honingh, Bondarouk and Brandsen (2020) found that, where teacher education supporting the development of school-home partnerships was enabled, positive attitudinal change toward families and developing partnerships with them was a particularly noteworthy outcome (*although whether this attitude was sustained was less clear*). Moreover, it also highlighted that the attitudes of those within control groups who were not subject to training and education were not positive and *'expressed antagonism and ambivalence toward families'* (p.231) particularly in terms of establishing relationships and coproducing with them. The research of Honingh, Bondarouk and Brandsen (2020) focused on the typical, non-SEND population, specifically *excluding* autistic children, as well as children subject to health programmes (*counter-obesity*) and children with '*special needs'* in general. However, if we look at the impact that this training had on teacher attitudes toward *non-SEND* families, then

apply that to the more challenging home-school relationships for autistic children *(considering the complexity of need)*, it suggests an even greater necessity for teacher education to encourage the positive attitudinal benefits gained from training them. Conversely it also highlights the risks from not doing so, potentially amplifying negative teacher attitudes toward these children and their families at the extremes.

5.4   *Importance of partnerships on parents, teachers and others*

Over twenty-five years ago, Sheridan (1997) acknowledged such interdependency of the home-school relationship on the outcomes for children. Her work, and that of Christenson (1995), both highlight the systemic impact of collaboration between families and schools, not only for children *'at risk of academic failure'* (Sheridan *et al.*, 2001), but also on everyone immediately connected to them, from families, parents, peers, teachers and schools, to engaging with authority figures or allied practitioners. Indeed, the importance of knowledge and understanding of the child gleaned from systemic practice has been understood for decades. For example, in describing specifically the role of school psychologists, Conoley (1989) explains

> *We need to be experts about children: who they are, where they live, what they need, and what can go wrong. We need to be family and school systems experts, because to fail to know families and schools, is to fail to know children* (p.556).

Within this statement the systemic influence on children's development and the need to understand it across multiple contexts becomes obvious. To know the child only at home, or only at school, is to know only half the child. We can apply this idea to the increased complexities attached to teaching and supporting autistic children, where doing so without *all* the information, not only impacts the child, but increases the demand and stress placed on caregivers, who are unable to maximise outcomes that result from effective collaboration (Sheridan *et al.*, 2001).

The wider benefits to parents and teachers themselves that accompany a good relationship, whilst powerful, are often overlooked (Kim *et al.*, 2013; Sutherland, 1991).

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As touched on throughout this thesis, stressors on parents and teachers of autistic children are significant and a high quality parent-teacher relationship is considered a strong factor in the reduction of parent and teacher stress and burnout and teacher attrition, as such relations support feelings of self-efficacy for both (Azad *et al.*, 2018; Johnson, Berg & Donaldson, 2005; Skaalvik & Skaalvik, 2010).

Again, our understanding of this is also not new, and was demonstrated in a study by Skaalvik and Skaalvik (2007) who showed '*conflict with parents*' was a stressor directly undermining teacher '*self-efficacy*', a key factor of burnout (Maslach, 1976), contributing to attrition. Given teacher attrition rates are so high, with more than a third leaving practice within five years of qualifying in the UK, and higher figures reported across the US (Education Executive, 2019; Johnson, Berg & Donaldson, 2005; McLean, Worth & Faulkner-Ellis, 2023; Worth, 2018), and considering conflict is shown to be mitigated by building positive parent-teacher partnerships, more research is needed to develop supportive and practical methods in terms of interventions, training, and education (Azad *et al.*, 2016a), to not only support the establishment of the parent-teacher/home-school relationship, but establish the *culture* and ongoing *context* for it to flourish.

5.5 *Original contribution to knowledge*

A gap in the literature exists in terms of providing a sustainable and evidence-based approach to address these issues. The principles of SwiS and the outcomes from this research contribute new knowledge in this area, offering a novel perspective, rooted in established theory and underpinned by psychological practice to support families and teachers within educational settings and in their ongoing pedagogical practice.

Part two

5.6   Interventions with parent-teacher partnerships: search strategy

In terms of research that centres on developing genuine '*systemic collaboration between parents and teachers of autistic children within mainstream education*' an overview of the extant UK literature was undertaken to understand what interventions and programmes of support had been explored to facilitate this. The initial inclusion criteria were selective to consider the above in the context of (a) *UK studies of interventions, to remain relevant to the working model of the UK pedagogical system*, and (b) *studies employing systemic family therapy attachment-based models, to be relevant to the evidence base of the SwiS approach*.

Studies that did not have parents and teachers working together, placing them as partners, were excluded, as such approaches are not focused on optimising systemic and collaborative partnerships, a central tenet of the SwiS programme and this research. Without a balanced and equal approach between parents and teachers, there is no genuine partnership and carries the risk of perpetuating power imbalances between them (Elsworth, 2003).

We can see this for example in interventions such as the Incredible Years School Readiness Parenting Programme (Hutchings *et al.*, 2020), where teachers deliver the programme *to* parents *within* the school setting. This power imbalance not only places parents at a territorial disadvantage, but positions teachers as having superior knowledge in aspects of parenting as well as being the experts in education, whether or not they have children themselves. The delivery of such instruction *to* parents *by* teachers, immediately sets the tone that implies parents are not doing a good enough job, that they are inadequately preparing children for life's milestones, such as readying them to start school, which is a *blaming* and *failing* stance. This places parents, many of whom already lack confidence to engage with schools or feel intimidated by such

interaction, in a subordinate position, raising their anxiety and further diminishing their likelihood of contribution (Elsworth, 2003; O'Toole, 2016; O'Toole, Kiely & McGillicuddy, 2019; Räty, 2010).

Equally, studies with a focus on parent training or teacher training supporting interventions done *to* the child (*such as behavioural change programmes*) as opposed to done *with* the child were also excluded, as these were also not collaborative, and more often had a focus on gaining control and compliance from the child and family, supporting educational agendas, rather than developing an optimally supportive and operational system around the child to support the more important child-development agenda. Again, this type of *done to* approach also has power imbalance embedded within it and therefore such studies were excluded.

5.6.1   *Search parameters*

Search parameters included a full PRIMO University of Plymouth search, including but not limited to databases such as PsycArticles, PsychINFO, Education Resource Information Centre (ERIC), Google Scholar, British Psychological Society, British Educational Research Association (BERA) and the British Library. Extensive combinations of key target search words included but were not limited to *parent*, teacher*, systemic family-therapy (SFT), family therapy (FT), attachment, systemic practice, home-school, parent-teacher, relationship, collaboration, inclusion, co-produc*, autis*, ASD, ASC, inclusi*, special education, intervention.* This search was originally conducted at the beginning of the research process in 2018, and reviewed again both in 2020 and 2023, capturing more recently published works, for example, Partners in Schools, a derivative of CBC (Azad, Marcus & Mandell, 2021; Azad *et al.*, 2021) explored and discussed in more detail in *Appendix E*.

5.7 _Limited research: an overview of parent-teacher interventions_

5.7.1 _Originality of SwiS_

No UK studies were found that _united parents and teachers_ to develop home-school partnerships around _autistic children_ in _mainstream education_ employing a _systemic attachment-based_ approach, therefore a wider _global_ search under the same criteria was also undertaken. This too failed to reveal _any_ published studies, further supporting the originality and contribution of SwiS.

As discussed in _4.5.2,_ a Cochrane library systematic review (Spain _et al._, 2017) found few studies have explored _systemic family therapy_ as an effective response to difficulties associated with autism in any context, with none using a RCT to support efficacy. As stated in _4.5.2,_ as far as can be established, SAFE for families was the first to use this approach (McKenzie _et al._, 2020; McKenzie _et al._, 2019; Mckenzie _et al._, 2017), and SwiS was the first to study this approach within an educational setting (Vassallo, 2023; Vassallo, Dallos & Mckenzie, 2020).

5.7.2 _Further widening of the search criteria_

To understand the research landscape more fully in terms of interventions to specifically support the _home-school relationship for parents and teachers of autistic children_, a further widening of the research criteria was undertaken, removing the requirement for a _systemic family-therapeutic_ or _attachment-based_ element, but retaining the focus of strong parent-teacher collaboration. At the time of writing and to the best of my knowledge no UK published studies were identified. A number of US published papers met the criteria for inclusion; however, these were focused across just two main consultation models; _Conjoint Behavioural Consultation [CBC]_ (Fallon _et al._, 2016; Freer & Watson, 1999; Garbacz & McIntyre, 2016b; Garbacz, McIntyre & Santiago, 2016; Ray, Skinner & Watson, 1999; Wilkinson, 2005) or derivatives thereof such as _Partners in Schools: An innovative parent-teacher consultation model for_

children with autism spectrum condition'; and *'COMPASS:* (**CO**llaborative **M**odel for **P**romoting competence **A**nd **S**ucce**S**) *A parent-teacher collaborative model for students with autism'* (Ruble & Dalrymple, 2002; Ruble *et al.*, 2013).

Both approaches have some similarities as well as clear differences in their approach to parent-teacher partnerships and care of autistic children, both between each other and with SwiS. CBC and COMPASS centre on evidence-based practices that actively seek *behavioural change in the child*, which inherently locates difficulties as being firmly *within* the child and would be a criterion for exclusion as it is contrary to the non-totalising systemic approach of SwiS. However, COMPASS, CBC and derivative studies do have an element of parent-teacher working and seek to understand the child's perspective, endeavouring to view autism from a difference model, a complementary approach to SwiS meeting the criteria for inclusion and explored more fully in *Appendix E.*

5.7.3   *Other approaches*

Further widening the search criteria by also eliminating the need for the studies to be autism specific and removing the need to have a systemic family-therapy or attachment basis returned increased results of studies targeting parent-teacher/home-school collaborative models to some degree; however, these were more often applied to typically developing children from diverse demographics. Examples include 'Getting Ready', a large US school readiness programme for the early years (0-5), targeting literacy, math and self-regulatory skills, the Incredible Years Parent, Teacher, and Child intervention programme (Reid & Webster-Stratton, 2001), originally aimed at children diagnosed with conduct problems, and 'Achievement for All' [AfA], a large UK programme with an emphasis on supporting vulnerability and disadvantage (Blandford & Knowles, 2013).

Whilst the scope of the literature search at this point was much broader, retaining only the *parent-teacher partnership working* criterion for inclusion, I felt it important to include a review of AfA within *Appendix E* as it was the only UK study that aimed to situate parents and teachers as *genuine partners*. AfA also highlights the level of difficulty and complexity surrounding the support of more complex and vulnerable children, where even significant financial investment does not necessarily translate to professional action and buy-in from leadership to drive the necessary culture change needed for inclusion and equity for the more vulnerable to be realised.

The aims of all these studies largely focus on improving academic achievement for children and add to the body of knowledge that supports parental engagement in accomplishing this. However, the deeper parent-teacher partnership that is so central to SwiS that supports improved child and systemic outcomes more widely, is still not fully established in practice. Therefore COMPASS, CBC, Partners in Schools and AfA are expanded upon in more detail within *Appendix E* to offer the reader *at this point* a review of each approach, highlighting the complementary and contrasting principles with SwiS.

5.7.4   *The difficulty with the educational inclusion landscape*

The experience of the AfA study in particular, outlined in *Appendix E,* highlights the difficulty with genuine culture change for inclusion more generally in UK schools, where the weight of educational policy and risk of falling short of government sanctioned academic performance measures is simply too great for schools, undermining any willingness to try. For example, despite the evidence of benefits to working with families, particularly in terms of addressing disadvantage (Azad *et al.*, 2018; Hornby, 2011), current policy and the punishment for *missing the performance mark* makes any inclination toward such investment aversive for school leadership. Such pressure for performance constrains any genuine shift in educational gaze toward a

wider view of learning (*beyond SATs/GCSE scores*) and discourages any intention to give equal priority to systemic relations alongside academic performance targets. If change is to occur, then the *fear* of '*what Ofsted might say'* must loosen its grip on schools and leadership. Therefore, we should turn our gaze to policy makers with whom some responsibility for this must reside, as they have largely created their own problem. While schools continue to be assessed in terms of *student grades* as the chief measure of a school's *success*, school leadership will remain focussed on the typical student majority to get the school an Ofsted *pass*, a culture that perpetuates exclusionary practice. Despite pronouncements from Ofsted that judgements on schools are made from an array of measures, which include supporting autistic and other children with complex needs, those measures are still rooted in administrative compliance and do not carry the depth of measurement or weight of importance to necessarily transform practice, which means when Ofsted demands are interpreted by school leadership, attainment is retained as the primary focus (Hallett & Hallett, 2023, p.367), reinforced by awards that are weighted in that direction.

5.8 *Mechanisms for change*

Returning to autism specifically, in 2001 the *Committee on Educational Interventions for Children with Autism*, part of the National Research Council in the U.S. conducted a review of programmes highlighting *communication* and *social learning* as being central to success in any programme (National Research Council, 2001). Exploration of the research literature has revealed some commonality in this, across all programmes and initiatives, identifying and targeting social and communication skills, considered a core *(deficit)* feature of autism (Ruble, McGrew & Toland, 2014). The studies and interventions discussed, indeed do this to varying degrees, centring on improving these skills within the *child*. The unique approach of SwiS views these '*communication and social learning'* imperatives more widely

looking at narrative and cultural change within the *system around the child*'. This is because understanding the child's perspective and helping those intimately connected to and working with the child to also understand and value the child's perspective, as well as modelling to others what a successful relationship and child outcome looks like, is a more effective teacher. This approach is more likely to lead to genuine inclusion of autistic people through wider *social* change than trying to eliminate autism and autistic characteristics through interventions of assimilation.

The dearth of autism-specific studies in this area suggests the SwiS framework offers a much-needed new vision of supporting autistic children in UK mainstream education. This does not negate importance of other studies and interventions such as COMPASS, CBC, and AFA, as they provide the necessary variation and contrast across the intervention landscape in terms of approach and priorities, as no one size fits all when it comes to inclusion of children. However, they do illuminate a gap in research and the unique contribution of the systemic attachment-based framework of SwiS, which is not currently considered within the extant literature.

Chapter 6

Methodological framework and justification of inquiry

6.1   Introduction

This chapter explores the complex methodological framework and processes undertaken to ensure a comprehensive and ethical research study. This includes the justification process for the subject and decisions made about methods of inquiry, together with research design and ongoing ethical considerations, supported by and expanded on within relevant appendices as referenced within the text.

6.2   Research aims and questions.

6.2.1   Research Aims

The overarching aim of the research was to explore parents' and teachers' experience of the novel programme SAFE with Schools [SwiS], to better understand how meanings associated with autism and relationships between caregivers are constructed and revealed through the systemic attachment approach of SwiS, an approach demonstrably absent across the research literature.

This research is not an evaluation of the SwiS programme. Rather, SwiS operates as a *tool* or *vehicle* to allow the essential members of the child's system or *'village'* to come together in a way that they might not have been able to do before. The study connects my personal belief in the power of the '*village*' (*discussed across Chapter 1 and Chapter 2 and what SwiS does. i.e. a supportive understanding system is a move toward genuine inclusion and parity in society, as it enables the autistic community and their families to understand, be understood, and to express themselves authentically and safely*). In simple terms, the interest in meaning-making spans both what happens within SwiS and how families and teachers construct meaning about

autism in relation to wider cultural and societal contexts. From a systemic attachment

perspective, by mimicking the *village effect* in a small-scale way, the research seeks to

better understand what might be experienced as helpful, and what might not, for key

caregivers of autistic children, using SwiS to elaborate and challenge some of the

assumptions about autism held by teachers and parents, revealing and highlighting their

explicit and implicit beliefs.

In addition, I wanted to employ a research design that might promote positive

changes in the participants. This was a wider moral and ethical stance of wanting the

research to help participants as a result of engaging in the study, as well as by the

subsequent dissemination of the findings.

6.2.2   *Research questions*

My initial research questions were to explore:

1. *Parent and teacher meanings and constructions of autism and how meanings were illuminated and evolved through experience of SwiS.*
2. *The parent-teacher relationships and meaning-making processes between them.*
3. *How the experience of SwiS is shaped by the individual needs of the family and school systems*
4. *How meanings that function within home and school systems are shaped by wider discourses, particularly the autism disability-vs-difference debate.*
5. *How SwiS is experienced as consistent or contradictory to the wider discourses about autism.*

6.3   *Methodological approach: the roadmap to choosing qualitative inquiry.*

Every parent and every teacher of an autistic child will have a different *autism*

story to tell. Parents and teachers might be talking about the same child but their

narratives about the meaning of autism to them will all be unique, as their experiences

will be modified by context. Whether context is influenced by socioeconomic,

educational, social, or intergenerational factors, or perhaps differences in available

resource knowledge or support (*or indeed any combination thereof*), context variations

will all impact how individuals understand and respond to their experience of autism, shaping the ultimate construction of that meaning.

It is argued within this thesis that the narratives of parents and teachers within the child's microsystem, working together around the child, need to be understood and reflected upon, in terms of whether the experience of taking part in SwiS altered any of those meanings or understandings of autism, or changed the relationships that influence how those experiences unfold. Connelly and Clandinin (1990) remind us that *'humans are story-telling organisms who individually and socially lead storied lives;* therefore the unpacking of these stories is something best revealed through qualitative inquiry, as it seeks to understand the subjective complexities and worldviews of autism from each participant, both separately and together.

6.3.1   *Developing a suitable methodological approach*

Clough and Nutbrown (2012) explain how methodology and methodological decisions made during qualitative research underpin and lend credibility to research findings. A fully justified methodology and decision pathway are essential, but that does not necessarily dictate that one must stick rigidly to a single approach if it does not suit the line of inquiry. Although Marshall (1996) tells us that choosing whether one pursues a qualitative or quantitative approach is not a preference decision made by the researcher, but a decision governed by the research questions and the phenomenon under investigation, it must be noted that as the researcher I have had an impact on this, as I have selected both the phenomenon to investigate and the research questions to ask. This has been influenced by my own experiences and constructions from interaction with the wider autism community and my understanding of both their position and my own. Therefore, the methodology has to some extent been shaped by my own ontology, epistemology and axiology, in short, influenced by my collective *worldview* on autism (Creswell, 2009, p.6).

Reflecting on Marshall's view, it perhaps lacks consideration of aspects such as the influence of power and politics, both of which have a significant impact on this research under a systemic framework and in the lives of the participants. In addition, my own experience, gained prior to the research (*where I originally came to understand that parents and teachers of autistic children had rich and complex stories*), steered me toward the type of exploration that would allow those stories to be told, where meaning and understanding gained from complex narratives and interactions could be interpreted, structured, organised, and made sense of. This story-telling approach took me away from the inherent reductionism of quantitative inquiry, toward a qualitative line of examination, to adequately reflect the measure of *individual experience* found in the diverse nature of the human condition. Therefore, for this particular investigation, it was hypothesised that qualitative inquiry would be the right fit (Creswell, 2009, pp.98-99), as it provides the flexibility to utilise aspects from different qualitative approaches, to create a bespoke methodology that is both relevant and appropriate to the exploration of the wider phenomena in question, *how parents and teachers of autistic children experience the novel programme SAFE with Schools [SwiS] and make meaning of autism within a systemic context.*

6.3.2   *Developing a framework: blending thematic interpretative approaches*

In terms of developing a qualitative framework, it was further determined that a combination of qualitative approaches was most appropriate to address the research aims and questions. Blending aspects of thematic analysis and borrowing elements from interpretative phenomenological analysis (IPA) provided a route to a deeper, richer exploration of my participants' meanings or constructions of autism that come from their individual stories and their experience of the SwiS programme, collected from a diverse range of data sources. These sources extended beyond the narrative interview, focus groups and written disclosures within reflective journals and included participant

observations, SwiS programme day video and voice, as well as field notes gathered from incidental interactions and meetings with my participants.

Data from the interview and focus group transcripts were analysed using thematic analysis to identify and extract common themes, whilst preserving the participant stories (*Appendix Z*). Elements of IPA enabled deeper analysis where greater exploration and interpretation was needed, providing a flexible approach to a very rich and complex set of data. Smith, Flowers and Larkin (2009) endorse this multifarious approach to complicated data sets, explaining:

> *there is no clear right or wrong way of conducting this sort of analysis, and we encourage IPA researchers to be innovative in the ways that they approach it* (p.80)

Within this study, such innovation was used in the analysis of individual stories across the exploration stage, coalescing threads of parent and teacher narratives, so that as they entered the SwiS programme their initial positions about the meaning of autism within a systemic context and their systemic relations across home and school were revealed. From this foundational position, themes were drawn out (Vassallo, 2023) allowing any changes occurring across the research to be better understood. This is discussed in more detail across the subsequent final chapters.

6.3.2.1   *Acknowledging the ethnographic contribution*

It must also be acknowledged that, as a parent of an autistic young person and an educator, I cannot escape my immersion in this field, as this demographic of parents and teachers are two populations with whom I am culturally embedded and intimately connected. Therefore, this research also naturally embraces elements of the autoethnographic, reflecting my way of being in the world '*consciously, emotionally, and reflexively*' (Jones, Adams & Ellis, 2016, p.10).

My unique position as both insider (*parent-educator*) and outsider (*not diagnosed autistic*) locates me firmly between these ethnographic and interpretative

approaches. The *autoethnographic* is important as it feeds into and lends authenticity to the analysis through my personal *connections* and *experiences*, whereas the *interpretative* is equally helpful (*being aware of my own biases and beliefs in those connections and experiences, particularly when I reflect on 'how' I interpret and analyse the words and interactions of others*), serving as an *interpretative compass* if you will. Therefore, as touched on in *2.2,* my years of living and working with autistic people cannot and should not be entirely detached from this research, as my connection to this community is an important part of both my experience and my evolved identity, such is the importance of being a parent and such is the impact of being a teacher.

Beyond this, my connection with the autistic community also provides an anchor point, a non-judgemental and friendly face that says, '*I understand',* without which, gaining the trust and cooperation of my participants may not have been so successful. This is particularly true with parents, as this group often live life on the margins of social acceptance and all too frequently not only experience the same exclusions as their children, but are also heavily judged as *at fault* for their child's differences (Clements, 2021; Weusten, 2011). Therefore, having a synergistic relationship with the participants justifies the autoethnographic influence sited within the interpretative framework chosen for this research. It helps me interpret and explain their story of how meaningful lives are created in highly emotionally charged and often *'messy'* circumstances, recounted with a level of authenticity that cannot be entirely realised through objective enquiry, requiring a sincerity that comes from shared experience. Given the chaotic, emotional, and uncertain parallels between autoethnographic research methodology and life raising autistic children in the 21st century, this is an apposite methodological contribution.

6.3.2.2 Justifying analysis tool adaption

Originally, my intension was to use Interpretative Phenomenological Analysis (IPA) exclusively as my analysis tool. This was largely because I had used it before, it was familiar to me, and my experience of it meant I was comfortable that it provided the necessary depth of meaning for uncovering how my participants made sense of their lived experience within their own context. IPA aims to explore in depth the nature of people's experience rather than simply semantic-cognitive constructions. It is excellent for distinguishing '*experience*' from *'an experience'* and the understanding that denotes the two as different (Smith, Flowers & Larkin, 2009). However, in this research as I was also interested in people's *understandings* (*for example of autism*) the requirement of exploration for depth of experience was not always viable or relevant. Sometimes things simply *'are'* just as people say they are and describe as such. That the meaning of someone's experience and their understanding of a phenomenon is communicable, simply and articulately without the need to further unpack. This is where the choice of thematic analysis was more suitable, something I discovered during the member validation process discussed *6.3.5.* It led me to concede that if I was to make meaning from my participants' experiences, I would need to engage with a blended set of methods that allowed for, and captured, meanings that were both clear and willingly offered through thematic analysis of narratives, as well as drawing on IPA for those embedded within a stream of consciousness, from memory, thought and feeling, requiring more nuanced exploration and deeper interpretation, supported by ethnographic immersion and observation. This included both the realities of what happened at home and in school in everyday life, as well as interpretation that only comes from implicit knowledge, cultural insight acquired from shared experience, and an ability to look at data in multiple ways. For instance, in relation to this research, one of those ways was to take a counterintuitive, but helpful, '*step back*' from the data, to

reveal meaning and what underpinned my participants' experience from a distance. Coincidentally, this was not dissimilar from the approach to problems presented within SwiS (*discussed in Chapter 4*). This allowed the *seeing of things* to unveil a broader picture, particularly the context, and the person's position within it.

Contextual relevance is central to systemic practice and family therapy, a core tenet of SwiS, and therefore plays an essential part in making sense of participant experiences (Dallos & Draper, 2015, p.194). Systemic practice and family therapy acknowledge that people are an embedded part of their social contexts, which suggests they do not always have complete autonomy. It explains that people are different in different contexts, that those changes emerge from how we are viewed and treated by others and by the system and discourses within the society we live. This shapes who we become in different contexts and within different dynamics where, as social actors in a social world, we play our role according to the constraints and influences we experience within our system. Dallos and Draper (2010, pp.92-94), explain this in terms of '*commonly seen patterns*' of family interactions, such as the *helicopter* mother or *uninvolved* father. These are not necessarily a result of personal choice, but a response to a set of demands and pressures that are socially constructed and quietly imposed by wider society. They rationalise that despite some societal enlightenment and increased awareness, entrenched discourses and cultural ideologies still paint women as the *nurturer* and men as the *hunter* and are seen in everything from our language conventions to policy decisions, which maintains our behaviour, embedding across generations, making change difficult. This step back from the data is in response to exactly that. It is driven from observing something wider, more systemic, or even tangential to the person or microsystem in which they reside, exploring the sociological pressures and cultural influences that shape them, rather than always *'digging'* further, based on the assumption there is something deep and undiscovered to pursue *within*

them. For example, the aforementioned *helicopter-mother*, when observed in context, might better explain their excessive presence in a child's everyday life. They might not be overprotective, but instead operating in an adjunctive role such as personal assistant or therapist to their child, a function driven by a lack of services, training, or societal acceptance, in order to support their child's *inclusion* in an *everyday* activity, inclusion that might not happen without their advocacy. The uninvolved father might not be voluntarily absent, rather forced into a decision to *go where the money is* to provide for the family, as often in families with autistic children, collective circumstances result in only one parent able to work whilst the other undertakes additional caring responsibilities associated with raising a neurodivergent child in a neuronormative world that is more often exclusionary and blaming. Therefore, the aforementioned '*digging'* is more about piecing together the wider context and what contributes to it, as the researcher turns sociological archaeologist (Clough & Nutbrown, 2012, pp.51-54). Knowing this about the data, and about the participants, is imperative. It is necessary to sometimes explore the data in opposition to the usual step toward it, where perhaps the *deep dive* might cause one to find something that simply is not there, as much as missing something that is, by ignoring the role of sociocultural context.

Stepping to the *side* of the data was also pivotal within this research to explore and understand the meaning that is transmitted by what is *not* said but by what is simply *known* between peers with similar experiences. The meaning of or response to an experience is sometimes revealed and conveyed instinctively. This was beyond inference, rather a more *visceral* form of communication, sometimes eliciting an unsaid shared acknowledgement of understanding between participants as they interacted across the programme whilst exploring their experiences together in a shared space. This was not confined to participant interactions but something that also occurred between participants and myself within one-to-one and group encounters. These *unsaid*

meanings or shared *'knowings'* exist where both parties have implicit knowledge, and therefore expectation, of a shared experiential understanding of something, where conversation moves at quite a pace and is often full of half-finished sentences because they are intuitively known and understood, therefore there is simply no need to complete them.

6.3.3   *Interpretive methods: analysis training and interrater sessions*

Incorporating such *intuitive* interpretation into data analysis requires careful validation. Therefore, having a second (*or in this case third and fourth*) person conduct interrater analysis alongside my own afforded a level of assurance that my interpretation and shared '*knowings'* were not *over-done*.   This not only provided a secondary layer of checks and measures to validate my data but created some lively discussion across a professional team of analysts (*not all of whom were connected with autism)* and brought a fresh view as well as a certain challenge and new level of objectivity to the data. The team consisting of a developmental psychologist with an interest in autism, a clinical psychologist, qualitative researcher and family therapist with an emphasis on systemic practice, a psychotherapist with a diverse cultural and spiritual focus and myself met monthly during field work, data collection and analysis periods. We shared anonymised transcripts and reviewed the analysis together, using my blended approach of thematic analysis and IPA. This multi-perspective approach supported the integrity and authenticity of respondents' words and disclosures. As a team we engaged in in-depth co-analysis of the data, not only within my subject of research but across diverse topics, enabling me to deepen my understanding and exploration of the impact of cultural differences on narratives and discover how other meanings, such as those of spirituality or faith, might also be revealed. More generally, this approach facilitates a broader perspective and awareness of analysis within qualitative research and was essential in mine.

Reflexivity and celebrating authenticity.

Qualitative research relies on capturing the individual within their real-world context, unpacking and making sense of the meaning behind participants' communications and disclosures. However, it also presents unique challenges compared to those of other research approaches. The absence of *manipulated variables* and *experimentation* does allow for deeper focus and understanding about the individual lived experience, rather than revealing *generalisable statistics* from the '*law of large numbers*' (Gravetter & Wallnau, 2013, p.207), which in turn allows a depth of inquiry with the subject of interest that can be unavailable within high-volume, reductionist, often distal quantitative methods. However, researcher commitment and proximity to respondents, avoiding disruption to and influence on the natural course of things whilst retaining authenticity, are often the biggest challenges with qualitative approaches, as it was in this case.

The foundation of shared experience and contextual understanding I had with my participants provided an unspoken connection and level of insight, which I fully acknowledge not only made recruitment easier for me, but also may have made communication and disclosure easier for respondents, particularly parents, as this shared experience provided me with a deeper understanding and awareness to recognise the nuanced aspects of their experience within their narratives.

6.3.5   *Validity enhancement*

The downside of this of course is the potential for bias and the influence of my own constructions on my participants' meanings, as conducting sensitive research brings with it considerable *'methodological, ethical and emotional challenges'* (Rolls & Relf, 2006). Therefore, to ensure a robust analytical process and the validity of any resulting data, it was important to retain an active view and *re-view* of my positionality, to avoid such pitfalls and lessen the potential for over-interpretation.   For that reason,

extra layers of *checks and balances* were implemented from the very outset, to enhance the validity of my analysis and findings and ensure that they held up to scrutiny. This multi-layered approach took the form of the aforementioned analysis training with blended methods combined with interrater analysis sessions, researcher bracketing, and a level of member validation with participants to ensure '*they meant what I thought they meant*'.

6.3.5.1   *Bracketing and reflexive conversations with myself*

Bracketing is an active and deliberate process that enables the researcher to be mindful of their own influence (Tufford & Newman, 2012). It identifies potential areas of bias that might develop from the researcher's own perspective and experiences, *bracketing* them to help acknowledge the influence they may have on research findings, helping to *set them aside* (Ahern, 1999; Fischer, 2009). Before I even formally began this research journey, I recognised how deeply involved I was within my sphere of study. Therefore, bracketing was something I knew was necessary from the outset. However, for me, engaging with the bracketing process did more than just highlight my own influence, positionality, and potential for bias. It also allowed me the freedom to approach my research, fully aware that I am an inextricable part of the social world I am researching, secure in the knowledge that I can conduct my work with reflexivity, rather than aiming for impossible objectivity. Bracketing has also helped with analytical blockages, by revisiting the research process, and recognising when I might be *too close* to the data. This complemented the interrater analysis, which dovetailed perfectly, providing balance to the process that not only prevented me from heading into analytical cul-de-sacs, but added a level of rigour to the unpacking of the data, ensuring participant stories were not occluded by my own vision and interpretation, reinforcing data validity.

Undertaking a bracketing interview at the very beginning and keeping a reflexive journal throughout have been essential tools on my research journey. Right away, my bracketing interview highlighted areas that were particularly activating and sensitive for me. These centred around bureaucratic barriers for accessing help, as well as an intolerance for apathy or abdication of responsibility by those in positions of power. It also highlighted some more emotional challenges, resurrecting feelings of aloneness and disenfranchisement, all areas which not only created significant frustration for me now as a parent, a teacher, and a member of the wider autistic community, but also triggered memories of my own difficulties as a *'different'* child, within a less-than-enlightened nineteen-eighties education system.

My research journal, which is constructed from a collection of raw and unrestricted written, electronic, and voice entries, together with *memos to self* of ideas or insights from the raw data, has provided an outlet and a reflexive space to work through these methodological complexities, so I might be mindful when they manifest and able to respond, unpack, or in some cases, simply accept them. These processes ensured a continual loop of reflection and review throughout the study and provided further balance.

Throughout this process, Ahern's '*Ten Tips for Reflexive Bracketing*' (Ahern, 1999), which I have adapted and loosely summarised in *Appendix F,* were helpful for my research, containing the blueprint to promote rigour within my data collection and analysis.

6.3.5.2   *Member validation*

Member validation, also known as member checking or respondent validation, is another important process within qualitative research that supports the accuracy and validity of the data collected (Creswell, 2009). As part of the validity checks of my

research, member checking was a critical part of the early methodological process to help guard against the risk of researcher bias.

There are a number of ways to conduct member checking, with different levels of validation, and researchers vary on what they actually *do*. For example, you can contact a participant to revisit a point in an interview that might come to light during the transcription process or when re-reading interviews. Perhaps a participant said something or started to explore a particular point, but the interviewer missed it. Instead of delving more deeply at that moment, they perhaps moved on or changed the subject, or the participant kept talking and the interviewer forgot to revisit. This happened to me several times as a novice interviewer, but even seasoned researchers experience this from time to time. When interviewing, one has a myriad of things in mind, therefore sometimes it is possible to miss something that is actually quite important. This is one way of checking with your participants to ensure you have fully explored their story. Another way is to send participants a draft of their transcript to ask them to look at it and acknowledge that it is a fair representation of your conversation. It can be a first draft or a corrected copy, full or partial, it doesn't matter; what you are looking to ensure is that it represents your time and interaction together. A third way is to summarise the key points or themes or *story* from that interview and to ask your participants to comment, validate, and respond to your summary, providing their insights. Researchers can also share their findings with their participants and invite comment, although this may interfere with hermeneutic consistency (*achieving a coherent explanation from the analysis of text*), particularly if this triggers respondent bias (*6.3.5.3*).

The process of member checking was of particular importance, given my positionality and immersion in the cultural and emotional world of autism and being a place and experience I shared with my participants. It was important for me to

acknowledge that, despite the rationale for my immersion in my research, there was a possibility of getting *too close* to the data at times, where I might fall into the trap of interpretation by transference, projecting my own thoughts and feelings onto a disclosure, creating a very different meaning to that which my participant intended.

I used a combination of methods as described above to minimise the risk of this happening. To validate the early analysis and ensure I was on the right track, I shared with my participants an uncorrected initial draft-transcription summary of their data and the key themes and meanings as I understood them. I met with some of them in meetings and focus groups, where we discussed these emerging themes and experiences; I spoke with some participants on the telephone, made incidental home/school visits and emailed with others, whatever form of communication suited my participants. This allowed me to share with them what I had initially interpreted from the data, both individually and collectively, from their interviews, journals, and field observations, and confirm with them that they did indeed *mean what I thought they meant*. This gave them the opportunity to *re-present* and re-state their intended meaning if they felt I had not accurately captured it. Whilst none of these interactions resulted in changes to initial findings, spending extra time immersed with my participants did result in acceptance, as well as further exploration of the data with some of them. It also allowed me to *sink into* deeper analysis of some of their experiences, with a level of confidence that my understandings and interpretations were valid, but more importantly were meaningful to my participants.

6.3.5.3   *Member validation risks: triggering respondent bias*

As a counterpoint to this, I also recognised the pitfalls of undertaking such a process. There is a risk with any level of member checking that you can enter into a regressive sequence of review, or instead of revealing participant stories and understanding their constructions, you actually trigger *respondent* bias, where your

participant from the outset, for whatever reason, either does not reveal the whole story or wishes to change or remove what they have shared, perhaps because they feel it does not reflect on them positively or they have rethought their involvement. If this happens it can drastically alter the research. Therefore, whilst member checking in general is helpful as it can reduce validity threat, it carries a risk of infinite regression (Robson, 2011). Despite this, the risk was not a strong enough reason to *not* do anything. Therefore, I made the decision to sample the early stages of analysis with my participants to provide the necessary reassurance that my interpretations were well-defined and veridical.

This early validation process was helpful in contributing to the peer reviewed publication (*Appendix G*) of insights and themes from the *exploration stage* of my research (Vassallo, Dallos & Mckenzie, 2020) and helped to formulate the methodology for my analysis.

6.4 *Procedure and measures*

6.4.1 *Participants and Recruitment*

The study aimed to recruit a total of 12 participant units *(a participant unit consisted of a minimum of 1 parent and 1 [main] teacher and a maximum of 2 parents and 2 teachers and any combination thereof),* to participate in stage-1, the exploration stage. As the research was in two parts (*exploration and intervention stages*), the participants could choose to exit after stage-1 the *exploration stage*, or as a unit, self-refer onto stage-2 the *intervention stage*, to undertake the SwiS programme if they wished to continue with both parts of the study. An anticipated uptake of approximately 50% was assumed for stage-2, commensurate with averaged data from education and parent programme studies (Dadds *et al.*, 2019; Drotar *et al.*, 2009; Foulon *et al.*, 2015; Sheridan *et al.*, 2013; Traube *et al.*, 2020); however, surprisingly 100% of participants self-referred onto the intervention stage.

6.4.2 *Purposive criterion sampling*

For this research, purposive-criterion sampling was used, as certain criteria had to be met to make the study valid and participation possible. Participants had to be parent-carers or teachers of an autistic child, and that child needed to be of primary school age, attending a local state mainstream school. The child's main teacher and one or more of the child's parent-carers needed to take part to create a working *unit*. Therefore, participation of parents and teachers was contingent on the other being willing to be a part of the study. It was critical that the child they shared care of was autistic as the research focus and programme was set in response to the needs and characteristics autistic children and their caregivers.

6.4.3 *Recruitment*

All participants were parents and teachers, recruited either directly or indirectly, via a SAFE with Schools brochure, poster (*Appendix H*) and presentation to a SENCO network within the Southwest of England, a National Autistic Society [NAS] parent support group, Southwest branches of the National Network of Parent Carer Forums [NNPCF], other civic and voluntary organisations supporting families of children with SEND, and through peer referral. As part of my voluntary and community activity, I have strong connections with community organisations and strategic partners within the local authority, working closely with both schools and parent networks for children with a range of SEND, enabling me to engage with these networks, to reach as many parents and teachers of autistic children as possible within the local area.

Some schools drove participation after receiving information or hearing about the study from their SENCO who had identified parents and teachers who might fit the criteria for the research. Other schools took part after responding directly to parental request for participation, discussed in *Chapter 7* . Although the autistic children of the participants did not directly participate in this study, they became indirect contributors

to this study, as parents and teachers worked together around the shared care of their child, including them in their SwiS activities and within their subsequent caregiver reports and narratives.

During recruitment, a further forty-three additional families requested to participate after receiving information about the research from parent networks. However, these were not successful, as school participation could not be established.

The home-school relationship dynamics were mixed. A few participants already enjoyed a positive home-school relationship but were motivated to explore opportunities for further development. Other parents and teachers were new to each other, but their relationship had been crisis-activated at the start. Some participants were in the position of already experiencing a difficult home-school relationship, with a few in positions of extreme opposition.

6.4.4   *Participants*

The initial 12 participant units were recruited and consented via the network of SEND organisations as described above from 9 schools across the Southwest region of the UK. Seven schools provided 1 participant unit, one school provided 2 participant units and one school provided 4 participant units.   The subsequent withdrawal of 2 participant units prior to study commencement, meant an additional round of recruitment was necessary. Two further participant units were subsequently recruited to the study as replacements; however, one previously withdrawn participant unit then asked to be reinstated after independently re-evaluating their involvement. They were of course welcomed back to the study, taking the final total to 13 participant units (*Appendix I*).

As all 13 parent-teacher units who took part in the exploration stage also self-selected to undertake the intervention stage, it was decided to extend the study and create two cohorts (A and B), delivering SwiS twice instead of just once. This was

important to ensure numbers did not overload the room, potentially overwhelm the participants, or compromise the delivery of the programme, as there needed to be enough time and opportunity for everyone to fully participate. However, numbers also needed to be sufficient to facilitate an active dynamic, not just between parents and teachers, but also between parents and parents, and teachers and teachers.

As detailed in *Appendix I,* Participants [N=32] consisted of 14 teachers comprising 13 teachers and 1 teaching assistant (*11 female and 3 male*), and 18 parents, comprising 13 mothers and 5 fathers *(all participating fathers attended with their child's mother, 8 mothers attended alone).* A further three fathers had initially elected to take part, but subsequently withdrew, due either to work demands, or family demands where they opted to take over family duties to enable the mothers to participate. Twelve of the children had a formal diagnosis of autism and one had a working diagnosis, having been on the autism pathway for more than a year, subject to chronic delays inherent in the diagnostic system.

Of the 13 children shared by the parent-teacher units, 8 were male and 5 were female. The current estimated sex ratio of children diagnosed with autism is 3:1 male-to-female (National Autistic Society, 2019), therefore our sample was inconsistent with the current gender ratio of *diagnosed* male to female numbers.

6.4.5   *Demographic information*

Basic demographic information was taken from participants. The current cultural and ethnic diversity of the Westcountry is inherently extremely low, which resulted in limited diversity within the sample. All participants were white, with a split of 85% White British, 12% White European with English as an additional language and 3% White Other. The socio-economic demographic was mixed, with 61% of parents employed either on a full or part-time basis (by default 100% of teachers were employed either full or part-time), all the fathers were employed as were 54% of the

mothers. More probing details of socioeconomic position and educational history were not taken, as they would not have contributed significant relevance to the study at this stage; therefore, to request this additional data would not be in the participants' interest and would have been ethically questionable.

6.5 *Research design*

To properly understand caregivers' stories and experiences and to respond fully to the research questions in 6.2, a dual-stage research design was developed which took place over the academic year 2018/19. This was a deliberate approach to understand initial positions about constructions and meanings of autism and caregiver relationships with one another, before exploring how the experience of SwiS was shaped by family and school systems, how meanings of autism were shaped by wider cultural discourses, and whether these were sustained within the experience of the programme.

Stage-1 (the *exploration stage*) consisted of a minimum of three research sessions for each participant. It began with a combined school visit, followed by a minimum of one individual participant session, and an individual stage-1 interview. This completed the exploration stage.

Stage-2 (*the intervention stage*) consisted of a minimum of four further sessions, including two full days of the SwiS programme. It comprised two full days of the SAFE with Schools [SwiS] intervention, conducted at the University of Plymouth, followed by between one and three focus groups, before completing the study with a final interview *(Appendix J)*.

6.5.1   *Exploration stage*

6.5.1.1   *Initial visits – information, orientation, and consent*

In response to a school's initial interest in the study, a visit was made to the setting to explain the research and gain the general agreement and commitment needed

from the school and potential participants. This was where interested parents and teachers were introduced to the researcher in a *get-to-know-you* session to understand the parent-teacher dynamic, provide participants with study information across both stages, confirm study fitness, and take informed consent *(Appendix K)*. Parents and teachers were then visited separately at a location of their choice, to discuss the research in more detail, ensure the participants' continued wellbeing, and to orient them again to both parts of the research including the SwiS programme. This ensured there was plenty of time for participants to ask whatever questions occurred to them over time, consider the intervention stage of the study and think about whether they would continue or exit after the exploration stage. Where participation for the exploration stage was established, and once all participant questions were answered, the reflective journal was issued. Meeting locations varied between school, participants' homes, and the university, where a research meeting room was made available to any participants who were more comfortable keeping their participation separate from home and/or school. Where more than one meeting was needed, this was accommodated. Meetings lasted between one and two hours.

6.5.1.2   *Reflective Journals*

The study offered all participants the opportunity to complete a reflective journal, recording notable interactions with their child for a minimum of four weeks and prior to the first interview. Journals focused on recording types of interactions and entries would be categorised by the participant into one of three categories: 1) a positive interaction – reflecting on what happened, what went well and how they felt about it; 2) an interaction where a difficulty was resolved or distress averted – reflecting on the event, what happened and how they felt about it; and 3) episodes of interactions that resulted in a negative escalation between caregiver and child, particularly if the interaction resulted in distress for the child, often described by caregivers as a

meltdown/shutdown. Caregivers also had the option to record additional *rating* detail about these negative interactions, against a set of three subscales attached to the third reflection option (*Appendix L*). The first was the parent/teacher subjective severity rating of the distress episode, the second, how long the episode continued for, and the third, how confident the participant felt in managing it. This was an optional subjective personal record for participants to complete if they wished, to see if they noticed any changes in these dimensions. Not all participants chose to use the rating scale and indeed some participants adapted its use, using the journal more as a diary, finding this an easier route to express their stories than just within interview. These journals formed part of the exploration data, which together with the initial meetings and first interview comprised the exploration stage of the study.

6.5.1.3   *First Interviews*

Interviewing is an established way to obtain data on a particular subject, and for nearly a century has been described as a '*conversation with a purpose*' (Bingham & Moore, 1931). I selected this approach largely because it offered the necessary depth of inquiry and exploration of parents' and teachers' meanings and experiences of autism, providing a platform for them to tell their stories anonymously, whilst having someone who understands their context listen to them. The role of sharing and shared experience for those supporting autistic children cannot be overstated (Banach *et al.*, 2010; Guralnick *et al.*, 2008). Having the freedom to talk unjudged and gain understanding and emotional support through such exchanges is for many a rare opportunity and therefore can be a cathartic experience. Beyond the literature, which supports such sharing as being positive action (McCabe, 2008; Singer *et al.*, 2012), my own conversations, interactions and experience within the autism community have also reinforced this. By comparison, the interview process (*which is a means of obtaining data as opposed to a specific therapeutic tool*) can often elicit a level of disclosure, not

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dissimilar to that seen in therapeutic peer support sessions, bringing forth through shared experience, a certain honesty and openness within respondents' narratives.

However, as Clough and Nutbrown (2012, pp.26-27) argue, simply hearing the words of interviewees is not enough. It is only through *radical listening* that the voice is truly heard within social research. This means hearing *all* the voices on a subject, not just the ones from the sample taking part. For this research such ideas extend to those who are systemically connected to autism: the autism community, other allied stakeholders, researchers, including the *voice* constructed by the political landscape, influencing the direction of social discourses attached to autism, and so highlighting the positionality of both the participants and the researcher situated within that paradigm. As Goodwin and Goodwin (1996, p.5) argue, social research is purposive, conducted to better understand something, to answer questions and create new knowledge. It must aim to bring about change, even if that change is only within the researcher, otherwise it is not research (Clough & Nutbrown, 2012, p.14). This reflects the enduring methodological approach of this research, which acknowledges that nothing happens in a vacuum, therefore the experiences of the participants undertaking SwiS, are explored and understood within the systemic context of autism. Everything counts.

That said, the spoken word does not represent the entirety of the data within this study. Written, and particularly observational data, are also key contributors. Therefore, the idea of *radical looking* (Clough & Nutbrown, 2012, p.26) complementing the concept of *radical listening* is bound up within the methodological process, where the researcher can view the subject from beyond the boundaries of what is known, and be informed by other viewpoints outside of their usual field of vision, enabling the potential for a shift of understanding. Radical looking is a process that *'makes the familiar strange'* (Clough & Nutbrown, 2012), transforming the researcher's knowledge of a subject, in this case the parent and teacher experience of autism, by

viewing it through a variety of lenses. This is a position that I agree with; therefore, it must be acknowledged that my participants' voice was heard not just through conversations and exchanges within the process of interview, but came also from participant meetings, observed actions, interactions, the written word and, perhaps albeit to a lesser degree, through those shared '*knowings'* of what was *unsaid,* set within the context of the wider socially constructed narrative surrounding autism. To that end, whilst the interview process was designed to make a large contribution to the data, it was not the sum of it.

The exploration stage interviews were planned to be intentionally discursive in part, allowing the participant the freedom to explore their own experiences and speak unencumbered on the overarching topic of autism. Whilst a semi-structured framework of questions was available as a flexible tool to guide discussion, this was not a rigid process, rather an evolving and responsive one, as there was a need to retain a level of flexibility to the data gathering to accommodate the mixed style of responding from the interviewees.

Having an outline interview schedule *(Appendix M-and Appendix N)* was helpful in that it provided additional focus, for example on dimensions of attachment, a central tenet of SwiS, whilst also acting as a prompt for myself as the researcher, as well as a support for participants who found conversation about their experience more difficult or emotive to articulate. Therefore, having more targeted questions to answer was indeed better for some participants, as it provided just enough structure for them to anchor to, enabling them to initiate their thoughts and share their experience and meanings of autism in a way that talking '*straight off the bat'* may not elicit.

It must be acknowledged however, that for some participants, the interview process was not the forum for sharing their experience, preferring the informality of the participant meetings, or the anonymity of *the group* during SwiS programme days,

where they could share their story whilst being '*lost in the crowd',* something I elaborate on in my analysis of initial parent and teacher positions in *Chapter* 7 . For other respondents, the interview schedule was largely unnecessary, as conversation was generally free-flowing, needing it only as a tool to probe and explore certain responses more deeply.

For the remaining participants, the interview schedule was wholly redundant, as having the opportunity to tell their story and share their meanings and experiences of autism was a welcome one, where rich and open narratives were proffered without pause or reserve across the data.

Interviews are designed so that the researcher can gain as much information as possible about a field of study, in order to contribute to a '*body of knowledge'* reified by the experiences and meanings of the participants (DiCicco-Bloom & Crabtree, 2006). However, without building in a level of flexibility within the very framework of the interview, such depth and richness would be hard to unearth, leaving much of what contributes to the understanding of a subject buried.

The first interview was designed to help understand the caregiver's initial positions; the meaning of autism in a systemic context, exploring the participant's story across dimensions of: 1) relationships: how autism impacted on family and home life, or classroom and school life, from the perspective of a parent or teacher, 2) participants' experience of autistic distress (*aka: meltdowns/shutdowns*): the effect on family and home, or school and professional life, and 3) parents and teachers perceptions of the others' context: exploring opinions and relationships. Examples of interview questions for both parents and teachers included: *"How did you 'feel' when you received/were informed of [child's] diagnosis?"* and *"How has autism influenced your relationship with [child]?"* It also contained elements borrowed from the Parent Development

Interview (PDI), a psychological measure of reflective functioning described by Slade (2005) as:

> *the essential human capacity to understand behavior [sic] in light of underlying mental states and intentions… an overt manifestation, in narrative, of an individual's mentalizing capacity.* (p.269)

It examined caregivers' representations of themselves as a carer and their relationship with their child, with questions such as *"Can you tell me when you and [child] last 'clicked'?"* However, as explained above, the aim was to allow the participant to share their story and provide the space for them to do so, not to analyse their caregiving, although such questions allowed further exploration of caregivers' understanding of the child's perspective, which was useful across the SwiS activities. Therefore, there was little uniformity in terms of interview outcome, as it was more important to allow their narratives to develop.

6.5.1.3.1 *The importance of place.*

Maintaining participants' wellbeing and best interests was at the forefront of the research. Therefore, in line with previous meetings, having complete choice of venue for the interview was important to ensure participant comfort. The importance of place in terms of individual wellbeing was a priority, as people cannot properly relax, reflect, and immerse themselves in their thoughts and feelings if uncomfortable in their environment. Crowded public places such as cafés were avoided, as this raised my concerns around privacy and anonymity for participants; however, being outside, perhaps somewhere quiet, such as a park, was offered as an option. Ultimately, all participants chose to conduct their interviews either at the participating school, within their homes, or at the university, whichever they chose as being a more convenient and comfortable location for them. However, within that, choices were varied. For example, one parent participant chose to use the school playground as their interview place, as being among the trees, in nature, in the place where they often observed their

child playing, made them feel more connected to elements of our discussion, providing a sense of being close to their child whilst talking about them. Another parent wanted to meet at the university, as for undisclosed reasons, they did not want anyone in their home, but needed a neutral space. The campus was familiar and held positive memories for them. Most teachers chose their classroom to conduct the interview. This may have been because classrooms can be very personal spaces for teachers, offering a sense of security or control, although it could equally reflect their high workloads and need for convenience.

At the close of the interview, participants were debriefed, and the journals collected. At this point, confirmation was obtained as to whether the participants wished to exit or stay with the study. A surprise within the research was that all participants asked to continue with the study, moving on to the intervention stage, therefore stage-2 consent forms were issued, and informed consent taken (*Appendix O*). This completed stage-1, the exploration stage of the study, and segued participants into stage-2, the intervention stage.

6.5.2   *Intervention stage*

The participants undertook the two-day SwiS programme *(the content, format, and implementation of which are detailed in Appendix D)*. Participation in the programme was consensually but unobtrusively voice- and video-recorded to capture the informal and natural exchanges and interactions between participants, which together with observations provided an abundance of incidental data. Following the programme, further data were captured in the form of post-intervention journals, follow-up focus groups, meetings and final interview.

In the weeks following the intervention days, parents and teachers were encouraged to continue with their communication, using the tools and activities shared with them during the SwiS programme. As I argue in my related publication:

It is important to emphasise that the (SwiS) programme is intended to facilitate and promote a continuing format for parent–teacher communication. (Vassallo, 2023, p.201)

6.5.2.1 Second Journals.

In addition, on the final SwiS programme day, all participants were issued with a new reflective journal in which they could again write down notable interactions and record feelings of competency for tracking and managing difficult patterns of interaction and any other post-intervention reflections. These were then collected at final interview.

6.5.2.2 Focus groups and meetings.

Between SwiS programme day-2 and the final interview, follow-up focus groups and meetings were offered to all participants. These served to catch up with participants to ensure their continued wellbeing, answer any questions and provide ongoing support if needed. They also allowed for some feedback on the programme and participants' experience of it, as well as the opportunity to explore *if* and *how* parents and teachers were using what they had learned, with each other and with their child. These meetings also provided important additional data to the research in terms of exploring participants' experience of SwiS and served to help support the all-important *'continuing format'* of communication and interaction between home and school after the programme.

6.5.2.3 Final interview.

The second individual interview was arranged with participants toward the end of the scholastic year, to collect the final data, including the second journals from those who had completed them, and conclude the participant contribution to the study. These interviews again followed a semi-structured approach, with a focus on understanding the participants' experience of SwiS and what was important to them, rather than a fixed

set of questions that might lead participants in a certain direction. For those who benefitted from a more structured interview, questions explored their experience of *'working together'*, any acquisition and employment of *'new strategies'*, changes in relationships and patterns of *'interactions'*, both with each other and with their child. It also explored any changes in their '*perceptions*' of autism, how it impacted them and their levels of '*confidence and stress*' (*Appendix P-and Appendix Q).* As with the exploration stage interview, how parents and teachers used this time to discuss their experience was flexible, allowing those who wanted to, to take the interview and share their experience in their own way. This concluded the participant contribution to the SwiS study.

6.5.3 *Additional data: Incidental data and the research journal*

My own research journal, reflections, and notes made across the research process to record my thoughts, observations and any interpretations from meetings and communications with participants, augmented the formalised data. This included non-video or non-voice-recorded interactions a well as some informal voice-recorded meetings and post meeting voice notes and came to provide an important contribution to the data in two critical ways. Firstly, the incidental and naturalistic nature of collection, enabled participant disclosures and experiential constructions that might otherwise be excluded from interview or journal qualitative data to be captured. Being away from the formalised setting of research interview or intervention group meant that for some, this was the moment for truly sharing their story. Secondly, being *among* my participants as they constructed their stories meant the reflective nature of the research journal allowed me to draw on my own personal experience, to record and examine theirs, a characteristic of most if not all autoethnographic research (Jones, Adams & Ellis, 2016).

Collectively, analysis of the data captured across both stages of the research, aimed to reveal parents' and teachers' experience of the SwiS programme, in the context of their understanding of autism, and raising and teaching an autistic child. As previously defined, a thematic analysis of the data (Braun & Clarke, 2006; Braun & Clarke, 2019; Clarke & Braun, 2014) informed by aspects of IPA (Smith, Flowers & Larkin, 2009) was designed to enable the participant stories to be shared through a blended approach. The data were gathered over a full academic year, the analysis of which revealed themes as set out in the relevant thematic tables in *Chapter 7 Figure 4 and Figure* 5.

6.6   *Ethics*

Working ethically is the cornerstone of research. Without solid ethical practice, research is compromised and meaningless. However, working ethically is not without its challenges, and can present dilemmas which require continued and careful reflection to resolve. For example, many researchers choose their field of study because of a personal interest or investment in the subject matter. I am no exception to this. However, having a personal interest in a research subject can be a double-edged sword and, without doubt, be ethically demanding. On the one hand, personal connection to a subject both inspires and motivates inquiry and exploration, as well as a deeper understanding of the *problem*, whilst on the other it can also create a conflict of interest between the researcher and the subject area they are researching, particularly when there is an imperative attached, such as where research might support improved outcomes for a particular population.

6.6.1   *Protecting participants*

Research (*and social research is no exception*) is more often driven by such needs. This means we can find ourselves exploring sensitive and difficult subjects with

people who might be deemed as vulnerable. When conducting research, the welfare of the research participants should always be of primary concern; therefore the easy thing to do would be to avoid such subjects altogether and explore more benign areas that ask easier, more palatable questions. However, these are generally not the ones that require our attention, meaning that research often comes from a place of inherent difficulty, emerging from real-world problems. This is where protecting participants from harm is so very challenging, as one must explore and ask relevant but often difficult questions of a population which may already be disadvantaged or at risk, and do this without causing upset or increasing vulnerability. One must explain and disseminate findings from data that were shared on the basis of identity protection, without compromising the anonymity of the participant in any way. Then, whilst retaining that anonymity, make public the data for the betterment of those who follow, often without affording any benefit to those who took part and made the research possible.

Often good ethical practice can also throw the researcher a *curved ball,* introducing ethical dilemmas that could not have been conceived when ethical approval was first sought for the project. Brooks, Te Riele and Maguire (2014) argue that once ethical approval for a project has been granted, working ethically should not be forgotten; instead the researcher should operate with

> *ongoing ethical reflexivity throughout the process of research, and that researchers must be sensitive to the complex and sometimes unexpected ethical concerns that may arise.* (p.3).

Being prepared for such dilemmas was an intrinsic part of the way this research was conducted. This was an ethically sensitive study, which raised many questions for me, not least whether I should even attempt it in the first place, something I explored and continuously reflected upon throughout the research process *(Appendix R).*

Such opportunity for researcher reflexivity was embedded throughout, supported by a team of experienced researchers, who not only provided the necessary guidance

and wisdom to balance my enthusiasm for this work with the meticulous care for my participants, but also embedded such ethical practice forever within me.

6.6.2   *Data protection*

Keeping the interviews, videos, journals, field notes and observations confidential and safe was a key priority and ethical necessity. This was an iterative process. Immediately after point of capture, the voice interviews and video footage of the SwiS sessions were uploaded to the secure university server and promptly deleted from less secure hand-held equipment.   Once the video observations and voice recorded interviews and focus groups were transcribed, corrected, validated and analysed, ensuring anonymity within any thesis entry, a commitment was made to the participants that the original individual voice recordings that could publicly identify their stories, would be deleted to further protect their anonymity and privacy. The participant narratives and disclosures offer very personal and professionally sensitive material and, as such, a condition of participation was to erase recordings as soon as possible. This is an undertaking I have duly fulfilled. The remaining hard and digital anonymised data will remain secure until 2027 when it too will be securely destroyed.

6.6.3   *Managing other ethical risks and complications*

As autistic people and their families are already at greater risk of mental health difficulties than the general population (Fleischmann, 2005), care was taken to fully explain the project to the participants, to ensure they had full understanding of the aims of the research and the methods being used. There was no need for deception within this research, therefore transparency was employed from the outset.

The possibility of unearthing emotional difficulties, given the potential for vulnerability and higher stress levels of both parents and teachers, meant that to ensure the ongoing welfare of the participants, a system of support needed to be in place

throughout. The intervention team of clinical and developmental psychologists and family therapists remained available to all participants during the whole of the study, for counselling and support. A couple of participants did indeed utilise this, engaging positively with the team outside of the research, not directly in response to their experience of the project, but through their ongoing situation and indirect activation of thoughts, feelings and ideas connected with autism.

As a core principle of the research was a sensitive one (*exploring relationships between parents and teachers - including when relationships are sub-optimal),* being prepared for and managing potential conflict between parents and teachers was critical. However, as all participants had volunteered to be a part of the study, the mindset could be considered inherently open, positive, and proactive, therefore even those who had experienced difficult relationships prior to the study may be considered to be more open to experience.

The retelling of any story generally involves more than just one person's experience and therefore requires from others their permission to share. The writing of this was no exception. Therefore, in consideration of the ethics of such disclosures, all necessary permissions were obtained from those who gave of themselves so graciously and selflessly to this research. Every participant was re-consulted at each juncture of the study to ensure willingness (*and fitness*) to continue, with participants providing informed consent at stage-1, the exploration stage, and again at stage-2, the intervention stage. As the research's principal investigator, I maintained a reflexive stance throughout, supported by an equally reflexive investigative team, and the study received full approval from the University of Plymouth ethics committee.

Chapter 7

Exploration stage findings: An interpretative analysis of participants' initial positions using multiple sources of data.

7.1   Introduction

This chapter provides an interpretation of the initial positions of parents and teachers undertaking the SwiS study, across stage-1, the *exploration stage,* in terms of their understanding and narrative constructions of autism and insight into the parent-teacher relationship. Set out in three parts, I will first turn to '*the data'* and the findings emerging from multiple data sources collected from across the research as described in *Chapter 6* to help illustrate parent and teacher narratives. The chapter will then turn to *'the participants and their expectations'* which provides an insight into initial positions, before setting out the *'findings and key themes'* for stage-1, the *exploration stage* of the research. This provides a foundation from which to understand the different ways parents and teachers were able and willing to construct and reveal their feelings, beliefs, attitudes and expectations, relating to autism, their connection with one another, their views of the educational landscape and the support available to them through participation in SwiS, illustrated by quotes and observations.

The chapter will conclude with a summary of the threads that underpin key themes and understandings revealed in this first stage of the study, particularly on dimensions of attitudes towards, and emotional impact of, autism, surrounding bureaucracy and the influences on home-school relations (Vassallo, 2023).

7.2   The Data

7.2.1   Unpacking the narrative: interrelated data

The elicitation, or *drawing out* of stories, is a complex and dynamic process, particularly as the interconnected reality of parents and family life, together with

teachers and school life potentially renders the *drawing out* less about finding commonalities and more about building a bigger story in itself, with each of the characters contributing something entirely unique to the whole. This poses the researcher a problem, as research often guides us to look for information in the form of patterns, of similarities or differences, or even similarity within difference (*or vice versa*), from which to draw conclusions and tell us something about the population or phenomenon we are researching. Research often has strict boundaries. It demands process, rigour, and results to produce something tangible and meaningful; something that one can proclaim as *a finding* in order to make a contribution to the knowledge in the world, to inform, to explain, or to bring about *impact,* otherwise, as some might argue, what is the point of research?

However, this is just one view of research and I have learned across this research journey that being *flexible* within that process can often better reveal what there is to be found, as people and their experiences do not necessarily conform to fit established processes. This aligns with my epistemological understanding that when researching people in their shifting contexts, particularly in the context of autism, the messiness of life does not simply translate to the required *neatness* of the accepted research paradigm. Instead, it is dragged kicking and screaming to the page, protesting with a resoluteness that, just like autism, no '*one-size-fits-all'*; there is no single unifying story or set of themes under which such experience can be subsumed and allocated. Stories and their themes, like life, are interconnected and infinitely complex and, as such, no *one* stands alone.

However, to avoid throwing our hands in the air in despair, we make sense of this natural chaos of life by organising experience systemically, where experience and story can form, reside, and also move in a multifarious and interrelated thematic *web* or *network*. The key experiences of those who took part in the SwiS programme have

been organised as such, revealing a narrative story through their experience of SwiS, bringing to light similarities and divergences in experience.

Drawing out and distilling important messages from the research is a complex and substantial responsibility and requires an appreciation of '*where people have come from*'. Understanding and constructing the experiences of the SwiS participants required every bit of flexibility from my choice of blended methodology to enable their stories to be revealed, exploring the initial parent-teacher dynamic, how they position their relationship with one another, how both parents and teachers make sense of their feelings and experiences of autism, and how those experiences are impacted and influenced systemically. This exploration is further supported by *thematic* findings of parent-teacher initial understandings of autism and home-school communication processes within *Appendix G* (Vassallo, Dallos & Mckenzie, 2020). This precedes *Chapter 8* findings where I explore the interrelated themes from detailed analyses of participants' narrative stories, drawn out through their experience of SwiS, coalescing to collectively address the main research questions within *Chapter 9* discussion.

7.2.2 *Exploration stage data*

From the data, I was able to reflect on participants' experiences and narratives to build a picture of the person and their relationships with their child, their respective teacher or parent, as well as with autism. The joint and individual introduction meetings of the exploration stage *(Appendix J),* helped develop an understanding of each participant within both individual and joint contexts, and the data from these sessions enabled me to *'get to know'* participants, to understand their background, what had led them to this point in terms of their experience of autism, as well as an understanding of each person's family and/or school dynamic. Observations of interactions were recorded in a variety of formats, including detailed reflections within my personal research journal. When considered in conjunction with the individual

meetings and subsequent interview and augmented by the reflective interaction journals, these data helped construct a picture of the parent and teacher narrative. This concluded the *exploration stage* data.

7.3 *Participants and their expectations*

7.3.1 *Reflecting on parent-teacher attitudinal and relational positions, observed from individual and joint meetings.*

Initial meetings with schools, teachers, and parents revealed such a variety of personalities, differing attitudes towards and constructions of autism, and varying states of relations, that the dynamic *in the room* once brought together for the SwiS programme days could not be predicted. Therefore, having the opportunity to develop a relationship with each of the participants beforehand was important. This helped build a picture of the parents and teachers, their relationships with, and attitudes towards one another by observing them together in the school setting and each in their respective *home* or *neutral* environments. I visited parents and teachers together in school, parents individually in their homes or in a neutral space, and teachers individually at their schools or again in a neutral space, before conducting the one-to-one interviews and moving on to the SwiS intervention.

Distinct changes in presentation were observed in many of the parents and teachers across the two different meeting arrangements, signalling a shift in power dynamics for some, with more subtle differences at play for others. What was evident was that the presentation of both parents and teachers was altered when in the presence of the other.

The initial position of parent-teacher relations was mixed across the participants, as were their motivations for taking part, with a larger number of parents and teachers seemingly at odds with one another (*or the school*) to some degree, versus some that appeared more collegial. However, closer analysis of the nature of underlying conflict

and difficulty revealed this varied from the interpersonal (*including variances in personal philosophies on autism, education, and inclusion*), right through to policy-induced conflict at a local and national level (*particularly around performance targets and school policy),* highlighting parents' and teachers' individual struggles with the inevitable bureaucracy resulting from this.

Initial meetings quickly uncovered a degree of *nervous anticipation* between parents and teachers about taking part in SwiS, which was frequently vocalised, regardless of the type of relationship each professed to have with the other. At the beginning, all were inhibited to some extent with most appearing to want to present the best versions of themselves, perhaps concerned how their revelations might make them look to others. Some parents were tentative, as they were keen not to '*rock the boat'* with teachers, who similarly expressed their anxieties about not wanting to '*let their school down'.* Common to both parents and teachers was wanting to be seen as good, kind, strong, knowledgeable, and in control, with any signs of vulnerability withheld at first.

7.3.2   *Parent and teacher expectations for participating.*

Most participants appeared to be keen to take part and all participants were clear that they hoped to gain something from the experience *(Figure 3)*. Even those who were '*strongly encouraged'* or even *'directed'* to participate by their school described the study as a '*rare opportunity*', sharing hopes and aspirations for themselves and their parent or teacher partner that might come from taking part. This level of optimism, even from those not initially disposed to engage with the research, highlights the need for access to such programmes and reinforces the dearth of support available to parents and teachers of autistic children.

Expectations	
Key themes of parents	**Parental quotes**
Hope that taking part will be helpful, seeking better outcomes for their child and less stress for parents	*I really want this to work, because we can't carry on like this, it's not doing [child] any good us being at loggerheads.* *I hope two days is enough to- you know, sort of 'get through' that we're not the enemy, or the problem, we're just doing our best, but could do with a hand from time to time.*
Seeking a better relationship with school	*I'd like us to be friends of sorts if you know what I mean. [Child] would be so much more relaxed at school if we were I think.*
Improve understanding of their child by others	*my hope is like, [teacher] will begin to 'get it'. If I can just let [teacher] know what I know about [child] and [their] autism, things might be easier ... [Teacher] doesn't see autism the same as me I don't think.*

Key themes of teachers	**Teacher quotes**
Hope it will support compliance with school goals	*Anything to get [parent] on side so [they'll] enforce what we're doing at school, at home. You know if we can have consistency across the two then maybe [they'll] perform better.*
Get parents on board	*With a bit of luck, I'll learn some techniques to get [child] to do what [they're] told. Do you have some that work on parents too (laughs)?* (Teacher)
Improve child educational outcomes	*If this has an impact on [child] then I'm all for it*
Rare opportunity for training	*I'll take whatever I can get. I mean, if it doesn't help with [child] or [parent], I might take something away that helps another child, you know. It's all useful really.* *I'm quite excited actually. Like, you know, two days training, AND follow-up, I mean, crikey, it's unheard of really (laughs).* *(sighs) I'm not sure to be honest. I'm managing my expectations (chuckles) you know, we don't get much training, and what we do get doesn't really help the more complex kids like [child].*

Figure 3 Parent and teacher expectations of participation

7.3.2.1   Parent Expectations

In initial meetings, some parents shared feelings of hope that participation would result in better outcomes for their child, recognising the impact of conflict between caregivers on their child and highlighting their desire to resolve any such difficulty and work more closely with their child's teacher and school.

These initial parental expectations suggest an optimistic view that new knowledge might be created by coming together with teachers, that sharing their understanding would help their child and help to diffuse home-school tensions. They also revealed a certain optimism, and perhaps assumption, that teachers would be as invested in this as they were.

7.3.2.2   Teacher Expectations

Indeed, teachers were invested, but for different reasons. Some comments did focus on child welfare, but in terms of initial expectations thoughts more frequently turned to classroom and parental compliance and performance concerns.

When questioned directly about what they hoped to get out of the programme, the response was quite mixed. Some teachers initially appeared less optimistic than parents, as if *going through the motions* perhaps from being disappointed in the past, whilst others were very enthusiastic and held a wider, more open view of the programme.

What teachers communicated most frequently was a lack of investment in *their* development and a frustration with the circularity of that, as within such a performance and target-focused education system, this had a knock-on effect in terms of properly supporting their students whose outcomes then reflected back on them. The scarcity of training, described by one teacher as being *'rare as hens' teeth'*, meant there was little initial focus on developing relationships with the parents, as thoughts defaulted toward

what might have direct and immediate impact in the classroom (*quick fixes*), initially

eclipsing ideas of longer-term potential systemic benefits.

7.3.3   *Reflections on power dynamics*

7.3.3.1   *Parents*

For a few parents and teachers, elements of power dynamics soon emerged.

After losing some of their initial reserve, some parents felt this was a safe space to *test*

the water on their relationship with their teacher or even *flex their muscles* in terms of

establishing themselves as key players in the partnership.

> *I don't know [teacher] very well, so it'll be interesting to see how well I'm accepted, you know, as part of the team, when I start sharing my views.* (Parent meeting)

> *it'll be nice to get [teacher] in a room with other parents, other teachers and autism professionals who know more than [them] and maybe [they'll] see that I am actually educated in this stuff you know, maybe then [they'll] start listening to me in future.* (Parent meeting)

Others, who had suspicions that their inclusion in their child's education as a partner

was suboptimal, saw this as an opportunity to review their relationship with the school

in more detail and gather '*evidence*' and '*ammunition*' which they might need to

challenge.

> *I want to see how other teachers treat their parents. I think it will be an eye opener, because they don't treat me good.* (Parent meeting)

> *we're always kept at arm's-length…I'm not sure that's right.* (Parent meeting)

For others, though, this was a chance to talk about their child with the one person who

knew them in ways that perhaps the parent did not. A chance to *fill in the gaps* in '*both*

directions' as several parents explained.

> *I'm quite excited really, because although we get on well, I've never had the chance to, kind of, really share all about [child] with [them]…It'll be interesting to see if we see the same things.* (Parent meeting)

> *this is what we've needed since day one, like, you know, the chance to sit down together and really talk about [child]. It's so simple really, but it's always*

seemed impossible to do for some reason…I'm really looking forward to it.
(Parent meeting)

7.3.3.2 Teachers

Some teachers initially took a more detached stance, as if keeping parents at a

professional distance (Hornby, 2011, p.6), preferring to adopt either an altruistic

attitude of wanting to be helpful, but with an undertone of intellectual superiority of

'I'm here to educate the parents', or one of duty, as if by taking part they were *doing*

the family a favour, reinforcing their professional authority. There was little

acknowledgement to begin with from some teachers that participation might be helpful

to them as well, with some assuming a more expert stance.

> *If this helps [parent] then I'm all for it.* (Teacher meeting)

> *my Head recommended I take part…if it helps get the parents on board, then
> that can only be a good thing, I guess.* (Teacher meeting)

> *I'll be honest, I don't think it'll make much difference, but I'll give it a go.
> [Parent] is in denial about [child]…but maybe this will show them that we're
> professionals here and we know what we're talking about.* (Teacher meeting)

However, amongst these comments, for other teachers, there was an immediate and

genuine enthusiasm to work with the parents, demonstrating their engagement whilst

also revealing a little vulnerability. Some feared being exposed as not having the skills

to support the children, risking the trust of the parent and feeling the weight of

responsibility to make the most of their participation.

> *there's so little of this stuff (autism support) available you know. I hope I can do
> it justice…[they're] a great [parent]. [Parent] certainly knows more than me
> about autism, so it's a sort of chance to like, learn a bit.* (Teacher meeting)

> *How often do we get a chance like this! Not often I can tell you. I just hope
> [parent] doesn't think I'm not up to it after this (nervous chuckle).* (Teacher
> meeting)

These teachers revealed a mix of secure and insecure positions through their narratives

and demonstrated their ability to be reflective in their approach. More widely, teacher

narratives also revealed the macrosystemic influence on schools and ultimately on them,

where cuts in services to schools and a lack of funding for training accounted for some

of the motivation to take part in this study.

> *training and programmes like this can be so expensive, especially for autism for some reason, which is why schools don't do it I think; we just don't have the money. That's why I- well, we, me and [head teacher] said yes to this, because we couldn't have afforded it else.* (Teacher meeting)

7.4   *Findings and key themes*

7.4.1   *Parents with and without teachers: perceptions and beliefs*

Parental narrative explored many aspects of their journey with their child,

sharing difficult stories that had impacted across different domains of family life.

Parental reflections about their relationship with their child revealed a focus on trying to

understand and make sense of their child's perspective and characteristics and finding

new ways to connect with their child. However parental ability to mentalise about their

child's experience was mixed, with high levels of emotional distress evident in their

initial positions (*Figure 4*)

7.4.1.1 Parents without teachers – initial perspectives on autism

Key Themes: Parents without teachers present		Illustrative example quotes
Abandoning conventional parenting	How parents made sense of life and autism to meet their child's needs	*I don't- well, you know 'parent' the traditional way so to speak. It's not exactly 'make it up as you go along' (chuckles) well sometimes it feels like that, but really its- I parent according to need, you know, and [child]'s needs are different to most other kids [their] age.*
Living in fear	Parents fear of would happen to the child when they were gone	*It scares me what will happen to [child] when I'm gone because I don't see much change- in support I mean, and I don't trust society to look after [them].*
Negative impacts of meltdowns	Emotional turmoil and anxiety parents feel in terms of child distress and the barriers that result from this	*(meltdowns) used to scare me, but after so many years, I just go with it now. I guess you become used to managing it. I just wish it didn't happen though, not for me but for [them]. [They] get so distressed, it's heart-breaking and I can't get close [them] to comfort them you know. I feel so useless sometimes.*
Resignation and disappointment with a different life – sense of loss?	The restrictions placed on the family and the longing for connection expected in parenthood	*I get so tired with it all, you know what it's like- and I miss [them], I miss the child that [they] were supposed to be, for the type of closeness we don't have- well we do have, but it's- it's different. Gosh that sounds awful when I say it out loud doesn't it, but it is different, I can't pretend it isn't.*
Living with judgement – inoculation against criticism	Managing parental blame and the emotional armour created by parents to navigate	*[child] was laying in the middle of the street, kicking and screaming. I needed to just wait it out- I could see people looking- I just thought 'go on, just one of you, I'm ready'. But no-one said nothing, not that day anyway (laughs).*
Parental distress and vulnerability - feeling unheard and dismissed, undermining confidence.	How parental confidence is undermined, and frustration created when excluded from expertise discussions.	*I wish professionals would listen to parents more, we know what we are talking about.*
Trust – cautious of the system	How parents experience interactions with 'the system' as often hostile or threatening	*I can't begin to tell you the trauma this has caused my child and quite frankly … they – (indicating school) shouldn't be allowed near children with autism.*
Commodification of school	Parents' perceptions of education and their child's place within it – the conflict between policy and inclusion and the impact on home-school relations	*policy at [school] is just draconian. Everything on it sets [child] up to fail, which makes me really bloody angry. It's like something out of a Dickens novel honestly. It's so punitive.*
Sense of isolation	Parents perceptions of being separate from the system and from society, and being without help and finding strength	*At the end of the day, we're doing this alone. No-one's going to help us. It's up to us.* *I'd walk over hot coals for [child] if I thought it would make a difference.*

Figure 4 Table of key themes of parents' initial positions

7.4.1.1.1 Abandoning conventional parenting

A majority of parents were confident about their child and more positive and honest about autism when discussing the subject alone away from their child's teacher.

Once they appeared to feel safe, reassured that this was a confidential, non-judgemental, non-blaming interaction, a relaxed atmosphere developed during informal parent meetings (*more so than within formal interview*). They began to speak openly, sharing their parenting philosophies, what autism meant to them, their hopes and fears, mistakes they felt they had made and what they did on a day-to-day basis to make things work for their family, sometimes parenting very differently from child to child and often relying on other children to help, resulting in feelings of '*guilt*'.

> *I mean for a while now we've been having to sort of abandon conventional boundaries (shared laughter) you know* (Parent interview)

> *I guess some might see me as a permissive parent. I prefer 'democratic' and the common-sense to pick my battles.* (Parent meeting)

> *I do things differently for [child] than for my other [child/ren]. I have to be a different kind of [parent].* (Parent meeting)

> *I think a lot of autism [parents] will say our perception of stress and our perception of what's normal and what we will tolerate is probably very skewed to a lot of families with neurotypical children. You know, my expectations of my children are very different if I'm honest and they probably shouldn't be, but they are.* (Parent interview)

Parental responses revealed a mix of some adaptive parenting strategies in response to difficulty, but more frequently parents used avoidant or reactive ones.

7.4.1.1.2 Living in fear

Here, parents suggested that often where autism is concerned, they did not have a *plan* in terms of their parenting, with some describing '*living in fear*', doing what they can to get from one day to the next and, almost without exception, most parents expressed concerns of what would happen to their child once they were gone.

> *I think it's 'the' question that keeps every forever-parent awake at night* (Parent meeting)

Several parents described themselves in this way, as '*forever parents*', revealing their expectation to be supporting their child for the rest of the parent's natural life,

accompanied by many descriptions of *'exhaustion'*. However, the exhaustion was not so much in the context of the child but appeared to be largely rooted in a *'battle perception'* for support and access to suitable education, in continued defence against parental blame, from lack of societal acceptance, understanding and tolerance, the fight to *'find their place'*, the isolation and rejection of their family and for some a sense of hopelessness for their child's future. This all coalesced to underpin their fear of what would happen to their child after they, the parents, died.

7.4.1.1.3 Negative impacts of meltdowns

Some parents shared specifics of the daily impact of autism on their family and the distress that caused. Meltdowns featured highly and were at the forefront of many parents' minds, revealing an intense fear of them and feelings of lack of control, particularly when going out in public, curtailing family activity and having to make or adjust plans according to their autistic child.

> *I would only ever take [child] with me (out in public) if I really, really had no other choice, and then it would have to be really scaffolded…but then the anxiety it would cause me knowing that I have to do it* (Parent interview)

> *I never got any advice of how to deal with that (meltdowns), um, when we got the diagnosis* (Parent interview)

> *it's got to the point where actually, it becomes dangerous because sort of six times a night, being woken up after like a few like, a very short space of sleep is like, over a long period of time starts to make you feel sick and yeah, it starts to really affect your daily function* (Parent interview)

7.4.1.1.4 Resignation and disappointment with their *'different life'* - how things had to be

For some parents, these disclosures about ways of coping did not so much elicit resentment from parents, but more often resignation that *'this was how things had to be'* for the family's survival, alongside disclosures of other difficulties that revealed the emotional impact of autism on parents.

A few revealed disappointment with their '*different life'* and '*different relationship'* with their child, which was at odds with the one they had imagined, whilst other parents felt such extremes of emotional distress that they experienced suicidal ideation, a situation which I observed nearly a decade prior (Vassallo, 2016) without improvement in terms of support for some, it seemed.

> *I'm going through the motions. Um - but just before [child's] birthday…I had a period where I just felt, it was like a couple of days where I just felt really, I just felt suicidal actually. I went for a run and felt like I could throw myself off a bridge.* (Parent interview) (Vassallo, Dallos & Mckenzie, 2020)

Interestingly, as with the '*living in fear'* theme, deeper analysis suggests that many of these feelings were not generated due to the child's differences, but rather due to the systemic response (*or lack of it*) toward their child and the family.

7.4.1.1.5 *Living with judgement - Inoculation against potential criticism or blame*

This might go some way to explaining why these disclosures were not simply shared in isolation. Instead, many were automatically, routinely, and instinctively, accompanied by serial *justifications* for their child's action or their parenting decisions, as if seeking understanding or approval, a discursive strategy to inoculate against potential criticism or blame from the listener.

> *[they]'re not a naughty [child]. [They've] got autism.* (Parent interview)

> *don't get me wrong, I don't just let [child] do what [child] wants when [child] wants, there are boundaries; they just look different from the average family.* (Parent meeting)

Conversely, some experiences and justifications were firmly, even resolutely communicated almost inviting, daring someone to argue with them, offering inflammatory remarks to others because parents were '*battle ready'* and used to defending themselves.

7.4.1.1.5.1 Developing emotional armour

These were practised retorts, part of the *emotional armour* some parents had forged for themselves over time and in response to criticism and disapproval for their child's natural characteristics or in response to their child's distress. Although these were communicated to me with an element of humour, or even defiance at the satisfaction of having '*struck back'*, the underlying anger and sadness was still very much evident across the parental narrative, with many parents becoming emotional when recalling such events.

> *I've had it at Sainsbury's before. Somebody turned around to me and went, 'That [child] needs a good smack!' and I turned around to her and said to her, 'Do you know what? I can't smack the autism out of my child just as much as I can't smack ignorance out of people.' I said, 'but if you want me to try, hang around!' Off she went.* (Parent interview)

Reflecting on these narratives from parents, I was aware they had activated my own memories of similar judgement experiences and it was easy to connect my emotions with theirs. The memory of how this felt, the unhelpful comments or criticisms from strangers with no knowledge or context of my life, spoken without thought during a moment of public distress for my child and myself, was still very much available to me. This surprised me, as it had been many years since I had experienced this; however, it made me realise that such encounters with strangers (*and sometimes not such strangers)* are at least partially responsible for instilling in parents of autistic children the almost universal *fear for the future,* because they reinforce to parents that the world is an intolerant and potentially hostile place for their children (Altiere & Von Kluge, 2009; Myers, Mackintosh & Goin-Kochel, 2009). This in turn strengthens mortality concerns of who will protect their children once they the parents are no longer here to advocate for them (Vassallo, 2016). Even after many years, those embodied feelings, imbued with the same anger, humiliation, and sadness, were as clear to me at that moment as they were when they happened, reminding me that these experiences run

deep and, although these feelings might be emotionally *'shelved'* in the everyday course of life, they remain very close to the surface, ready to undermine confidence or ruin a day.

7.4.1.1.5.2 *Avoiding engaging in justifications*

Other parents were demonstratively less confident, immediately communicating their difficulties defensively, even apologetically, as if they felt in some small way *on trial by me*, expecting and therefore seeking to head off judgement.

> *I don't justify my parenting anymore; I do what suits our family. Until they've walked a mile in my shoes (nervous laugh, sigh)* (Parent meeting)

This automatic justification of *action* or *inaction* within their parenting decisions and responses, even within informal discussions of autism, arrived with such regularity, I wondered how habituated these families were to attack, even from those *within* their sphere of experience or own support network. This also offered an explanation for the defensiveness of their disclosures, even to a peer who could empathise with their situation, and to some degree explained the defensive positions parents took with schools.

7.4.1.1.6 *Parental distress and vulnerability - feeling unheard and dismissed, undermining confidence.*

Where parents were almost united was their belief in their *knowledge* and *expertise* about their child and their child's needs, which oddly did not always translate to *confidence* in their own parenting, communicating a level of vulnerability. In discussions of interaction with schools, parents described their frustrations at being dismissed, or having their value and contribution diminished, all of which had the potential to undermine their belief in their parenting knowledge and could explain some of their lack of confidence:

> *I know my [child]'s needs, but I need help meeting them.* (Parent meeting)

> *I don't always get it right, you know, but my intention is always '[child] first'*
> *and what [they] need.* (Parent meeting)

7.4.1.1.6.1 Parental frustration: feeling unheard

Outward frustrations and feelings of hopelessness embedded in their child's school experience and therefore their family life didn't so much *seep* but *flood* into conversation within our more informal peer exchanges, as if someone had taken the lid off a pressure-cooker. Not being heard was a regular area of frustration across parental narrative.

> *why don't they (school) listen to me. They make everything so much harder you*
> *know, and it trickles down - it affects us every day - at home - everything.*
> (Parent meeting)

> *I am the expert on [child], I wish the professionals would credit me with that. I*
> *have something to say and so does [child].* (Parent meeting)

7.4.1.1.7 Trust: cautious of the system

Parent narratives also revealed a vulnerability about their lives, and some were quite open about their level of distress during one-to-one discussion with me, but which they kept otherwise veiled during *joint meetings* with teachers.

> *I just don't want to be here anymore; I can't bear to think what the future holds*
> *for [child] if this (systemic experience) is as good as it gets* (Parent meeting)

> *It's been really, really tough. It's been the most challenging and hair-raising*
> *start to any (school) year that I've experienced in my life this year…And um,*
> *there's times I've just felt really crushed by it all* (Parent interview) (Vassallo,
> Dallos & Mckenzie, 2020).

When later questioned, some parents felt such disclosures might have left them '*vulnerable to the system',* perceived as weak or inadequate as parents.

As the most common root of parental distress was difficulties with school, which held concerns around child mental health, poor educational outcomes, bullying, anxiety-based school avoidance and exclusion, a few parents explained they were '*guarded'* as they did not want to appear *blaming* of the teachers, raising concerns about teachers

taking comments *personally*. For some they felt teachers were already overwhelmed and did not want to exacerbate their situation or *burden* them further; however for others they feared *reprisals* on their children when they were not there to protect them. Parental feelings of being let down by the system were not reserved exclusively for schools, but also extended to allied services, citing waitlists, bureaucratic red-tape and a lack of ongoing support, which compounded their struggles, adding to the weight of their distress and evident within their narrative.

> *they (school) know nothing [about autism] and have no interest in learning, they just want to tick Ofsted boxes, they're useless at SEN, and it's me that has to pick up the pieces. Every-Single-Day.* (Parent meeting)

> *[child] has school-based anxiety and is on a waitlist for CAMHS, but we've been waiting over a year and we're still not close to being seen.* (Parent meeting)

7.4.1.1.7.1 *Guarding and apologising*

Stepping from informal to more formalised interview, responses to interview questions that expanded on our previous frank conversations were initially replaced with more guarded comments from some parents, as if afraid to open up again *on record* with these emotive exchanges. Unsolicited promises of *good behaviour* during interview were proffered at the end of individual informal meetings, as if parents felt they needed to apologise for their prior candour that on quick reflection of their disclosures they might be judged as *bad*, wanting to convince me that this *frankness* was simply a momentary lapse, that going forward they would be *good,* which in parent speak equated to *not sharing your pain and vulnerability, lest you be deemed unfit.* Parents proceeded to bury or minimise their feelings with closing justifiers of *'don't mind me', 'I'm having a bad day', 'it's not that bad really'*, to somehow claw back their words a little, so as not to trouble anyone or risk their true experience being exposed to another, or worse to their child's teacher. Indeed, within interview some of the parents who previously engaged in unbridled discussion took a more muted tone at first.

the teachers are 'quite' good, so I don't want to be the complaining parent (laughs)...because no matter how bad the child is it's always the parent's fault. You know what I mean? You blame the parents. (Parent interview)

This guarded disposition of some parents sat in contrast to earlier revelations. However, reminders of confidentiality and anonymity slowly helped bring forth a more open, authentic discussion, becoming less reticent to share their difficulties and, as they relaxed, they began to acknowledge their own distress and anxieties within the interview process:

> *we're not in a good place at the moment, so it's a lot of negative more than positive, which is really hard...we're struggling at the moment with them (school) providing a basic level of care* (Parent Interview)

> *We've had one of the best family Christmases we've ever had because everyone was just so relaxed, which then made my anxiety levels go up at the thought of [child] coming back to school, and that's turned out to be exactly as we anticipated (mimics explosion).* (Parent Interview)

> *It all came to a head before Christmas and meeting with the school. I was getting so worked up, I had to leave the room to calm down before I started shouting and swearing about how much they failed [child].* (Parent Interview)

> *we're just at our wits end particularly with all the school stuff. [Spouse] was really worried I was just going to end up in hospital at some point.* (Parent Interview)

> *I mean [their] diagnosis was nearly two years ago and we're at crisis point now still. Um, if anything, it's almost got worse...it's just chaos and pain and heartache and distress and confusion* (Parent Interview)

7.4.1.1.7.2 *No faith in the system – doing battle*

This level of initial self-protection from parents, their fear of going *on-record* in any form, reflected a significant lack of trust in anything concerning their children, with those approached by their school to take part in SwiS, suspicious, perhaps viewing the research as insidious in its intention, as a way of *catching them out*, that services in whatever form were not to be trusted.

> *I can't trust anyone to be honest, everyone just lies* (Parent meeting)

> *I don't have a lot of faith, time, or respect for [names practitioner], I can't stand the [person]. And I don't think [named practitioner] likes me very much*

because I don't sit there and kind of 'soak up [their] wisdom', I argue back…and unfortunately [they] had to agree that it was a possibility…that it was- (autism). (Parent interview)

This feeling that they could not trust anyone involved with their child meant the experience of navigating services and education for some parents was frustrating and confrontational.

why is it that I have to constantly go into battle with those whose job it is to support us. Can you explain it? Because I certainly can't. (Parent meeting)

it's all about 'this' (rubbing finger and thumb together signalling money), it's not about children at all (Parent meeting)

For others, reflecting on the school experience was emotional for them, particularly in terms of missed opportunities for spotting difficulties that spanned years without help or support materialising for their child. This gave rise to both anger and parental guilt.

it's NEVER (angrily) been picked up (sobs) which I was- when I found out yesterday and I was talking to [husband] last night, I said…[child's] been here (school) 'FOUR' years, to me that should've been picked up, that [they] can't do this stuff, but it never has been. (Parent Interview)

why didn't I see it myself - I should've seen it myself. Now [they're] struggling and it's my fault (Parent meeting)

7.4.1.1.7.3 Seeking Diagnosis: "I'm not a bad mum, but I should have seen it".

This type of self-admonishment was frequent within parental narrative and often connected to the parent's inclination to obtain a diagnosis for their child, perhaps as a form of vindication of their parenting to stave off the parental blame. Despite parents' outward conviction that they were not to blame for the difficulties their child was experiencing in school, they were clearly worn down by the constant conflict, having to defend their child's needs and their parenting choices, which many internalised, imbuing feelings of doubt that they might be responsible for the difficulties after all. This dissonant position was difficult for some parents to navigate and seemed to underpin some of the distress that had embedded over time, staying with them, making reflection difficult.

I find it (autism) difficult to think about too much to be honest. It's too overwhelming (Parent meeting)

I wanted a diagnosis to prove to people I wasn't a bad [parent] (sobs). (Parent Interview)

I guess it (diagnosis) was kind of a relief...I felt - in so much sort of pain for so long...I was sort of at that point really, where personally I just felt in, almost like I couldn't (tearful) differentiate between emotional and physical pain in a way, so yeah, it's terrible thinking about it...I find it quite hard to look back. (Parent interview)

7.4.1.1.7.4 Strength in numbers, comfort in the crowd

It must be acknowledged that for some, trust issues meant the interview was still not the forum for sharing their experience, preferring to wait for the obscurity of the SwiS group interaction where each could say their truth, but be reassuringly '*lost'* in the crowd.

I must admit, it's easier to talk in a group isn't it (shared affirmatives of agreement from parents). There's definitely strength in numbers. I feel much less alone in this now which is amazing, because I've felt isolated for so long...I've often wondered what the point of it all was and how long I could realistically do this for (Parent comment, SPD)

it's really hard to talk about without losing my rag. Seeing your child fail at school and knowing the school could easily do better, it's hard not to take it personally you know, especially when you constantly get, you know, (imitates teacher whining) 'I've got 30 other children in my class blah blah blah', I don't care about that, I'm interested in my child, and it's clear they're not-, sorry, it's really frustrating and I can't say this to the school, so you're (myself and other parents) getting it instead (shared laughter) (Parent comment, SPD)

7.4.1.1.8 The commodification of school: 'School is a business now though, isn't it?'

For those parents who acknowledged a good relationship with their teacher, incidental conversation and '*aside comments'* provided clues that, despite some of the declarations of '*positive relations'*, the dynamic was not necessarily as comfortable or as established as portrayed, with underlying tensions existing between home and school.

On deeper analysis, these tensions did not necessarily just proceed from the personal, but were also a consequence of systemic challenges that parents described as

'a barrier' to parent-teacher connection. This was particularly focused on the

'commodification' of school (Ball, 2004) which parents felt more strongly than teachers.

Parents identified the differing agendas in terms of policy aims (*performance targets*

and accompanying Ofsted awards) and the individual needs of children as opposing

forces and therefore the root of disconnection between home and school, which

undermined their faith in the system.

> *School is a business now though, isn't it? I mean, since when did schools have CEOs? Really? It's ridiculous.* (Parent comment, SPD)

> *it's not really education any more is it, not in the truest sense. They just, like, teach kids to the test, to tick boxes on exam results, and then, like, run around like headless chickens trying to tick the Ofsted boxes. No one actually stops to see if any of this is any good for the kids* (Parent comment, SPD)

This recognition of bureaucratic conflict saturated the narratives of most parents, who

described many of their difficulties as failings in *'the system'*, a system which the

school and services were part of. Although they had sympathy for teachers, most

parents felt education was no longer child-focussed and their children were only

welcome if they benefitted the school.

> *I feel for the teachers though. What are they supposed to do? Do the right thing by my child and risk their results going down a smidge, which means they might be in trouble or worse, might lose their job, or follow 'the programme' (signals sarcasm with air-quotes) and to hell with the special needs kids?* (Parent comment, SPD)

> *I'm glad we are all here, but I struggle to believe this will change the culture of the school once we get back, 'cause they really don't want our kids if the truth be told* (Parent comment, SPD)

7.4.1.1.9 Sense of Isolation: 'we're doing this alone'.

There was considerable high emotion within the parental narrative, recalling

experiences with their child and expressing anger and frustration in terms of navigating

the system. Parents spoke of challenges around autism and, with the exception of

behaviour, which a few parents occasionally sited within the child as being a

characteristic of autism, most challenges parents experienced (*including responsibility*

for triggering behaviour) were external to autism, highlighting the responsibility for these challenges as shortcomings within the system *around* the child, including their own contribution as parents, rather than with the child themselves. As one parent explained when I asked *'is there anything you would want to change or have support with'*:

> *(sigh) Just somehow change the fear to go out, because of judgement when [child] got meltdown down outside-, and the judgment of people (sobs) - and how to cope with those situations (signals frustration, anguish).* (Parent interview)

In this sentence the parent describes their isolation, not being able to go out for fear of what might happen if their child's behaviour escalates and they are not supported, or worse, rejected by society (Myers, Mackintosh & Goin-Kochel, 2009). It signals their desire for, and value of, a little normalcy with their child, their desire as a parent for education to understand and support their child, to relieve the meltdowns and resulting distress, not just for the child, but for themselves also, a sentiment echoed by many parents. They desire simply to be able to go out without judgement from others, or fear of it from any setting, whether that be the public, amongst other playground parents, or from teachers at school. Encapsulated in that one sentence was their child focus, their unconditional love, and acknowledgement that they are not currently equipped to do this alone. Although it can be difficult to ask for help in any situation (Bohns & Flynn, 2010), parents described feeling increased vulnerability when doing so, as they are often subject to the parent-blame discourse (Clements, 2021; Colker, 2015). Despite this, parents describe continuing to ask for help despite rejection and experiencing the shame and guilt that accompanies blame. The adage of developing '*a thick skin'* was common across parent narrative, with several parents describing having to '*suck it up'* (criticism and blame) so their children could be helped. Parental narrative explained this as '*going with the territory'* and as '*payment*' for what little help they could get for their child. Their self-sacrifice was evident, they wanted to learn to *thrive* not just *'cope'*, but not

change their child in the process, rather, be able to accept them as they are. They wanted to help them so they could be together, parent and child, doing everyday things. Parental responses reinforced that there was little help from a systemic perspective and parents felt they were indeed '*doing this alone'*.

7.4.1.1.9.1 Finding strength: 'I'd walk over hot coals…'

What was universal for parents was their desire to do anything to help their child, with many communicating a sense of aloneness in this endeavour.

> *Sometimes I can just cry if I'm honest with you, I'm thinking- because I want to take it (behavioural distress) away from [them], I want to take whatever is going on in there away from [child] to act like that, then I sometimes I question myself, "Did I do something wrong, have I sparked this?" Have I triggered this, have I - whatever, and then again you get the guilt that comes into it that you know, it's - you think, "God, I wish it wasn't you that was going through this, I wish it was me" as any normal parent would.* (Parent Interview)

These aspects of their initial narratives communicated feelings of isolation and having little control or influence over their child's experience, a separateness from their schooling and those within school, together with a sense of desperation, particularly in terms of time pressure, with many looking forward in fear of the next transition to high-school and beyond into adulthood. Some parents described '*wasted time'*, revealing a level of resentment at the system and those within it for not actively supporting their child's potential when it could have had the most impact. For most parents this was not rooted in concern for their child's level of academic attainment or choice of career but centred more around future independence and seeing their child achieve this before they, the parents, died. For most parents of typically developing children, their mortality fear diminishes as their children grow and become independent autonomous people. The reverse is more often true for parents of autistic children (Vassallo, 2016), where what happens to a child when parents are no longer around to care for them is a fear that most parents of autistic children live with on a daily basis, especially where independence is uncertain and social care is poor.

the 'State' is a poor parent, I don't want that for [them], but time's moving quicker than progress, and that terrifies me. (Parent meeting)

they (system) bang on about 'early intervention this and early intervention that', but there are just no services, and what there is, has such long waitlists, for us it's sort of 5-years-too-late intervention. We needed it when we needed it, feels a bit late now. (Parent comment SPD)

Assisted living? Have you seen Panorama! (Parent comment SPD)

7.4.2   *Parents with teachers – observations on a shift in dynamic*

These honest revelations that were more tempered within the confines of the school environment or the presence of the teacher, meant the demeanour of many parents was quite different. Such fears remained undisclosed, with some parents saying very little, remaining reserved, even closing down or deferring to the teacher. This may have been because this was early days within the research and trust had not yet been established, or because parents of autistic children frequently endure judgement and report a lack of allies (Altiere & Von Kluge, 2009), so tend towards *self-preservation*, closing down in self-protection. However, it could also indicate a sense of intimidation, perhaps activating memories of their own school days, generating a power imbalance or an exacerbation of feelings of isolation, all of which are reported from parents of autistic children in the wider literature in their dealings with schools (Hornby, 2011; Smit *et al.*, 1999, p.13).

> *it's difficult for me to deal with this stuff you know. Every time I have to talk to the school, I just go to pieces. I'm right back outside the headmaster's office myself, waiting for a right rollocking for something or other. I feel it in my stomach, and I hate it. But then I feel worse because I'm being a crap [parent] not advocating for my child.…They get you on the back foot from all directions...I wish I was better at this stuff* (Parent comment, SPD)

A few parents adopted quite different positions. Some who began as quite confident at home in discussions of autism, became more overtly so within the school setting, as if displaying a show of strength, communicating their knowledge, controlling

the conversation and sending the message that this was their child, they had the knowledge and they should be heard.

> *It frustrates the hell out of me, because I'm the parent here and they (school) need to pay attention to what I have to say. I've raised [child] and I know what's best for [them]…to be honest, I'm rapidly losing patience and I have told them so.* (Parent meeting)

For some teachers this self-assurance did not evoke a collaborative response, but resulted in a notable *step back,* preferring to adopt a passive role in the moment rather than a move toward a co-constructed meeting with the parent. This was reflected in teachers' body language and physical demeanour (*which changed during these joint meetings where parents were more assertive*), and in their after-meeting comments.

> *I just have to let [them] go and have [their] say…it's no good me trying to say anything, [they] have to be in charge.* (Teacher meeting)

> *You see! (Gestures to prior joint meeting). It's really difficult to make headway with [child] when [parent] insists on doing things [their] way.* (Teacher meeting)

For a few teachers, their comments appeared to reveal a sense of frustration at parental strength and authority, as if it somehow undermined theirs, that only one person could adopt such a confident position, only one person could be in charge, with some drawing parallels between parental strength and confidence and the difficulties the teacher experienced with the child.

> *[parent] does pander to [them] a little bit. So, just being a bit firmer with [them], because if probably-, if [parent] was as firm with [them] as I am, then [they] might get a little bit further with maybe being able to have a more positive time. (Teacher interview)*

> *yes, they've done all the (autism) courses…but in my classroom I will do it my way. I'm in charge* (Teacher meeting)

Other parents who were very relaxed and comfortable at home in the context of discussions of autism, were markedly less confident with teachers in general, with some visibly uncomfortable within the school setting, finding it difficult to speak, becoming noticeably anxious, their narratives later revealing their own negative school

experiences or thoughts of their own neurodivergence only recognised in themselves from raising their child.

> *I was like [child] you know. I recognise a lot of myself in [them] now, I couldn't fit in to school either and it was an awful time. It still makes me shudder when I think about it* (Parent meeting)

> *it's made me ask so many questions because a lot of it I thought, hang on, but that's exactly what I did as a child…[spouse] said, "My goodness, no, that's what 'I' did" then we did start thinking… Are we on the spectrum? Is it just that we've learnt to fit in?* (Parent interview)

What united all parents was that their behaviour, confidence, and verbal expression underwent significant and notable changes between joint and individual meetings, across school and home/neutral settings. A mix of caution, reserve or assertiveness was clearly in play when interacting with teachers and evidence of parental vulnerability and emotional turmoil was only properly revealed when given the space, anonymity, and privacy to do so. This suggests parents did not feel confident in their relationships with teachers to *be themselves*, as one parent described feeling '*under scrutiny'*, where a chink in their *armour* might result in attack, usually about their parenting. This level of caution, reserve, or assertiveness from parents about teachers has a systemic effect, as attitudes or tensions are likely to be felt by the child, communicated via parents' own emotional states, or ways of talking and being when interacting with teachers and school. This has the potential to undermine children's sense of safety and attachment to their school-based caregivers when leaving home and transitioning to the school environment (Vassallo, Dallos & Stancer, 2023, p.167) exacerbating any anxiety the child may be experiencing.

7.4.3   *Teachers with and without parents -perceptions and beliefs*

For most teachers the difference in dynamic with and without parents was less pronounced but still evident. Within the joint meetings conducted at school, teachers generally retained a professional demeanour, which for some was more aloof, and for a

few communicated an air of superiority, control, and *professional distance* (Hornby,

2011, p.6) *(Figure 5 below).*

7.4.3.1   Teachers without parents: initial perspectives

Key themes: Teachers without parents present		Illustrative example quotes
Maintaining a professional façade	How teachers received the research process with suspicion ad were initially constrained by context	*This is entirely confidential, isn't it?* *I'm not sure my personal feelings about autism really come into this?*
Feelings of 'them and us'	Making sense of how teachers position parents – often in opposition	*You might be a teacher but you're an autism parent first*
Teachers not caregivers	How teachers constructed their perception of the role of teacher and how teachers differed in this perception	*I can't be everything to [child] … I'm employed to teach.* *I just want [child] to feel safe in my classroom*
Wanting to make a difference	Teachers navigating the desire to help with demands of the job, bureaucracy in terms of performance agendas and a lack of training	*it's tough sometimes you know, coming in every day, not knowing what you're going to face. All I can think about is how can I help [them], but sometimes I just don't know where to start.* *there's so many things I'd love to try with [them] but I can't, there's just not the flexibility in the system.*
Fear of judgement	How the meaning of autism is shaped by competing agendas of general performance culture over inclusion and meeting individual needs, framing the label and the child as a 'problem'	*the teacher who's observing the rest of the class just sees the rest of the class are distracted by what [child's] doing. Because she's looking at our pupil premium children and our other children that aren't necessarily making progress, and she thinks they're not making progress because 'that's' (referring to child's behaviour) happening every day.*
Differences between longer serving and early career teachers	How teachers differed in their attitudes and perceptions of autism, the child being individually or collectively 'unique'	*the trick is not to panic, they're not aliens you know- (chuckles) like, they're just kids really, but kids who need my attention a bit more I guess- I don't know. Everything changes depending on the kid.*

Figure 5 Table of key themes of teachers' initial positions

7.4.3.1.1 *Maintaining a professional façade*

Context plays a huge part in all our lives. For example, I am a different person at work than I am at home. In my home life I am a wife, mother, sister, daughter, friend, and I function as such. I am relaxed, unguarded when alone or among those I love and trust. At work, as fond as I am of my colleagues, and as much as I love my job, I am different. I am an educator, and that responsibility stays with me throughout the day, even in my most relaxed moments. As a social actor in this context, I am still *in character* in relation to my environment. A similar *'difference'* could be expected of teachers, as the classroom and school can be very personal spaces for teachers, reflecting their teaching styles and ways of being as *educators,* which will likely be different from who they are at home. When meeting with teachers, the lack of setting change, remaining in the environment where teachers ordinarily hold an authority position, may have supported ongoing feelings of control, maintaining their *teacher* persona, a context from which they could not easily *switch*. This could account for the difference between parents' and teachers' initial disclosures. At home, people are generally their authentic selves. Therefore, whilst parents were equally in control at home, they were safe, unconstrained, and essentially *themselves*. Teachers on the other hand stayed within their personal classroom space, the power of this space meaning many were still in *teacher mode* during initial conversations, making reaching them on an emotional level difficult and disclosures less forthcoming.

Teachers also revealed a certain insecurity and vulnerability by what they did not say, as opposed to what they did. When exploring the narrative with some teachers, they did not initially have the confidence in the confidentiality of the research process to fully engage with it, fearing any presentation that might lead to them being perceived as less objective or not *in charge*, as posing a risk to their professional standing. In many ways, this sits parallel to feelings of judgement experienced by parents.

Equally some teachers felt they needed to sustain the school narrative, constrained from speaking freely in case any comments were traced back to them and put their position at risk. As one teacher told me:

> *You're very welcome to use what I say, I think it's important. But you will take care my comments can't be traced back to me, won't you?* (Teacher meeting)

This sentiment was echoed by a number of teachers who described researching such a sensitive subject as *'risky'* for them professionally. This might explain why within both joint and individual meetings, the professional demeanour of many teachers was initially *professionally distant* (Hornby, 2011, p.6), beginning interactions using lots of (what might be considered as) pedagogical rhetoric, avoiding personal opinion, and resisting when questioned any revelation of how teaching their child or engaging with the family made them *feel* as *people* as opposed to *teachers*.

> *I'm a teacher first and foremost* (Teacher meeting)

Even within individual informal discussion, initially teachers were *slow to warm*, constrained and continually taking emotionally based questions away from themselves and bringing it around to the child, focusing largely on the child's attainment, what they *do* for the child educationally, and majoring only on positive professional feelings, finding it hard to engage and reflect on the deeper emotional aspects of what teaching meant to them and how it made them feel.

> *I'm so pleased about what [child] has achieved, [they've] come such a long way in a short space of time.* (Teacher meeting)

> *I did struggle during Term 1 because [child] has so many needs, I wasn't sure which one to tackle first. [Researcher: How did you feel about having [child] in your class] Well, I, I wanted to make sure [they] had the best start to the year. [Researcher: How did teaching [them] make you feel, personally, emotionally?] Um, (pause) it's tricky, because they have such strengths you know, I just wanted to bring those strengths out.* (Teacher meeting)

When responding to *direct* questions about their experience of teaching their child in formal interview and how they *felt* about it, many teachers' responses continued to be avoidant of any internal emotional processes. Instead, conversation was again deflected

toward more central pedagogical objectives and outcomes, replacing emotion with description of how they supported the child with their school experience.

> *[child] really enjoys [their] maths. [They're] getting on with their maths now, as when [child] is part of the whole class. Um, [child] goes out for phonics but then [child] comes back and [they're] fine…So, yeah, [they're] doing really well I'd say.* (Teacher interview)

> *when [child] first joined us, speech and language was one of the biggest issues… [child] wasn't speaking clearly…[child] speaks in sentences now…the progress made since [they've] been in the school has been quite phenomenal* (Teacher interview)

To begin with, affective expression was noticeably lacking for these teachers, who instead stuck firmly to the educational narrative of how the child was making '*expected levels of progress*', how they had progressed so much whilst at *their* school.

What was most surprising was that many teachers were overwhelmingly positive about their child during initial meetings, highlighting the child's strengths and uniqueness, significantly downplaying any discussions of distress behaviour or difficulty. Therefore, in the face of the overwhelming evidence of poor outcomes and the excessive rise in exclusions for autistic children (Ambitious About Autism, 2018d; Hall, 2023), the research on parent and teacher attitudes highlighting difficult relations (Schultz *et al.*, 2016; Starr & Foy, 2012), and the Department for Education's own admission of the current failings of the SEND system nationally evidenced by serial reforms in one decade (Department for Education, 2023), begged the question: *what's 'your' secret* and if all in the garden is rosy *why are you here?*

7.4.3.1.2 Feelings of 'them and us'

Despite sharing a professional link with teachers as a fellow educator, this knowledge did not elicit the same strength of peer connection with teachers that I experienced with parents. Teachers knew I was an educator; however, on several occasions still described me as an '*autism parent*'. This suggested my personal knowledge of the parental perspective somehow eclipsed any understanding and shared

experience that I had with them as teachers working in education. I was positioned (as one teacher said) *'naturally on the parents' side',* as if the parent-teacher context meant sides *must* be taken. This strength of feeling and type of *positioning* perhaps indicated an entrenched unconscious bias that, for some teachers, parents were simply *opponents* in their day to day working lives and they were *in battle* (Hornby, 2011, p.5), meaning for them a partnership perspective was not on their radar. When asked if they actively worked towards partnerships with parents, one teacher explained *'it's tricky because I have a job to do'* as if parent partnerships interfered with the teaching process. From these teachers' perspectives, parents and teachers were separate with very discrete, compartmentalised roles, missing the circularity of their influence in caregiving, or absenting themselves completely from that role.

7.4.3.1.3 *Teachers as teachers, not caregivers*

It must be noted that for some teachers, responding sensitively to the emotional needs of the autistic child in their care, *was* their default position. For these teachers there was a genuine warmth, caring and attachment to their student, continuing the circularity of care, understanding and attempting to meet the child's continued attachment needs, keeping them close and mentalising about them, even if that proved a challenge.

> *We try not to do one-to-ones, and [child] just doesn't need a one-to-one TA, [child] sits close to me, um, because we have that really, we get on really well.* (Teacher interview)

> *I don't always feel like I get through to [them], so it makes, it's almost, uh, makes you a bit sad because…I don't know if [child] feels safe…I shouldn't be teaching [them] maths before I know that [they're] safe.* (Teacher interview)

> *the first thing I did when [child] came into my class was try to make sure [they] felt secure. I mean, it's my job isn't it. They're my responsibility.* (Teacher meeting)

However, in other cases, teachers' perspective of the *separateness* of the parent-teacher role was clear; they were educators, *not caregivers*. This seemed to translate into the

view of the teacher that the child should be able switch contexts from home to school and *detach* the significance of their parent and what that parent provided as a caregiver whilst in the classroom. To some teachers, the child seemed to be something different when they stepped through the school gates. Rather than a child that required the continued input of caregivers, they were an entity to be filled specifically with education, with all their non-education needs somehow temporarily suspended until home-time or delegated elsewhere within the school.

> *They're in school now, this is not their home.* (Teacher meeting)

> *[They're] very capable, and [child] knows that.* (Teacher interview)

> *Do you know what, when [they're] in here (classroom) [they] can follow the rules.* (Teacher interview)

> *[child] needs to get on with it in school, simple as that* (Teacher meeting)

Many teachers did see their children as capable and able, at least in some key academic areas if not more holistically. Nevertheless, attention to the significant emotional needs of these children often jarred with the teachers' own needs, for example the impact this level of *'neediness'* might have on performance targets. This appeared to add to teachers' stress, as children do not *switch off* their needs when they come to school, particularly emotional and attachment ones. Analysis of initial positions revealed that some teachers found this level of emotional responding quite frustrating, understanding attachment as dyadic, existing between parent and child. This meant that some teacher perceptions about emotionally or behaviourally based difficulties with the child tended toward being the responsibility of the parent, suggesting teachers did not always consider their own contribution to situations, as they did not recognise themselves as important caregivers in the child's system, nor did they want this as a part of their role.

> *I just don't want to cuddle. It's getting to the end of term, and children are too close all the time* (Teacher interview)

> *It's my job to teach them, not to raise them* (Teacher meeting)

In discussions of emotional support in the classroom, a number of teachers made more than one reference to their school's *pastoral support*, not so much as an '*addition to*' the teacher role, but more of an '*instead of*'. *Nurture spaces* or *pastoral hubs,* which were physically separate from the classroom, some teachers saw as being designed to provide that caregiving element, a perspective that further detached children from teachers and teachers from caregiving.

> *[child] can access the [pastoral base] if they need to* (Teacher meeting)

As children have different experiences throughout the day, their attachment systems might be activated at any point, requiring a response from caregivers in the moment to meet those attachment needs. Therefore, sensitive responding is not something reserved just for the home (Verschueren & Koomen, 2012). However, centralising it to a specific *space*, such as a pastoral room, suggests to the child that care is not available in the classroom, therefore the classroom may be an unsafe place. This knowledge might then be expressed through anxiety and distress in the child. Such expression then reinforces to peers and staff that those who require, or are sent to *nurture spaces*, are in some way *needy* or too demanding of individual attention from teachers. Instead, they are to be kept separate, away from *bothering* others.

> *the idea was to set [them] up a base that was called [child's] base with the visual timetables, [their] computer there, and that [they] would come in and have this settling in time. Well! (exhales frustratedly) [They] would go straight past it and never use it!* (Teacher interview)

In this example, the child resists the *outsourcing* of their emotional needs to a *designated space,* eliciting frustration from the teacher as they were faced with providing for the child's emotional needs themselves. This was similarly felt by other teachers who felt the pressure of this in terms of *time pressure*, impacting negatively against their performance targets.

> *The trouble is I have to prepare them all for their SATs…it's looming and some of them are just not ready* (Teacher meeting)

7.4.3.1.4 Wanting to make a difference

Following reassurances of confidentiality, like parents, more relaxed and open discussion began to flow from teachers, although drawing this out took longer that with parents. Narrative, in terms of how they as teachers wanted to make a positive difference to their student's educational outcome, were uppermost in many teachers' thoughts; however, due to the reticence of some, whether this is what they *truly* felt or what they thought they were supposed to say as a teacher remains unclear. However, after a while, teachers did begin to share their vulnerabilities and reveal their attachment to the children.

> *it's heart breaking to see because [they] can't tell you what's wrong, [child] just shrugs [their] shoulders and you just want to know what's going on in that little head of [theirs] and that's probably a real challenge for both of us because I can't help [them] because [they] can't tell me…I feel a bit helpless when [they're] like that and that's not nice* (Teacher interview)

For many teachers their desire to make a difference was also tempered by the constraints of their role within the education system and the freedoms, or lack thereof, to explore *a different approach* with their students, particularly in the face of increased '*marketisation*' of education, demoting inclusion efforts below concerns of pleasing Ofsted (Hall, 2023, p.75). Teachers explained that where innovation did not fit with the agenda of the school or wider education system the flexibility to *'try something new'* in practice was often refused and many of the teachers felt stymied.

> *we're supposed to be a 'trauma informed' city, but then you look at things like our behaviour policy (shrugs). Everything in education is geared around targets and compliance.* (Teacher meeting)

> *I've asked repeatedly for autism training. This (SwiS research) is the closest I've got.* (Teacher meeting)

> *we have our hands tied so much with you know, we can't do art therapy, we can't do Lego therapy, we can't do anything like that…it's frustrating* (Teacher interview)

7.4.3.1.5 Fear of judgement

Concerns around judgement of their professional standing in terms of performance and meeting the wider school agenda were also strong competing priorities in teachers' daily experience. These were not disclosed in front of parents but were at the forefront of the minds of many teachers when away from parents. The underlying feature of these anxieties being the impact their autistic student was having on this picture, how they might be *judged* as educators and how this reflected on them as teachers.

> *so, another teacher was doing an observation of my lesson. [Child] was playing with Play-Doh but [they] came up, in the middle of the lesson, everyone there watching, joining in with the lesson, but [child] came up and needed to show me. So I just said, "Yes, that's brilliant. Can you now go and do work?" (shooing motion with hand) and off [child] went. But obviously, in the lesson observation, it's not an ideal scenario because you're being observed on your teaching of the class.* (Teacher interview)

This particular interaction demonstrated the impact of *performative pressure* on teachers' ability to respond to a young child seeking an attachment connection in the moment and highlights why teachers might seek to *outsource* this level of connection to pastoral support. Optimal childrearing encourages parents and caregivers to be responsive, following the child's lead with warm and sensitive responding, yet in this scenario the *fear* of being judged while being observed led to the teacher dismissing the child in their moment of attachment need.

7.4.3.1.5.1 Policy shaping the meaning of autism to teachers

Such concerns meant teachers' initial positions about autism and teaching autistic children were being shaped by the wider systemic influence of policy and school demands for results. For some teachers, this seemed to impact how they *viewed* the child and what the *meaning* of that child had become to them.

> *So when Ofsted came in, [child] was (supposed to be) taking part in the phonics session and [child] wasn't, [child] was rolling around on the floor. The children were largely ignoring [them] because they're used to what [child]*

does, but all Ofsted saw was 'this' (teacher signalling their frustration with their hands - gesturing to the floor), and it was absolute horror that that's what [child] was doing, even though the (other) children were largely engaged and-and doing what they were supposed to be doing, all that came out of that lesson observation was [child]. (Teacher interview)

(I'm) even wondering what the point of trying to mainstream [child] was… 'is this right for [them]'? and, 'is [child] right for this school'? (Teacher interview)

7.4.3.1.5.2 The meaning of the child and autism as 'problem'

These concerns reveal the pressure teachers experience in terms of performance culture. As some teachers relaxed into their narratives, their concerns about the educational system, lack of professional support and disillusionment with their role as educator, together with questions about the family situation and parenting of their student, began to emerge. This became more pronounced as their early narratives developed, where flashes of resentment toward the child became more evident, and the meaning of the child to some teachers was one of a '*problem*'.

I want to say [they] didn't do it on purpose, but it would still get me down…I've come to resent having [them] in the class to be honest (Teacher meeting)

When [child] is finding it funny to, let's say, mimic and criticise and swear … it breaks my concentration…this is not a good situation (Teacher interview)

Other teachers' narratives of *child as problem* made plain educational constraints, describing the difficulty of teaching even a willing learner if their learning needs varied from those of the majority. For some teachers, they were simply not resourced or trained to provide an inclusive classroom where every child could access meaningful learning. Instead, narratives revealed the desire to again *outsource* the responsibility of these children to teaching assistants who could provide separation between the autistic child and the rest of the class.

if [child] had a one-to-one, that 'problem' would be solved…until now [they've] been happy to play at the back of the class, but now [they're] not…[child] wants to learn…and that's very difficult to manage in the class (Teacher interview)

In this example, the teacher seemed to construe the child's desire to learn as a *threat* to the stability of their class environment, resisting inclusion, fearing disruption that would then reflect on them professionally. This perhaps signals a lack of confidence from the teacher in their ability to respond to the differences in their students, contributing to the interpretation of the meaning of the child as being a *problem*.

The meaning of autism for teachers also revealed different beliefs and ideas about what autism was. Most began by engaging in person-first using terminology *(see introduction)*, viewing autism from a clinical perspective. This is a common approach from practitioners, who often work from a medical model and therefore consider autism a '*disability*', whereas a greater proportion of parents who may have started their autism experience with that view *(having taken much of their information from the same clinical perspective)* had made a shift toward identity-first language. Indeed, this resonated with my own experience, as one of ongoing learning and enlightenment.

7.4.3.1.6 *Differences between longer-serving and early-career teachers*

Where many parents understood autism as a facet of identity, a set of characteristics that made their child unique, teacher attitudes were not so straight forward. Like parents, initial analysis suggested that most teachers did view the child as unique (Vassallo, Dallos & Mckenzie, 2020). However, further research revealed that some teachers incorporated this with the disability label, meaning views and expectations of these children were not always very high. Teachers were still influenced by stereotypes, evidenced by their genuine surprise when their autistic students displayed their talents or behaved *typically*, challenging their core beliefs about autism.

> *[their] creativity is amazing actually and that surprises me for an 'autistic child', that [they] can be so creative and [they're] very focused.* (Teacher interview)

when [they're] doing maths, I sometimes forget [child] has autism, [child] has such an aptitude for it. (Teacher meeting)

For some teachers the '*uniqueness'* of the child was more in comparison to the '*commonalities*' of the rest of the non-autistic children, setting them apart not necessarily with an individual uniqueness, but a more generalised *collective* autistic uniqueness.

> *I would say that many other children, obviously, they're individuals like anybody else, so you can't like say like, 'this is autism' but for a lot of other (autistic) children, telling them what is going to happen is perfect.* (Teacher interview)

Further analysis revealed a more complex and dichotomous picture. Longer-serving teachers tended to fall back on previous experiences, relying on old strategies and communicating a *universal* knowledge or perceived wisdom of autism, frequently rooted in behavioural methods, underpinned by stereotypes and misconceptions from perhaps more outdated understandings and a medicalised model, whereas their narratives revealed there were clear priorities, finding methods to gain compliance in the classroom and keep autistic children *'quiet'*.

> *I have seen children whose anxiety levels go down when you start to read from a script of a SATs paper, not up…they relax more and then it's 'QUIET' (exhales strongly and sighs with relief) and they're doing a SATs, and they would prefer SATs every day* (Teacher interview)
>
> *It's a case of 'managing' them really, so, you know how it is with autism, giving them time out etc.* (Teacher meeting*)*

For these teachers, their approach resulted in more of a *one-size-fits-all* in terms of teaching autistic children. However, this was more obvious in those teaching younger children, where perhaps differences and individualised needs in the children compared to their non-autistic peers were not yet so apparent, requiring less differentiation. Where teachers employed previously used *'generic'* strategies expecting them to work on all autistic children, they openly communicated their frustration, finding it difficult to accept when they did not.

(Sighing and speaking frustratedly) I was very used to speaking in short sentences, making everything completely predictable, making everything completely safe…but nothing works with [them]. (Teacher interview)

Others took a more dismissing tone, avoiding conversations of an individualised approach or the idea that new understanding might be more helpful, holding on to generalised thinking about autistic children as a single group requiring the same input, that *'this is what you do with autistic children'*. This was communicated with a level of confidence and intransigence, resisting any reflection on the subject.

(emphatically) Visual timetables! They work every time. (Teacher meeting)

(confidently) I've lost count of the number of children with autism I've worked with, I should know what I'm doing by now (chuckles). I mean if I haven't 'got it' by now… (rolls eyes). (Teacher meeting)

Staying closer to the medical model, longer-serving teachers were more heavily influenced by the label, which became totalising for some, and a rationale for exclusion for others.

[Interviewer]: when you see [child] as a whole child, as a whole person, how much of that person is autism?
[Teacher]: I would say most of it (Teacher interview) (Vassallo, Dallos & Mckenzie, 2020)

I have been teaching long enough to see children with special needs who perhaps traditionally would have been in a special school…you have to balance the best wishes of the child with special needs with the best wishes of the other children in class. (Teacher interview)

Early-career teachers were surprisingly less influenced by the label, where the meaning of autism meant a chance to get to know the child and understand the nuances of their character, adopting a more flexible, balanced and secure view of autism, able to take the child's perspective when supporting their needs.

well autism is so many things isn't it. I learned that on placement; they're all different, you just need to get to know what each child needs (Teacher meeting)

I came back into the classroom, and I thought 'the biggest issue is noise level' and I saw, I don't know why it only 'just clicked' then but I thought maybe it would be better if [child] was towards the back of the room, and literally one small move to the back of the room has had a huge amount of progress (Teacher interview)

> *the beauty is in the 'punch the air' moments, you know, like, when they respond, or get something, or like talk to you differently, you know, when it's an achievement, not like a school achievement, but like a [child] achievement.* (Teacher meeting)

Given the meaning of autism to early-career teachers was on the whole less fixed and more positive, it suggests that despite their protestations of a lack of autism training, these teachers might initially possess a level of flexibility, enthusiasm, and ideas that autistic students would benefit from, something that perhaps becomes eroded over time, in longer-serving teachers. As teacher identity is fundamentally connected the situational context of school and therefore to their students (Pearce & Morrison, 2011), the feedback teachers get from inclusion success would likely reinforce that identity and feed into their positive feelings of being a teacher. However, their identity could equally be undermined by persistent unsupported difficulties often experienced with autistic students, diminishing the sense of satisfaction they get from teaching the *'mainstream'* typical majority student. Interestingly the current mainstream educational agenda, jarring against the inclusion agenda, was succinctly highlighted and expressed by one teacher, describing themselves as '*an educational eunuch'*, powerless to formulate the individual needs of children against macro-educational policies and the general performance expectations attached to them. Such restrictions to creatively practise and see positive results in their most vulnerable students could account for diminished feelings of efficacy and the attrition rates of more than a third of teachers leaving the profession within five years of qualification (McLean, Worth & Faulkner-Ellis, 2023; Perryman & Calvert, 2020).

7.4.3.1.7 *Teacher influence*

Teachers' feelings about autism were not restricted to the child, but also proliferated to some degree from the teacher's relationship with the parents, with some

teachers making connections between difficulties in the classroom and the parents'

behaviour.

> *I've also found that [child's] parents are quite anxious, and I feel that sometimes [child's] anxiety sort of stemmed from their anxiety and sometimes I'd, we've had meetings and I wonder sometimes whose anxieties I'm allaying most.* (Teacher interview) (Vassallo, Dallos & Mckenzie, 2020)

> *[parent] definitely rules the roost, [they're] definitely in charge, and a lot of [child]'s mannerisms and language are a spit of [their] [parent].* (Teacher interview)

Whilst this is a reasonable connection, as parent-child relationships will of course

impact the child, rarely did any of the teachers connect the contribution of *their*

relationship with the child or the parents as in any way influential on events, although

some teachers seemed to have more of an insight into this than others.

> *[child] sees me and mum talk and, I don't know if that helps facilitate, because [they] could see that we're getting on really well?* (Teacher interview)

Again, this seemed to suggest that most teachers underestimated their power and

influence not only over the child, but also over the family, that again, as explored in

7.4.3.1.3, what happens in school is in some way *separate* or *tangential* to the child and

family experience, compartmentalised and forgotten once outside of the school gate.

This is interesting, as teachers fully understood the influence of parental action on the

school environment but were less aware of the bidirectional influence of themselves in

the child's homelife, which was clearly articulated within the parental narrative.

> *for example, we spent three hours last night trying to understand from [child] what happened in school today and, from what I understand, it was all over [child's] uniform. If the teacher had just asked me, I could have offered some advice and saved all this hassle, but instead we have to pick up the pieces all evening. (Parent meeting)*

> *[Teacher] was off sick one day last week and [child] loves [them]. If the school had just rung me in the morning when they found out, I could have prepared [child] for that. But no, surprise-surprise, it was 'all change' when we got there- (shrugs) utter disaster for the whole day. (Parent meeting)*

Again, these comments resonated with me, as I reflected on the *'bad old days'* the

number of evenings and weekends our family spent *unpacking* events from the school

day which had thrown my son into an emotional tailspin, usually over something simple

that could have been resolved, or better, avoided altogether, had communication

between the school and myself been better.

7.4.3.1.8 Feeling vulnerable

Many teachers identified a lack of training for supporting autistic children as

being problematic. Their sense that they '*lacked knowledge*' impacted their feelings of

control in the classroom and their ability to be effective educators.

> *I think we had one like, (thinking out loud) did we even have an assignment on it (autism)? I don't even know if we had an assignment on it, a little bit at uni? And then I think I had experience on placement 'once', but I hadn't had any formal training as such about it.* (Teacher interview)

> *It feels a bit unfair to like, increase the SEND agenda in mainstream schools, but not match it with appropriate training for teachers, I mean, it's not fair on us and ultimately, it's like, not fair on children either. I'm not sure how long I'll be a teacher for to be honest, because it's not really how I imagined it.* (Teacher meeting)

For some, these different disclosures trickled, developing across our exchanges as trust

was established and interactions and observations were built on. For others, it quickly

became an outpouring, with many frustrated by an education system that, as one teacher

described, left children '*ill-prepared for life*', undermining their feelings of efficacy and

satisfaction as a teacher.

> *It (inclusion for autistic children) all looks great on paper, but it prepares children for absolutely nothing in practice.* (Teacher meeting)

> *Between you and me, it's all about keeping Ofsted happy and the rating up. We just teach to the test really.* (Teacher meeting)

> *it's just the whole money making thing now with education, and that's what frustrates me… I think it's the red tape that frustrates me more…having to tick boxes for the government* (Teacher interview)

The inflexibility of the system and the '*overwhelming*' workload described by many

teachers, included their frustration with the '*evidence*' they had to produce of progress

made by the children. Some felt quite cynical about this process, one teacher describing

it as a way of '*identifying the undesirable children*' as a precursor to a '*managed move*' out of the school. Many teachers were tired, and a few felt professionally out of their depth at times, often asked to teach areas that were not their specialty and manage situations they were simply unequipped for.

> *I remember this time last year I was crying all the time about maths and how much I hated maths and how I couldn't do it, whereas this year…I think it's a bit more behaviour that I've cried about.* (Teacher interview)

> *I'm not a psychologist or a doctor, I don't have the skills…it's not fair on me to solve such complex problems* (Teacher meeting)

Indeed, the pressure that teachers explained they felt led to a number of teachers who took part in this study either moving jobs or leaving the profession altogether within the following two years.

There was plenty of light to contrast with the elements of shade depicted by teachers working with these children and their families. There were anecdotes of humour, with many teachers finding the fun in their relationships with their children and the feeling of satisfaction at the child's achievements. However, overall, initial teacher positions, in terms of their relationships with parents and students revealed significant challenges (Hornby & Lafaele, 2011). Teachers were also on the whole less open, more guarded and self-protective, particularly in the presence of the parents, offering more candid assessments of the difficulties experienced with their child and parent when alone with myself or in the company of other teachers. This gradual unveiling and disclosure of feelings and experience was similar to those of parents, but took far longer to draw out, with many reconfirming confidentiality across the process.

> *...am I allowed to say?* (Teacher interview)

> *(whispers/mouths) this is confidential, isn't it?* (Teacher interview)

> *I'm not overly comfortable saying anything if I'm honest, as these things (research) bother me. I'm never convinced they are 'really' anonymous and it's my career you know.* (Teacher meeting)

What this signalled was that, similarly to parents, teachers felt equally vulnerable; that their positions felt fragile and insecure, with an inherent lack of confidence in the educational system, from all of those navigating it.

7.5 Conclusion

Thematic threads woven across this exploration stage of the research revealed a complex mix of positions and perspectives from both teachers and parents, who held differing views of autism and each other.

In terms of relational positions, few parents and teachers were genuinely comfortable in their connection with their corresponding caregiver and power dynamics were influential across many of the parent-teacher relations. Most parents were focused on working with the school to share their knowledge so their child could access the *right support*, whilst many teachers explained that *doing the right thing* for the child, was just not that simple. In general, parent and teacher knowledge of one another meant that neither truly demonstrated an understanding of, or empathy for, the other's context and the extent to which that context might influence their ability to support the child. What also emerged from deeper analysis of initial positions was that none of the parent-teacher units knew how, or trusted enough, to be their authentic selves with each other, even when discussing something as important as the development and wellbeing of the child they shared care of.

Both parents and teachers described significant fear. Parents held deep rooted fear for the future for their children, and teachers were fearful of teaching them. Both parents and teachers described fear of judgement from others as part of this, parents in terms of their parenting, and teachers in terms of meeting wider educational performance targets, both barriers to a more systemic relationship between them.

Fear of macrosystemic pressures and bureaucratic demands of the educational agenda together with fears of systemic hierarchical judgement (*parents by teachers and*

schools, teachers by school leadership and Ofsted) fed into parent and teacher perspectives, influencing the meaning of autism and the child for them. Universally parents were warm and positive about their children on an individual level, appreciating their child's strengths and uniqueness, although for a small minority of parents the meaning of autism held a few negative connotations, siting problems *'within'* their child, as opposed to externally derived challenges. That said, parents never lost sight of their child's gifts and abilities and came from a position of absolute and unconditional love for their children.

Parents who expressed the weight of care and fears for the future more often referred to the negativity within certain autism discourses and the lack of cultural acceptance of autism, as well as social attitudes toward difference more generally. They also felt the inflexibility of bureaucracy, observing the prescribed homogeneity demanded within the education system at a national level that underpinned accompanying policies at school level, immediately disadvantaging their children on dimensions of environment, behavioural demands, educational choice, and ways of learning.

Teachers saw something similar, but more from a professional and career perspective, shaping the meaning of autism as *problem* for some, and *stress* for most. Therefore, for teachers, meanings of autism were mixed. A surprising finding was that longer-serving teachers (*in contrast with early-career teachers*) presented a more cynical or jaded attitude to teaching autistic children, as well as to teaching more generally; that these children represented '*hard work*', and in some cases revealed a level of resentment and even fear of having to *'deal with'* (*a common turn of phrase amongst teachers*) autistic children.

It must be noted that teachers found teaching children with additional needs more stressful in general and this was not restricted to autism, although autism was

described by teachers as the '*most challenging*' in terms of accommodating individual needs. Teachers described children with more overt behavioural presentations as more stressful to teach than those who were passive and compliant. This finding may link to and support the more common avoidant patterns of attachment found in teachers (Acer & Akgun, 2010; Kepalaitė, 2012) explored in *Chapter 4* .

Some longer-serving teachers held the belief that their experience of '*children with autism*' afforded them a level of expertise that the child and family would '*benefit*' from, whilst simultaneously were also less open to new ideas themselves, being more cynical about the utility of this research, couching their participation as '*doing a favour for the family*' rather than the opportunity to gain something new in the way of learning for themselves. However, they also perhaps better '*understood*' the strength of school priorities and were possibly more realistic about the pressure performative measures placed on their practise and how those might hinder utilising SwiS going forward.

The relative absence of such cynicism and limiting attitudes from early-career teachers, together with their sustained belief in the child's individual uniqueness, strengths and abilities, their optimism for the child's future and their role in being able to make a difference to that child might have been sustained for several reasons. Improved teacher training methods and a more contemporary worldview could account for this optimistic approach. That said, it may also have represented a little naivety, that early-career teachers simply had not had time to become similarly accustomed or disillusioned.

Overall, initial positions of parents and teachers were mixed in consideration of their caregiver roles and attachment contribution with their children. In general, parents placed greater understanding, acceptance and value on teachers as *bridging* attachment figures for their children than teachers did. However, initial positions of parents and

teachers revealed that neither considered the relevance of their own attachment needs on their systemic relationship with one another.

Chapter 8

Intervention stage findings: An interpretative analysis of participants' experience of SwiS using multiple sources of data - themes, relational, and systemic changes

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8.1 *Introduction*

This chapter presents the findings from Stage-2: *the intervention stage* of the research. It offers an interpretative and observational analysis of participants' experience of the SwiS programme, exploring how parents and teachers construct meanings of autism through engagement with SwiS (*including strategies and activity elements*) and how this influenced parent-teacher, parent-child or teacher-child relations. Findings are illustrated by quotes, observations, and examples (*supported by relevant appendices*) from participants' emerging narrative stories. These are presented as themes, the interpretation of which were extracted from data across the SwiS programme days, focus groups, post-programme meetings, and final interviews, as well as research journals, observations, and interactions captured throughout the SwiS research. This section is supported by *Appendix W,* a reflective overview of participants' general experience and engagement with SwiS, highlighting some of the positive and challenging aspects, how this influenced participation and connected to key themes and subthemes, and how participants drew different things from the experience.

8.1.1 *Overarching themes*

Two interconnected overarching themes emerged from the SwiS research; *Relationship Change* and *Systemic Impact*. This is not a surprise, given SwiS is a systemic framework with the intention of supporting relationships and communication for improved problem-solving between parents and teachers. These overarching themes contained within them key themes and subthemes from the *intervention stage* of the

study, integrating initial positions from the *exploration* stage of the study as the basis for reflection and direction of travel.

The data revealed that overall teachers and parents experienced positive *relationship change* with one another, which appeared to have a wider *systemic impact* on their child, with themes such as *time spent together, emotional impact* and improved *knowledge and understanding* as critical pathways in this development, and more crucially, the maintenance of this change. For example, after taking part in SwiS, many parents described feeling '*more relaxed'* and '*less anxious'* about how school would impact their children and subsequently the family. Teachers also felt more relaxed and less anxious about teaching the child and in terms of understanding and best meeting their needs, underpinned by the developing partnership and communication with parents. The *systemic impact* revealed in the data occurred as a result of the interaction of different aspects of the research; the synergistic effect of combining different elements of SwiS that suited the unique context of each caregiver. For example, with less home-school conflict and increased communication, some parents and teachers reported their children were more settled and engaged at school, with some children displaying less anxiety, describing feeling more supported by the improved parent-teacher relationship. Parents and teachers also reported experiencing individual positive change in their relationships with their children, and improved confidence to help their child.

The themes and subthemes that emerged were highly interconnected in terms of supporting relationship change and experiencing wider systemic impact, with parents and teachers exploring how their customised use of the SwiS elements influenced their relationship with the other and with the child they shared care of. These interrelated themes are illustrated within this chapter and their meaning and implications discussed further in relation to the research questions within *Chapter 9* .

8.2 *Key themes and subthemes*

Key themes emerging from the research were complex and highly interrelated, reflecting the nuanced nature of parent-teacher relations and the individual experiences and expectations of those taking part *(Figure 6)*.

Overarching Themes: *Relationship change and systemic impact.*		
Key Themes	**Subtheme examples**	
	Teacher	**Parent**
Time spent together was a good investment	Changing **communication**	Changing **communication**
	Reducing power dynamics	Reducing power dynamics
	*Getting to know 'you' - **humanising***	*Getting to know 'you' - **humanising***
	Contextual understanding (each other and the child)	**Contextual** understanding (each other and the child)
Emotional impact	**Fear, Anxiety and stress** reduction	**Fear, Anxiety and stress** reduction
	Change in **perception** of the other	Change in **perception** of the other
	Child **meltdown** reduction	Child **meltdown** reduction
	Trust and Confidence – can approach the parents who will support the child's education at home and share information	**Trust and Confidence** – can approach the teachers who will support child emotionally **bridging attachment** and share information
	Sharing experience with others – **more information**	Sharing experience with others – **less isolation**
Knowledge and understanding	Improved problem solving (activities)	Improved problem solving (activities)
	Systemic proliferation - what helps and what does not	Systemic proliferation - what helps and what does not
	Sharing information is critical	Sharing information is critical
	Strategies and learning	Strategies and learning
Bureaucracy as a barrier	**Performance targets** on school needs not child needs (attendance, rigid behaviour policy, academic output)	**Performance targets** on school needs not child needs (attendance, rigid behaviour policy, academic output)
	Box ticking – fighting for support/services	Box ticking and fighting for support/services
	Teacher education and training	Parent education and support
Time Pressures	Teacher Training	Parent education
	Workload stressors	Workload stressors
	No time to reflect	Getting to school
	No time to try new things	Everyday things take longer
	Meeting targets – moving children on	Fear for child's future – wasted time

Figure 6 Master table of key themes

8.2.1   *Time spent together was a good investment.*

The only almost universal message from both parents and teachers was that *time spent together was a good investment*. This was common even to the minority of teachers who were less engaged, as well as the one parent-teacher unit where participation did not improve their relationship. Despite competing *time pressures* and workloads on all participants, being able to come together to discuss in person something as important as the welfare and support of a child was critical and something that was not currently being managed within the usual home-school communication framework.

> *you don't get the time to sit and talk so honestly* (Teacher interview)

> *what a difference it makes to sit down and really unpack something with the teacher and see that they understand. It's like a weight's been lifted.* (Parent comment SPD)

> *you can't do this normally, but if you could, if you could just get together with the parents of your SEND children at the beginning of the year, my god what a difference that would make!* (Teacher comment SPD)

This connected with the overarching theme of parent-teacher *relationship change* and to their experience in multiple ways, providing the catalyst for many of the other themes and sub-themes that emerged from the narrative. A brief look at an example flow chart *(Figure 7 below)* shows how this one action has multidirectional influence on these and ultimately parent-teacher experience that emerged from the *intervention stage*.
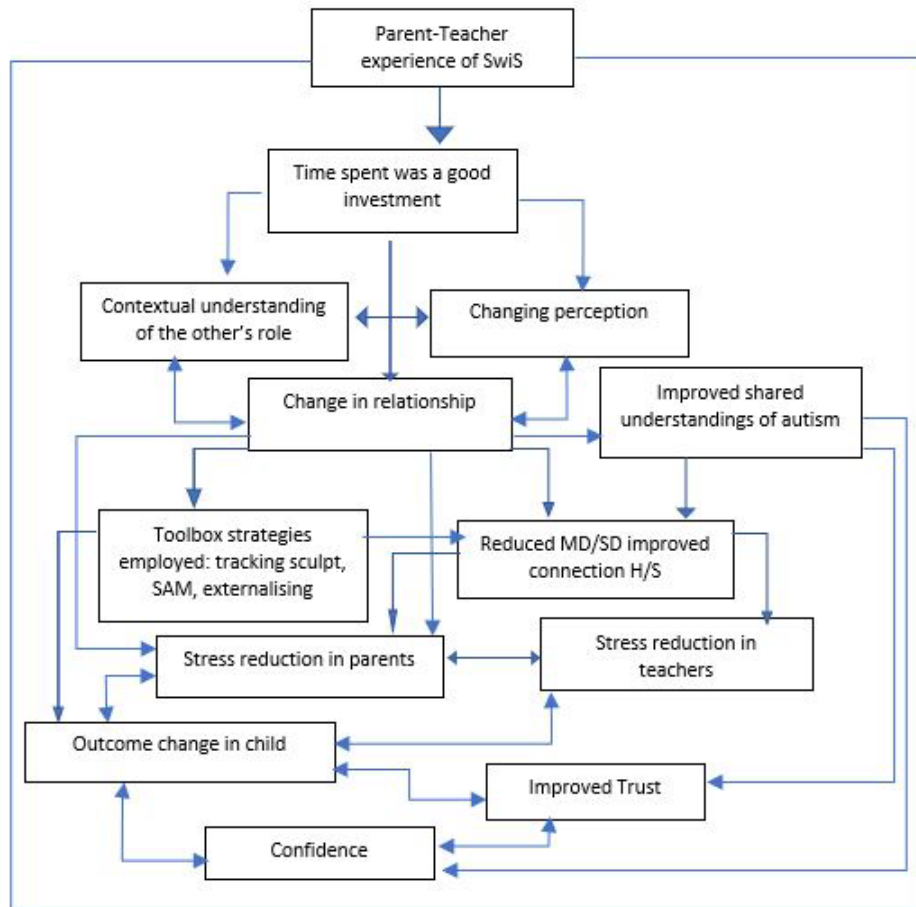
Figure 7 Key theme - Time spent together was a good investment

(Abbreviation key: MD=meltdown SD=shutdown H/S=Home-School)

8.2.1.1   Safe situation in which to communicate.

Parents and teachers identified the informal and warm welcome as helpful. The

opportunity to '*grab a cuppa together*' with time to acclimate themselves with the

venue and with each other in a *neutral space* offered a relaxed atmosphere, facilitating

more open and genuine relations.

> *I think I felt comfortable and safe there (at SwiS venue), which was quite*
> *empowering really* (Parent meeting)
>
> *It was a nice change knowing I could concentrate on what we were talking*
> *about without someone pulling me out for something or other* (Teacher meeting)

From a research perspective, this was more than simply a practical courtesy. To have

the opportunity to meet and chat with each other over something as *everyday* as a cup of

tea or coffee, and gently introduce themselves to one another as equals to discuss

something as important as the developmental needs of a child, for most parents and teachers was a first (Lavelle, 2015). It aimed to negate the frequent power imbalances that both parents and teachers report when interacting with each other (Elsworth, 2003), something experienced by many of the SwiS participants and discussed in *Chapter 7*

An explanation for this may be that often parent-teacher communication about the child is *crisis activated,* only coming together when something has gone wrong (Vassallo, 2023). For example, from a teacher perspective, this might evoke fears about receiving combative parents, coming into their space to defend their child. For parents, meetings taking place within the confines of the school, having *difficult* conversations within the teacher's *territory*, often in their child's own classroom, sat on small chairs, evoking feelings of subordination, may put them at a psychological disadvantage (Venkateswaran *et al.*, 2018). Therefore, the environmental and situational introduction to SwiS was no accident and, by convening for the SwiS programme days in a *neutral space* that was relaxed and supportive, territorial positioning and associated advantage or disadvantage was, in part, lessened.

The above illustrates how subtle differences in context can impede the development of full and equal partnerships between home and school, parents and teachers, a partnership that is the cornerstone of genuine co-production. Since co-production (*predicated on 'equal partnership' status with parents*) is now *expected*, written into policy, and supposedly embedded within educational practice, it raised the question, *why was this such a novel experience for them all*?

8.2.1.2   Humanising: getting to know 'you'

Both during and after SwiS, parents' and teachers' narratives offered some illuminating insights into a shifting perspective. Interestingly, words that were used frequently across their narratives were '*human*' and '*humanising*', with reference to the other as *'people'* being presented as somewhat of a new idea. This was a repeating

theme that parents and teachers expressed with tones of surprise and relief, that they had discovered this about the other, highlighting a level of *dehumanisation* which had developed between them, and within the education system, but which they now had an opportunity to overcome.

> *I think we're more aware of each other as human beings, and I work with them as a teacher-parent which I think sometimes is useful actually.* (Parent interview)

> *[parent] actually said how nice it was to meet as people rather than [child's] mum or [child's] teacher, and [they're] right, like, you forget that we all have real lives outside of school, you know, we're all just people doing the best we can.* (Teacher meeting)

> *it is quite a big step to take for some teachers to be seen as a human, rather than as a teacher.* (Parent interview)

Some parents felt this was the most significant change emerging from their experience of the study, which catalysed other changes, such as new respect for them. This was particularly meaningful for those parents with small support networks, as feeling humanised brought a level of parity and closeness with the teacher that meant the support for their child became extended, eliciting changes both in parent and teacher behaviour and attitude toward one another, succinctly expressed by one parent who said, '*I'm more than just 'that' mum now*' (Parent comment SPD).

This was more of an embodied feeling for some who found it hard to articulate, but still felt it strongly; for others it was the most significant outcome of participation, being fundamental to the change in the parent-teacher relationship.

> *I'm kind of walking along (with teacher) quite happily chatting away…as a human being, not as, because we, we, it's kind of well yeah, we've been there, we've done that, we've talked about [child] all day and it's, we both just needed to talk as…human beings.* (Parent interview)

> *I think at least 'we' know, you know, it, it's that seeing each other as a human which I think actually is quite important because it, it, it's, yeah, and I, I'd say that's the biggest change really.* (Parent interview)

For teachers, they were able to let their guard down a little and share their own human vulnerability, which was both notable and welcomed by parents, who responded with support.

> *You know, [teacher] opened-up about [their] own anxieties to me, um, which helped me understand and obviously, it helped in a way because [they] knew what [child] was feeling a little bit as well.* (Parent interview)

> *[parent's] given me loads of pointers for when [child] gets upset. Because there have been a few times where, well I've honestly felt out of my depth with [them]…but sharing that with [parent] meant [they] felt [they] could trust me more, I guess? I don't know. You know- it's, it's like here I am, doing my best, but I could do with a hand you know. And [they] did (relaxed shrug)* (Teacher comment SPD)

8.2.1.3   Contextual understanding: increasing empathy: reducing blame

Beyond the '*getting to know you*' process was the development of contextual understanding and the conversations that evolved from that. This was powerful in terms of incidental exchanges between parents and teachers and became a strong theme. Contextual exploration occurred on two levels: developing *knowledge and understanding* of the other caregiver's situation, including what *workload stressors* they were subject to and having empathy for that, as well as sharing *knowledge and understanding* of the child in different contexts.

For some parents and teachers, understanding and appreciating the role of the other was initiated and supported by the SwiS activity '*A day in the life of' (Figure 9*). Sharing their daily experiences, particularly the difficult moments, helped with understanding the other's perspective, enabling parents and teachers to communicate something about themselves with the child and support one another with explanations or advice for resolving difficult situations experienced. For parents and teachers recognising and making sense of the other's position was easier when not immersed in the emotivity of the moment or the crisis activated meeting. Phrases such as '*I didn't know'*, '*I had no idea'*, '*I'm so glad you told me that'* and '*that makes so much sense'*

were high frequency utterings between them as understanding was reached, knowledge

exchanged, and plans formed thanks to the new information being shared.

> *I didn't know [child] was so sensitive to weather conditions, [parent] and I have planned for stormy days now* (Teacher comment SPD)

> *We've had a chat and I'm going to get to school a bit earlier morning and afternoon to help [teacher] with transition until [child] feels a bit more secure* (Parent comment SPD)

Parents and teachers also uncovered differences in the child across contexts, some of

which came as a surprise to the other.

> *we told [teacher] a lot about our philosophy and, you know, our- you know, how we feel we're trying to get the best out of [child]. And obviously, [teacher] was saying, well, you know, [they don't] have the same problems that we do because if anything, [child's] just going to disappear or go quiet rather than have any kind of meltdowns. Um, but I think one of the things [teacher] felt was, you know, are we talking about the same [child]? You know...that it could be so different in terms of what [child] would be like at school.* (Parent interview)

> *what's interesting is that I can't get [child] to read, but at home [child] never has [their] head out of a book...but [parent's] explained, it's the type of book, so we're looking at making different books available to [them]* (Teacher comment SPD)

In many cases, empathy abounded for the other, and for most participants there was a

general spirit and feeling that, although not everyone was in exactly the same boat,

parents and teachers all had a shared purpose and were seeking the opportunity to better

understand and make positive changes in the life of the child they care for, which would

then help them in their own lives and caregiving roles.

For teachers, the storied discussions of context sharing helped increase

understanding of the parents' role and experience, something that had been missing

between them.

> *I had no idea how much [parent] was doing you know, [they're] juggling so much and there's no respite from it for [them]. I understand now why [parent] needs a little more support, which I can do you know, make life a teeny bit less stressful for [them] (satisfied smile)* (Teacher comment SPD)

> *you don't get that opportunity as a to teacher to work one to one with parents, so a rare enriching opportunity I would say* (Teacher interview)

> *I know now what pressure [parent] is under. I didn't know that before. It's, it's just hard because you see so little of them…you just don't know anything*
> (Teacher comment SPD)

This new-found *knowledge and understanding* of the parent perspective helped to decrease some of the misconceptions and assumptions which were exacerbating feelings of blame and criticism of parents in terms of problems with children. Knowing a little about what they did day to day, what demands they had, enabled an appreciation of the parental position and resulted in a change of perception in many cases.

Teachers began to appreciate the differences in child presentation between home and school and explored the emotional and competing stressors experienced by parents whose children were resistant about going to school and then melting down at home. Most importantly they recognised the systemic influence of school and home together, whether or not they saw any evidence of distress in the classroom.

> *So [child] was very calm, quiet, didn't want to draw attention to [themselves] and bottled it all up and had it (meltdown) at home. [Parent] had everything at home and you hear parents say that and you just kind of think, "It can't be that bad, can it? It can't be that awful?" But then they share their experiences at home, and you just remember that they're people.* (Teacher interview)

> *unless you make the time to do that, (talk to parents), and we don't have the time with day to day practice, unless you 'make' the time to talk to them properly, you don't recognise that this quiet little child at school could be really explosive at home, because of everything that's happened in school and just by saying to them, "Oh, how do you feel about that?" might totally change the experience that [parent's] having at home.* (Teacher interview)

For parents, a better understanding of the teachers' context was important for them to envisage their child in the classroom, the influence of the teacher on their child, and the pressure teachers were under. This elicited empathic reactions from parents for their child's teacher which they had not previously felt.

> *it's (SwiS) been really, really helpful. It's been helpful because I've been able to, um, talk to [teacher] so much more better. Doing it (SwiS); [teacher's] had an understanding of how [child] is at home, I've had an understanding of how [child] is in school, and we've both had an understanding of each other.* (Parent interview)

to be fair…it is a big classroom [teacher] has to deal with anyway. But just how [teacher] handles [child], just shows me how much of an understanding [teacher] does have. (Parent interview)

honestly, I had no idea how unsupported [teacher] is…there's no training in this stuff you know, they're just thrown in at the deep end and told to Google it (autism), just like we were funnily enough. It's shocking really and completely unacceptable. (Parent comment SPD)

For some parents, this enlightened perspective of teacher load and wider school context for their child generated a shift in opinion, highlighting the impact of a disconnected network around the child. By exploring '*how things really are*' for teachers, a level of transparency and honesty about how things were in the classroom began to form. This was highly valued by the parents, one of whom reflected '*it's such a relief really, because I don't feel quite so in the dark now*' (Parent comment SPD). This fed into subthemes of increased *trust* and *confidence* as parents commented they felt they could approach the teacher more openly and have conversations about their child, something that was reciprocated by teachers.

This newfound relational transparency highlighted to some parents the daily macrosystemic challenges teachers faced. Performance targets, increased workloads, lack of training, within a '*prescriptive inflexible curriculum*' (*described as such by teachers*). and *negative time pressures* on teachers were not lost on parents. In particular, the incompatibility between inclusion and performance targets which were often at odds with their children's developmental trajectory was construed as a significant *bureaucratic* barrier by parents, highlighting that while academic performance measures remained the only real priority for schools, realistically little genuine change for the appropriate inclusion of their child was ahead.

Inclusion only works if your kid is academic and going to smash their SATs and stuff, then they'll be fine, because the school looks good. If they don't then they (schools) don't want them (Parent comment SPD)

Whilst in some cases this exacerbated parental frustration with the education system at a macrosystemic level, it simultaneously galvanised their determination to *team up* with

the teacher and jointly take control of the situation at a microsystemic level, eliciting

from parents an empathy for the teacher, and at the same time increasing engagement

from themselves.

> *I realise now it's all about individual people and their intentions at the end of the day. The whole (education health and care) bleedin' system is a shambles and no-one's going to fix it. You know, if I want things to change for [child] before [they're] an adult, then I have to make the right connections and make it happen myself. If me and [teacher] can understand each other better and get on and work together, that's probably more better for [child] than shouting about policy and rights and all that. We won't need to, we know [child] and we'll just get on and do what needs to be done for [them].* (Parent comment SPD)

> *Parent: [teacher] now knows I will be an additional resource for [them] where [child] is concerned.*
> *Teacher: Yep, and ditto for me*
> (Parent-teacher comment SPD)

However, what did emerge was the feeling that any changes in school would not

necessarily be supported by wider school plans. Conversations between parents and

teachers excluded involving the wider school system.

> *This (communication) is probably something [parent] and I need to just do between us…I don't think there'll be much support for it on a daily basis, no.*
> (Teacher comment SPD)

Instead, their discussions centred on just '*getting on with it between them'* but *'on the*

quiet' in some cases, suggesting a lack of confidence in school leadership to support the

parent-teacher partnership and any genuine co-production.

> *I know my SENCo will support me but [SENCo] doesn't get a lot of support [themselves]. [Headteacher] won't want to know if it involves paying out for anything* (Teacher comment SPD)

Whilst this commitment to working together was admirable between participant

teachers and parents, it suggested such an ongoing format of communication or appetite

for culture change within the school would not be easy to maintain with subsequent

teachers across subsequent years. This highlighted the importance of genuine *buy-in*

from schools for parent-teacher partnership working to be successful.

8.2.2   *Emotional Impact*

The emotional impact of autism on parents and teachers observed through SwiS was a key theme, as both sets of caregivers experienced a range of emotions during participation. This was unsurprising as the programme encouraged reflection and exploration of feelings and, when doing so about something as emotive as children you care for, responding emotionally is to be expected.

8.2.2.1   *Anxiety and Confidence: changes in perception of the self and other*

The stripping away of any loaded environmental context during the SwiS programme saw much of the parental reserve and professional constraint observed during the exploration stage of the research eventually lift, and many of the participants reported they saw a '*different side*' to their respective collaborative partners or indeed felt as though they were now perceived differently.

> *I think [parent]'s amazing. I really think [they're] amazing. I don't know how [parent] manages it, I really don't. And I would love to find some help for [them].* (Teacher interview)

> *I think the two days, [they] saw me a bit more as a person rather than a teacher and therefore a bit less intimidating, in that, you know, [they] could approach me if [they] wanted to, um and that kind of made a difference.* (Teacher interview)

An important finding was that parents reported feeling less anxious and intimidated by the *authority* of teachers that would have previously held them back from engaging, challenging, and most importantly sharing with the teacher their knowledge of their child, knowledge that when combined with the teachers' could help find solutions to problems. This signalled a shift toward a more equal and mutual partnership. This included those parents who would generally acquiesce to all things *school based*, who were able to find their voice and share it with newfound confidence.

> *Ordinarily I would struggle in these sorts of meetings (referring to the SwiS programme and meeting the teacher), but I found myself talking about [child] like I knew what I was talking about, because I did, I do, and it gave me- you*

know, a sort of confidence that I had something valuable to say. (Parent meeting)

Some parents felt more empowered by their increased knowledge of autism gained from the psychoeducation element of SwiS.

> *The bit about the attachment theories was fantastic, yeah, I really found that helpful, that was, I'm so glad that was in there...because it was explained in a way that everybody could understand* (Parent interview)

> *This (circle-of-security) has been really useful. I can see where [child] might be feeling unsafe and how [their] anxiety would be triggered...it's opened my eyes* (Parent comment SPD)

Others found that the opportunity to share their experiences and have them validated in front of their child's teacher, not only by other parents and teachers but also by the SwiS team, was an important part of the confidence-building process.

> *Sharing my experiences here is important, and important that [teacher] is hearing similar things from other parents. I feel like [teacher] believes me and will listen to me now* (Parent comment SPD)

During the SwiS programme days, this reduction in anxiety for parents was supported by teachers, many of whom discarded any display of authority, attending with a more relaxed informal approach. This was helpful to parents, providing the context for a more balanced relationship, something many teachers were attuned to.

> *[teacher's] so relaxed and friendly* (Parent comment SPD)

> [Teacher]: *We're both enjoying ourselves, it's been good for each of us to do this, as it's helped demystify our relationship a bit I think.*
> [Parent]: *Definitely and I can talk to [child] about [teacher] in a way [they] will feel- well like we're more connected, I guess...*
> [Teacher]: *That's really important, and I can do the same, so it's a bit more of a team approach for [child] and for us (both laugh)* (Parent-teacher comment SPD)

This was a common response from parents and teachers within the study, and again links to the power and strength of the *'village'* when raising a child. Importantly, this connection was largely sustained beyond the programme, generalising to their ongoing daily interactions with one another.

I'm not afraid of school or [teacher] no more. I'm part of [child's] education and it's really great (Parent meeting)

I'm just more confident with speaking to them (parents). Because at the beginning of the year, you know…as a teacher, you are nervous to meet some of the parents, but I don't know, I was sceptical, and now actually, they're lovely parents and they just want what's best for [child] and, yeah, we communicate a lot more now, which is good, which is what we needed to do. (Teacher interview)

For parents and teachers who had previously expressed a more aloof connection with one another, the SwiS days resulted in them maintaining relaxed conversation, sharing humorous exchanges with one another, more confident in their communication once they had returned to their daily routines. This was articulated by one parent who in a subsequent parent meeting told me '*It's so much better now. We can talk more freely'* (Parent meeting)

8.2.2.2 *Caregivers need a secure-base too.*

Interestingly, the contents of initial conversations between most parents and teachers during the SwiS programme were about anything other than the children they shared care of, as if each was assessing the other, searching for commonalities, before approaching the one thing that they had in common. Assessing for commonalities, looking for a non-threatening shared basis of understanding is something people often do when embarking on new connections, something I touched on in *4.5.4*, which raises a further question, *why did parents and teachers avoid the one subject that they had in common? Why did they seek a 'different' connection?* Some parents explained this approach in their communications with the teacher through their narrative.

probably that (taking part in SwiS) has changed the 'how', yes, but 'when' and 'how long' probably hasn't changed massively, but yeah, it's ah slightly more sort of informal, but it's like more informal because we talked about other things other than [child] you know…we both just needed to talk as, human beings. (Parent Interview)

it's important to for me to know the sort of person [teacher] is you know? [They're] in [child's] life, like all day every day…it's not just about the teaching you know. I mean we keep an eye on who our kids play with and the sort of you

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know, influence they are- they have on them. Why wouldn't I want to know more about the teacher? It makes sense to me anyway. (Parent comment SPD)

By talking to the teacher about things other than their child, parents expressed a sense of getting to know them better as *people,* a theme that intersects with the *humanising* element of relational exploration and connects strongly with the idea of establishing a *secure-base* before more *'difficult'* things could be tackled. This highlights the idea that the need for a secure-base goes beyond just the child; it is in fact important for everyone within the system, and essential before more *'tricky'* conversations or problems can be tackled safely together. However, this could not be established without better knowledge and contextual understanding of the other.

Therefore, understanding the *real* person behind the parent label or teacher façade was important to participants. For example, for parents, was the teacher the kind of influence that was compatible with their parental and familial values? Was the teacher's experience and understanding of autism in *their* child good enough to support them properly? Did the *person* match the impression that parents had of them from their children? Did the teacher engender trust? Parents saw participation in SwiS as a chance to find these things out, as there was little opportunity to do this under normal circumstances and, on finding this out, most parents *relaxed*. Equally, parents also wanted to dispel myths about themselves to the teacher, to share their context and reassure the teacher that they were a *'good'* parent, as opposed to *'that'* parent.

Teacher comments revealed underlying similarities. Talking to parents as *people* and not parents, engaging in simple conversations about anything other than the child, helped teachers gain a deeper understanding of who the parent was, as opposed to just their student's mum or dad.

it's helped me understand [parent] better. I've got a sense of who [parent] is now and I know how to approach [them] going forward. (Teacher meeting)

[parent] goes out of [their] way to come and speak to me which [they] didn't do before, before the intervention…because [they] could see that I was there, and I

could see that they were there, and you're sharing stories. Well, it makes people 'people', doesn't it really? We need more of that, I think. (Teacher interview)

For some teachers, their connection with the parent enabled them to relax to the point where they could let their guard down and be completely honest, showing their awareness and empathy of the parent's trepidation when navigating the educational system, whilst simultaneously showing their support and desire for partnership and solidarity.

> *gosh you're completely different here. You're so much more confident. We could use that in some of our multi-agency meetings we really could (both laugh) we need to get together and make a plan! (Both chuckle)* (Teacher comment to parent SPD)

For the majority of parents and teachers, once discussions turned toward the children, the incidental exchanges observed were light, friendly and empathic. Throughout the two programme days, frequent utterances such as; '*oh I hear you*', '*we're the same*', '*what a coincidence, we've experienced that too*', and '*let me give you my number, I can help with that*', emanated from interactions between parents, between teachers, and between parents and teachers alike, as within the unstructured and informal time, they spontaneously shared experiences and exchanged knowledge with one another, across schools, across families and most importantly across contexts.

> *one of the most powerful things we did was that just having that group of people from lots of different schools, sharing stories that were quite dissimilar, and sharing stories that were similar and then parents saying "oh yeah I've had that with my child, it's a nightmare" it was really refreshing for the teachers and for the parents as well* (Teacher interview)

8.2.2.3   Reinforcing perceptions

It must be acknowledged that for a small minority of teachers, time with the parent did not improve negative assumptions of the parent held before the SwiS programme.

> *I can't help but notice there's little change in [parent]. Even here [they're] grandstanding. At least [they're] consistent (laughs).* (Teacher comment SPD)

In this first example, the teacher and parent went on to enjoy a more effective relationship in terms of the child, which although it did not result in an increased *'liking'* of one another, *did* result in better communication between them and an understanding of a complex family situation the teacher was not previously privy to. In addition, they also found common ground to implement consistent use of strategies which resulted in improved outcomes for the child in terms of reduced distress and meltdowns.

> *[child] is a lot more, um, easier to kind of calm now…so [they] won't have such big outbursts…That (SwiS) kind of gave us a bit of more background on, um, why the children sort of were doing what they were doing…and it was really interesting to see when, um, I sat down with [child's] [parent] and we did a spider diagram of all the influences on [child's] life at the moment (describes complex family situation) we could understand why [child] acts the way [child] does. Um, and that was really helpful to do, and I think it would be beneficial to do that with parents for every child* (Teacher interview)

The fact that the teacher found the child *easier to calm*, could be explained by improved *knowledge and understanding* of the child from the parent and an unconscious increase in empathy from the teacher. A contributing factor may also be explained by the child picking up on increased parental confidence *about* school, supporting the child's feelings of safety *in* school.

In this next example, the teacher was partly correct in her assessment of relational difficulties of the parent; a cultural difference which was openly echoed by the parent within their own narrative.

> *a lot of that (SwiS psychoeducation element) just went over [parent's] head to be honest and [parent] didn't really engage with that anyway because that wasn't about [them] and [their] child…[parent] finds it very difficult to relate to others- to other people* (Teacher interview)

The parent did indeed favour a personal focus; however, the teacher's underestimation of the parent's ability to *take in* and *understand* the information from the psychoeducational aspects of SwiS was less accurate. In the corresponding

conversation with the parent, and contrary to the teacher's assumptions, the parent

revealed the psychoeducation element of SwiS was particularly useful for them.

> *I started looking a bit differently at [child's] behaviour and [their]
> feelings…what, and how [they] can feel and, yes- Yes! I understood 'why'
> [child] was doing this.* (Parent interview)

Discussions with the parent revealed they had no difficulty understanding the more

theoretical aspects of the sessions, beyond finding the translation aspect tiring (*English*

was an additional language), expressing that the attachment discussions helped them

make sense of their child and their child's needs, enabling them to look at their child

with fresh eyes and a greater understanding of what their child feels and experiences *in*

the moment.

> *I understand [child] so much better now, what is in [their] head and [their]-
> (points to heart) (tearfully).'* (Parent meeting).

Whilst these less positive parent-teacher examples represent a minority of

relations and attitudes within this study, these were very familiar to me in my ongoing

work and connection with families, teachers, and schools, as being common scenarios

and attitudes between parents and teachers.

The above teacher example illustrated an enduring tendency from the teacher

toward low expectations of the parent, which was echoed in their view of the child. For

a small minority of teachers, descriptions of the children were commodified (Ball,

2004). Labelled '*low attainment'* children, these perceptions connected to descriptions

within the narratives that were weighed down by educational performance pressure

('[child's] high maintenance') containing little expectation of further development

('unfortunately [child's] not very able'). The high frequency use of the word

'managed' within a few teacher narratives, in concert with multiple references of the

child needing a *'one-to-one',* signalled the teachers' desire to separate their autistic

student from the main class, to have them *'dealt with'* by the TA. Judgement and

passive-aggressive criticisms of parents, veiled as sympathy or understanding, were also

embedded across the narratives of a few teachers which corresponded with low expectations of the children.

> *I think it is hard for [parent] to apply discipline* (Teacher comment SPD)

> *I think [child's] on [their] tablet (iPad) a fair bit* (Teacher interview)

> *I'm still not convinced it's autism. I'd approach [child] differently at home if I was [their] parent* (Teacher meeting)

This raises the question whether attitudes about parents shape teacher expectations of the children, or vice versa, something I reflect on in *Appendix S*.

It must be noted that this was *not* the same for many teachers; however, similar attitudes in terms of low expectations of the child and opinion of the parent again corresponded with the longest-serving teachers, perhaps suggesting that the historical and entrenched parental-blame bias and deficit views of autism are difficult to change (Cleary, West & McLean, 2023; Jacobs *et al.*, 2020; Waltz, 2015).

8.3   *Connecting themes around the SwiS activities*

The activities themselves became an emerging theme from the data. Therefore, in this section the SwiS activities will be discussed in relation to how they contributed to understandings around autism and the relationships between caregivers and teachers and fed into the emergence of the themes set out above.

8.3.1   *Knowledge and understanding: using SwiS activities to deepen relationships.*

> *"it is unlikely that any intervention will be more significant in strengthening parent-teacher relationships than making room for them to talk to each other"* (Miretzky, 2004, p.841).

Although improved parent-teacher interaction was a positive outcome, the research revealed that parents and teachers were often in a *knowledge-deficit* position, *stuck* in patterns of poor communication or conflict with each other, not knowing where or how to start in terms of problem-solving areas of challenge or disagreement around the child as the information was incomplete. Many parents and teachers were highly

stressed and equally *stuck* in negative cycles of interaction with their child, unable to

'get off the merry-go-round'.

> *Trying to get [child] to school, argh. It's the same every single day, the same battle, the same arguments. I'm exhausted to be honest; we're just going round in circles and getting nowhere.* (Parent comment SPD)

> *I don't know where to start [child] is just so complex, I never seem to quite know how to help and [they're] getting more upset and won't engage which is frustrating the hell out of me because it's like groundhog day and I end up sending [them] out most of the time.* (Teacher comment SPD)

They were seeking help to slow down their thinking, step back and unpack their

situations, sharing knowledge and understanding of the child and using this together

with the tools and strategies to begin problem-solving together. Emerging themes

across the research showed the activities and theoretical content of the SwiS programme

to be instrumental in establishing this.

The activities as set out in *Appendix D, Part-2* were designed to be flexible,

complementary, and synergistic, supporting the psychoeducation element of SwiS,

underpinned by the high-quality time spent together. Parents and teachers were quick to

identify activities that might be helpful in their individual situations and found ways to

adapt them according to their particular needs, communicating this with their respective

parent or teacher.

8.3.1.1 Using the 'day in the life of' and 'tracking' activities

The day in the life of activity *(Figure 9 Appendix D, Part-2)* was the first

activity parents and teachers undertook, each bringing an extract of their *story* to the

first session. Depicting a typical day with their child, the positives, the challenges, and

the impact on the family or classroom, most parents and teachers found this a good way

to begin difficult conversations and most felt a strong imperative to share their *truth*

about interaction with their child with the other.

> *I drew it warts-n-all, because there's no point pretending everything's perfect, because it's not, it's a bloody nightmare most of the time and it's important*

[teacher] knows what we go through just getting [them] to school in the morning (Parent comment SPD)

When I was drawing this, I did wonder if [parent] would be mad, but I thought it's best to know the truth of a situation. There's no point sugar coating it. (Teacher comment SPD)

Many parents drew the morning routine of getting their child to school and the difficulties this presented them. Anxiety-based school avoidance and stress around organisation were common. Most common were parents' depictions of their children's anxiety about bullying and environmental challenges, which was shared with teachers who were more often unaware of the school-based difficulty impacting at home. Teachers drew a variety of scenarios that they were finding challenging, most of which elicited knowledge from parents about what might be underpinning the difficulty and suggestions of *'what to try'*.

Although the '*day in the life of'* activity was helpful in context sharing, it did not always unpack a problem, or convey information in sufficient depth for the respective parent or teacher to immediately reveal a solution. However, it did consistently illuminate problems in a fun and engaging manner. This enabled sharing in a *non-blaming* way which then initiated deeper more exploratory conversations between parents and teachers who, having established the problem, used the *'tracking'* activity (*Figure 8 and Figure 12 Appendix D, Part-2*) to further unpick a situation to identify what might be helpful and where and how things could be done differently. The flexibility of the activities meant they were often used in combination as a means to help parents and teachers in the problem-solving process.

Within both the *day-in-the-life-of* and *tracking* activities (*which as demonstrated in Appendix T were often complementary*), many parents depicted challenges of motivation in their children to attend school. School resistance was common due to anxiety around such issues as organisation, for example having the right *'kit'* for school and fear of sanctions for small *stationery* transgressions. Similarly sensorial difficulties

such as class noise and the morning *'chaos'* or the wearing of the *wrong* uniform because the school mandated uniform was sensorially challenging, also contributed to attendance difficulties and concentration problems, previously interpreted as non-compliance or defiance. Teachers found this information helped illuminate the difficulties parents experienced and offered some explanation as to '*why'* they, and their student, might start the school day off on the wrong foot. This fed into the attachment element of SwiS and the complex *emotional impact* for both caregivers and children. By establishing and maintaining the idea of a continued home-school secure-base (*Appendix U*), the school aimed to offer the child as safe a space as they enjoyed at home to feel supported and understood in these attachment situations, where teachers became *'bridging'* attachment figures, helping to smooth transitions from home to school and back again.

> *We've discussed [child's] anxiety around coming into class in the morning and we're going to talk to [child] together and see what changes we can make to the morning routine so [child] feels more comfortable coming into class which might help with their meltdowns* (Teacher comment SPD)

Parents also found it helpful to envisage what the teacher was navigating throughout the day, particularly if the morning routine had not gone well. It helped build a picture of what their child was experiencing throughout the day, which in turn helped explain the regular '*fall-out'* they experienced at home at the end of the school day (more recently conceptualised as *after-school restraint collapse*) (Loewen Nair, 2017). It also increased empathy between caregivers, which led to a willingness to find solutions through shared problem solving.

> *It's so obvious when you stand back and look at it…but you just can't see it in the moment when you're trying to settle the class first thing in the morning* (Teacher comment SPD)

> *[Teacher] now knows what's happening…and [child] knows [they're] not going to be in trouble…it's already a lot easier in just one week* (Parent comment SPD)

Both parents and teachers quickly spotted *circularities* and began to identify how *their* experience with the child was both influencing, and being influenced by, events throughout the day. Parents explained this knowledge supported a continuing narrative with their child about their daily experience, helping to reveal any challenges, which could then be shared with the teacher where needed. This had an immediate impact on the child.

> *For the first time yesterday [child] didn't scream at me when I asked about [their] day. [They] actually told me stuff...I think it's because [child] knows if there's a problem, me and [teacher] will talk and sort it out, so it's kind of safer now, you know what I mean?* (Parent meeting)

In this example, the *village effect* of the system around the child operating in harmony was powerful. Increased communication between parent and teacher, which was observed by and included the child, increased feelings of safety in the child, that those around them were *interested in them* and would work together to resolve issues.

8.3.1.2 *Tracking - Slowing things down and reflecting*

The tracking technique *(see Chapter 4 and Appendix D, Part-2)* was the most widely used and discussed activity across parents and teachers. The spirit of the research understands the importance of parents and teachers building on what they already do well. By first using tracking to look at interactions or situations that were positive or where a meltdown had been de-escalated or averted, caregivers could unpack any situation and review it step by step. This helped parents and teachers to slow down, step back and view situations without becoming embroiled in the *emotional impact* of the moment. When applied to more challenging situations as seen in the *'day in the life of'* scenarios, *tracking* directed parents and teachers to pause and understand how the child might be feeling at each point throughout the interaction. By encouraging increased mentalisation of the child's emotional state, parents and teachers were able to reflect on how they as caregivers might be contributing to the situation.

Parents described tracking as the most helpful of all activities as they were able

to unpack difficult interactions, identifying where their own contributions might

escalate a situation.

In this first example, the parent experienced difficulties when leaving the house

in the morning to go to school, a familiar scenario for many of the participants. By

unpacking each step of the scenario, the parent could recognise that multiple tasks

happening at point of transition were confusing and overwhelming for the child,

resulting in distress and refusal to leave the house.

> *The strategies that were taught, the tracking, that's fantastic, that's, I think that's really, really helped us in our daily life because it's given us the opportunity to unpick things. Particularly with like the mornings where they were going, they were getting difficult, it's because I was trying to do too much, putting too much focus on other stuff and actually the focus needed to be on just getting [child] to school, that was really helpful, and without that tracking, I would not have necessarily unpicked that, because you're going against your own programming of "oh I need to do this and this and I want you to do this and I must organise that, and you can't leave the house with this". But it's like, actually none of that stuff really matters because it's going to be better to get [child] sorted out first so you're not fighting with each other, so that was really good.* (Parent interview)

The parent also refers to overcoming their own *'programming'* in this case the influence

of *perceived norms* of family life, the intergenerational pressure (Tam, 2015) that says

good housekeeping equals good parenting. Such inherited perceptions were placing

undue demands on parental time and resource, causing additional stress and diverting

their attention from the emotional and attachment needs of their child *in the moment*,

occluding the parent's ability to reflect on interactions with their child. As the child

was preparing to transition from home to school, an activity that represents a significant

attachment situation for them (Vassallo, 2023, p.198), the preoccupied behaviour of the

parent contributed to the child's transition stress. However, by *tracking* the interaction,

the parent was able to slow down their thinking, step back from the situation and set

aside distraction. This then increased reflection about their child's mental state, avoiding points of escalation.

> *I think out of all of it, it would be the tracking that I find the most useful, the most helpful to be able to unpick and sort of think "right you know, what happened there? What could we do? You know, how did that escalate?" And to sort of try to bring it back.* (Parent interview)

8.3.1.2.2 Tracking - Teachers

For teachers tracking was useful in the classroom with students as it provided a route to understanding the child's experience of a situation when they were not in an emotionally communicative state or when teachers were not able to accurately capture what had happened to distress the child.

> *With [child], the tracking, that really helps and then that was when [they] picked up a pencil and was like, well, actually, no, that didn't happen, not this-it happened differently…it just got [them] to sit and talk through what was going on and let us in…normally you'd have to wait half an hour or an hour for [them] to calm down. This let us do it straightaway. That's it. That's at school, we're done now, we're finished. No more consequences…normally it would've been one that carried on at home as well.* (Teacher interview)

Instead of feeling anxious about an ensuing meltdown, teachers expressed increased feelings of confidence to *'cope'*, that having a *'few tricks up their sleeve'* was protective against their own emotional escalation in response to the child's distress and disruption to their classroom, increasing their feelings of self-efficacy.

> *I think because when we learned all the strategies and with the tracking and things, and I think because I'm now more confident on how to approach a meltdown. Again we don't have many because [child's] so settled now* (Teacher interview)

This was common across teachers and, although in the previous example the child had become distressed, tracking helped the teacher connect with the child and support them immediately post meltdown. The activity provided the child with a distraction from their distress as well as gentle mechanism to communicate it. They were able to correct the teacher's assumptions about what had happened (*which was empowering for them*) and *draw* events as they experienced them, removing the pressure to organise their

thoughts and verbalise them into a coherent response. The child could express their

feelings through pictures and explain what had happened, giving them the opportunity

to become calm and receive comfort from the teacher who was now more aware of the

child's mental state. This helped resolve their distress while at school, minimising their

time *in distress*, reinforcing the child's trust in their teacher and the teacher's own

confidence to meet the child's emotional needs, consequently mitigating what was

carried home.

8.3.1.2.3 *A shift in thinking*

Tracking proved an adaptable technique, with both parents and teachers using it

in different ways. Some drew pictures with their children, some used it in conversation

with a partner-parent/teacher/child, some tracked in their heads reflectively, others

engaged it as a conversation guide. This resulted in a variety of adaptions across

different situations, although employing it to explore school resistance was the most

common. Teachers also reported they used tracking more widely, helping other

children in their care.

> *tracking is something that I've used a lot and not just with the children that were involved in the study…but also children without ASD that were just presenting challenging behaviours, and what I really, really like about the behaviour tracking was, it's something you can do with the child* (Teacher interview)

In this completed tracking scenario (*Figure 8),* a parent and teacher were able to reflect

on such a situation and how the child was feeling, revealing how the lack of effective

parent-teacher communication impacted the child, making them feel unsafe,

contributing to the child's resistance to go to school, highlighting very effectively the

importance of parent-teacher relations.

Child gets up asks mum "*is it school today?*" Mum says "*yes*" – child runs and hides in room

Mum gently helps child dress. Now late, mum rushes to make breakfast - child gets undressed

Dad reassures child. Helps them dress, brush teeth, & get down for breakfast

Child in distress, protesting they want to stay home, but complies & eats breakfast

Mum clears breakfast & asks child to put on shoes – child complies but can't find them

Child crying, parents get frustrated & also look for shoes but can't find them either

Now late for school, dad is cross, shouts child must wear their trainers

Child gets upset, says no as they will be in trouble with teacher & lose play time

Parents still cross but reassure child it will be okay – they will speak to the teacher

Get to school late. Teacher is busy. Mum quickly explains lateness & shoes to receptionist

Receptionist takes child to class but leaves without explaining shoes or lateness to the teacher

Teacher is annoyed punishes child for being late and having wrong shoes - loses their playtime

Child distressed all day – vows not to go to school tomorrow

Tracking a circularity …Late for school

(Vassallo, 2023)

Figure 8 Tracking a circularity – late for school

In this one summarised scenario, both caregivers initially needed to contribute to the conversation to unpack what had happened point by point, reflecting on how the child might be feeling at each stage of the interaction. Such scenarios around child distress and meltdowns were common across participants and highlighted to parents and teachers that individually, they did not have all the information, that each needed the other, or needed the input of the child, or both. Importantly, in many cases, parents and teachers who had previously experienced child meltdowns but felt they were *random* with no discernible *cause* were now able to identify triggers and the influence of systemic action or inaction that stemmed from missing information between them,

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highlighting the proliferating effect on the child's emotional security. This was most profound for teachers in terms of how the meaning of distress behaviour from their children changed.

It's not naughtiness, [child's] just reached [their] limit (Teacher comment SPD)

I personally learned so much from that, yeah, particularly how children actually think and what happened to their behaviour then (Teacher interview)

So it's kind of understanding and not taking it personally you know (Teacher interview)

Most importantly teachers stopped taking behavioural responses from the child personally, instead taking a slower more reflective approach combining what they learned during the programme with information from parents. This helped reduce their own defensiveness that might have escalated or maintained difficult situations, which, armed with this additional knowledge and context from the parent, illuminated the *systemic impact* through changes in the children at school, without directly involving them or subjecting them to any intervention.

[child] definitely seems so much more confident in the lesson…the work that [they're] producing is now beautiful and you can see that [they're] more confident because of the work [they're] producing, whereas before [child] was feeling quite reticent or was having shutdowns (Teacher interview)

after talking with the parents, we know what we can do in [their]situation to bring [them] out of [their] shell…so I mean, actually it 'is' to do with intervention because we're talking to the parents to get that information. (Teacher interview)

[child] goes to school now in the morning, no problem. I never expected that. (Parent meeting)

Emotionally, children felt '*held',* that having their parents and teachers on the same page was reassuring, enabling them to feel the school was a secure-base and they were safe and could therefore '*take a chance'.* This was reflected in their behaviour.

Parent: I think having [them] be aware that we've got this kind of web around [them], seems to have given us some kind of support in some way which I can't put my finger on. [Child] kind of knows without knowing exactly what it is we're doing or we're talking about, that we're 'interested' in [them] in some way. Teacher: I think that's affecting [them] at school, because [they] started teaching other children…I've never even seen [them] talk to somebody that

[they] wouldn't normally talk to let alone try to explain something. (Parent and teacher focus group)

8.3.1.2.4 Influencing reflection

Increased ability to reflect on their children's feelings and mental states from both parent and teacher caregivers was an important finding of this study. Reflective functioning, central to attachment formation (Fonagy *et al.*, 1991) contributes to emotional regulation of the self and understanding of others and is essential in the development of healthy social relations (Slade, 2005).

Many parents within this study were initially reticent to engage with anything connected to attachment *(4.5.3)* having previously experienced *blame* for their child's difficulties during interactions with practitioners, where unhelpful assumptions that a child's distress was a result of insecure attachment (*ergo poor parenting skills*). Such conflation of *autism* and *attachment* from practitioners, where difficulties with the latter was suggested to be responsible for the former, was a common parental report (Vassallo, Dallos & Stancer, 2023, p.173). However, closer analysis of the SwiS parental narrative suggested levels of reflection with their autistic child improved for some parents. This was in line with Enav *et al.* (2020) who found parents of autistic children had similar (*and occasionally higher*) levels of reflective functioning with both their autistic and typically developing children. This was an interesting finding as many of the initial positions of the parents revealed that they were entrenched in high levels of emotional distress and conflict with wider systems *(7.4.1)*, perhaps less conducive to, or impeding, mentalisation about their child. One explanation for this might be the motivation that parents feel to understand their autistic child's feelings, beliefs and intentions. This might account for why parents found the tracking so useful, as it supported effective reflection as well as enabling their children to engage in sharing their mental states more effectively.

I've now noticed more…like [they're] not feeling comfortable…and you're like, "Okay, I can see where things are starting to turn" and you can react to it sooner instead of leaving it until it's too late…and we can avert that big, massive meltdown (Parent interview)

things that I might have perceived as meltdowns…are [them] in the moment, [they're] feeling an emotion…we had a couple of things which have happened, but I can see why they're happening now (Parent interview)

Many parents reported an increased frequency of pause and reflection using tracking as the main tool to do this in difficult and even everyday situations, reflected in self-reported improved confidence levels and feelings of closeness with their children.

I'm closer to [child] now and I think I'm a better parent (Parent meeting)

I think [their] meltdowns are less…nothing is getting too out of control because I am more confident, so I feel I can manage better because I have this toolbox, but also yeah, because [child's] not losing control or you know, the mornings, now I'm focusing on [them] so [their] needs are met…it's putting my attention where it needs to be…so it's more harmonious, and when things are not going the right way, we're actually pausing for a moment and yeah, reflecting together about how you know, what would be a better way of doing this (Parent interview)

This was not limited to relations with the child; parents also reported improved familial communication with spouses and siblings, where impact proliferated across the family.

For teachers, increased feelings of efficacy and improved reflective function seemed to be linked, an interesting finding and one that could be an area for further study.

I think because we learned all the strategies and with the tracking and things, I think I'm now more confident on how to approach a meltdown. Again, we don't have many because [child's] so settled and I'm better at reading [child] now (Teacher interview)

The more *'tools'* and knowledge teachers had, the better equipped and more confident they felt in managing difficult situations, meaning they were more inclined to engage on an emotional level with the child and have the cognitive capacity to consider the interaction of both their own and the child's emotional state. This is in line with Dexter and Wall (2021) who found increased reflection improved teachers' perception of

efficacy, a protective factor against burnout (Boujut *et al.*, 2017), a factor in teacher attrition.

> *to see the change in [child] has been really nice…[they're] engaging again more in lessons… [child] seems to have settled back which feels really nice.*
> (Teacher interview)

8.3.1.3   Sculpt – Exploring support systems.

The sculpt activity was also embedded across the *knowledge and understanding* theme of the study. This playful activity conducted with the children at home or at school helped some children offer information to their caregivers about how they felt in terms of safety and connection with others in a way they were less able to articulate previously. Parents and teachers contrasted this with their own conceptions of the child's experience of support and feelings of security across contexts. Differences in understanding between parent and child and teacher and child led to changes both in the home and at school according to how the child perceived those contexts. This resulted in an overall lowering of anxiety for many of the children as changes were made. Parents felt more aware of how to make their child feel comfortable, discovering important people within their child's school context they did not know before, but could now facilitate, in terms of supporting their child's friendships, providing the context for them to flourish *(Appendix V for SwiS example)*.

Teachers were able to do the same and found this task equally helpful, working with the parent to facilitate friendships and increase feelings of security within the school context. This also helped teachers establish a better relationship with the child, independent of the parents, integrating their knowledge and understanding of school becoming the extended the secure-base *(Appendix U)* and the importance of '*bridging*' attachment relations provided by teachers, maintaining the child's feeling of safety until they return home to their primary attachment figure.

I think [child] can now see that support network…that obviously came from when we did the support map…where we were in relation to the child…I think that [they] recognised I'm someone [they] can approach and talk to when [they're] not feeling 100%. (Teacher interview)

8.3.1.4 Externalising techniques – making difficult conversations easier.

As detailed in *Appendix D, Part-2,* the externalising activities used (*SAM and clay modelling*) are important as they support a non-totalising, non-blaming approach to the difficulties experienced by children and their caregivers. Parents and teachers were able to use these established therapeutic techniques outside of the programme days and found them particularly helpful to start conversations with children around difficulties they were experiencing without siting the difficulty within the child, and therefore the child as the problem. One teacher who used the SAM activity reported

I used SAM with [child] last week, and it turns out [child] has a more positive view of autism than I thought. [Child] sees autism as something 'extra' they have, something other children don't have…it's what makes [them] good at learning maths and science. This really made me think about how often I talk, and think about autism in a negative way…and I should stop doing that because [child] doesn't see that at all (Teacher comment SPD)

As the above example demonstrates, this approach was significant in supporting attitudinal change and meaning-making in caregivers towards their child and autism.

Importantly, using externalising activities to explore social and emotional experience, allowed teachers and parents to gain greater *knowledge and understanding* of their child's perspective of the world and their sense of self. Parents described the activities as '*fun*', reducing demand on the child and being something they could all share in. Teachers described the externalising activities as '*helpful*' in relation to using them to establish one-to-one connections with children, supporting a *team* perception with the child, as well as using them with other children as an inclusive class activity. One teacher's report highlights how these techniques can be used with all children, not just autistic students. When using the modelling activity more widely with the whole class during their PSHE session to explore emotional literacy, a non-autistic child, not

previously on the teacher's radar, was able to articulate through representation significant difficulties they were experiencing that had gone undetected. This allowed a gentle conversation with the teacher to follow and exploration of the problem, which the teacher then shared with the parents, between them, finding a way forward.

> *I only did it (externalising activity) with the whole class so as not to make [child-a] stand out. [Child-b] is one of my more independent students, no diagnosis or anything, but [they've] been managing [describes problem] for ages without saying anything to anyone. I wouldn't have had a clue if we'd not done this together* (Teacher meeting)

By externalising problems, siting difficulties away from the child, parents and teachers were able to come alongside their children, making difficult conversations much easier, presenting themselves as *allies* as opposed to authority figures.

8.3.1.5   Psychoeducation - SwiS content

Most parents and teachers engaged strongly with the neurological theories surrounding autism. From a parental perspective a key focus and resulting questions centred on sensorial experience, how to provide comfort and adapt environments, as many believed this was the root of much of their child's distress. Teachers were also keen to understand this, but interestingly, more from a behavioural perspective. The compliance culture embedded across schools could explain this perspective, as child distress is disruptive in class and something teachers highlighted as challenging.

Most teachers agreed with parents that sensorial challenges underpinned some of the children's *behavioural* presentations in the classroom. However, teachers were again split in their approach to this between longer-serving and early-career teachers. Longer-serving teachers shared their own practices for '*desensitisation*', so children could engage in the same way as '*everyone else*', their view of inclusion often reflecting '*sameness*'. Conversely, early-career teachers focussed more on environmental adaptions which might suit the autistic child, blending this with what would still be acceptable for the other children in their class. Early-career teachers suggested more

individual and creative adjustments for children but shared more concerns about *time pressures* as a barrier to inclusive practice.

Knowledge of autism theory varied across the participants, with parents on the whole demonstrating a deeper awareness and greater knowledge and understanding than teachers, who were more conversant with behaviourally based methods. This was not surprising, as historically school-based training about autism and associated interventions have had a broad compliance focus rather than an individualised approach.

8.3.2   *Reflecting on reflective journals*

The reflective journal was probably the most time-consuming element of the SwiS programme for participants and was the least popular in terms of fidelity to it, with comments from parents and teachers reflecting this sentiment fairly equally. A minority of participants who engaged strongly with the journal during stage-1 remained engaged with writing down their experience during stage-2. However, a majority of participants had a much lighter touch with their journals, with some avoiding them altogether.

Analysis of journal data revealed twelve participants did not complete their second journals at all. Reasons for this varied; however, some explained that the journal simply was not their preferred communication tool, that *'writing this stuff down'* was *'difficult'* for them. Others felt they had said all they wanted to say and were actively using the SwiS tools, particularly tracking, to slow down their thinking and unpack different challenges, making the journal superfluous as they were already reflecting on situations.

For some, the journals provided ongoing opportunity and prompt to slow down and step back from situations and to put into practice what they had engaged with across the two-days. For others, it became integral to their reflective practice, a place to review and even offload and decompress. Others found little need or use for it and did

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not engage with it a second time. However, follow-up discussions found that those who abandoned the reflective journals felt that ongoing reflective conversations and the level of insight the activities provided meant they no longer had need of them.

Many of those who did not complete their journal at all during stage-2 also made only minimal entries during stage-1 and felt they had nothing additional to offer in terms of insight, having participated in the programme days, focus group, meetings and interview. This reinforces the importance of a varied approach to data collection; like autism, one approach does not fit all. A further nine participants made only minimal entries in their second journals for similar reasons, with some feeding back that the second journal was unnecessary, especially as things were now going well. This was interesting as it was made clear to all participants that recording positive interactions was as valued as challenging or difficult interactions. However, in conversations with several teachers, I asked why they had not recorded the more positive interactions to reflect upon or utilised the meltdown comparison scale. They explained,

> *I know things are better, but it's hard to put a number on it (meltdown scale). Plus, I wouldn't want the school to think everything is okay now, because although it is for [child], that's just one child. I still need support going forward, and if I say things are good, I might not get that.* (Teacher meeting)

> *We need help when things are going wrong, but now things are good, we just want to enjoy it and build on it. I don't really want to be reminded of the difficult stuff with [child] and start comparing it, because it's so good now.* (Teacher meeting)

> *To be honest, once I was back to work, it was business as usual. I didn't have time. I'm just grateful things are better for [child], and [parent] and I are talking, that's a big load off, because the pressure is just the same, I've just got one less student to worry about.* (Teacher meeting)

A few parents and teachers cited increased time constraints specifically as a contributing factor for not completing the second journal, with teachers explaining they remained under pressure of workload. Parents were keen to *catch up* on other things now that (*as one parent described*) time spent *'battling'* with school had lessened.

> *I've got a million things I can do now during the day, now I'm not waiting for the inevitable call from school* (Parent meeting)

Other parents, like teachers, were simply overwhelmed with *life* and did not prioritise

the journal, instead preferring to use the more practical SwiS strategies.

> *I'm going to be straight with you, with the operations and decorating, I haven't made huge amounts of journal notes, I did the tracking. But that (journal) is somewhere in a box, in my-uh (laughter) if I come across it, I'll bring it over. I know which box it's in. It's in my downstairs shower at the moment (laughter).*
> (Parent interview)

Those who did use the journal found it helpful, with a few parents and teachers asking

for more sheets to record additional interactions, incorporating their reflections with

their experience of SwiS.

> *even though I didn't know, I didn't know if the impact of it, doing the diaries, was really nice to note down your interactions with them because you don't always recognise that actually with certain children you do have positive interactions because you remember the big explosive ones…And to think for myself actually, did I react in the right way at that time or could I have done something different?…I think everybody should have to do that as a teacher*
> *(Teacher interview)*

> *I found it really educational, as in, it taught me by putting stuff down on paper, or actually thinking about what am I going to, or observing, rather than just being in the moment each day, it gave me a bit more of an external perspective on how I was reacting and sort of actually seeing what was going on rather than just being 'in it' which was really, really helpful, I think that's been 'monumental'.* (Parent interview)

Metaphors about life such as being in a *'whirlwind'* or *'storm'*, being *'swept along'* or

doing *'battle'* were common, particularly among parents, reflecting their *normal,*

regardless of their relationship with the school. Again, the simple process reflection, of

being able to '*slow down*' their thinking and take a '*step back*' to regain perspective,

seems easy; however the recurring theme of *time pressure* for teachers, and especially

parents, meant it simply did not happen within everyday interactions. Like many of the

SwiS activities, the journal gave parents and teachers the chance to do this and, for

those parents and teachers who were experiencing life as being *out of their control*, it

was helpful.

> *I think maybe it gave me the opportunity to like, pause for a moment and actually look at 'why' that's happening and 'what' is happening rather than just being drawn like, swept away with everything all the time and again, having that*

record of what happened enabled us to sort of see why is that happening, why-where did that come from and what happened next, and when this happened, was it definitely worse (laughter) you know, depending on how we reacted to it? So it was hard, I'm not going to say it was easy, but without that (journal) there wouldn't have been the opportunity to learn from it, and I think because so often you do feel like you're just being swept down a river and you're like, you're just trying to like just get through every day, by having that external observation side to it, it did also give you a bit of grounding away from it as well, so that did help (Parent interview)

The external perspective generated by the action of reflective journal writing, although challenging, enabled some parents to see their situation more systemically, looking at their own contribution to problems they were experiencing. Similarly to the teacher, they were able to revisit challenges and walk through events slowly, objectively and, in conversations with both teachers and parents who engaged strongly with the journal, this action helped to deepen their understanding of their child's perspective.

8.3.3 *An observation on cross-cultural differences*

As might be expected with any intervention, programme, or therapy, elements of the programme did not suit everyone, and some found the multi-family/multi-professional element to the SwiS programme was not the most comfortable or helpful approach for them. Cultural and language differences meant that the sharing of personal experience had a different effect on some. For these parents, telling their story was still very important; however the open forum was not their first choice of setting, preferring time one-to-one with myself, or their child's teacher, to reflect on their own situation.

In my country we don't share like this, only at home with close family or friends, people I know a long time, so I prefer to just listen in those bits. (Parent meeting)

Whilst it has been shown that for parents of autistic children engaging in shared experience with other parents is helpful and even comforting (Bray *et al.*, 2017), for these parents this is not something they would ordinarily do within their own cultural context and following what was said in a group setting was tiring and effortful.

> *I enjoyed it, but I was very tired after the first day. I always get tired when I must translate from [own language] to English a lot.* (Parent meeting)

It may be that for these families a more comfortable setting would have been to talk on a more one-to-one basis with the teacher

> *A good thing was you had some chance to speak to um teachers…that was a good thing…you know, we could always ask them, and have a chat with them, whenever we want, but in that two days…with more chances yeah, that was good.* (Parent interview)

> *it was more time to speak um in a- how to say- in a-hmm-sorry. In a quiet place. So that um- that was benefited because as I said, I have a very good relation with [teacher] but sometimes there is not that much time you know, to speak more about something. But, yeah, it was good.* (Parent interview)

The importance of cultural difference was a finding that requires further study, something I discuss in *9.3.3.1*

8.4 *Conclusion*

The key themes explored across the intervention stage of the research revealed not only the importance and complexity of relationships between parents and teachers, but importantly the influence on the child. The child is in a triadic relationship with parents and teachers; therefore, how they interact impacts the child directly. Themes also highlight the wider systemic influence of policy on everyday life, such as the dissociation of education from the developmental needs of children and the individual nature of human beings, creating divides or power dynamics which act as barriers to relationship formation, without which there is no joint problem-solving, but instead promotes a blame culture. Time together was a strong theme, because as soon as parents and teachers had the space to connect, most did so without too much encouragement and immediately started to establish a knowledge base for each other, sharing understanding, the foundation for the beginnings of trust. The proliferative effect of this had an impact the children, on dimensions of feelings of safety and security, lowering anxiety and increasing interaction.

The research revealed the individual nature of each parent and child relationship, and each teacher and student connection, but equally the overlapping elements that existed between them. Findings also revealed a desire to connect and operate as a team, with techniques helpful in facilitating this. This seemed to help to overcome the undercurrent of bureaucracy, which was embedded throughout, as parents and teachers reported feeling *'blocked'* by the lack of services, the requirements of policy and subsequent pressure to respond to school-based agenda and performance culture, as opposed to child needs. Reinforcing relations between parents and teachers went some way to help throw off the weight of this.

Chapter 9

Discussion of participants' experience, themes, and changes

9.1 <u>Introduction</u>

This final chapter returns to the inspirational root of this research, that of my own experience of home-school relations both as an educator and a parent of an autistic young person, set against the home-school relational difficulties experienced by parents and teachers and the poor outcomes of autistic children within UK mainstream education.

Having experienced both positive and challenging home-school relations and the impact of each on my own child, his teachers and our family, my aim for this research was to find out the extent to which improving systemic function impacts experience and outcomes for all involved. I wanted to know if working systemically using the systemic attachment-based approach of SwiS as a facilitating framework, might reveal meanings associated with autism and offer teachers, parents, and their children something of the *village effect* that was present across the life course of Donald Triplett (*autism's Case-1*), observed within Indigenous Australian culture, and learned from my own experience. In addition, I wanted to understand whether implementing such an approach might be limited by wider social and political contexts that currently shape school systems and parent-teacher relationships.

<u>*Summarising the research and the research questions,*</u>

In *Chapter 6* these overall interests were articulated as a set of broad research aims and questions designed to explore:

1. *Parent and teacher meanings and constructions of autism and how meanings were illuminated and evolved through experience of SwiS.*
2. *The parent-teacher relationships and meaning-making processes between them.*
3. *How the experience of SwiS is shaped by the individual needs of the family and school systems*

4. *How meanings that function within home and school systems are shaped by wider discourses, particularly the autism disability-vs-difference debate.*
5. *How SwiS is experienced as consistent or contradictory to the wider discourses about autism.*

It is important to state from the outset of this discussion that the findings illuminating the research questions reveal such overlap and interaction between them that trying to present *'responses'* to each question *discretely* is not a straightforward exercise. Therefore, although I have signposted the reader to each research question throughout, it is the entanglement and intersectionality revealed across the findings relating to these questions that reflects the complexity of autism and how SwiS was experienced and should be recognised as such. Similarly, analysis of participation in SwiS revealed multiple themes *(Figure 6)* from parents' and teachers' narratives which helped to understand how they experienced this process and how that might shape the way caregivers think about and respond to autism, the meaning-making processes between them and the wider influences on their children. However, like the research questions, these themes are highly interconnected, with each influencing the other, consistent with the complex nature of autism.

This research is also somewhat of a methodological endeavour, in as much as through SwiS, it seeks to explore and discover more about the meanings and representations teachers and parents hold about autism, to observe how those meanings and representations are constructed and located in the wider contexts of schools and discourses within society, influencing how the system around the child operates, how autistic children are viewed and responded to, and how differences between their caregivers have an impact on that.

The initial meta-orientation driving these questions, which emerged increasingly clearly during the process of, and findings from, the research, was the centrality of the issue of *how to build a stronger caregiver system around the child*. Specifically, what SwiS offered in terms of how best to achieve this and what it also revealed about the

nature of the caregiving systems. Would an attachment-based systemic approach to autism be experienced as helpful for parent and teacher caregivers? What effect might it have on their children? Would this exploration help explain the influence of wider sociocultural discourses and institutional structures on parents' and teachers' constructions and meanings of autism? Could learning from this inform practice?

Therefore, this final chapter draws together the learning and key messages from the research, with an aim to provide new insight in this area.

9.2   *Discussing the research and responding to the research questions*

9.2.1   *RQ1-Parent and teacher meanings and constructions of autism and how meanings were illuminated and evolved through experience of SwiS.*

In terms of meanings and constructions of autism illuminated through SwiS, teachers and parents came to the research already demonstrating a wide range that had developed from an integration of their own experience as caregivers, and their knowledge-base evolved from their training and curiosity on the subject. Strikingly, it appeared that overall parents had a greater depth of knowledge about autism than teachers, having typically engaged in extensive study of evidence and information relating to autism over many years, developing a considerable level of *expertise.*

From analysis of their narratives, parents' knowledge was revealed to be constructed from active reading and substantial research. As autism was so central to their everyday lives, parents described reading *'everything they could'*, not just about autism, but also wider child development literature, something parents often found confusing and time-consuming, trying to extract the valid information from less reliable and occasionally dangerous sources. Although parents often initially pursued scientific information having been signposted by clinicians and practitioners during the diagnostic process, as parents' ideas about autism formed and they began to relate these (*or not*) to their child, parents revealed their tendency to *'specialise',* delving more deeply into

areas that were relevant to them to support difficulties in their everyday experience, for example, the literature base to help understand differences in sensorial experience. Within their narratives were references to the plethora of *courses* they had attended over time. The courses parents sought themselves revealed a mix of approaches, from the academic to autism community-led learning, which when considered overall may account for why the perspectives of many parents with children in mainstream education, had evolved over time from *autism as a deficit*, toward *autism as a difference*. That said, although parents tended intuitively toward systemic behaviour, desiring, and understanding the importance of, collaboration and working with others, parents had little knowledge of, or exposure to, systemic approaches to autism and relations around the child, as these had not been represented in their learning and, in the case of attachment, had become aversive, having been presented as a blaming approach. Therefore, the approach of SwiS, whilst being new to them was also *'comfortable'* for them as their inclination to operate systemically felt *'right'*. Interestingly, on multiple occasions, the adage of *'it's not rocket science'* was declared, in relation to the approach of SwiS in the context of being surprised that no-one had thought of this before.

For some parents, their synthesis of learning and the influence from it was revealed through their communication styles when taking part in the SwiS activities, understanding and often expressing a mix of established psychological terms, as well as language more relevant to current autistic-culture. Parent narratives also revealed other courses they had experienced, that were *'suggested'* by clinical services or by schools. These tended toward more general child development *parenting classes* or introductions to autism *(from a medical deficit perspective)* frequently focussing on behaviour management, a subtle reminder of *parent-blame* and *autism as a disability* discourse embedded within professional practice and influencing parental constructions. Most parents revealed they did not initially resist attending recommended *'parenting classes'*

as they were vulnerable to such influence, often being new to autism, and for some, new to parenting. Therefore, when faced with the unfamiliar (*a diagnosis of autism)*, parent narrative revealed an initial *fear* of what they *did not know*, feeling gratitude for, but at the mercy of, advice from those they believed *did know*. This deferential position toward clinicians and other practitioners was notable across parental narrative as contributing to *power dynamics*, with some parents still embodying the suggestion from early days of diagnosis that they might be to *blame* for their child's differences and distress, despite their acquired depth of autism knowledge and expertise on their child telling them otherwise.

In contrast, teachers often felt they had *limited* knowledge of autism, despite the desire and intention to learn. Some teachers mentioned brief courses within their initial teaching qualification and updating via the school systems. Others revealed a complete absence of any training relating to autism or SEND in general in their initial teacher training. Instead, they described relying on a combination of *'gut instinct'* handed-down *folk wisdom* from senior teachers of previously used strategies that *'worked in general with autistic children'* and their own experience, mostly '*trial and error'*, based on what worked (*or did not*) with previous autistic children they had taught. What was not surprising was that *'universal'* strategies about *'what worked'* with autism, passed down from other teachers or gleaned through school-delivered courses, were largely aimed at *changing the child* with either *'social skills'* training and/or behavioural control. This is to be expected in handed-down knowledge, as historically approaches to autism in schools were (*and broadly still are*) rooted in behaviourism and compliance. Adequate training and contemporary knowledge about autism from a systemic perspective were clearly absent from most teachers' experience. This might explain why many of the teachers demonstrated such enthusiasm for the psychoeducation element of SwiS, particularly latching on to neurobiological

information, which some teachers *'knew already, but enjoyed the refresher'* and others were hearing for the first time. What was also interesting was how many teachers took this information in isolation to make sense of autism *within* the child, looking for a neurobiological *explanation* of why the child presented as they did, rather than the systemic one the information was presented with. This highlighted that the strength of the *totalising* discourse of autism revealed in some teacher narratives was hard to move away from.

9.2.1.1   Influences on the meaning of autism

What was evident at the beginning of the research was the emotional impact associated with caring for autistic children, in particular the pervading sense of *fear* and apprehension from caregivers, something I have frequently observed in my work with families experiencing challenges around school and teachers struggling with how to support. The *fear,* largely expressed as anxiety, had multiple sources, including policy direction, social isolation and lack of appropriate knowledge (*especially from teachers*), each of which played a part in shaping not just the meaning of autism to parents and teachers, but influenced what parents, teachers, and children meant to each other.

9.2.1.1.1   Parents

Such is the influence of school on family life that parents often talk in terms of the kind of year they and their child have had, as being based on the relationship with the teacher, although often they are not able to articulate why (Vassallo, 2023, p.224). Parents within this study were no exception with many referring to previous teachers and experiences that in some cases they were desperate to either replicate or avoid. The memories of such experiences remained fresh to many parents, some of whom became emotional during these discussions, highlighting the magnitude of consequences of a good or bad relationship on the family. To parents, teachers really mattered and

unpacking the cycle of influence in a reflective way, using simple therapeutic techniques, helped to contextualise *why*.

For parents, many carried a sense of urgency to see their child's life improve and a lack of connection or conflict with a teacher immediately signalled the potential loss of progress for their child, both academically and socially for an entire academic year, a long time in a child's life. Some parents described *steeling* themselves against the expectation for wider difficulties and daily distress from their child in this scenario, *expecting* a rise in anxiety and emotional fall-out after school, which parents acknowledged raised such anxiety in themselves, they felt sure was picked up on by their children.

When reviewing their experience of SwiS, parents and teachers integrated their understanding of the psychoeducation element of the programme with the activities. An example of this was a parent using their interpretation of the extended circle of security (Vassallo, Dallos & Stancer, 2023, p.173) to explain that, when looking at their child's home-school experience through an attachment lens, something they had not done before, they realised their own anxiety about what their child faced at school *(parental fear of unresolved bullying, sensorial challenge, social isolation and peer exclusion)* may have not only transferred anxiety to their child, but contributed to undermining *trust* between them by making their child then question *'why'* they had to attend school if it was so dangerous. Mentalising about their child's thoughts and feelings about going to school, the parent worked through possible '*trains of thought*' from their *child's perspective* that they might be trying to process: *'if [parent] is anxious, there must be something to fear – if there is something to fear, then I am not safe there (school) – if I'm not safe there, 'why' is my [parent], my secure-base sending me there – maybe '[parent]' is not safe too? I feel unsafe and want to resist both [parent] and school'.* Whether this is indeed what the child was feeling is not known, but the point

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was the parent was attempting to become more attuned to the child's mental state, highlighting to them the importance of the extended secure-base and therefore the relationship with the teacher. As discussed further below, teachers were not free of anxiety either, but were often anxious for different reasons. Therefore, in terms of a continued cycle of care and security, when adding the teacher into the mix as an equally anxious receiving caregiver (*observed in the context of the child's home-school transition cycle and the attachment situation this implies*), the importance and influence of the parent-teacher relationship and their contribution to, and maintenance of, their child's anxiety and distress became clear to both.

9.2.1.1.2 Teachers

Teacher anxiety generally emanated from a different source. Some teachers who initially described the thought of having to navigate daily classroom challenges as *'wearing'* and *'demoralising'* also disclosed situations where they were fearful and more often frustrated. Most teachers expressed a desire to '*do a better job*' with their autistic students but did not know '*where to start*'. All teachers at some point raised concerns about the behavioural presentation of the child in school. However, reasons for this varied (*class disruption, time consuming, and rejection by peers were common*). For some, anxiety about distress behaviour was not necessarily rooted in being physically at risk from their children, but more about the effect on their careers. Non-compliance and disruption in the classroom risking reprisals from leadership, thinking they (the teacher) were '*not up to standard*' unable to uphold strict behaviour policies or meet performance targets, was top of the list of anxieties. This reinforces the complexity of difficulties around inclusion of autistic children, who often require more flexibility in terms of their educational environment in order to succeed but exist in a culture where teachers have less autonomy to offer this. This suggests the impact of the

'slide' toward authoritarianism (Reay, 2022) within education in recent years is being felt as much by teachers as by children and families.

For teachers, autistic children posed a direct *threat* to their careers, which is inextricably linked to their own emotional wellbeing. They described their relief at policies allowing the child to be taught '*outside of the classroom*' instead of having to navigate challenges directly. Such avoidant strategies were common within the narratives of teachers who relied on the '*TA in the corridor*' approach to teaching autistic children in order to maintain the *expected* equilibrium of a classroom filled with children all learning in exactly the same way.

9.2.1.2 *Changes in thinking*

Participation in the SwiS activities revealed some initial differences and shared beliefs between caregivers and some subsequent *changes in thinking* in terms of perspectives and constructions of autism from parents and teachers. For example, many parents and teachers had previously used *'time out'* not as a punishment, but as a strategy to support emotional regulation in response to distress, providing space for the child to *'decompress'* and relief for the caregiver from witnessing the distressing meltdowns and shutdowns in their children. As some parents and many teachers were influenced by deficit discourses of autism to varying extents, they held shared beliefs in such management techniques (*embedded with misunderstandings such as 'autism means the child has an innate preference for aloneness and separation'*) as valid, often *go-to* responses. These revealed the influence of dominant discourses of '*autism as a disability to be managed*' on caregiver constructions of autism, as opposed to thinking about the child as of course in some ways different and unique, reflective of individual differences, but also simply as a *'child'* with similar attachment needs and emotional responses to those of their non-autistic peers. For teachers especially, ideas that autistic children had attachment needs and teachers' own systemic influence around the child

might contribute to or escalate behavioural distress did not seem immediately available to them. Instead, further *solutions* to what was perceived as *problem behaviour,* included distancing tactics, such as increasing the '*separation*' (*child's desk moved away from peers*) or '*removing the problem altogether'* (*teaching children in corridors under TA supervision away from the class*), both avoidant strategies adding to the level of exclusion experienced by autistic children. Whilst such strategies supported the management of teachers' stress levels, which were indeed lower when teaching quieter or compliant children, as well as the macrosystemic demand that played to the *performance agendas* of schools, they did not respond to, or develop, individual children. Such pressure from school policy to *'manage'* autistic children in this way sat contrary to some teachers' declarations about respecting the uniqueness of each child (Vassallo, Dallos & Mckenzie, 2020), suggesting a dissonant position (*ethos vs action*) that might have been uncomfortable for them.

By introducing and synthesising attachment ideas from SwiS, such as the *extended circle of security* and systemic techniques such as *tracking,* most caregivers evolved a *change in thinking* about autism, albeit to differing degrees. Many were able to step back from counter-productive *'management'* strategies such as *'time-out'* (*which remove opportunity for connection and reinforce isolation*) to look at conflict not as an *autism problem* residing *within* the child, but to recognise and reflect on the multiple contributions and attachment needs from all those *stuck* in negative cycles of interaction *together*. This enabled caregivers to consider and lead on alternative responses such as shared *'time-in',* a chance as one parent described to '*get off the merry-go-round'*.

Engaging with techniques that offered an opportunity to visually represent sequences of events and unpack challenging situations helped to reframe difficulties previously blamed on *'the autism'* so the child was not centralised as *the problem.* This seemed to have quite an effect on caregiver interpretation of conflict situations. Instead

of feeling *confronted* by problems, caregivers were able to view them *alongside* the child. Caregivers and children were suddenly allies, in many cases a new experience for both of them, facing difficulties together, difficulties which more often interconnected, appearing to be created or exacerbated by a mismatch in priority and need, between child and caregiver, rather than defiance or non-compliance from the child alone. For example, caregiver demands to follow instruction according to their agenda (*a transition, action, or attentional demand which may be difficult for an autistic child as it may represent an unknown or challenging situation*) often revealed an activated attachment need in the child. However, analysis of caregiver narratives revealed these were frequently overlooked in the moment, overruled by adult constraints, which were often rooted in time or performance pressures (*getting to school, adhering to the curriculum, progressing academic scores*). By recognising the clash between caregiver imperative and the child's sense of security in the moment, considering everyone's needs, thoughts and feelings in a situation (*including what might be activating for caregivers themselves and contributing to escalation responses*), parents and teachers were able to slow down their thinking and reflect, giving them the opportunity to *'do things differently'*, to try a different approach.

Sharing scenarios of difficulty *between* caregivers also seemed to be helpful, as each could identify moments where things *'started to go wrong'* and problem-solve possible solutions with the other, rather than hold each other responsible. This was an important finding of the study as when it was successfully put into practice, which in some cases resulted in a considerable reduction of meltdowns for children, a *loosening of thinking* in terms of *totalising* ideas of the *child as problem* or difficulties being *all autism*, also occurred. Parent-teacher communication seemed to focus less on *problems due to autism* and more on '*what were the barriers to participation for their child and*

what they could do to remove them', suggesting an interesting and important shift in perception.

9.2.2 *RQ2-Parent-teacher relationships and meaning-making processes between them.*

What also became apparent across the research was that a *'process'* was going on between parents and teachers. Most parents and teachers were enthusiastic, engaged with the idea of the study, keen to explore and learn together, with the exception of the minority of teachers whom I earlier described as seemingly *'going through the motions'*.

What was soon revealed was that regardless of the state of the parent-teacher relationship, even where relationships were professed to be strong, with caregivers *'on good terms'*, both parents and teachers felt quite isolated from each other, as most knew little about the other's daily life or situational context, an important element in parent-teacher relationship building and child rearing (Bronfenbrenner, 1979). The word *'just'* from both parents' and teachers' early narratives was a frequent uttering and quite revealing (*'if they could 'just' do this' 'if they could 'just' do that'*), as it signalled a frustration about the other and perhaps inferred that the other was not trying, or worse, did not care, a blaming stance. This suggested that regardless of the state of their *perceived* relationship, neither had much insight into the understanding, constraints and resources of the other and may explain the intensity of theme of *'humanising'* theme that emerged from the intervention stage of the research.

9.2.2.1 *Contextualising, humanising, and developing an appreciation of the other – externalising problems.*

To break the cycle of siloed perceptions of the other and increase understanding, context building activities within SwiS were helpful in establishing shared knowledge, which for many parents and teachers helped in the development of a deeper appreciation

of each other and of the child. Activities that supported the externalising of problems

rather than siting them *within* the child, were particularly powerful, such as *tracking,*

SAM, and *a day in the life of.* These helped caregivers understand and interpret

problems as difficulties *'occurring'*, as '*coming into their lives'*, rather than *because of*

the child or because of *'autism'*.

Many parents who used the tracking activity to unpack the difficulty of *getting*

to school were supported to view this in terms of barriers that they and their child faced

together, rather than further labelling their child as a *'school refuser'* and siting the

problem within them. The *'day in the life of'* activity, was instrumental in starting

deeper conversations between caregivers. The act of drawing or writing something so

personal and fundamental to your everyday world, then sharing that experience with

someone who is a co-caregiver but essentially a stranger, although challenging, set the

context for interest and connection between parents and teachers. A happy side-effect

of what was being depicted in the little drawn vignettes of experience, was that they

were often *unclear* to the other caregiver, creating confusion about what was being

represented. This *confusion* was surprisingly helpful, as it was the catalyst for further

exploration, prompting questions and curiosity from the other caregiver about what they

were seeing. This drew parents and teachers deeper into each other's contexts in a way

that simply *'telling the other about their day or situation'* (a conversation which could

easily be misconstrued as *complaining)* could not do.

They were now curious and interested in each other and as a result gaining

knowledge and understanding of the other fed into the *humanising* effect. Both of these

themes emerged as particularly strong from the contextualising process, highlighting

how many parents and teachers initially seemed to view the other as simply a *role* or

function, rather than a person, which when added to the *value-positive, value-negative*

commodification of children to schools (Ball, 2004) was no basis to foster good

relations. As the humanising process continued and parents and teachers established closer connections with one another, the meaning of the other changed, and comments such as *'that's their job' 'that's what they're paid for'* were replaced with more appreciative and empathic responses. As time progressed, I witnessed many utterances of *'I had no idea'* and the occasional *'you don't get paid enough',* said with shared understanding and humour. Engaging in such supported explorations about their daily interactions with the child they shared care of, whilst unpacking difficulties together, seemed to offer a new view of the other and an understanding of the other's wider responsibilities, levels of support, and personal resources; each realised that together they were greater than the sum of their parts. This new *knowledge and understanding* seemed to elevate respect for the other, even when initial positions between parents and teachers were suboptimal, an outcome that even the *strongest* relationships within the cohort had not previously achieved.

9.2.3   *RQ3-How the experience of SwiS is shaped by the individual needs of the family and school systems*

A positive change in parent-teacher awareness in terms of incidents of child distress and caregiver contribution to that distress, both at home and in the classroom, was revealed when more structured and facilitated connection between them enabled deeper exploration and understanding of the attachment needs of the child. By sharing knowledge of the child and ideas about the distress that perhaps were only known to each caregiver in their own context, brought forth suggestions from the other based on their contextual knowledge about how to comfort and support *in the moment*. Pertinent questions and explorations between parents and teachers about possible triggers and stressors to illuminate the difficult situations they were experiencing (*for example transitions between, or distress from, taking part in certain activities such as the sensorial challenge of physical education lessons or navigating the dining hall, the*

unpredictability and isolation of time in the playground, or the emotional challenge of peer-to peer miscommunication), were supported by use of systemic techniques to unpack them.

9.2.3.1 *Slowing things down and working together*

The techniques contained within SwiS were frequently *adapted* by parents and teachers to shape them and make them relevant to their own unique situations. One possible explanation for this is that, whilst therapeutic systemic techniques are inherently flexible, they also provide a structure for exploration, led by those involved, informed by their unique needs, interests and contexts. This gives caregivers a myriad of ways to explore and understand difficult situations either with their children, with each other, or for themselves, and to support tricky conversations. This type of approach allows caregivers to slow down their thinking and reflect on interactions to consider how those involved might be feeling and what they might be thinking *'in the moment'* as well as paying attention to their own emotional states and contributions to a situation. This was not something parents or teachers were used to doing but found particularly powerful in breaking negative cycles of interaction. Parents and teachers shared nuanced knowledge about the child in different scenarios, which were explored and unpacked in detail. This seemed to help to demystify challenges that resulted in escalation of distress at home or school and that appeared to have no cause. This was particularly helpful around sensorial sensitivity and distress from specific fears or phobias that teachers in particular were less aware of *(Appendix X example).*

For parents and teachers, increasing their awareness of their child's experience from an attachment perspective and orienting their attention toward their child's feelings using established structured therapeutic activities in SwiS, appeared to result in an increase in their overall ability to engage in reflection. The activities inherently facilitated caregiver discussions and thinking about their child's mental state, which

opened conversations about the child's nuanced needs and for caregivers, understanding of their own needs and what they brought to each situation. What was also striking was that once given the techniques to do this, many parents and teachers quickly became innovative. They did not wait to experiment; they simply '*took them and ran with them*', adapting the techniques in multiple ways, including with the child, in ways that had not yet been shown to them but appeared useful. Their grasp and integration of the psychoeducation element that complemented all the techniques, particularly the incorporation of attachment principles and the circularity of care (Marvin *et al.*, 2002; Powell *et al.*, 2013), extending the child's secure-base with teachers as *bridging attachment figures* (Vassallo, Dallos & Stancer, 2023, p.173) suggests they recognised scope and flexibility of these supports which could be shaped to reflect their unique situations. This was also indicative of a synergistic effect of elements within the SwiS programme that, when brought together seemed to strengthen problem-solving behaviour, increasing parents' and teachers' willingness to '*try*' new things both independently and with the support of each other.

Parents and teachers now had more *information*, *sharing experience* and what they knew about their child with each other across contexts, increasing joint understanding of the child, predicting, and potentially averting, distress situations. Both used techniques '*with*' their children to explore difficult situations that might have previously resulted in escalation. The established non-blaming stance of SwiS, provided children with a new form of communication to unpack events from their perspective and share how they were feeling, exploring '*what happened*' without feeling interrogated or '*ganged up on*'. Caregivers reported how this allowed gentle conversations to begin and encourage the child to have a voice in a way that direct conversation would previously not have allowed, possibly being interpreted as '*attack*'.

From the child's perspective, knowledge of the collaboration between their parents and teachers who were paying increased attention to their emotional needs appeared to have an immediate effect on many of them. With parents and teachers now communicating more effectively about their child's emotional needs, a number of caregivers reported a rise in child confidence across social and academic situations, such as putting their hand up in class, speaking in front of others and being willing to take part in group work, all examples from teacher narratives. Parents attributed this effect to their children feeling *'held'*, that they did not need to worry about explaining how they were feeling all the time as they knew parents and teachers were communicating well *about* them. One family recounted a conversation with their child, who explained they felt that their caregivers were now *'interested in them',* with another sharing their child felt as though parents and teacher now *'had their back'*. These new-found feelings of security in their child's daily explorations seemed to ease the transition to school for some children and their families, resulting in a knock-on effect of improved attendance, a key performance goal for every school. For many parents and teachers, a reduction in meltdowns and shutdowns for their children was the most significant change. Feeding into the key theme of *emotional impact*, this reduction in distress decreased caregiver anxiety and increased parents' and teachers' sense of efficacy in their caregiving, improving their *trust and confidence* in themselves and each other, and making meltdowns easier to manage when they did happen.

Whilst the above highlights the positives of parent-teacher engagement in the research process, it must be acknowledged it was not all *'plain sailing'* for everyone. A few teachers described feeling the weight of responsibility of entering into discussions with parents and wanting to manage expectations of change, as they felt they were not well supported by their leadership to properly invest in parental engagement outside of mandated meetings such as parent evenings, unless they wanted to *'do it themselves'* in

their own time. Others were wary of parents more generally, especially if they were distressed themselves or on occasion combative. Unpacking the narrative revealed teachers often felt as ill equipped to *'deal with parents'* (*who, as previously noted, frequently knew more about autism than they did*) as they did their children. Some teachers acknowledged that they felt on the back foot, avoiding parental interaction wherever possible, often having the TA *'run interference'* with the parents because the TA spent *'far more time with [the child]'* than they did. This contributed to the cycle of negative interaction and feelings of continued separation between home and school and was also a source of frustration to parents who felt their children were being increasingly isolated and disadvantaged socially and academically, experiencing *exclusion by inclusion* whilst they, the parents, were being held at arm's length, removing any opportunity to remedy this.

Parents described being made to feel their child was a burden to the school, not so much by the teacher, but often by wider school staff and leadership who were frequently described as *'unapproachable'* and *'disinterested'*. The message this communicated to parents was that they were not welcome, and their child was not *'worthy'* of discussion with anyone more qualified than a teaching assistant. Although parents spoke very highly and respectfully of teaching assistants, they also knew they held little power in terms of decision-making for their child, making parents feel shut out and tangential to their child's education, and frustrated at the paradox of being criticised for a lack of engagement. This also revealed a common miscommunication between home and school about what constituted *'engagement'* from parents. Were parents welcome in the full co-production definition of a genuine equal partnership between home and school? Or were they required to simply be available to respond to requests to augment the school's academic agenda, such as offering additional reading and homework support? That *discrepancy* feeds into wider inquiry about how

educational culture is *truly* responding to systemic practice underpinning co-production policy. This requires further research; it underpins '*what teachers do'* within such a top-down system as the school culture and direction of travel exert enormous influence on the parent-teacher relationship.

Recognising that factors such as these may be in play when asking parents and teachers to work together was critical. Therefore, understanding the emotions, sensitivities and anxieties emerging as a consequence is essential to build and maintain *trust* and *confidence.* Too often the crisis-activated nature of any shared interaction between caregivers can initiate an *emotional* and blaming response (*problems are due to poor parenting / lack of teacher training*), so being able to slow down and unpack problems when saturated by them *in the moment* can be difficult. By first addressing feelings of safety and security in parents and teachers through a shared focus of exploration and interest, caregivers were able to use the systemic approach of SwiS to guide them and the tools to gently engage with difficulties according to their own circumstances in a non-blaming, more objective way, *unsticking* them from cycles of interaction that had previously held them in *battle positions*.

9.2.4   *RQ4-How meanings that function within home and school systems are shaped by wider discourses, particularly autism disability-vs-difference debate*

Understanding how constructions and meanings of autism developed for parents and teachers was revealed to be inextricably linked to the process of relationship development between them. Although *time spent together was a good investment* (*a key theme from the findings*) and was experienced as helpful for parents and teachers overall, simply '*getting parents and teachers together to talk'* and hoping for the best was revealed to be too simplistic and likely insufficient to make meaningful and sustained impact. Whilst making room for this process to happen was essential in building a connection, on its own many caregivers struggled to know where to start.

Frequently *stuck* in negative patterns of interaction, not just with their children but also with each other (*patterns that were usually defensive, often holding inaccurate information or unhelpful beliefs about the other, and about the child*), were further encumbered by other barriers such as relationship history, blame (*mutual and systemic*), and external pressures, particularly *time pressures*, which interfered with the communication process and any redress of the relationship.

These parent-teacher relational difficulties were often highly sensitive, emotionally charged, and defensive in nature. An explanation for this could be because, where autism is concerned, it remains largely a mystery, with stigma and dehumanising attitudes still attached to the label across sections of society, embedded with unhelpful stereotypes (Den Houting *et al.*, 2021). Couple this with so few answers and such ill-defined and often conflicting ideas and beliefs about what autism *is (ideas drawn from multiple perspectives such as medical, social, integrative, identity models)* means there exists a *muddle* of discourses from which caregivers draw their information and construct their meanings in the first place, which when integrated with the demands of their own lives and careers, can function differently, clashing and creating conditions that pull caregivers in opposite directions.

This may be because differing perspectives and beliefs about autism seemed to create conflict about what was important to teach children, how the children should be responded to, and *who should do what (families wanted teachers to be warmer, schools wanted parents to be firmer*). To further complicate matters, teacher attitudes seemed to be divided on this and were further influenced by the school.

9.2.4.1 Unexpected finding: Differences between longer-serving and early-career teachers

The division in teacher attitudes was an unexpected finding from the analysis that was not an initial research question and seemed to be related to their length of

service. For example, within this study, teachers more than parents initially presented with a *deficit* discourse about autism, such as requiring interventions for children to *fill skills gaps*, *build resilience* and *gain compliance.* This tended to be more prevalent in longer-serving teachers and less pronounced in early-career teachers individually, although it was suggested by some as being the default position of their *school* which they felt steered them toward this approach. This seemed to be driven by a mix of pressures such as medicalised disability discourses within education *(preserving a deficit perspective 'within' the child and again, a tendency to 'totalise' them as the 'problem')*, that are incompatible with inclusion agendas. These performance measures of behavioural expectations and academic outcomes (*the homogeneity of everyone learning the same thing, the same way, achieving the same results*) were an important influence, as the results were set against career development of roles across the leadership of the school, which not only has a bearing on teacher workloads, but came to shape their attitudes, such as *'targets would be met more easily if they did not need to spend so much time on teaching autistic children differently'*.

Although most teachers acknowledged the uniqueness of their autistic students (Vassallo, Dallos & Mckenzie, 2020), further analysis revealed that for longer-serving teachers a *'collective'* uniqueness was often in play. Despite changes in wider societal discourses, including greater awareness of the unique autistic perspective, some teachers' beliefs about autism meant they tended to initially approach all autistic children in a similar way, such as *all* autistic children respond to a visual timetable, prefer to sit alone, or are entirely literal. Therefore, an initial *'one size fits all'* approach was common within teacher narratives. This was accompanied by a weariness about teaching autistic children when universal strategies did not work that was difficult to conceal and did not go unnoticed (*or in some cases unchallenged*) by parents who were keen become involved to avoid their child becoming stereotyped. However, received

wisdom from parents was challenging for some teachers, especially when their ideas about autism differed and they felt unsupported by their leadership who expected them to provide individual attention to children and offered no training of how to engage with parents as partners.

Some teachers described wanting to just '*get on with the job of teaching*' in the way they had been taught to teach, which they felt they did well, sharing the benefit of their experience as effective educators. One teacher explained how teachers do not necessarily consider *going back to school* a positive, simply because policy now dictates all children wherever possible should be included within mainstream and are entitled to receive *an education appropriate to their needs* (GOV.UK, 2015, p.92). They understood teaching practice alters over time but felt the goalposts had moved substantially in recent years to *accommodate all children* whilst simultaneously *excluding* many and describing the inclusion vision as a '*failed experiment*', which many teachers agreed it was, as offering thirty-plus children an individual education was simply '*not doable*' for one person.

Therefore, whilst professional development to *'manage'* autistic children was welcomed by teachers, to change the way they practice *because of them* was a step too far for some. Some longer-serving teachers' concerns were also focused on how having the '*more complex children*' in class impacted their other students in terms of disruption to their progress. Some felt inclusion offered little benefit to the autistic child themselves, given their teaching mandate from the school was to ensure general progress from their majority students first and foremost, which they described as '*teaching to the test',* an element of the job they were not so enamoured with. Teachers who were somewhat *disillusioned* with the inclusion agenda described this as *'sacrificing'* the most complex and vulnerable students to a *'babysitting'* culture, especially in cases where the school and teachers did not know how best to support

them. They described schools and training as *'not geared up'* to meet children's needs, which meant their role was to simply keep their most vulnerable learners physically safe and '*evidence*' some semblance of *activity* during the school day to *'tick the appropriate boxes'*, evidence which the teachers described as often being *'overly facilitated'* by TAs in corridors. This led to some teachers questioning what the *'point'* of mainstreaming these children was as they were clearly not flourishing.

In contrast to longer-serving teachers, most early-career teachers held more of a *difference* model perspective from the outset and drew from such discourses within their interactions. This meant they often felt torn as many connected with parent-majority philosophy of *difference* but were under as much pressure from the performative aspects of policy as their longer-serving counterparts. Whilst early-career teachers demonstrated less interest in the label overall, and more interest in *getting to know* the child individually, they were also the most vocal in their narratives about their frustrations teaching autistic children. However, this frustration seemed to be rooted in the incompatibility of policies, resource limitations, and a lack of flexibility in the system to *try* new approaches and be the '*innovative educators*' that they wanted to be. Some felt they were *'letting down'* their autistic pupils, which impacted their feelings of efficacy. This might explain why they seemed to come to this research more enthusiastically than longer-serving teachers, some of whom I describe as '*going through the motions'*. It is possible that the ideas explored within the SwiS programme, and the array of techniques shared with them appealed to the contemporary worldview of early-career teachers in general, perhaps preserved by their youth in some cases or fewer years teaching in others, which helped sustain their inclusive philosophy to education to this point.

Alternatively, the possibility of a new and flexible approach such as SwiS that they could engage with *in spite of* the wider educational system, as opposed to *because*

of it, made it an interesting and valuable one; an optimistic small step toward resolving what seemed to be a *no-win* situation for teachers, stuck between *a rock and a hard place* in terms of performance and inclusion agendas. It must be noted that, whilst the differences observed between longer-serving and early-career teachers which were captured from a broad range of data sources may be indicative of legacy attitudes (*parent blame, meaning of autism as a deficit*), this was still from a small sample size, therefore drawing firm conclusions between the two should be approached with caution. It might, however, suggest another area for further study.

9.2.4.2   *Parents, teachers, schools, and the differing function of the label*

What was evident was that teachers in general felt leadership and policy makers placed inclusion second to general performance on standardised measures, maintaining an emphasis on academic results, which meant the meaning of autism was in many ways connected to teachers' job security; meanings of autism intimately linked to careers which are dependent on policy demands and decisions. Therefore, if the performance of the many students who can successfully access a standard educational delivery was impacted by accommodating the needs of the few who cannot, for teachers, the education of autistic students would remain a *'wicked problem'* (Armstrong, 2017) until inclusion becomes the primary measure of a school's success, allowing its philosophy to be upheld in practice.

As majority of parents favoured a *difference* perspective, they were more influenced by the difference discourses, prioritising *choice* and valuing the *alternative worldview* of their children. For parents, the meaning of autism as a difference meant their agendas were often incompatible with educational priorities. They favoured social and emotional development over academic progress, believing in and wanting to champion their children's individual talents and interests, which appeared less important and were possibly less visible to schools, who often adopted a more *totalising* approach

to autism, guiding their teachers and practice accordingly. How parents viewed their

children (*as individual people of value*), how teachers perceived them (*a mix of

vocational motivation and a threat to their career*) and what these children meant to

schools (*threat to budgets, performance, and professional standing*), placed teachers in

particular the middle of a '*tug-o-war'* between pressure from parents and from school.

From this we can see how such initial differences in beliefs, priorities, and sources from

which caregivers draw information and construct their meanings can function

differently between home and school systems, positioning parents and teachers in direct

opposition, when they need to be working together to raise the child in their care.

9.2.5 *RQ5-How SwiS is experienced as consistent or contradictory with the wider discourses about autism - building a stronger caregiving system around the child*

Through the experience of SwiS, improved relations seemed to result in better

outcomes for children, parents and teachers. For these children, having the wrap-around

support from home to school and back again appeared to be central to their educational

performance, but more importantly for alleviation of anxiety and improved feelings of

safety. This directly influenced their attachment relations, for example, how they

reacted to shifting context from school to home or vice versa. For parents, knowing

what is happening *in* school and being able to support a cohesive approach *at home,*

appeared to help mitigate distress when the child came home. For teachers the same

seemed true in reverse. Having an active system able to sensitively respond to the

child's needs through improved reflection, effective communication and collaboration

with one another was key, coming full circle from earlier discussions of *'the village*

effect' and coproduction principles discussed in *Chapter 1 and Chapter 2 .*

Arguably, with the rise in mental health difficulties in children, such relational

improvements are very much needed as an alternative to the current disconnected and

minimal forms of communication between caregivers, and the behaviourally based

interventions of compliance used with autistic children, as these approaches overlook the more complex emotional processes and attachment needs of children. This increases challenges for caregivers who, when faced with difficulties and distress from children, often misunderstand ideas of attachment and have few methods of effective communication and techniques at their disposal to problem-solve with. With a few exceptions, most parents and teachers undertaking SwiS not only gained new knowledge about autism, but also explored and better understood the attachment needs of their child, themselves and each other. This helped caregivers to improve their understanding of their child's perspective and recognise moments within interactions when their own attachment system might be activated, thereby contributing to emotional escalation. This increased understanding of themselves and each other seemed to improve their confidence and the efficacy of their communication during interactions with their child and with one another. Parents and teachers reported that they better understood their stress points in relation to the child and wider pressures and could *'step back'* from, and review situations in the moment that might have previously seen them *'drawn in'*. This simple act also saw them engage in more effective problem-solving behaviour together and, where it was prevalent, reduced conflict between them.

At this point in time, a systemic attachment approach is generally absent within mainstream education for autistic children, their families and teachers, therefore the framework of SwiS was overall received as *different* to any others that they had experienced. For caregivers, the *non-blaming* approach was a novel experience, as most parents and teachers had either been positioned as *'at fault'* at some point for the distress and externalising responses of their child or were accustomed to locating problems *'within'* the child as a consequence of their *'differences'*. Therefore, not having *'someone'* (*parent, teacher, child*) or *'something'* (*autism*) to blame for problems was somewhat of a novelty for them based on prior experience. Explanations

of attachment which moved away from *parent blame* discourses and extended to explore teachers as *bridging attachment figures* with their own needs and attachment styles, provided a new dimension to their role, illuminating why they felt or reacted the way they did in certain situations, such as the use of avoidant strategies to approach problems in the classroom. Overall, caregivers showed a *shift in thinking*, understanding that nothing happened in a vacuum, that the relationship between parent and teacher was pivotal, not just for the caregivers' sense of support and security, but also for the child. Just as a child can be negatively impacted by two feuding parents, they were also not immune from conflict between their parent and teacher and the insecurity of that relationship. Indeed, in their exploration of the triadic relationship, an important realisation for caregivers was that the child they shared care of not only had a relationship with each of them, but also had *a relationship with the relationship* that existed *between* parents and teachers (Karamat Ali & Dallos, 2023).

For parents and teachers this was reinforced as, although children were indirect participants in the study, they appeared to benefit quite quickly. Many parents and teachers described increased confidence in their children, seeing a greater willingness to interact and *'take a chance'* socially and academically, as well as a reduction in anxiety, with fewer, less intense meltdowns. Some parents and teachers attributed this to increased feelings of security and safety, as relations between caregivers were strengthened, making children who are in a triadic relationship with parents and teachers not only feel more widely supported across the different contexts of their day, but also better understood.

Findings from the study highlighted that offering a basic framework for communication and an array of established systemic techniques for problem-solving was powerful in supporting the construction of a stronger caregiving system around the child from parents and teachers, even from an initial position of established conflict.

However, for this to endure, the stronger system requires several things; the ongoing commitment from both caregivers and school leadership to a continuing format of relational engagement between parents and teachers, the employment of the adaptive therapeutic tools, supports and strategies to help maintain positive interactions between caregivers and the child they share care of, and importantly, the opportunity to reflect on this.

9.2.5.1 *Bureaucracy, performance culture and resisting a totalising approach to autism*

Embedded throughout the research was the thread of bureaucracy, where the needs of autistic children, which impact on their parents and teachers, go unmet due to political and bureaucratic manifestos because performance and inclusion agendas work in opposition to each other, an established *'wicked problem'* in inclusive education (Armstrong, 2017). What schools are mandated by policy to achieve is often different to what children and families need from education to ensure that they thrive. Schools and teachers want children to achieve good exam results. Many parents and families indeed want this too, but more importantly they want their children to have friends and be accepted, included and happy. However, what teachers must deliver for the sake of school targets and their careers is often not what children need to receive for their individual development, sense of belonging and feelings of security. The diverse nature of raising and teaching autistic children, and the multifarious influences on such, means that to best support autistic children, 'one size fits all' in terms of a standard educational model is often simply not possible. This reinforces the educational perspective that *autism equals problem,* underpinning a *totalising* discourse that all difficulties are due to autism and therefore reside within the child.

To *'do the right thing'* for autistic children in the current educational climate is difficult, as their system of support needs to work optimally and flexibly around them to

respond to their different needs sensitively and in a timely fashion. However, too often autistic children are told that kind of responding is not available to them; instead they need to *'adapt'* and should *'fit in'* with others as the world will not be so flexible when they get older. This is a dangerous precedent to set as it sends the message to children that their needs are not valid, often shaming them as *weak* or *inept* because they are different. It does not teach them to question how they are treated, or resist what *'feels wrong'*, rather it teaches them to accept whatever is *dished out* by others, without complaint or question, because their difference invalidates their voice. Parents are often encouraged to drive forward the *resilience agenda* to *toughen up* the child, a process often resisted by parents who then enter or re-enter the *parental-blame* cycle as their mode of responding is often interpreted as being too permissive from the current educational standpoint. The reality is that this approach is often a misappropriation of resilience and could be interpreted as an excuse to ignore any voices that might signal the need for individual responding. What is needed is resilience within the system and from individuals within the system, to adapt to need and show flexibility to differences. This was reflected in the research, as all participants had a unique experience of the SwiS programme, with each taking from it what they needed, and adapting elements to best support their particular situation and their individual child.

Upholding this type of flexibility is incompatible within a rigid prescriptive system of education, which now operates on a business model, prioritising homogeny for efficiency, often veiled as *'equality'* so that everyone gets *the same*. Unfortunately, such a blanket approach to the development and education of autistic children means this type of *'equality'* does not translate to *'equity'* and as a result not all educational experiences are created equally, contributing to distress and resistance from children to that experience, which increases conflict between caregivers and the child, and consequently between parents and teachers.

The weight of performative culture was felt by all teachers, some of whom believed school leadership would not be prepared to invest resource (*time or money*) unless there was a measurable *return* on that investment, with others suggesting they were only permitted to attend this research because it was free and because one of the SwiS days was organised to coincide with an inset day. Whilst some teachers felt their schools were more progressive, keen to engage with new approaches, this feeling of school reticence to take a risk and invest in wider approached in training and development does align with the difficulty I experienced with recruitment in this study, where applications from more than forty parents were unsuccessful, as participation from the school could not be secured. It also might indicate that schools are looking for, and are more reliant on, *compliance-based* interventions, such as behavioural approaches that complement increasingly authoritarian attitudes being seen in education currently (Reay, 2022), as opposed to more radical ideas, such as the systemic approach of SwiS, that might challenge this direction of travel.

As controversial as this might be, in recent years we have seen an insidious but significant departure from a more democratic education system where critical thought, individualism, and diversity are welcomed and encouraged. Instead we seem to have moved toward increasingly authoritarian practices, requiring obedience, compliance, limiting choice and freedoms (Reay, 2022). The rise in '*zero tolerance*' behaviour policies that appear to be designed to specifically alienate *'non-standard'* students (Clarke & Lyon, 2023) should be of concern, as they sit in direct contradiction to the espoused inclusion agenda that is supposed to support the individual needs of our diverse student population. The political direction of the education system suggests it may have prioritised *correction over connection*, overlooking the need for children as emotional beings to feel safe, to have freedom of expression, and the opportunity to connect with a variety of others authentically, organically, and individually along the

way. This was an important point made by both parents and teachers who experienced SwiS as being consistent with inclusion discourses rooted in systemic co-production, but in stark contrast to the existing performative culture of education and the reality of practice, bringing into sharp relief the current incompatibility of the two and the need to prioritise the former.

9.3   *Strengths, limitations and challenges*

As with all research, there were strengths, limitations and challenges across the research process that need to be considered and acknowledged.

9.3.1   *Ethical considerations*

A strength of this study was its strong ethical core across all aspects of the research process, remaining a priority from start to finish. As this is ethically sensitive research of a potentially vulnerable population, the protection of my participants was my primary consideration. Therefore, strict anonymisation and data protection measures were taken to ensure participant privacy and anonymity. Many participants, although keen to take part, were nervous about being identified, particularly when discussing children as their privacy had to be assured. Therefore, all participants were issued with unique codes to protect their identity as these codes would not mean anything to external readers not involved in the study. However, it came to light that the participants had not protected their codes from each other, meaning there existed a risk that if a participant read the final research, they may be able to identify *who said what* if codes were presented within final write up. The result of this meant that codes had to be retrospectively removed from quotes within the final presentation and review of the thesis and replaced with simple terms of teacher/parent. For integrity and ease of cross-reference, identification codes are visible against quotes within the analysis tables;

however for anonymity, these are not publicly available and have been restricted to the research and supervisory team in line with the ethical approval of this study.

Ensuring the integrity and interpretation of the data was another strength. A robust methodological approach was maintained throughout, and strict validity enhancement employed to including bracketing and interrater checks to avoid over- or skewed interpretation, a risk within qualitative inquiry.

9.3.2   *A unique approach*

A further strength of this research was the unique approach of SwiS as a framework. Tackling difficult subjects and often *avoided* conversations, such as misunderstandings of attachment and *'stuck'* cycles of interaction, captured participant interest. By providing the means for participants to connect explorations with their individual circumstances, parents and teachers were able to engage with the SwiS content and approach and make sense of experience relevant to their context. This made it more meaningful to them. More often, support, training and intervention programmes around autism are general and didactic in nature, with little opportunity to apply, practice and review what has been explored, especially in relevance to one's own circumstances.

9.3.3   *Participant sample*

The sample of participants was both a strength and limitation. In qualitative terms the number of participants was quite substantial, offering a good range of experience from which to draw out themes. However, compared to the entire population of parents of autistic children in mainstream primary education and their teachers within the UK, this was a relatively small sample, therefore conclusions drawn should be treated with caution and highlighted for further study.

The low ethnic and cultural diversity of the Westcountry was also a limitation of the study. This lack of cultural diversity was reflected in the participant sample where all participants were white and only sixteen percent were of non-British origin.

9.3.3.1   *Cultural differences*

Of the participants of non-British origin within the study, an additional limitation was noted in terms of cultural differences for immigrant families where English was an additional language. For some of these participants the group sessions did not work for them; they preferred the one-to-one elements of the study, gaining more from this than the two-days of group activity. This was due to a range of reasons. Firstly, an existing language barrier made participation challenging. Despite being good English speakers and having access to translation, having English as a second language and processing considerable information, some of which was quite complex, was tiring for participants, who reported that they struggled to keep up and engage deeply in the activities.

Stigma and cultural views around communicating about difficulties associated with autism also meant that engaging in such a forum, did not offer the same benefits of shared experience for them as it did for others. In daily life, these families reported that they tended toward a small inner circle of friends, mostly from their home countries, upholding their cultural traditions, which did not necessarily fit with the direction of the study. These families suggested that a more individualised approach would be better suited to respect their cultural disposition. Equally, the same participants came to the study with a feeling of wanting to be *'instructed'*, told *'what to do'*, and how to *'fix'* problems. At first glance, this might suggest a position of disempowerment within the family, that they feel their parenting was somehow lacking, that the autism was *'their fault'*, or that they were disengaged in their parenting, and just wanted someone else to resolve their difficulties. However, what was revealed were more complex cultural

differences. Within some families, a preference for a higher level of privacy, combined with a deference for professional expertise *(both appropriate according to their culture and experience)*, alongside issues related to second language processing, limited deeper, more meaningful engagement. Improved explanation and extra one-to-one time at the beginning of the programme to ensure understanding might help alleviate some of those cultural barriers. Alternatively, a more individualised version of the SwiS programme could be considered, as the flexible nature of SwiS and its family-therapy basis means that adaptions in circumstances such as these would be feasible and would respect cultural diversity in the same way that we aim to respect the autistic perspective.

To explore this concern, a cross-cultural extension of this research is currently being undertaken by a postdoctoral research team, with myself as a consultant, to understand how the systemic approach of SwiS might be adapted to be helpful to families and teachers of non-British origin.

9.3.4 *Practical implications*

Taking part in SwiS presented some practical implications for all participants representing a significant logistical undertaking by both schools and families that should be considered during further research.

For families, time off work and childcare arrangements were the two main logistical challenges faced. Although it was not a specific difficulty in this case, travel to the designated programme venue, cost of travel expenses, and ease of access should also be considered. Time off work for parents might mean the use of paid annual leave for some, and for others, who might be self-employed or on zero-hours contracts, it might mean loss of income or a reduction in earnings. For families who already feel the extra costs of raising an autistic child (Knapp, Romeo & Beecham, 2007; Knapp, Romeo & Beecham, 2009; Sharpe & Baker, 2007; Westminster Commission on

Autism, 2016), it is important that any support offered is not having to be rejected because it places an unnecessary financial load on families.

Teachers might face similar logistical difficulties in terms of childcare and access; therefore consideration of these issues is equally important, as is the potential for work to *'pile up'* on their return, resulting in longer hours and increased stress, adding to their load.

For schools, having teachers attend two days training away from the classroom represents a significant financial and operational commitment, in terms of finding a temporary replacement for their teachers, which if not able to be covered *'in school'* could be expensive and difficult to access. Operationally, having teachers take part could also be challenging for schools, juggling staffing rotas to cover not only lessons, but also joint practitioner meetings with allied professionals, as well as other duties normally undertaken by teachers as a matter of course in their role. However, this could be balanced by the benefits to teachers from improving their ability to work more effectively with parents and develop skills to work with an increasingly diverse range of children.

Finances are always a consideration for schools, who not only operate on increasing costs with limited budgets, but also face competing priorities from a crumbling educational infrastructure, as seen in recent reporting across the UK (Helm, 2022). Many school buildings from swift post-WWII rebuild and 1960s educational reform are in a poor state of repair, past their intended life-span, no longer fit for purpose or pose a danger to staff and students (Weale, 2023).

This places difficult decisions on schools who must decide where best to spend their budgets. Finding money to support autistic children is not high on the agenda when trying to stop the roof from leaking or keeping the plumbing working. However, where autism is concerned, the financial responsibility of programmes to help students

reach their potential should not be looked at in isolation as an individual *'school'* problem. Many, if not most autistic students in mainstream schools have the potential to become independent productive individuals, with jobs and careers. By receiving an appropriate education that allows them to play to their many talents and strengths, the likelihood of this is increased. Their peers also gain something by way of opportunities to learn about and appreciate diversity, making acceptance and understanding of diversity more *'everyday'* a lesson that all people need to learn for the sake of developing a compassionate and inclusive society and one that autistic children can teach their peers. However, for those who do not experience an appropriate education, a lifetime of exclusion and reliance on family and the state for financial support and care is a more likely outcome together with all the costs, financial and otherwise, associated with that. For every autistic student that does not require this level of support, the cost of such early investment is tiny compared to *'whole-of-life'* costs and lost life-chances. This micro-to-macrosystemic systemic impact on outcomes and opportunity (*both positive and negative*) was understood by Bronfenbrenner (1995b) as a kind of *ecological proliferation* that had wider bi-and multidirectional influence, an understanding that could benefit schools and teachers interacting with all parents of all children.

An important barrier to participation in future engagement with SwiS could be the short-term effect it might have on the child. Having both their teacher and parent unusually absent for two days and the potential disruption to their usual routine this may cause should not be overlooked. This was considered within this study and efforts to minimise disruption to the child were made by holding one of the days on an inset day so the child could be cared for by a known and trusted caregiver and, where both parents attended the programme, one of the caregivers left early to ensure continuity for the child. Indeed, several potential participants chose not to take part, feeling the level

of disruption to their child might be too much at that time. Future studies should utilise the flexible nature of the SwiS approach to alleviate as much as possible the impact from this.

9.3.5 *Maintenance and sustainability*

The findings from this research suggests that parents and teachers experienced SwiS as helpful and participation had a positive impact on their relationship with one another, as well as on their child. This resulted in a demonstrable enthusiasm from parents and most teachers for a continued systemic approach to their triadic interactions with their children. However, a few teachers expressed concerns about the sustainability of a systemic approach in the face of macrosystemic influence, where systemic attachment ideas do not match the business agendas of schools which look for economies of scale in blanket approaches and quick fixes. These teachers believed that due to the increasing academisation of schools reinforcing the idea of education as a business, *proof of concept* would be needed before schools would accede to a level of genuine culture change that supports systemic ideas. As the systemic attachment-based approach of SwiS represents new thinking in relation to parent-teacher communication and the support of autistic children in mainstream education, a few teachers expressed concerns that, once participation was over, they would be under pressure to revert to their *'established ways of working'* and that commitment to a continuing format for communication would be difficult to achieve and maintain. This suggests that change is needed at a policy level, because if schools do not have genuine inclusion and coproduction at their heart, any learning from the experience of SwiS may be ignored whilst its systemic ethos still sits in opposition to regimes of performance and financial targets.

That said, if a systemic attachment approach can be framed and established as having positive impact, then a whole-school adoption is possible. This was

demonstrated by one participating school who sought to introduce SwiS as a whole-school approach after experiencing positive effects on their participating teacher, family and child *(Appendix Y testimonial).*

9.3.6   Data

The data collected across this research was vast and varied, providing data elements for further research that were beyond the scope of this thesis. Additional data were collected from my time at a participating school where I spent a day a week over an academic year, immersed in this area of study, observing and working with parents, teachers and the children. This culminated in the above-mentioned *whole school* pilot of SwiS being conducted. The data and results of this have not been included in this study but will form the basis for further research.

9.4   Future considerations and next steps

The overall positive outcome from this research suggests the systemic approach of SwiS has the potential to be further developed and adapted to address an existing gap amongst the array of approaches and programmes employed in mainstream primary education to support autistic students. As a small-scale illustration of the *village effect* showing the difference that can be made to families, teachers and children from a systemic attachment perspective, this research raises questions of how it might be upscaled to demonstrate what is needed to support success in education for autistic children.

As with all novel research, further exploration is needed to understand whether there is potential for wider impact beyond the scope of this study, namely that of the parent-teacher-child triadic relationship. Future focus might consider adaption for secondary schools, impact on sibling carers, wider systemic relations such as spouse relations for parents and teachers, as well as exploring impact on teacher attrition.

Importantly, the systemic attachment-based framework of SwiS may have potential to be helpful to all children and their parent-teacher relations, beyond those with a diagnosis of autism, as difficulties in the family and in the classroom are not limited to autistic children. As a matter of some urgency systemic approaches documented in this study need to be explored with diverse communities across the UK. Arguably these approaches have the potential to change the educational landscape but first we must ensure that all parents teachers and children can benefit from them. In many cases this will likely involve development of new iterations of SwiS, through working with communities to consider relevant factors influencing experience of systemic ways of working, related to cultural preferences and language.

Although SwiS was found to be helpful in enabling parents-teachers relations, communication and improved problem solving, it is not a panacea, and we cannot ignore the socio-political influence that has woven its way through this research emerging from the narratives of the parents and teachers who took part. This suggests such an approach may be resisted, in part due to structural and political issues across education and within schools, where the neoliberal discourse upholding the more economic normative concepts of identity (*one size needs to fit all*) is maintained. The *'business'* of education seeks to *'fit'* children to the ideal of becoming the next generation of economically productive (*employed*) consumers, using schools and teachers as the vehicle to ensure that happens in a predictable, standardised but '*competitive'* way. Teachers under pressure to meet such targets must ensure all pupils achieve the same prescribed outcome. Their vocational inclination and autonomy to be innovative educators responding to individual need, but overwhelmed by workload and performance pressures, shifts their priorities from *child need* to *school need*. This immediately highlights for *segregation* those children who might impact *school data*, data that acts as the proverbial *Sword of Damocles* over the heads of school leadership

and teachers to meet the educational, budgetary and bureaucratic targets upon which their careers and livelihoods hang. This performative pressure undermines inclusion intention within school culture, as evidenced by the high levels of educational exclusion (*both internal and external*) for this group of children.

Parents on the other hand can become stuck in a cyclical political blame-game, condemned for their children's individual differences, where being unable to *'fit'* into a narrow-prescribed educational framework and environment that does not meet a child's needs is interpreted as *challenging* or *deviant*, pathologised as deficit in the child rather than any deficiency in the system. Appeals for adaption and flexibility to limit distress remain ignored, considered as *'pandering',* until children become damaged in some cases or can no longer attend school, which again only becomes prioritised when absenteeism begins to impact '*the numbers'*. Rather than meeting this with the necessary support to help children back into school, a punitive approach levies fines and criminal records at parents who have been crying out for help. Faced with mandated attendance and the *'it will build their resilience'* argument, parents who recognise and support their child's different perspective and experience of the world must then *'do battle'* for acceptance of it, some becoming necessarily combative to protect their child's mental health. This is another *'growth'* area in schools, with rising amounts of funding being channelled into education to support the mental health of *children* who are experiencing increasing distress and anxiety in school, with little questioning of *why this is happening*. And so, the cycle persists. Schools and teachers versus parents and children, with different agendas, priorities and beliefs, in conflict with one another, when each is really *in need of* the other. Here the systemic impact on diagnosis is highlighted. To defend their child's wellbeing and parental decisions, parents are often forced to seek and accept increasingly pathologising labels to *'prompt the system'* to offer help to them, to defend against criticism and offer some vindication of their

parenting. To help moderate the effects of pathologising their view and experience of the world, autistic people and the wider autism community have attempted to take ownership of these labels to draw the discourses away from deficit ideas, toward a neuro-affirming *difference* perspective. However, some of the contemporary discourses about autism as a '*difference*' are not really subversive enough to shake the political weight of required assimilation and sameness within education. Such discourses strongly state that autistic children should be recognised as different (*and not less*) but fail to properly challenge capitalist ideology that continues to oppress children and families by seeking to either shape them to fit that ideology or reject them if they do not.

Engagement with SwiS has illuminated the above and perhaps offers at a microsystemic level a way of subverting the pathologising discourses of autism as well as a way for teachers and parents to have some hope of better outcomes whilst also having a shared outlet to express some of their frustrations with educational (*and to some extent*) political systems. However, this is not, in itself, enough. To be effectively implemented we need to understand and try to change the wider political systems under-pinning schooling that continue to hold innovation and collaboration at arm's length.

9.5 *Concluding thoughts*

Reflecting on the overall findings, positive changes have been observed in the parent-teacher relationship around the child as well as within caregiver-child relations. This can in some part be attributed to the changing understanding gained by parents and teachers as key members of the child's microsystem, which were explored, revealed, and maintained through the SwiS activities and in their resulting new ways of working together, having created their own communication style going forward. The systemic approach of the SwiS framework offers the opportunity for genuine change in often difficult home-school relationships of some of the most vulnerable children in

mainstream primary education. This research has offered a small-scale glimpse of *the village effect* on autistic children, their families and teachers, illuminating a different path and approach when supporting autistic children.

The current state of mainstream education for children with SEND and particularly autistic children is failing and has been doing so for many years, evidenced by the serial reforms introduced by successive governments and the continued poor outcomes of the autistic community. However, these reforms are often rehashes of existing policy that expect a different outcome. Therefore, different thinking and a different approach are required if another generation of autistic children is not to be similarly failed and their caregivers similarly stressed and overwhelmed. The aim of the research was to find out if it was possible to create a cohesive system around autistic children and if so, would it be experienced as helpful for them and for everyone concerned; to examine what that would look like, and what that would mean for wider understandings of autism and parent-teacher relationships. Therefore, as stated in the introduction, the study is not about SwiS in itself, but about the process, where specially selected therapeutic tools and established activities from systemic therapy that may be helpful in creating a cohesive system, were combined as a framework to facilitate this exploration.

Whilst systemic family therapy, attachment-based approaches are not new, using them in the context of home-school relations to support autism-related problems explored through the framework of SwiS, *is* and represents new thinking in terms of inclusion. The flexible structure of SwiS allows for meaningful engagement without being so prescriptive that it loses its relevance to the individual. An opportunity exists to make significant changes in problematic relations that provide the basis for significant change for parents, teachers and children without a massive departure from current ways of working and with minimal investment. Essentially SwiS provides a

framework for tackling issues that contribute to oppression and marginalisation and as such could be extended to other areas of social challenge, including mental health, before these issues escalate and become entrenched in meaning as being a '*social problem*'. Existing knowledge and collective experience clearly demonstrate that current approaches are not working and that something has to change to prevent another generation of children from being failed. While we continue to force educational inclusion through '*integration*' and '*compliance*', approaching autism as a '*discrete*' problem rather than weaving the individual threads of *difference* through the rich fabric of our society, genuine inclusion will remain out of reach and society will not grow in terms of its ability to embrace diversity and all the benefits diversity brings.

Education is ultimately governed by policy and politics, an enormous task with overarching aims, making rapid change and response to complexity in context a continued '*wicked problem*'. Therefore, instead of waiting for the glacial pace of policy to enact change at a macro-level, we should consider that autistic children may do better in the innovative and motivated hands of appropriately supported key caregivers at a micro-level, adopting a more a bottom-up, inside-out, or groundswell approach to systemic change.

I still believe it takes a village to raise a child, which is important, not just in terms of the benefit to the child, but for the impact is has on the *villagers*, our wider society. Therefore, it makes sense to support the development of that village found in the combined strength and expertise of parents, teachers, and schools, to help them so that they might confidently take the lead and create change together, to be unafraid of difference, and to create the *secure-base* from which the child can safely and *authentically* explore, be included in, and contribute to the wider world.

To move forward, our world needs different kinds of minds. Every child has value and purpose, and we should not lose sight that their purpose might be to unsettle

the complacency of norms, to provide contrast in worldview and bring forth tolerance, compassion and different thinking in others. Because *without deviation from the norm, there is no progress.*

My beautiful son aged 4 years, on the beach at Margert River, Western Australia, walking in his father's footsteps, making patterns in the sand. Happy.

Appendices

Appendix A

Reflecting on the wider inequalities within health and education, contributing to poorer outcomes for autistic people.

The inequity of health care – the autistic mortality crisis

Within health care, an absence of understanding of the autistic perspective among medical practitioners, starts with a lack of training about autism. Limited access to support for autistic people to help them with challenges associated with the neurodivergent perspective, starts early in life, which together with stereotyping and misunderstandings from practitioners, creates barriers to healthcare access. Such misunderstandings maintain the siting of any difficulty in communication or behaviour, solely within the individual, rather than in a mismatch in understanding, and are critical factors in the general health inequities experienced by autistic people and the risks associated with diagnostic overshadowing (Crane *et al.*, 2018; Foley & Trollor, 2015; Milton, Heasman & Sheppard, 2018). Having personally been involved with advocating for access to appropriate healthcare for many autistic people and families, who would otherwise not have been seen by a practitioner, my own family included, I have seen first-hand the difficulty and potential dangers of this. Among clinicians in healthcare settings, a lack of knowledge about co-occurring health conditions such as epilepsy, and mental health problems such as anxiety, exacerbate the situation, which together with misdiagnoses and missed opportunities for care, often due to environmental challenges or miscommunication between the clinician and autistic patient, leave autistic people increasingly vulnerable and often untreated (Autistica, 2017).

In addition, an endemic problem exists with the overmedication of this group with psychotropic and other medications (Alfageh *et al.*, 2020; National Health Service, 2021), often prescribed to subdue the individual, should any response or presentation be misinterpreted as *challenging* by health professionals (Esbensen *et al.*, 2009; National Health Service, 2021), and given largely for the benefit and ease of those providing care, not for the welfare of the individual receiving the medication (Branford *et al.*, 2019a; Branford *et al.*, 2019b; Sharpe *et al.*, 2019b), I make this point, not as a departure from the focus of this research, but to draw parallels with attitudes from medicine to education and other services involved with autism, where interventions (i.e.

social skills training) are often rooted in what is good for those around the autistic person, rather than what is good for the autistic person themselves.

Such is the scale of overmedication of this population, that NHS initiatives were introduced in 2016 to try to tackle it: 'STOMP', '***ST**opping the **O**ver **M**edication of **P**eople with learning disabilities, autism or both with psychotropic medications*', and its co-initiative 'STAMP', *'**S**upporting **T**reatment and **A**ppropriate **M**edication in Paediatrics'* (National Health Service, 2021).

Such inappropriate, unnecessary, and over medication of autistic adults, young people, and children, has contributed to the poor health outcomes, rising numbers, and costs, of unnecessary inpatient care, and early death statistics for this community (Autistica, 2017). In a longitudinal study, Esbensen *et al.* (2009), found that autistic people who began medication were more likely to remain on it long term, with high rates of sustained polypharmacy, consistent with an increase in prescribing practices in psychiatry for this sector, and contributing to cumulative side effects and risks of adverse drug reactions. The aforementioned misunderstood presentation differences, and the presence of co-occurring conditions such as a learning difficulty or anxiety, highly prevalent in autism, were key predictors of over medication and the likelihood of long-term polypharmacy, particularly of psychotropic medication (Logan *et al.*, 2015). Autism child studies support this, showing that between 60-64% of children are being prescribed at least one psychotropic medication, with 35-41% of those taking at least two and >15% prescribed concurrent medications from three medication classes, for a median length of time of at least a year (Logan *et al.*, 2015; Spencer *et al.*, 2013). Such polypharmacy is a growing public health issue generally (Chang *et al.*, 2020), but despite the link of polypharmacy to early death and reduced quality of life in autism, change is slow. In the UK, preventable tragedies such as the case of Oliver McGowan, have led to a review of practice and the foundations of enhanced training for medical practitioners, however, as yet, neither have led to any significant reduction in prescribing (Alfageh *et al.*, 2020).

Health inequities extend beyond critical care and mental health services, with many autistic people unable to even access GPs or other health practitioners, such as dentists or pharmacists for more general healthcare and treatment. The importance of GP understanding of autism is crucial, as they are the gatekeepers to wider health services. However, in a National Autistic Society study, almost 40% of GPs reported they had never received any formal training in autism, with an even greater number

expressing a lack of confidence in being able to properly support their autistic patients (Unigwe *et al.*, 2017).

This is of concern not only for general health, but mental health also, as GPs are often the first line of help for mental health support. Without that, unchecked, chronic mental health difficulties will continue to contribute to the high suicide rates found within the autistic population. Suicide is an additional factor in the early death statistics for autism, and the second leading cause of death for autistic people. If you are autistic, you are nine times more likely to die by suicide than the general population (Autistica, 2017), with research suggesting that 66% of autistic adults have considered suicide (Cassidy *et al.*, 2014).

All the above continue to contribute to the unacceptable mortality statistics in autism. In a European study of autism and health, autistic people in Sweden could expect to die at least 12-16 years before their neurotypical peers, a statistic supported by Autistica's '*Personal tragedies, public crisis*' report (Anderson-Chavarria, 2022; Autistica, 2017; Hirvikoski *et al.*, 2016; Westminster Commission on Autism, 2016). Factor in any level of learning difficulty or disability, and that number jumps to a life expectancy cut short by 30 years (Autistica, 2017; Hirvikoski *et al.*, 2016; Sharpe *et al.*, 2019a). Given the sociocultural, educational, and attitudinal similarities, the geographical proximity to the UK, the similar general health outcomes between the two countries, and the experiences of the autistic community here, these outcomes from a close statistical neighbour, suggest a similar life expectancy for autistic people in the UK (Autistica, 2017; Hirvikoski *et al.*, 2016). In view of this, we could justifiably consider autism as a life limiting condition.

In financial terms (and at the risk of being unintentionally *ableist*), *'society's systemic failure to accommodate autistic people'* (Bottema-Beutel et al., 2021) cannot be ignored, as autism has a considerable financial impact on the public purse, with costs purported to exceed £32 billion per annum across the autism population in the UK alone (Westminster Commission on Autism, 2016). In the US, the annual cost exceed $268 billion in 2015, a figure that is expected to rise to $461 billion per year, by 2025 (Howlin & Magiati, 2017). This is the current human and financial cost of society's oppression of autistic people and rejection of the autistic perspective, one that is growing and is wholly unacceptable (Milton, 2016b).

The inequity of life-chances: education to employment

Similar inequities occur in access to education. Within education, autistic children have significantly poorer outcomes compared with their academically-similar non-autistic peers (All Party Parliamentary Group on Autism, 2019). In 2018 Ambitious About Autism [AAA] published statistics showing 26% of autistic students in mainstream education achieved 5-GCSEs A*-C (9-5 in new grading), compared with the 61% of their non-autistic peers (Ambitious About Autism, 2018b). The 61-26% gap does not stop at attainment, as underpinning this disparity is a significant inequity in *access* to education. In 2018, Ambitious About Autism also published data that showed a 4% increase overall in school exclusions across all school children in England. However, for autistic students there was a disproportionate rise in exclusions of over 60% across the country for this population (Ambitious About Autism, 2018a). These poor educational outcomes, together with social exclusion and lack of understanding underpinning the deficit-focused negative discourses that persist about autism, combine to further disadvantage this population and limit future life-chances, particularly in terms of employment opportunity. Less than 16% of autistic people are in full-time employment, with only 21.7% in any kind of work, the lowest statistics of any work-able *disability* group (Autistica, 2021). For those who do gain employment, most are engaged in menial work, with few in roles commensurate with their ability or qualifications, and even fewer individuals pursuing *dream jobs*, the desired fulfilling careers they have trained for, are qualified to do, and have a propensity to excel at.

Appendix B

Reflecting on shifting perceptions of autism

In recent years, much of the autistic community has worked hard to try to move the dominant social discourse around diagnoses, away from linear, deficit medical models of autism, toward a more nuanced *difference* model, one that focuses on the whole person, their strengths as well as challenges. Since the diagnostic changes within the DSM-V (American Psychiatric Association, 2013, p.55), there has been a shift in clinical perception, where many clinicians and practitioners now recognise uneven or *spikey* profiles of ability, skills, and capacity, and acknowledging difference does not always mean deficit (Mac Carthaigh, 2020). However, despite this recognition, such profiles are also regularly misunderstood, and can be misinterpreted, often remaining anchored in deterministic thinking, with a propensity to over-generalise across autistic people. For example, verbal ability is often erroneously linked to more generalised ability such as the skills needed for successful daily living, assuming because a person can talk, these daily living skills are in place, and so the person requires less understanding, adjustment, or support. However, in reality, the opposite might in fact be true (Milton, 2012a). Even when a unique profile of ability is recognised, this still fails to capture the whole person, because when diagnosis is made, it is a momentary *snapshot* of an autistic individual. It can be perceived by others that this is the person, forever frozen at the point of diagnosis, leaving no vision for the growth, change and development over time, including the influence of environment and opportunity (Bronfenbrenner, 1995a) that is experienced by all humans. Similarly, the clinically applied *severity* levels within DSM-5 (American Psychiatric Association, 2013) which estimate required levels of support, and the descriptions of *function* within ICD-10 (World Health Organization, 1992), are all applied according to what is *observed about* the individual, rather than what is *experienced by* them. (Williams, 1996a). Although diagnoses can convey the message that support may be needed, such as economic help, daily living provision, and educational services, this does not illuminate strengths, as medical diagnostic manuals are of course not competency-based frameworks. Indeed, within the autistic community, it is often anecdotally said that when autism is referred to as *mild* or *severe*, it is *not* referring to how the autistic person experiences their autism, but rather how non-autistics experience it when interacting with them.

Whilst everyone experiences the world in their own unique way, I fully accept that autistic people can experience and respond to the world in markedly different ways from most non-autistic people. Most autistic people I have interacted with over the years, and those I have consulted with throughout this research, have been clear and unequivocal about their, or their children's, varied perceptual experiences as well as the pathologising responses of others creating some, if not much, of the difficulty they experience. Whether that response is direct, such as in a mismatched social interaction (Crompton *et al.*, 2020; Milton, 2012b), or more indirect, such as the ill-considered design of a learning environment that is sensorially challenging and inaccessible to the learner (Milton, Martin & Melham, 2016), the *othering* and resulting oppression of autistic people, is real. This experience is encapsulated in the words of Donna Williams (1996b) an autistic artist, teacher, writer, and autism consultant, when she wrote

> *right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced. (p.14)*

In this one sentence, Williams sums up how demonstrably absent the authentic autistic voice has been in determining constructions of autism and consequentially how power-*less* autistic people are in determining their own lifepath. Instead, autism has been conceptualised, pathologised, and for too long the narrative *owned* by those with only indirect experience or observation of it (Milton, 2012a).

Again, education provides us with a good example of this. For years, autistic children and their caregivers have explained the challenges they face getting through the day within an educational system and environment that is insensitive to their needs; the lack of understanding and knowledge of autism, the perpetual sensorial challenge, differing learning preferences and cognitive styles, the intolerance, othering, loneliness, marginalisation, the constant battle for support, and consequential poor outcomes when it fails to materialise. Explanations of how to fix it (*starting with better understanding and teaching of acceptance to all children, so that a sense of belonging is a right for all, not a club you have to pass a test to get into*), have fallen on deaf ears, evidenced by failing inclusion agendas, resulting in policy change requiring serial SEND reforms (Department for Education, 2022a; GOV.UK, 2014a). Inclusion policy and educational support frameworks in schools EHCPs, TAMs, TACs, TAFs, MASPs, IEPs, EHATs, all designed to *help*, have done little to improve things, as they fundamentally miss the point - they generally aim to *change the child* rather than altering the environment and promoting genuine inclusion, understanding and acceptance, which has kept outcomes

for autistic people poor on an existential level, rendering them as *dis-abled* as they ever were.

Examples of macrosystemic impact from policy on microsystemic support, teachers, parents and children

Macrosystemic policy impact on microsystem support delivery

An example of how macro-level decisions can interact and exert influence on a child's system, impacting the child themselves, can be seen in the policy shift from 'Statements of Special Educational Needs', to 'Education Health and Care Plans' [EHCPs] in 2014 in the previous set of educational reforms for SEND. Statements, which previously ceased at age 19 (if still in school), were replaced by EHCPs, which supported a child into young adulthood, across more than just school, ending at age 25 - unless the young person went onto university, at which point, the plan would cease early (*another inaccurate assumption that if a person can attend university, then they no longer need support*) (Department for Education, 2017; GOV.UK, 2015), with no follow-up to check if university was successful and the young person moved into employment and on to independence, or indeed if they dropped out after the first semester. The change came from a government policy decision to end the statementing process, as statements were considered too bureaucratic and took too long for children to receive the support they needed. This was done in line with the new Children and Families Act 2014 (GOV.UK, 2014b), and educational reforms of the time (GOV.UK, 2014a; GOV.UK, 2015), introduced to afford vulnerable children more protection and progress the inclusion agenda.

On the face of it, this was a wholly positive change, suggesting that more children might be fully included and receive more appropriate support, more quickly. However, like many policy decisions made at a macro level, the reality did not reflect the initial intention once it cascaded down to practice level and to the individual child. EHCPs turned out to be similarly time consuming and resource heavy (Richards, 2021), often taking many months even running into years to realise, with schools (and more recently families) still holding most of the process load, and local authorities often taking similar or longer time as the statementing process, to agree to assess and issue an EHCP. Even once issued, EHCPs are still largely left with schools to deliver, just as statements were, as engagement from health and care professionals has never been consistently established (Boesley & Crane, 2018).

Within half a decade, MPs and educators were again calling for further reform, as this new system was resulting in unsustainable increased load on schools and teachers, as well as increased bureaucracy and adversity for families and children already struggling. A decade later and another generation of children have, according to the House of Commons Education Committee, been left with unmet needs and inadequate support, due in part to a lack of guidance, training and resources, resulting in poor quality EHCPs, suggesting the EHCP process was not fit for purpose (House of Commons Education Committee, 2019). At point of writing, yet another set of SEND reforms have been introduced (Department for Education, 2023), aiming to resolve the persistent issues which continue to plague the system, the proposals of which at a micro systemic level offer little real hope of change for the individual child, and indeed may see a further diminishing of support (Bamsey *et al.*, 2022).

Macrosystemic policy impact on microsystem members – the effect on teachers and attrition

Such macro policy changes often have other systemic impacts. For example, the combination of lack of educational support for students in classrooms, together with increased teacher workloads, and the juxtaposition of their creative pedagogical autonomy set against performative and accountability agendas (*known challenges for teachers*), might undermine feelings of efficacy and contribute to burnout and thoughts of leaving the profession (Perryman & Calvert, 2020).

Observing policy decisions such as the EHCP in its context, as part of a wider political inclusion agenda within mainstream education, means it requires teachers to educate children with increasingly complex and individualised needs. One might accept that this alone could contribute to teacher burnout and attrition, however closer scrutiny reveals it is more systemic than that. Responding to inclusion policy and teaching children with diverse needs may not in itself be a problem (Hagaman & Casey, 2018). However, the teaching of children according to an inclusion policy, installed without the requisite training for staff, might be, as again, this undermines teachers' feelings of efficacy (Perryman & Calvert, 2020; Saloviita & Pakarinen, 2021). The stress of having to navigate externalising behaviours in the classroom might also be predicted as being a key reason for teachers to leave. However, as Boujut *et al.* (2017) explain, teachers only *'experience stress when they feel unable to manage the education needs of children… or reach educational goals'*. Indeed as Perryman and Calvert (2020) also explain, it is not necessarily the children or behaviour that present the challenge, but the lack of professional support for teachers to *help* children. This signals a wider systemic

problem at play, specifically the conflict created between policy decisions on inclusion at a macro level, and the lack of appropriate training and student support in terms of EHCPs needed to realise that inclusion agenda, filtering down to the micro level of the classroom. Such conflict proliferates across teachers' daily working conditions, affecting and often undermining overall feelings of efficacy, and so influencing teacher attrition. In simple terms, teachers feel they do not have the right tools for the job (Hagaman & Casey, 2018).

Tools such as EHCPs are not only designed to help the child, but also help those around the child provide effective support. The protracted nature of the EHCP process means that necessary supports for the child may not actually materialise for some time, often leaving the incumbent teacher to cope whilst inadequately supported themselves. This additional pressure might contribute to, and accelerate, a teacher's decision to leave, evidenced by their attrition rate in recent years, where, according to the Joint General Secretary of the National Education Union, teachers leaving the profession within five years of qualifying, has jumped from a quarter [26%] to almost a third [32.2%] (and rising) in the seven years between 2012 and 2019 (Department for Education, 2019; Education Executive, 2019). Interestingly, this rise mirrors the timing of the previous SEND reforms, which were universally criticised by the education sector and within government review (House of Commons Education Committee, 2019), suggesting a mesosystemic influence of policy decision, cascading down and impacting teacher attrition.

Macrosystemic policy impact on microsystem members – the effect on children and parents

For many autistic children, just being able to access school often hangs by a very delicate thread, where the smallest of events can occur to derail such a fragile relationship (Reed, 2021). Macro- to microsystemic events, even indirectly related to the child, might be impactful enough to upset the balance. In an example but real-world scenario, a small change in parental working hours, which is not directly related to the child, might cause a minor change to the availability of a parent. This in turn might alter school drop-off or pick-up times slightly, or even result in the need to utilise a breakfast or after-school club (Martin, 2022). On the flip side, as the current cost of living crisis has demonstrated, macrosystem funding decisions may significantly impact the child's microsystem, as schools under increasing financial pressure are forced to abandon relied upon before and after school clubs in a bid to save money (Martin, 2022) which in turn may impact parental ability to work, and so push a family into financial

hardship. This could result in a significant change of circumstances for a family who might have been previously *just managing*, creating conditions for an even more drastic change, such as a house move or worse, the loss of a home, with consequences for the whole family. Parental stress, food and shelter insecurity, and the potential for wholesale change within the family, such as a parent forced to work away, or the family moving to a new area and new school, would be destabilising for any child and their family. However, for autistic children who are already marginalised, such drastic wholesale changes could be catastrophic to their feelings of security, stability, and wellbeing.

Whilst these are all hypothetical scenarios, they represent some very real systemic challenges in terms of support within education, for teachers' wellbeing, and for autistic children and their families, demonstrating the power and influence of policy from a macrosystemic perspective.

Appendix D

The inaugural SwiS study: setting the context and introducing the SwiS manual.

Part 1 - SwiS research – setting the context.

The inaugural study

The SwiS programme was carried out by myself as the principal investigator, with collaboration from the wider SAFE team, consisting of both clinical and developmental psychologists and family therapists.

The research took place at the university, offering participants an accessible city centre location, and a *neutral* space in which to participate, upholding the attachment principle of the safe-haven, a secure-base from which to explore, in this case, the exploration of relationships (Waters & Cummings, 2000). Parents and teachers who share education and care of an autistic child (*henceforth referred to as parent-teacher units*) invited to join the programme, consist of a minimum of one parent and one teacher, and a maximum of two parents and two teachers.

The SwiS programme framework

The programme is presented as *continued professional development* (CPD) and should consist of at least six sessions. This is a deliberate approach to encourage participation and to make it easier for schools to engage with the approach. The initial session is an orientation meeting between parents and teachers to introduce the programme. As with this inaugural research, an additional individual session can be added to meet with parents and teachers separately, to discuss any concerns and answer questions about the programme prior to participation. This is followed by the two days of SwiS content (*as set out below in the content overview*). Subsequent follow-up sessions in the form of focus groups, enable parents and teachers to come together again, to iteratively review, reflect, and work on the development and implementation of their ideas, maintain the consultation process with one another, around a shared problem or challenge, helping to embed and establish a continuing format for communication. The length of non-programme sessions is benchmarked at around two hours, however when using the SwiS framework, timings should be flexible, according to the needs of the group and the size of the cohort (Vassallo, 2023).

Dates for the programme days are set across consecutive weeks and provided to schools and participants. The time allowed between the two programme days is for participants to absorb what they have taken part in, and to spend some time reflecting on, and applying their explorations and learning from Day-1, bringing their thoughts and questions to Day-2. A gap of one-to-two weeks is recommended between all sessions, to enable parents and teachers to reflect on the content they have engaged with and have sufficient time to try out and review techniques and ideas within their shared problem-solving.

Within this study, the decision as to which cohort the parent-teacher units would be assigned, was made first in consideration of participant needs and the school timetable, particularly where some flexibility was required to ensure participation was possible. Attending the SwiS programme represented a considerable investment by parents, teachers, and the school, as they devoted two intensive days to the programme, and subsequent time *in school* for focus meetings. Schools released their teachers and subsidised the relief cover for both days as there was no funding within the project to compensate schools for this. Working parents took annual leave, and as the intervention days stretched beyond the school day, most parents, regardless of whether they were employed or not, needed to make alternative arrangements for childcare for both days, organising partners or family to take over the school run.   For those participants who required it, we allowed them to choose their cohort according to the set dates. For those with more flexibility, we randomly allocated the remaining caregiver units across both dates, resulting in seven units for cohort A and six for cohort B.

Participants were invited to the university campus teaching and presentation space for the two main SwiS programme days. Unusually for universities, the campus is compact and is situated in the heart of the city centre, making it fully accessible by public transport or walking distance for most of the participants who were located within the city. For those with greater access needs, coming from further afield, parking on site was made available. The campus location was a deliberate choice for this first trial of SwiS. We were kindly offered use of space within several participating schools; however, to ensure participants were able to completely focus on the programme, it was important to provide a neutral space until parent-teacher relations were more established, to free participants as much as possible from interruption and the potential influence of power dynamics that may occur in a school setting.

The importance of a comfortable context

Prior to the first day of the SwiS programme, parents were provided with detailed maps and information of how to find and access the room. Upon arrival, participants were offered a range of refreshments and snacks, continually available throughout the day, and housekeeping details were shared. Time was also allocated at the start for participants to acclimate to the environment, and if they wished to, begin to mix and socialise with others, something many did freely. The room was set out in an informal 'U' shape of tables and chairs within the centre of an airy room, so everyone could see each other, but equally had plenty of personal space and opportunity to move around. For comfort, attention was given to lighting and airflow, choosing a room that was more than large enough to accommodate the participants, was well ventilated and had good natural light. Despite best efforts, the room did become warm in the afternoon and additional breaks were added to the sessions to ensure participant comfort as far as possible.

To start the session, participants were asked to choose where they would like to sit, as long as they sat with their corresponding parent/s and teacher/s. Again, this was important, as preparation conversations with participants, prior to the programme days, revealed two parent-teacher units who had a preference to sit near a door. Knowing this, I was able to ensure this was accommodated. These considerations may appear excessive; however, it was a deliberate approach for good reason. Research shows that parents of autistic children are more likely to have a higher incidence of autistic traits, or indeed be autistic themselves (McKenzie *et al.*, 2021; Sasson *et al.*, 2013). Therefore, as far as possible, the aim was to provide a space that would not present sensorial challenge to those who experienced it and would offer a relaxed atmosphere and enable the participants enough time to feel calm and welcome within the space. Despite this being a voluntary research project, it was important that participants felt comfortable and under no pressure to take part, as this might influence and alter their responses and contributions, potentially skewing the data.

The following format was consistent for both SwiS cohorts during the inaugural study and offers the basis for a manual for SwiS.

Part 2 - SwiS Programme Days – Manual

Content overview

Day 1:
- Introductions,
- an overview and orientation of SwiS,
- shared understandings and contested aspects of autism, including theory and neurodevelopment, introducing attachment and the concept of the secure-base
- relationships between home and school, '*a day in the life of'* and *'sculpting'* activities,
- the systemic-relational perspective: positive and problematic cycles (including meltdowns and shutdowns), using *'video consultation'* and '*tracking*' activities.

Day 2:
- Welcome and review,
- further exploration of meltdowns and shutdowns - intervening cycles, including *'externalising'*, and the '*Self Autism Mapping - SAM'* activity,
- attachment theory - exploration and comforting,
- autism and attachment - the '*circle of security'*, and extended secure-base,
- entering the children's worlds - areas of special interest.

SwiS content and activities

The two programme days allows parents and teachers room to talk and *be together*. However, this is augmented by activities, which are carefully designed to relieve some of the pressure that might be felt when interacting with another person so intensely for so long, especially if that relationship is new or in conflict. The activities also provide parents and teachers with important information about the child whose care they share, within each other's context, something that might not have been previously not available to them. This is intended to take them on an exploratory journey requiring mutual input in order to derive new knowledge about the child. These shared activities are designed to be both practical and informative, but also contain an element of fun. This is intended to help reduce some of the inevitable tensions of being in such an environment, and help parents and teachers relax in each other's company.

<u>*Day-1*</u>

Introduction, orientation, and overview of SwiS

Day-1; once everyone is settled, introductions are made, starting with the SwiS presenters in their professional contexts, all of whom should have experience of neurodiversity, and be able to share with participants some background about their own

contexts and connections to autism. Parent-teacher units then address others in the room, saying a little about themselves and the child they shared care of, including their child's name (*or previously agreed pseudonym*) and specifically a little about their child's personal interests in the context in which they know and care for them. This introductory group activity is significant, as it is important when developing a collegial and collaborative atmosphere, to be reassured that our experiences shared with others, have something in common. It is also the opening and closing of the circle in terms of the programme, as caregivers start and end with the interests of their children.

Both SwiS and SAFE programmes, having embedded within them a fundamental group dynamic, maintaining the overarching intention that parents and teachers (*within SwiS*) and families (*within SAFE)* see themselves as consultants to each other, able to share their lived experience as well as their acquired knowledge and skills around autism.

Psychoeducation – shared and contested aspects of autism, theory, and neurodevelopment

The model of SwiS is shared with caregivers, explaining its attachment and systemic theoretical underpinnings, and the integration of ideas and techniques from these theoretical approaches that make up the SwiS content. To initiate engagement, focus is oriented on the support of key difficulties parents and teachers frequently report experiencing, such as anxiety, distress, and externalising behaviours, particularly meltdowns and shutdowns and theoretical links made to these.

An initial introduction to the concept of the *secure-base* is made early on, for parents and teachers to hold in mind throughout and consider in terms of how their children feel particularly at school, and how as caregivers, their own needs, anxiety, and stress, might have systemic influence on their child and on caregiver responding (Vassallo, 2023).

Simplified theory around sensorial experience, particularly the eight senses and ideas of integration, modulation, and environment (Ayres & Robbins, 2005; Bailey & Baker, 2020) are introduced, together with more contemporary understandings of the autistic experience. Monotropic (Milton, 2012a; Murray, 2018) and double empathy theories (Milton, 2016a; Milton, 2012b), are explored in contrast to established but often contested theory, such as theory of mind, executive function and weak central coherence (Happé, 2021; Happé & Frith, 1995; Milton, 2012a; Tager-Flusberg, 2007). The exploration of debates and discourses such as difference/deficit perspectives of

autism, offers parents and teachers the opportunity to ask questions and apply theoretical constructs to their own unique situation.

Relational activities

Understanding the relational perspective between parents and teachers, as well as between child and caregivers, across contexts, is important. Children do not only have separate relationships with their teachers and their parents, they also have a *relationship with the relationship* that exists *between* their teachers and parents (Vassallo, 2023, p.219). Therefore, to function optimally, parents and teachers need an understanding of each other, an understanding of their relationship with the child relevant to their context, as well as an understanding of the other caregiver's relationship and perspective. Developing this is important for caregivers.

A day in the life of…

This is the first activity parents and teachers should engage in and is pre-SwiS *homework* for them, completing it independently and bringing it to Day-1 *(see Figure 9 below*). Each should fill in a template of a typical day in their life with their child, drawing a representation in a format that was comfortable (*such as stick figures*), but one that sets their context and *tracks* their day in terms of interactions and caring responsibilities with their child. As an ice-breaker activity, parents and teachers then share their *homework*, talking through their day with one another. The idea is to provide a platform to share understanding of each other's experience with the child and provide some background to that experience.

One of the difficulties in communication between parents and teachers is often the lack of context each has about the other. Without that information, incorrect assumptions can be formed, adding to ideas and judgement about the other's competency as a caregiver. *'A day in the life of'* activity, gives parents and teachers the opportunity to share their perspective with one another, and perhaps elicit an appreciation and deeper understanding of the other's efforts with the child, as well as the wider daily demands placed upon them.

SAFE with Schools

A day in the life of...

In preparation for our first intervention day, please draw a pictorial representation (i.e. stick figures) of a typical day in your life, to include interactions with your child/student, and bring it with you on the first day of the programme. You do not need to fill out all the boxes, alternatively if you need more space, please continue on the reverse.

1	2	3
4	5	6
7	8	9
10	11	12

Figure 9 A day in the life of...

Sculpt – Exploring support systems

The sculpt activity is designed for parents and teachers to do with their child as well as with each other, outside of the SwiS sessions. Either independently or with caregiver help, the child maps out members of their system that are important to them, positioning them in terms of how close they feel to each member within their system and how close they feel members are to each other. It provides a *map* of a child's representation of closeness with the system around them, as well as who they consider is in their system, with the distance between each figure representing the closeness of connection (*see Figure 10 below*). The parents and teachers can also *map* what they think the child perceives and the differences in perspective between the two, and indeed how each caregiver experiences their own system. It allows for conversations to develop about the type of connection and communication between various members of the child's system, as well as identification of forms of support, not just for the child, but for the parents and the teacher in relation to the child.
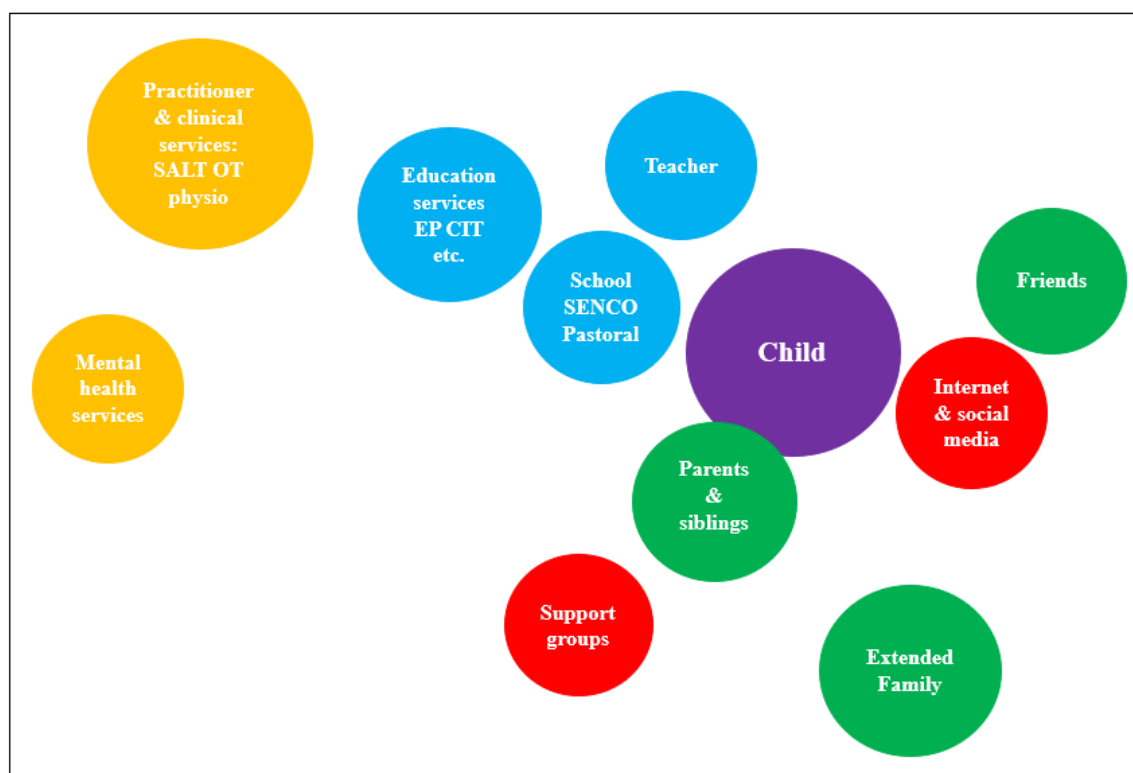
Figure 10 Sculpting activity – Exploring support systems

Sculpting is very flexible, and can be done with pen and paper, or with objects or tokens. Some participants might draw their *sculpts*, others might want to use more tactile mediums such as buttons or counters, which enable a *dynamic* version of the activity and for conversations to develop if perhaps caregivers perceive different relational patterns to those of their child.

Positive and problematic cycles from a systemic-relational perspective

An underpinning orientation of the SwiS approach, focuses caregivers to consider the thoughts and feelings of the child they share care of and how caregiver relations might impact them. For example, exploring how a lack of communication and patterns of interaction between home and school might result in unhelpful escalations between the two contexts (Vassallo, 2023).

This element of SwiS draws on aspects from family therapy in terms of ideas of mutual influence, circular patterns of interactions. It is a non-blaming approach, encouraging caregivers to *slow down* and *stand back* from situations they might otherwise be unhelpfully draw into or miss by being *too close*. It begins by recognising caregiver expertise, guiding parents and teachers to focus on positive cycles of interaction, to review when things went better than expected, acknowledging what they are already doing well and to build on that, before moving on to unpack more problematic cycles.

Video consultation and attempted solutions

Parents and teachers are shown a video of a problematic cycle about a father struggling to get his autistic child to school and what happens once they get there. This particular clip was deliberately selected as it depicts a shared and common problem experienced by both parents and teachers, although other similar videos relevant to common problematic cycles could be used. Parents and teachers then problem-solve together by analysing events as they unfold in the video. They look at what went well, where they could predict the child's response, what could have been done differently and so on. They are supported to observe the relational and attachment dynamics involved, review the *attempted solutions* (*see Figure 11 below)* used by the parent and receiving teacher, and consider the outcomes from this.

Looking in detail at attempted solutions used through unpacking video examples, is a non-blaming way of allowing caregivers to *slow down* and *step back*, to view familiar situations together without feeling personally scrutinised. Observing the stress and similar challenges experienced by someone else, provides a window on our own experience, showing us how our own wellbeing and personal resources such as anxiety, stress, and energy levels etc., might interfere with our ability to find solutions to problems. For example, when in a personally depleted or emotionally aroused state and experiencing the same repeated challenge (*such as resistance to going to, or, coming into, school*), positive intentions that drive our efforts to resolve difficult

situations might actually escalate them, especially, as when in this state we are less likely to be able to accommodate and process feedback, often causing us to persist with solutions that are not working and are instead creating further escalation.

One such solution explored within SwiS is the idea of *time out*. Time out is a well-intentioned attempted solution to autistic distress in a child. In this context it is not used as a punishment, but as a de-escalation and protection strategy. A child who is displaying significant distress or resistance to something would be given time away from the situation in a low-arousal space to provide the environment to regulate their emotions and begin to calm down. Time-out is commonly considered by caregivers across contexts as an effective way to support children who are in a state of high anxiety and at risk of melting down or shutting down, or in the throes of experiencing either. Some autism discourses suggest that being alone, in a quiet space that is not sensorially challenging, is helpful for children, mitigating the environmental factors or demands of the task they were resisting, which would maintain their distress. Whilst these ideas are rooted in a sound understanding of the sensorial differences of autistic people, from an attachment perspective, they have the potential to undermine attachment relations, as Vassallo, Dallos and Stancer (2023, p.175) argue:

> *this potentially misses a connection opportunity, and consequently may leave a child feeling rejected and isolated, with no-one available to help them organise their feelings, negating their attachment needs 'in the moment'.*

Child is agitated, will not get dressed, and is late for school

Attempted solution

Encourage, insist, get angry. Withdraw, anticipate meltdown etc.

Time out (de-escalation)
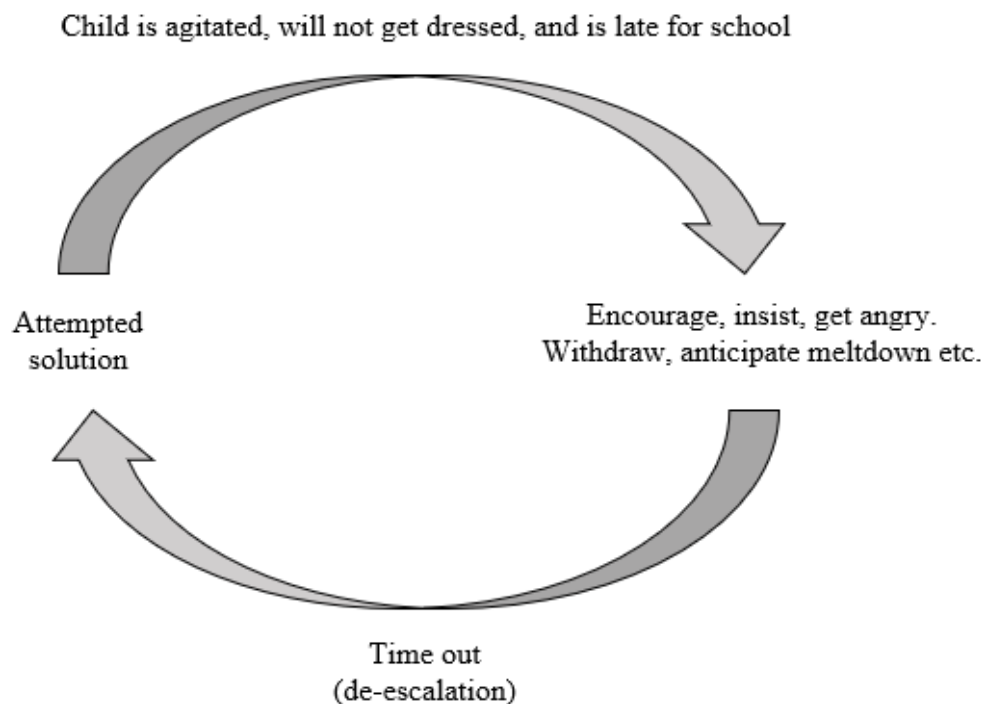
(Vassallo, Dallos & Stancer, 2023, p.175)

Figure 11 Attempted solutions and escalation of problems.

Instead, parents and teachers explore alternative ideas, for example *'time in'* and when that might be more appropriate. Similar to time out, *time in* removes the distressing elements that are escalating or maintaining the situation, but instead of separating the child from the situation, the child and caregiver move off together, with the caregiver coming alongside the child, being simply present, undemanding, but providing the opportunity for connection and enabling attachment needs to be met *in the moment*.

Tracking activity – breaking it all down.

Caregivers also discuss *exceptions*, focusing on situations where something went well or perhaps an escalation and subsequent meltdown/shutdown was averted by employing positive strategies. This helps both caregivers to view positive interactions in detail, to unpack, expand, and share with each other *'why'* something went well or was recovered, so that it might be understood and repeated. It also interrupts *totalising*, the thinking by caregivers that interactions are *always* negative *because* of the autism, as representations and experiences of autism can cause *problem-saturation*, and lead caregivers to overlook or dismiss '*the good stuff'*.

By engaging with the tracking activity, caregivers are again encouraged to slow down, stand back, and observe patterns of interaction more critically. They are also able to view interactions from joint, as opposed to individual caregiver action, particularly where there are more systemic consequences, where patterns may develop and become embedded, often without us noticing, because *all* the information is not available to us.

The tracking activity is an established systemic technique and is key within the range of SwiS activities as it can be used by parents and teachers individually, together, or with and without their children (*see Figure 12 below*). A situation or difficult interaction is given context or a title in the central circle to keep everyone focused on the situation. The '*what happened'* is then mapped out in incremental detail, in each of the smaller circles, with attention drawn to what the child and caregiver might be experiencing and how they might be feeling at each pint in the interaction. This allows caregivers the necessary space and time to see moments where a situation might have been escalated, or where an alternative path might have been taken.

Tracking/circularity Journal-log

Participant Number ....

Situation
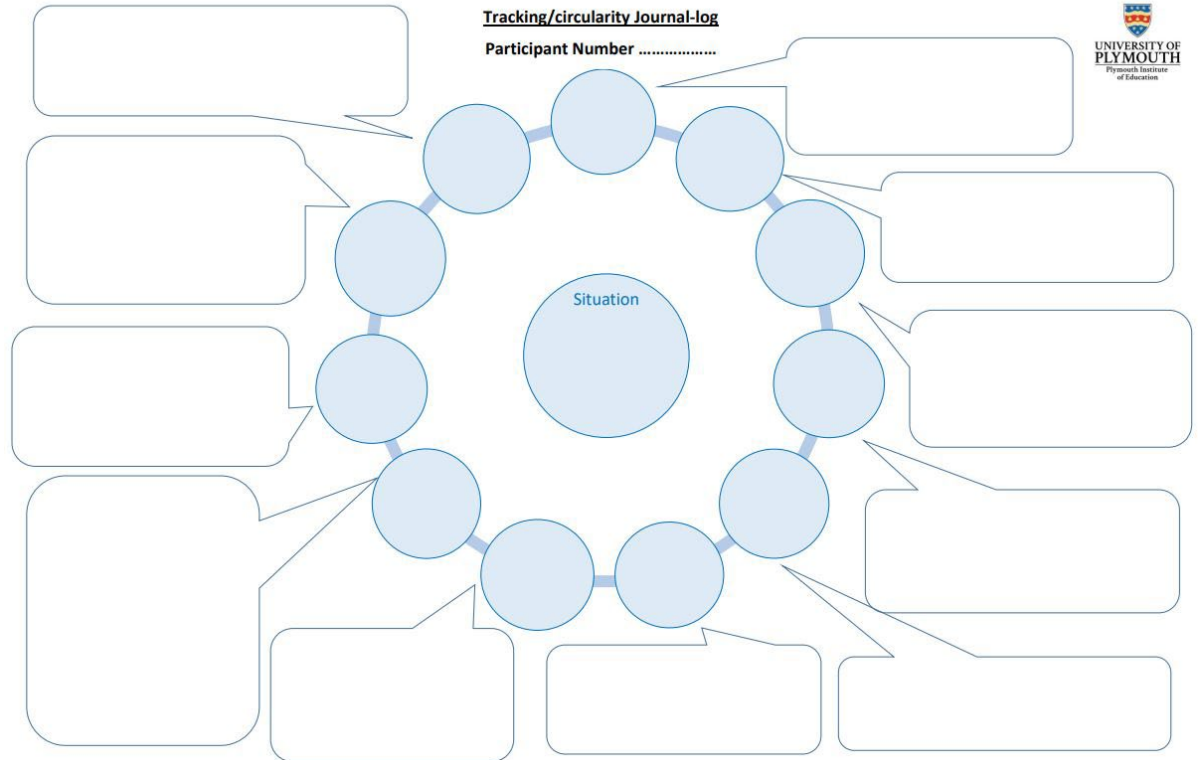
Figure 12 Tracking a circularity (Source: Own collection)

These templates are flexible and can be adapted for use within individual context. For example, adaptions with children might include drawing pictures or key words then used for discussion or reflective conversations.

Importantly, by tracking situations together, caregivers can *'fill in the gaps'* of a given situation, as tracking provides the opportunity to identify moments where communication might have broken down, or misunderstanding has occurred. The completed circularity example *(see Figure 13 below)* highlights this.

Tracking a circularity
…Late for school

Child gets up asks mum "*is it school today?*" Mum says "*yes*" – child runs and hides in room

Mum gently helps child dress. Now late, mum rushes to make breakfast - child gets undressed

Dad reassures child. Helps them dress, brush teeth, & get down for breakfast

Child in distress, protesting they want to stay home, but complies & eats breakfast

Mum clears breakfast & asks child to put on shoes – child complies but can't find them

Child crying, parents get frustrated & also look for shoes but can't find them either

Now late for school, dad is cross, shouts child must wear their trainers

Child gets upset, says no as they will be in trouble with teacher & lose play time

Parents still cross but reassure child it will be okay – they will speak to the teacher

Get to school late. Teacher is busy. Mum quickly explains lateness & shoes to receptionist

Receptionist takes child to class but leaves without explaining shoes or lateness to the teacher

Teacher is annoyed punishes child for being late and having wrong shoes - loses their playtime

Child distressed all day – vows not to go to school tomorrow

(Vassallo, Dallos & Stancer, 2023, p.176)

Figure 13 Tracking – Slowing things down; exploring positive and negative cycles of interaction.

Day-2

Welcome and review.

Day-2 begins with a welcome and review of Day-1. Parents and teachers also bring with them for discussion, tracked examples of problematic cycles they have experienced. The idea is that parents and teacher break down situations and explore possible solutions by bringing their knowledge and understanding about the child and what might be underpinning the difficulty, sharing their ideas about what might help resolve the situation, problem-solving together. As these examples might include more

stressful but common situations such as meltdowns and shutdowns, caregivers are introduced to attachment ideas and externalising activities to further support them.

Externalising activities

Externalising is positioned as something of an antithesis to more *totalising* conceptions of autism. Instead of siting problems *within* the child, where difficulties are seen as happening *because of the autism*, externalising, conceptualises problems as '*outside of*' and '*away from*' the child, framing the '*actual*' difficulties being experienced, such as anxiety, a lack of understanding, rejection, frustration, etc., as being difficult '*things*' that a child and caregiver can then visualise together. It allows for sensitive and gentle discussion, about how these difficult '*things*' have come into their lives, rather than framing '*autism*' (*and by default the child*) as being the problem. It adopts *a less blaming or failing stance in relation to the difficulties.* (Vassallo, 2023, p.216), and connects to a way of thinking that children might find easier to identify with. For example, difficult '*things*' such as meltdowns or shutdowns might be discussed and conceptualised as a '*beastie*' that does what it wants and upsets them. This type of visualisation takes a problem and sites it away from the child, allowing both the child and caregiver to look at together. This also immediately removes ideas of blame and reinforces a supportive stance between child and caregiver. Using the example of a meltdown/shutdown, a distressing event for both the child and those around them, this approach avoids communicating to the child that being upset and overwhelmed is somehow their *fault*. It also removes the pressure and demand for them to *stop* being upset (*an expectation often made of autistic children experiencing a meltdown/shutdown to suppress ad invalidate their feelings rather than resolving them, an expectation generally made for the comfort of others, rather than the child*). Instead, this approach supports gentle conversation and comfort between the caregiver and child, to understand what makes the meltdown '*beastie*' turn up in the first place, and what they can do *together* to gain control of it or get rid of it altogether.

By seeking to *dissociate* the person-problem, it makes space for the caregiver to *slow down* and come alongside the child to gain a better understanding of the child's viewpoint; looking at the difficult '*beastie*' as opposed blaming the difficulty on *autism*. This mitigates the risk that the child becomes all about *autism* in a negative way and feels blamed for it (Stancer, 2023; White & Morgan, 2006). The child can then comfortably retain autism as a part of their identity, whilst safely, with their caregiver, more confidently explore challenges as being separate to that.

Modelling a problem

Using creative methods such as modelling clay or drawing, parents and teachers are encouraged to consider how to playfully work with their child to make a representation of the '*beastie'* and give it a name (an example from the SwiS research was the name '*Grumps*'). The physical action of modelling and lack of demand for any particular output (*some might just be lumps of clay with holes poked in them, others might be elaborate and sophisticated models*) allows for *descriptions* to turn into *emotional exploration* and a sharing of perspective, enabling the caregiver to become an ally to the child and for them to tackle difficulties as a *team*.

SAM – Self Autism Mapping

Adapted from the SAFE for families research, the Self-Autism-Mapping (SAM) activity is a flexible adaptive technique, designed to create opportunities for conversations to take place, to better understand ideas and perceptions of autism. It supports autistic identity, giving the child a simple way to open communication with others about their autistic experience in an affirming way that places control in the hands of the child. It enables focus on the child's strengths, talents, and abilities, as well as areas where they might need more help, but without adopting a deficit stance. Importantly, it also exposes *others* to the idea that autism is interesting, is nothing to fear and is a facet of human identity as opposed to something so different there is no basis for connection to the person, a dynamic not unusual between autistic and non-autistic peers. It also highlights that sometimes autism is not relevant at all, that problems and successes can occur, and exist, independently of anything directly influenced by autism, and other times where autism might be highly influential, in both positive and challenging ways.

Self Autism Mapping - SAM

Not sure:
Aspects where you are unsure if autism is relevant or influential

Autism positive:

Aspects where autism is positive. How being autistic is positive and/or helpful.

What do we do to use or maximise these opportunities?

Autism challenging:

Aspects where autism is challenging. How triggers or contexts can make being autistic more difficult.

What do we do to minimise discomfort or distress?

(Vassallo, Dallos & Stancer, 2023, p.178)

Figure 14 Self autism mapping – SAM

When considering challenges, SAM is another activity that seeks to help systemic understanding, by enabling others to listen, and ask questions. It enables a move away from a totalising perspective (*autism is negative, the child is all autism*) and the deficit-based autism discourses that suggest *autism* (*and ergo the child)* is a problem. The SAM activity allows for a 'loosening of thinking' in terms of others' conceptualisations of autism, making room for positive ideas about autism to be explored by both the child and those important to them (*see Figure 14 above).*

Parents and teachers can often hold very different understandings and beliefs about autism, from viewing autism as a social difference to autism being a biologically based disability and everything in between. Knowledge of contemporary developments around autism is often mixed, with variances in terms of respect for, and accommodation of, the autistic perspective, commonplace. SAM is also designed to be helpful for caregivers to explore their own perceptions of autism, independently of their child. It supports honest dialogue and examination of individual viewpoints and a *loosening of thinking* in terms of what autism really means (Vassallo, 2023). This can be challenging for parents and teachers, who may hold deeply embedded ideas about

autism, which may have come from experience and training, but equally from the wider social narrative and stereotypes, guiding and limiting expectation. For example, parents and teachers often have a strong neurological perspective of autism, which can influence totalising attitudes, that the child is '*hard wired*' in a particular way and is therefore *'fixed'* (Stancer, 2023). This can result in an automatic assumption, or perception, that difficulties are because of the autism, making it hard for others to accommodate the possibility that difficulties might actually have other relational or contextual components, originating and/or being maintained by an interaction of these factors that includes their own influence on a situation that is less about autism and more about what is *socially constructed* (Vassallo, 2023, p.220).

Extended Circle of Security (CoS) and Bridging Attachment Relations

Returning to the core theoretical framework of attachment, parents and teachers are introduced to an adaption of the Circle of Security (Marvin *et al.*, 2002; Powell *et al.*, 2013) and the extended secure-base *(see Figure 15 below).*

HOME:
Parent/carer – family relationships and demands, safe place.

FAMILY RULES:
Familiar and predictable.

Preferred attachment strategies of parents.

PARENT
Secure-base

TEACHER
Safe-haven

SCHOOL:
Teacher/TA – educational demands, social relationships, attachments.

SCHOOL RULES:
Formal and informal, explicit and implicit.

Teachers' preferred attachment strategies.

Child must navigate two sets of rules and attachment systems. Especially demanding for an autistic child. Important for family/teachers to communicate, similar to the need for parents and grandparents to be consistent and in agreement with one another.

(Vassallo, Dallos & Stancer, 2023, p.173)

Figure 15 The extended secure circle including the parent and teacher / home and school bases.

Day-1 discussions of attachment and the importance of a secure-base, connect with this, as parents and teachers synthesise the information gained from the activities to *fill in the blanks* and form a picture, to understand the complexity of the child's experience in the home-school cycle, and how they as caregivers influence that experience, both directly and indirectly. They are invited to make sense of their child's experiences and together explore potential solutions to challenges. For example, unpacking the situation of going to school, exploring what is creating distress and stopping them from going to school.

The idea of the child having a consistent safe-haven at school with the teacher as a *bridging* attachment figure providing an ongoing secure-base is explored, together with notions of parents' and teachers' own attachment orientations as being influential on interaction with the child.

Entering the Children's worlds – areas of personal interest

As a final element to the programme, caregivers come full circle and enter the world of the child, using their knowledge and understanding of them, something they touch on at the very beginning of the programme.

Areas of deep personal interest (*sometimes referred to as areas of special interest, or areas of particular interest*) can create useful opportunities to form connections with autistic children as it allows a *step toward* the child on their terms, providing an '*important avenue for increased understanding and change*' (Stancer, 2023, p.152), as it allows caregivers to explore the child's world, instead of insisting the child resides in theirs. Parents and teachers are invited to discuss these interests and look for commonalities and opportunities to '*bridge*' the child and adult worlds, using the child's interests as a way forward, without encroaching on, or worse, destroying, the sanctity and comfort such interests provide. Like SAM, personal interests allow conversations to begin and *stories* to be shared, and children are able to talk about something so beloved to them, conversations feel less intense, more comfortable, and easier to engage with. Conversations such as these build trust and reciprocity and offer caregivers the chance to really listen to the child and for the child to feel heard.

Maintaining and reflective conversations – the follow-up sessions and focus groups

Follow-up sessions or focus groups are intended to provide a pathway to ongoing interaction between parents and teachers to support the home-school relationship. Caregivers come together post programme days to share successes and discuss any difficulties The sessions aim to promote the continuing format of

communication and discussion between the key members of the child's system, which is important for strengthening relationships and central to maintaining the systemic focus of SwiS.

Appendix E

An overview of relevant parent-teacher partnership studies within the extant literature

The following provides a more detailed overview of the included studies with a parent-teacher partnership element, contextualising shared and contrasting aspects with SwiS.

Overviewing COMPASS

COMPASS is a manualised programme of intervention for schools, in two parts: consultation, and teacher coaching. Described as a *'consultation framework for helping individuals with autism spectrum disorder (ASD) achieve optimal outcomes'* (Ruble, Dalrymple & McGrew, 2012, p.vii), it has undergone RCTs and independent evaluation of its aims, which are to *'improve IEP goals and associated educational outcomes of autistic students'*, increasing a sense of *'competence'* in students and their teachers' ability to effectively teach them.

A core feature of COMPASS is the initial coming together of teachers, parents, and in some cases other involved practitioners, to set the foundations of the intervention by contributing their knowledge about the child, to establish the right support and information, customised for each student. This level of consultation is a principle shared by SwiS, as a common element of both SwiS and COMPASS is the acknowledgement of parents as the experts about their autistic children, and the contribution of knowledge from others (teachers specifically) about the child in contexts outside of home. This initial meeting is facilitated by trained COMPASS consultants who are described as the *'glue'* in this arrangement (Ruble, Dalrymple & McGrew, 2012, p.ix), ensuring successful delivery of the initial *'consultation'*, as well as the subsequent *'coaching'* to teachers; the latter designed to embed and adapt the learning from the consultation, into teacher practice, with the COMPASS consultant and the teacher as ongoing partners (*rather than the teacher and parent*). This is a fundamental difference to the SwiS approach, which has a systemic framework, siting parents and teachers in a non-hierarchical partnership, acting as consultants to each other (*rather than simply recipient consultees to an expert other*), maintaining their collaboration.

COMPASS is described as person-environment focused. It aims to establish an *'understanding of the student's current personal and environmental challenges'* (Ruble,

Dalrymple & McGrew, 2012, p.101). However, its outcome measures of developing functional skills for IEP goal optimisation and behavioural change in the child, whilst enhancing consultees' (teachers') feelings of self-efficacy to do this, tends towards a culture of obtaining compliance, but presented as educational goals, which is where COMPASS and SwiS differ fundamentally. By focussing on change in the student, there is an inherent gaze of the '*autistic child as the problem*' locating difficulties within the child, without fully engaging with the systemic influences around the child. This is exemplified in the COMPASS manual which suggests adopting an '*educational approach*' to resolve '*problem behaviour*' by pinpointing and then equipping the child with '*skills and knowledge*' they need to overcome or '*replace the problem behaviour*' (p.104). Whilst it does state it attempts to adopt the child's perspective and understand the function of behaviours, it does not necessarily unpack the processes contributing to the difficulty or consider possible systemic influences of parent-child and teacher-child relations, in any depth. Nor does it consider the parent-teacher relationship as influential, and just as importantly the triadic nature of relationship the child has with the parent-teacher relationship (Vassallo, 2023). By not considering the role of emotional connection, development, attachment, or relational dynamics that feed into our sense of being or might contribute to or alleviate difficulties being experienced (for example anxiety), the COMPASS approach responds only to the *surface* of problems, locating those problems *within* the child, placing the weight of any *problems* on them, that says difficulties are *their* fault. This limits the opportunity to find meaningful solutions to such difficulties that might in fact have a *shared* basis. Such approaches are common across autism interventions.

The idea of the *child and autism as problem* is reinforced across the manual. For example, in the context of '*problem behaviours*', future COMPASS consultants are instructed to

> *help participants understand the links between the observable (problem)*
> *behaviour and the underlying impairments in autism that are influencing the*
> *behaviour*' (Ruble, Dalrymple & McGrew, 2012, p.118).

This is as opposed to helping those within the child's microsystem who might be contributing to, or maintaining the behaviour, to take a step back and reflect on *their* influence on the situation; a critical element of SwiS.

COMPASS does allow parents and teachers to work together, albeit briefly during the initial consultation phase, to share information about the child, augmented by

COMPASS consultant observations. However, this interaction is limited to synthesising the information about the child to reach a consensus of what priority target social, communication, and learning skills will be included in the teaching plan, which is then facilitated by the COMPASS consultant together with the teacher, to the general exclusion of parents and the child. Parents can attend the consultant-teacher coaching sessions if they wish, but their attendance is not considered essential or encouraged and would not form an integral part of these meetings. This is surprising given the positive response of parents and teachers to their interaction within the single session, highlighted as impactful and differs from SwiS in terms of keeping parents as peripheral rather than essential to the process.

Parents and COMPASS

A decade prior to manualisation, Ruble and Dalrymple (2002) identified the need for parent-teacher partnerships when conceptualising their COMPASS intervention, explaining that *'successful interventions can be developed when parents and teachers work as a coordinated and collaborative team'* (p.76). However, whilst the COMPASS intervention *suggests* a focus on parent-teacher collaboration, in real terms, parental contribution goes no further than '*degrees of tokenism'* when viewed from the perspective of, and applied to, the '*Ladder of Citizen Participation*', (Arnstein, 1969), an established theory and graphical representation that has been widely used in the UK to gauge co-production and partnership function in areas of education, health, social care and across local government (Norton, 2021; Worcester County Council, 2023).

COMPASS aims to help the child achieve IEP goals, by identifying the child's strengths and weaknesses attributed to autism, together with the environmental and educational supports that foster educational success and a sense of competence within the autistic child (Ruble, McGrew & Toland, 2014), by coaching teachers and evaluating their adherence to the plan through COMPASS consultants, who provide the ongoing facilitation and teacher coaching (Ruble & Dalrymple, 2002). There is little parent-teacher partnership interaction or any parent involvement or contribution beyond an initial three-hour consultation, suggesting whilst both parents and teachers are consulted in terms of goals for the child, the relationship between them is not central to process. The work linking parents and teachers is conducted through the *expert* COMPASS consultant within the school setting, who acts as a *middle-person*, making

this an expensive and perhaps less sustainable intervention if transferred to the UK context.

Although COMPASS does not have ongoing parent-teacher relations at its core, it does incorporate an element of baseline consultation with parents, and later provides parents with reports and feedback. COMPASS also has some shared principles with SwiS, such as seeking to understand the child's perspective and bringing parents and teachers together to share knowledge of the child. However, this is starkly contrasted by some diametrically opposed principles such as the propensity for siting problems *within* the child, as opposed to the SwiS ethos, which seeks to look at problems systemically and relationally, siting them external to the child.

Conjoint behavioural Consultation

Conjoint Behavioural Consultation [CBC], has a considerable literature base which has evolved and developed over almost three decades across different demographics and educational settings (Sheridan, 1997; Sheridan & Steck, 1995; Sheridan *et al.*, 2009; Sheridan *et al.*, 2017). It has a conceptual framework that draws from ecological-systems and behavioural theories (Sheridan, 1997).

CBC is an externally facilitated service delivery programme for teachers and parents to work collaboratively to identify mutual areas of concern and achieve targeted behavioural change via a set of agreed behavioural improvement goals, constructed through a home-school partnership model. (Azad *et al.*, 2018; Fallon *et al.*, 2016; Garbacz & McIntyre, 2016a; Ray, Skinner & Watson, 1999; Wilkinson, 2005). It is predicated on a strengths-based model of the child, a shared principle with SwiS, and has a data-driven process of improvement based on promoting '*positive school-related social-behavioural skills and strengthening teacher-parent relationships'* (Sheridan *et al.*, 2017).

CBC does retain a focus on working with both parents and teachers as *'consultees'* together; however its application as an approach to autism is a relatively new development (Azad *et al.*, 2016a), although a single case-study paper by Wilkinson (2005) did suggest some success with CBC as a parent-teacher collaborative intervention for overcoming *'challenging behaviour'* and saw *'teacher ratings of behavioural control'* (p.307) improve, as classroom compliance increased. Prior to this development, study of the earlier literature around autism and caregiver consultation, tended toward interventions where any consultation, or work with parents and teachers, was with them separately (Azad *et al.*, 2018).

CBC has been well received and accepted by both schools and families, and the benefits understood in terms of including cross-system service providers (Sheridan & Kratochwill, 2007; Sheridan *et al.*, 2017). Its results are positive, suggesting some improvement to child *behaviour*, and show promise in terms of having a mediating effect on conflict within the parent-teacher relationship around child outcomes (Kim *et al.*, 2013; Sheridan *et al.*, 2017). This would be expected, as parent-teacher stress is impacted by *'behaviours that challenge'* and poor child outcomes which reflect performatively on the teacher and drive parental fears for the future. If child behaviour is more manageable and educational outcomes improved, the fear and stress for both caregivers are lessened.

However, CBC is time and resource intensive, and similarly to COMPASS requires ongoing facilitation by external consultants (Azad *et al.*, 2018). This means that fidelity to the intervention can be problematic and again, expensive for schools to maintain. Fidelity to an intervention is important, as interventions such as CBC are meticulously designed from years of research to target specific outcomes. If they are then not engaged with as originally set out, they run the risk of not delivering the results intended or previously achieved in study. Lapses in implementation or shortcuts in delivery, often undermine intervention efficacy, which at best might result in the intervention having no effect, at worst, being detrimental, something reflected in the UK study Achievement for All (AfA) discussed later in this appendix (Humphrey *et al.*, 2020). Therefore, realistically, interventions need to consider flexibility, adaptability and affordability in their delivery if they are to be effective without considerable and ongoing external input, which is largely unsustainable.

Partners in schools

More recently, Johns Hopkins Assistant Professor in the Department of Mental Health, Gazi Azad and her team have been exploring home-school collaboration, and the ecological impact of the parent-teacher model of communication in autism, (Azad & Mandell, 2016; Azad *et al.*, 2016b) and during the latter phase of the SwiS research, published *'Partners in School' (Azad, Marcus & Mandell, 2021; Azad et al., 2018; Azad et al., 2021).*

Like CBC, *Partners in Schools* is also a consultation model focussing on parent-teacher communication and aligning evidence-based knowledge and practice across home and school settings to improve outcomes for autistic children. Developed from the CBC model (Azad *et al.*, 2018) it is consultant led, aiming to improve problem-solving

through external facilitation. It emphasises the need for high quality collaboration and communication together with '*mutual support and shared expectations*' between parents and teachers, acknowledging that communication between parents and teachers of autistic children are often suboptimal, with both caregivers experiencing difficulty sharing their concerns with one another in a way that allows for shared problem-solving (Azad & Mandell, 2016; Azad *et al.*, 2016a; Azad *et al.*, 2018).

The study focused on implementing consistent practice across home and school contexts; exploring cross-contextual concerns; sharing of important information about the child; the education of one another about evidence-based practices and the chance to work together to identify and prioritise a mutual area of difficulty to solve problems, using the consultative model (CBC) as the vehicle for improved communication (Azad *et al.*, 2016a).

Partners in School identifies effective communication as a mechanism of change through home-school collaboration, observing this from an ecological perspective; a view complementary to SwiS which also acknowledges the influence of mesosystemic relations. However, SwiS goes further, focusing not just on the quality and impact of parent-teacher communication on one another, but also the multidirectional influence of such relations, particularly the *relationship that child has with the relationship between caregivers* (Vassallo, 2023). Whilst Partners in School considers observable factors that influence parent-teacher communication such as parental self-efficacy and teacher experience, teacher expectations, and training in parental communication, it does not explore more nuanced *individual* human factors that underpin or inhibit such communication, such as the emotions, experiences, and feelings activated in caregivers. These variable and dynamic influences occur within and across people, shaping human development and interaction, making relations infinitely complex. SwiS understands this process and whilst it does not attempt to unravel every eventuality of interdependent influence, it does acknowledge and make space for emotional, cognitive, and experiential factors, contributing to caregiver interaction.

Achievement for All [AfA]

AfA is an ambitious, well-funded (£31 million over two years, for a 454-school pilot), well designed, but inherently complex *whole school improvement programme* requiring significant commitment from its participating schools. It is designed for all pupils (Blandford & Knowles, 2013, p.3), but specifically aimed at improving academic outcomes (specifically English and maths) as well as wider school outcomes (such as

attendance, behaviour, aspirations and self-esteem) for the lowest achieving twenty percent of vulnerable or disadvantaged pupils. It targets children with *special educational needs and/or disabilities* (SEND), including autistic children, children who are part of the care system, identified as *looked after children* (LAC), and children whose family socioeconomic circumstances are sufficiently disadvantaged to qualify them for *free school meals* (FSM). Critically, it has a focus of developing relationships, particularly parent-teacher relations through improved and continued communication between home and school, devoting a core strand of its design to parental engagement.

The scale of AfA is inherently resource heavy as it is an intensive programme, taking place over a two-year period, including multiple external coaching sessions, associated study paperwork and training for teachers, as well as the development of three '*structured conversations'* with parents per year. Comparison with SwiS in terms of scale and resource allocation is unrealistic as SwiS is a manualised approach, takes place in one term (a two-hour induction session, two full days training and three two-hour follow-up focus groups), with the intention that participation sets the foundation for a continuing format of communication between individual parents and teachers going forward without the need for continual external facilitation.

AfA's extensive focus has four core strands/modules – *teaching and learning, leadership for inclusion, wider outcomes and opportunities*, and *engaging with parents and carers*, targeting of multiple areas at once, seeking a synergistic effect across educational domains. This type of multi-pronged approach aims for whole school improvement and attitudinal change, proliferating across teachers and staff, to students and their families, driven by commitment from leadership. This approach changes multiple variables at once, whilst SwiS is more individually focused, concentrating on systemic relations around a child. That said, the nature of SwiS is also in a way proliferative, with the potential for wider effects on other areas of school function. However, its main focus is to build on relational foundations with the influential adults around the child.

School improvement vs systemic approach

It is important to acknowledge the difference between *school improvement programmes* and more systemic approaches such as SwiS. School improvement programmes generally focus on realising a school's core function of optimising teaching and learning practices and generating improved educational outcomes for students. They are often a top-down initiatives (Luyten, Visscher & Witziers, 2005), in the case

of education, perhaps driven more by policy and national standards, in response to evaluation, judgement, and the *'terrors of performativity'* (Ball, 2003; Done & Knowler, 2022) than motivating those around the child to *do the right thing* at an individual child level, growing improvement from the roots.

As it is the *school* that is being improved, not the *individual*, arguably school improvement programmes are an attractive proposition for school leaders who under the pressure and gaze of the *Ofsted rating* may see quick results at a cohort rather than individual level, which might temporarily raise the overall general performance of the school. The prestige and benefits that come with running a *high performing school,* or punishment for failing to do so may motivate schools to look for quick fixes. Such school effectiveness approaches have been criticised as being largely atheoretical, with too narrow a criteria for efficacy, rooted in blunt statistics rather than a move toward a theory for genuine and sustainable school improvement that comes from the complex understanding of what underpins areas of success (Luyten, Visscher & Witziers, 2005). In addition, school effectiveness research often identifies characteristics of *high-performing* schools, using them as a model for *underperforming* schools, without depth of attention to wider culture, composition or context of the school, which might then perpetuate the exclusion of certain *'types'* of student, as described by Ball (2003, p.10). Therefore, one might argue that school improvement is more of a *one-size-fits-as-many-as-possible* numbers game, where *individuals* are collectively *scooped up* into a programme that may or may not benefit them, as they are not the focus, with little *tailoring* to the individual need. However, if enough students show an overall statistical improvement in programme *target areas* (usually academic output), then the programme will be deemed successful and the school *improved.* Indeed, this approach is not unique to the UK. There have been similar responses in the US and Australia, where missed performance targets result in *'flying squads'* of practitioners from more successful schools, parachuted in, to rescue underperforming schools in their image (Klenowski & Wyatt-Smith, 2015).

Systemic approaches such as SwiS differ, as they respond on a microsystemic level, and as such have more of a *bottom-up* perspective, with a strong theoretical base, supporting others to support individual children in a way that is unique to them; a synergistic approach of systemic influence which then impacts (and supports improvement) more widely. Whilst a school could be considered a system in its own right, school improvement programmes still view outcomes at a *universal* level, reviewing *overall* statistics (usually academic performance and financial targets as a

measure of success), rather than individual needs, contributions, and outcomes that might measure educational success differently (Luyten, Visscher & Witziers, 2005). That said, a strength of AfA is its parental strand, arguably a step toward a *'parent-teacher-system-around-the-child'* approach.

Establishing the parent-teacher connection

Reviewing the parental engagement-relationship strand of AfA, suggests it does in principle, strive toward the partnership rung of the participation ladder (Arnstein, 1969). However, implementation was more problematic. In the pilot, most participating schools identified this element of the programme as having the most impact and success (Humphrey & Squires, 2011, p.54). Parents had a point of contact with a '*key teacher'*, who knew the child well (*an important factor in parent-teacher communication as parental trust and confidence is influenced by this*), supported by three *'structured conversations'* per year of the programme. These were aimed at developing *academic goals* through stronger relationships that enabled parent-teacher working to help children achieve them, together with improved higher quality communication, aimed at increasing parental engagement and agreement on shared academic priorities. The idea was establishment of such positive home-school connections would then see a reduction in the need to meet over time, making AfA more sustainable, as sustainability after cessation of funding was consistently one of the biggest concerns for school leaders, describing the parental strand as time consuming and expensive, and unsustainable.

Despite schools identifying the parent strand as the most critical aspect to the programme, it also tended to be the element they most compromised on in terms of fidelity across both studies (Humphrey *et al.*, 2020, p.35), with some teachers only allowed time to carry out one or two conversations with parents over the year. That said, schools in the pilot upheld this element as being the most successful, describing it as *'the most powerful part of the project ... an absolute roaring success'* (Humphrey & Squires, 2011, p.58), complementing the overall positive assessment of the AfA pilot on various dimensions (Humphrey *et al.*, 2013; Humphrey & Squires, 2011).

AfA Outcomes

Whilst the pilot outcomes of AfA were positive, it must be noted that these were greater both at school and student levels, where problem*s* were *less significant* to begin with (Humphrey & Squires, 2011, p.112). Schools and students with more complex needs, for example those experiencing high levels of social, emotional and

communication difficulties, had less-positive outcomes even within the pilot (Humphrey & Squires, 2011, p.113), reinforcing the premise that tackling academic goals are unlikely to be successful without first establishing a secure-base for children and an optimally functioning system around them; a system that can work together to problem-solve and support social and emotional needs of everyone within the child's microsystem, a core and unique principle of SwiS. Once a child is secure in their learning environment with a consistent support system around them, academic achievement is more likely.

Sustainability and fidelity

In a surprising turn, the positive elements and initial overall success of the AfA pilot, were not found in the wider national rollout of the programme returning an unfavourable report, where *'Achievement for All resulted in negative impacts on pupils' academic outcomes'* and *'had a detrimental effect on learning'* (Humphrey *et al.*, 2020, p.5). The programme was also deemed to have no impact on wider goals such as social connection, self-esteem and aspirations.

There may have been many reasons for this, not least the acknowledged methodological limitations (Humphrey *et al.*, 2020, p.8) and inconsistencies in implementation, which on review saw some *cherry-picking* of programme elements based on the stated *flexibility* of AfA, that in practice lowered critical participant survey responses, diminishing impact assessment (Humphrey *et al.*, 2020, p.21). The lack of fidelity, particularly to the *'structured conversations with parents'* element, due to teachers not being given time to engage with this by their school (Humphrey *et al.*, 2020, p.62), may have also contributed to undermine the '*synergistic'* effect of the programme strands together, adding to the unfavourable evaluation.

An additional noteworthy finding was the influence of *leadership for inclusion* which after favourable associations between leadership engagement and programme success in the pilot, acting as a *'catalyst without which other good things are unlikely to happen'* (Humphrey *et al.*, 2013, p.1222), was introduced as a *fourth* strand for the wider roll-out of the programme. Within the pilot, leadership had a positive influence on the implementation and commitment to the programme and was identified as the key driver for programme fidelity. That said, during the pilot context was optimal, as schools were heavily funded and school leaders could actively support the project without too much risk, therefore, schools could remain focused on programme delivery. However, in the wider roll-out of the programme, results found that the more *leadership*

for inclusion was implemented, the worse children did in '*levels of attainment*' (Humphrey *et al.*, 2020, p.37). It is feasible that when leaders critical in the success or failure of the intervention (*they determine the level of commitment and fidelity to the programme and lead culture change [or not] within the school*) were faced with competing priorities in terms of resource allocation, time constraints, Ofsted demands, and staffing instability, consigned AfA to taking somewhat of a back seat. Mindsets quickly shifted from innovative inclusion to meeting targets, succumbing to performance pressures, and shifting agendas to meet policy demands. This included the aforementioned *cherry-picking* across the programme, delivering only *'key elements'* (Humphrey *et al.*, 2020, p.5) that aligned with school agendas, eliminating others essential to the synergistic effect of the programme. For example the parent engagement strand was often the first to go, which despite its recognised impact and benefits, was considered too time-consuming for teachers, distracting them from the school's academic focus (Humphrey *et al.*, 2020, p.42-44).

This of course was just one of many difficulties experienced in the wider melee of implementation and fidelity issues of the programme across the pilot and wider roll-out, where fidelity and implementation shifted from more optimal in parts to poor, where the sheer scale of the project in both trials may have contributed to this; revealed in the tension and confusion expressed as to whether this was an intervention aimed at supporting a target group, or a programme seeking culture and attitude change to improve *inclusion and outcomes* for all. (Humphrey *et al.*, 2020, p.63). Further evaluation suggested such difficulties did not account for all the negative results, there were also theoretical challenges in terms of a *'loose'* theory of change, where inherent faults in the model were also found to be in part accountable, making the results *'difficult to assess'* (Humphrey *et al.*, 2020, p.61).

Appendix F

Bracketing with Ahern's top-ten tips.

'Preparation' and the reflexive journal:

1. Note taken for granted interests, assumptions, questions and positions of power and culture.
2. Developing and maintaining a critical perspective through self-evaluation. Knowing my own value systems
3. Conflict of interests and own 'triggers'. Acknowledging my emotional responses
4. Maintaining neutrality, role conflicts and recognising gatekeeper interests (doing someone a favour)
5. Recognising a lack of neutrality, the seeking or avoidance of certain situations, participants, or data. Identifying the reason for difficult feelings (guilt, disengagement, anxiety) using the reflexive journal and/or the support of colleagues to identify the origins of difficult or unresolved emotions raised during the research process.
6. Where is the surprise in the data? Consider whether it is really saturation or a block.
7. Turning blocks into opportunities. Look for areas of additional data that might illuminate further (as conducted with the additional whole-school pilot and revisiting SAFE pilot and feasibility study)

'Post-analysis' – why did I write that?

8. Beware confirmation bias and paths of least analytic resistance (articulate respondents = ease of analysis)
9. Is the literature review representative of the research problem or a reflection of the author?

'Feedback' – from self and others

10. Acknowledgement of bias and its resolution is good – it does not mean I should not be researching. Be your own best critic and be prepared to review your analysis. Co-coding with others defends against 'analytic blindness'.

Adapted from Ahern (1999)

Appendix G

Peer reviewed paper

Parent and Teacher Understandings of the Needs of Autistic Children and the Processes of Communication between the Home and School Contexts

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ABSTRACT

Introduction: Autism is a spectrum condition with symptom presentation varying widely. Teachers and parents face challenges in supporting autistic children. There are similarities in how teachers and parents make sense of autism, but there may be differences in priorities and approach potentially leading to misunderstandings. Where parents are actively engaged in their child's school life the impact on outcomes is positive. SAFE with Schools is a new intervention in development designed to support parents and teachers of autistic children to build collaborative relationships. The study aims to explore understandings among parents and teachers, areas of difference and agreement and perceptions of communication between the two contexts.

Methods: Teacher–parent units (N=32) for 13 autistic children, were recruited. The parents and teachers completed reflective journals and carried out semi-structured interviews focusing on the aims of the study. A blended thematic interpretive approach drawing from IPA and Thematic Analysis methodological approaches was used to analyse the resulting data. The analysis proceeded by extracting themes for the parents and the teachers separately. Subsequently these were compared, to identify which themes appeared for both and how they were employed in similar or divergent ways.

Findings: The following 6 themes emerged from the data: *Each Child is Unique, Behavioral Differences between Home and School, Building Positive Relationships as Essential to Child's Wellbeing, Emotional Impacts of the Autism, Bureaucracy as a Barrier and Feelings of Control.* Although these themes were shared by teachers and parents there were differences in emphasis and expression in practice between the two contexts.

Discussion: The findings related to various bodies of both clinical and educational literature which highlight the need for interventions such as SAFE with Schools that take a systemic, attachment-based approach to facilitating strong relationships with and around the autistic child.

Keywords: Autism; School-Home; Systemic; Communication; Intervention

INTRODUCTION

Diagnostic criteria for autism centres on difficulties with socio-communicative interaction and restricted repetitive behaviour [1], however, autism is a spectrum condition with a wide range of presentations, vastly differing severity of symptoms and a variety of co-morbid conditions. For example, it is now widely recognised that symptoms may look very different in girls compared to boys with autism [2]. Children can also exhibit hypo or hyper sensitivity to a wide range of stimuli [3]. In addition, diagnostic criteria can be changeable and hard to interpret. For example, in 2013 Asperger Syndrome was removed from DSM-5 and a number of associated conditions combined under the umbrella term Autism Spectrum Disorder [4].

Clinicians also struggle with the overlap of symptoms between autism and other conditions, in particular attachment difficulties [5,6]. Consequently autism can be a confusing condition and generalisations about the autistic child are problematic.

Parents and teachers focus on the individual child in their care, but understandings, structure, priorities and norms at home and school may still differ and in some cases there can be a sense of helplessness, disagreement and confusion about how to respond to symptoms. In such situations home and school may be in conflict

and responses to problematic behaviour can be inconsistent, further exacerbating misunderstanding and contributing to very high numbers of formal and informal exclusions among autistic children [7,8]. Limited research does suggest some commonalities, however, in difficulties experienced by families and educational settings, particularly around secondary issues associated with autism, such as mental health problems and extreme emotional outbursts referred to as 'meltdowns' which may be particularly troublesome and concerning both at school and at home [8-11].

Social constructionist perspectives alert us to the fact that explanations and theories, including diagnoses of autism, are not simply objective entities but are given meaning in the ebb and flow of interactions and conversations at home and school [12-14]. Despite DSM-5 criteria, the meaning of 'autism' may vary in these different conversations and importantly in the interface between home and school. It might be suggested that parents and teachers need to be 'educated' in what autism is. This is hard to achieve given the debates between professionals, but also because what 'autism' means has to be translated specifically for each unique child, family and school. More radically, social constructionism suggests that how autism is understood, emerges from these interactions at home, in school and between home and school. The child, families and teachers are actively participating in constructing the autism discourse and what it means and implies. Conversely, there is opposition to these ideas, particularly within the autism community, where the discourse focuses on neurodiversity as a central feature of identity for autistic individuals. In such debates, care should be taken to avoid unfairly minimizing or negating the very real struggle experienced by families, teachers and autistic people themselves, who require a differentiated approach to their development and education

What autism means may also differ depending on context. School and home may have different beliefs, understandings and competing priorities which can potentially conflict and make the system around the child disjointed and unable to support the child in a cohesive way [15]. Parents and their children may argue that the 'difficulties' they experience at school are not necessarily generated by a personal deficit, but exist as a direct result of having to navigate the neuro-typical world, within a prescriptive framework that is not able to adjust to perceptual and experiential differences [8]. Research regarding autism is also continually evolving and parents and teachers may have different awareness of developments and of the political stances that are being adopted [16]. For example, whether the parents and teachers wish to refer to the child as 'having autism' or being an 'autistic child'. These terms have different implications for how the child is viewed, for their identity and for strategies to manage behavioural, emotional and educational issues.

Research comparing how parents and teachers make sense of autism is limited. Stone and Rosenbaum [17] explored parents' and teachers understandings of autism and found that both teachers and parents in contrast to a panel of experts tended to 'view autistic individuals as less cognitively impaired than research findings' indicate, but this was most marked for parents. They also found that in contrast to teachers, parents of children without intellectual disability tended to view autism as a more transient condition and that most children will 'outgrow' the autism. They go on to argue that this more optimistic outlook might 'serve a useful purpose in facilitating their ability to cope with the disorder' [17]. They also argue that parents and teachers both focused more on emotional factors than a panel of experts. This study highlights that such

differences in understandings between teachers and parents may lead to conflicting expectations about academic achievements and the need for social and emotionally oriented assistance.

The attitudes of parents about school and teacher efficacy to support autistic children are frequently negative, and school and teacher attitudes about parental efficacy can be equally contentious, often with parents and teachers positioning each other as part of the problem instead of the solution [18,19]. The relationship and communication style between teachers and parents can range from; supportive of each other but disempowered or lacking in confidence to make adequate change to the child's behaviour and progress; to combative and blame focused, where each will blame the other for the child's behaviour and poor outcomes. Conflict between parent and teacher may share similar negative impacts to those reported widely in research into triangulation of family dynamics [20,21]. However, where a child has a diagnosis of autism, the potential for misunderstanding and disagreement is arguably greater in terms of understanding what the condition is, how best to manage the condition and to nurture the emotional and educational development of the child [17]. Where families are positively involved in their autistic child's school life, however, child behaviour, parental self-efficacy, sense of safety and effective support for the child are shown to improve [22-24].

This study stems from the development of a new intervention called SAFE with Schools which brings teachers and parents together to build stronger relationships around the child to enable the child to flourish and help parents and teachers to work consultatively together. Conflict and misunderstanding between parents and teachers involves viewing one another negatively, rather than as an essential source of support [25]. Positive interactions between systems of care, in this case, collaboration between parents and teachers, are known to be developmentally beneficial for typically developing children and children with disabilities alike [26,8,23], as well as being mutually supportive for parents and teachers [27]. SAFE with Schools is a systemic attachment-based intervention which acknowledges the importance not only of parents and teachers as attachment figures for autistic children but also as providing a cohesive supportive network around the child to facilitate transitions between home and school, enhance a sense of safety and comfort and develop mutual understandings. This study contributes to the development of this intervention by exploring parents' and teacher's understandings of autism and of the processes of communication regarding autism. Specifically, the study addressed the following questions:

- What are parents' understandings of the needs of ASC children in the home and the school setting?

- What are teachers' understandings of the needs of ASC children in the home and within the school setting?

- What are the areas of agreement and disagreement between parents' and teachers in their understandings of the two contexts?

- How do parents and teachers perceive their communication, especially areas of conflict and areas of co-operation?

This study is Stage 1 – The Exploration Phase of a larger programme of research focusing on the development of the Safe with Schools intervention for assisting teacher–parent relationships, communication and problem-solving. The findings will contribute to enhancing the effectiveness of the SAFE with Schools programme.

METHODOLOGY

Participants and recruitment

Teacher–parent units (N=32) for 13 autistic children, were recruited to the study via brochure and presentation to a West of England SENCO network, local autism family support groups and personal self-referrals from the regional autism network.

They consisted of 13 teachers and 1 teaching assistant and 13 mothers and 5 fathers (all participating fathers attended with their child's mother, 8 mothers attended alone) from 9 schools in the South West of the UK. All but one child of the parent participants had a formal diagnosis of autism, with one child on the autism pathway, confirmed by educational psychologist at a pre-diagnostic stage. Of these 13 children, 8 were male and 5 were female.

The current ethnic diversity of the West Country is inherently extremely low, which resulted in limited diversity within the sample hence all of the participants were white, with a split of 84.5% being White British and 12.5% White Eastern European with English as a second language and 3% white other. The socio-economic demographic was mixed, with 67% of parents employed either on a full or part-time basis (by default 100% of teachers were employed either full or part-time), 100% of the fathers were employed as were 54% of the mothers.

Design

Data collected for the study consisted of two parts

Reflective Journals: Parents and teachers were provided with and asked to keep a diary of notable interactions occurring between themselves and their child, at home and at school. They were asked to focus on:

- Successful interactions: Reflecting on what happened, what went well and how they felt about it;

- An interaction where a difficult or challenging behaviour was averted - reflecting on the event;

- Episodes of interactions that resulted in a negative escalation, challenging behaviour or an autistic meltdown/shutdown.

Interviews: Individual semi-structured interviews were conducted with parents and teachers to explore their understandings of autism and their experiences of the impact of autism in relation to:

- Relationships: The effect of autism on family and home, or classroom and school life;

- Participants' experience of challenging behaviour and meltdowns/shutdowns: the effect on family and home, or school and professional life;

- Parents and teachers perceptions of the each other's contexts.

The interviews also drew on questions from the Parent Development Interview, for example, in focusing on their reflections about an episode between them that went well or was problematic and their mentalisation about the child [28]. Interviews were conducted either at the participating school, in the parents' or teachers' homes, or at the university, whichever the participants chose as a more convenient and comfortable location for them.

PROCEDURE

Participation in the study required at least one parent plus the child's main teacher to take part and up to two parents and two teachers,

one of which must be the child's main primary school teacher. Future study would accommodate multiple parents to account for blended family contribution and multiple teachers to accommodate specialist and job-share teachers. Neither was required for this particular study, with parent-teacher units containing two, three or four members. Agreement from the school was also obtained. Interested parties (school, teacher or parent) who contacted the researcher, were given information about the study and asked to discuss it with the respective others, to ascertain a shared interest in taking part. An initial visit was made to the school, meeting with a member of the School Leadership Team (Head, Deputy Head and/or SENCO with mandated authority) to gain the school's consent, and to meet potential parent and teacher participants. This initial visit served to provide prospective participants with an overview of the study and enable any questions to be asked. Interested parents and teachers were then visited separately to discuss the research in more detail, to ensure the participants' wellbeing and fitness to take part, to take informed consent and issue the interaction reflective journal that all participants were required to complete for a minimum of four weeks. The interview was then arranged and conducted and the reflective journal collected which concluded this phase of the research. The study was approved by the University of Plymouth ethics committee.

ANALYSIS

A blended thematic interpretive approach drawing from IPA and Thematic Analysis methodologies was used to analyse the accounts from the interviews and open-ended comments in the reflective journals. The analysis proceeded by extracting themes for the parents and the teachers separately. Subsequently these were compared, to identify which themes appeared for both and how they were employed in similar or divergent ways. This is an important aspect underpinning this research, as it provides the rationale for the intervention. By understanding how parents and teachers understand autism and the areas of agreement and disagreement between them, areas of difficulty and challenge can be identified and problem-solving behaviour supported through the intervention.

FINDINGS

The findings are presented in terms of the most prominent themes that were shared between teachers and parents. Although themes are presented as shared, within them there were differences in emphasis and differences in how the themes were evident in daily interactions at home and school. The child referred to in quotations is indicated by the insertion of CWA (Child with Autism) (Table 1).

Each Child is Unique

This contained the underlying theme that each child is unique and that despite the generic nature of the diagnosis they remain unique, including how they learn, interact with other children, show their feelings etc. Comments such as 'I always thought G was just being G' or 'that's typical K, that is who she is' permeated the parental narratives in interviews, meetings and journals. Although all parents accepted their child's diagnosis (which some parents had expected and others did not, but all had undergone a battle over), with many engaging strongly in the clinical autism discourse, most described their child as 'not fitting the typical profile' of the condition. Instead, they highlighted their unique characteristics, of how autism affects them differently, often pointing out their child's strengths, talents and typicality,

Table 1: Themes shared between teachers and parents.

SL.NO	Theme	Subthemes
1	Each Child is Unique	• Autism is variable and influences each child differently • Understanding autism and how it relates to each child • Importance of not losing recognition of the child's uniqueness as a person • Impact of the label on approach to, and expectations of, the child • Diagnosis not very helpful in offering guidance for dealing with challenges • Acknowledge aspects of the child applicable to any child (being 'normal') • Build on competencies of the autism • Parents wanting child to be understood
2	Behavioral Differences between home and School	• Autism is related to anxiety • Child shows more emotions, anxieties at home • Attachment (transitions, comfort and manifest anxiety) • Holding it in - disguising feelings, anxieties at school and meltdowns at home
3	Building Positive Relationships as essential to child's wellbeing	• Relationships at school and at home - Impact of attachment • Varied relationships home/school - Sometimes felt other was doing a good job sometimes other (P or T) was not doing a good job - blame • Autism as requiring more supportive relationships • Need for reassurance through structure • Communication with home/school is important but not always easy • Practical constraints • Misunderstandings due to lack of opportunities for communication
4	Emotional Impact of autism	• Coping as a challenging, draining, stressful and exhausting • Autism as rewarding and creative • Impact on other family members • Relationship impact (husband/wife, friends, family) • Sense of urgency and a need to 'tell their individual story' to someone who would listen • Parents feeling alone and resigned to situation • Parents fear about future
5	Bureaucracy as a barrier	• Funding a barrier for support for P,T and CWA • Red tape and inflexibility of the system to adapt to the child's needs - adjustments limited • Battle perception for any help - crisis response only not proactivity • System not working for the teacher/family. Underlying pressure for results and to comply with all the rules without variation • Lack of services and being *"fobbed off"*.
6	Feelings of control	• Importance of maintaining control • Challenge to 'who I am' (adequacies/inadequacies of parenting/teaching a CWA at odds with expectations and/or prior experience) • Feelings of being out of control or loss of control

particularly when able to contradict expected autism deficits by showing, for example, empathy, humour or creativity:

"Has been an eye opener to have an autistic child, but she is so unique and special in her own way that you couldn't not love her...we'll get pictures or we'll get like, I love you sort of like, letters or things like that, and when I get pictures on my cover, I can walk from my bedroom that she's stuck pictures up and are like, "I love you mummy" (Parent).

This reflects Stone and Rosenbaum's [17] findings of more positive views of autistic children's abilities by parents, than those of experts, which may be due to parents' knowledge of their children being deep, nuanced and underpinned by an optimism and desire for a secure future for them:

"I just think...it's nothing wrong. He's just unique. Yeah, he's just unique, maybe in some areas better than others, in some areas maybe a bit behind but he's a lovely guy" (Parent).

Teachers on the other hand were mixed. Some approached their pupils from a unique perspective, by getting to know the child first, to understand them and their individual characteristics:

"It was just that period of transition of getting to know each other and actually that we- mum, dad, I and [CWA] met, we did like a mindfulness colouring activity and I said to her- '[name],' I was like, "...what's your

favourite picture to colour?" and she said, "Horse," like horse pictures so I found lots of different pictures of horses and we sat and we just coloured for 20 minutes and talked about how we could make her experience at school better" (Teacher).

Other teachers were initially more label focused, with a more classic view, adopting a clinical perspective of autism in preparation of teaching the child. In some cases, however, there was a realisation that the child did not fit their preconceptions:

"It's also made me realise that not all children with autism are what they show on the TV if that makes sense, so you will get this picture of children with autism to be very much you know, won't look at you, won't talk to you or flap, whereas this child is if you saw him in the street, you would not know that there was anything wrong if that make sense, until he had a meltdown... And that's made me realise that actually you- I can't treat all the children in here exactly the same" (Teacher).

This split strongly reflected teacher's prior experience of autism and how long they had been teaching, particularly if the number of years teaching predated the more recent educational reforms for inclusion of children with SEN within mainstream schools. Those with more years of experience seemed to maintain more homogenous or fixed ideas about the condition, the classic limitations of autistic children and the expectation of certain behaviours:

"I have had experience of working with children with autism and I always find– personally, I kind of understand how to read them" (Teacher).

In some cases the label became totalizing for teachers, explaining all that the child was:

Interviewer: *"And when you see [CWA] as a whole child, as a whole person, how much of that person is autism?"*

Teacher: *"I would say most of it"*

In contrast parents noticed that at times their child was the same as any other child:

"Sometimes uh it can be like that [CWA] will uh will behave normal that nobody will notice that he's got uh maybe autism" (Parent).

For these parents their flexible view of autism influenced their expectations for the future:

"We keep saying he will be having a normal life and he's kind of person who he will do uh...he won't let harm...others harm himself because he knows what he wants to do and he's quite confident" (Parent).

To less experienced teachers, the autism diagnosis was less influential; they tended to focus on the child, to understand what 'makes them tick' and enjoy their qualities:

"She, she's very... Yeah, she just loves to follow the instructions properly which is amazing... So clever. And she like draws these beautiful pictures and she can verbalize beautiful stories as well" (Teacher).

Teachers who were label focused with an expectation of what the child would be like, were in most cases contradicted by the reality of teaching them, recounting their surprise at how different teaching their student was compared to what they had anticipated and previously experienced, finding 'usual strategies' commonly applied to autistic children did not work and making comparisons to more 'classically autistic' children they had previously worked with. Comments such as *"He is surprisingly bright"* and *"He's really funny!"* highlights the power of the label to limit the expectations of others about the child's ability. This finding was linked to the parental desire for their child to be understood and frustration when who they are as a person was not recognised:

"His teacher doesn't get it and never will" (Parent).

To less experienced teachers, the label was less meaningful and the ability and potential of their child was not so surprising. This may be accounted for by a combination of factors; the increased public awareness of autism within the general populous, the fact that young teachers may have had autistic peers when they were at school (which for some was not long ago - norming for them what older teachers would not have experienced) and the improvement in inclusive practice within teacher training in recent years.

Behavioural differences between home and school

This theme was almost universally common to all parents and teachers, and almost entirely focused on challenging behavioural presentation. However despite this, no pattern of unification emerged. All parents and teachers experienced difficulties, but parents and teachers responses toward each other about it varied. What was consistent, was the level of parent or teacher stress, frustration or concern, related to the perceived degree of difficulty they had from their child and the level of disruption, destruction, distress or aggression they experienced at home or school, which also influenced their opinion of the corresponding parent or teacher:

"I remember this time last year I was crying all the time ...I don't think really I've cried about work like my teaching and the children's learning, I think it's a bit more behaviour that I've cried about" (Teacher).

"We're just at our wits end particularly with all the school stuff, I was really worried was just going to end up in hospital at some point... we're getting to a point where we kind of feel like we're a family in crisis" (Parent).

For some parents and teachers, their child's behaviours were consistent across both settings, being equally challenging to manage. Meltdowns or shutdowns were commonplace, oftenoccurring without parents and teachers understanding what triggered the distress or withdrawal. However, this area of shared experience between parents and teachers did not always serve to unify them in their approach or communication with one another. In some cases it did bolster the parent-teacher relationship, each empathising with the other's role, increasing the level of positive communication between home and school settings. However, in others it fuelled a more critical approach, that the other was somehow responsible for the child's behaviour, which had a knock-on effect into the other's context. Parents were critical that school did not offer the flexibility needed to support their child or their child was 'blamed' for something out of their control, or the school did not understand them:

"It's so important that the school system get it right now. And because they've not only not got it right but they've actually got it in so incredibly wrong, it's been damaging and detrimental, um you know some of the behaviour we've had from [CWA] at home is again, it's so clearly a correlation with his experience at school" (Parent).

Teachers were equally critical of the emotional state in which children were sometimes brought to school. Comments such as *'thanks mum'* from teachers, reflected their anticipation of a 'bad day' with the child, being of parental cause:

"I've also found that [CWA] parents are quite anxious and I feel that sometimes her anxiety sort of stemmed from their anxiety and sometimes I'd we've had meetings and I wonder sometimes whose anxieties I'm allaying most" (Teacher).

Difficulty also arose when those differences were divergent across settings. Very often parents would experience meltdowns at home but school would see no sign of distress or challenging behaviour from the child, only compliance and sometimes withdrawal. In these cases parents were seen by teachers as too permissive, lacking in discipline or beinginadequate, lacking the resources to battle with the child. Whereas parents felt that children disguised anxiety which built up at school and they had to cope with when the child came home:

"Mrs. V she said she's coping very well in school but as soon as she gets home it's a different matter...I think she holds it in at school" (Parent).

In some cases teachers confirmed that they had difficulties identifying anxiety in the child but did not approach parents to help them unpick the difficulties:

"[CWA] was having worries and anxieties that I couldn't pick up on because she wasn't communicating with me but then I totally understand that as part of her autism" (Teacher).

Other teachers were able to communicate with the parents in a supportive way and understand what was happening in both contexts:

"I've built up a really good relationship with the parent who, you know, the child was fine at school and they masked it really well, didn't they, in

school, and then she was just completely having meltdowns at home. So I was able to try and support mum through that as well" (Teacher).

Parents and teachers agreed that autism will present itself differently at different times and in different situations at school and home. It also included the idea of 'triggers' and need to identify these:

"I feel like she's actually learning and engaging and enjoying it which makes me feel like I'm doing something right, whether I'm doing anything I don't know. But, yeah, it makes me feel... And I feel like I can handle the meltdowns a bit better now because I've started to find those little triggers" (Teacher).

Building Positive Relationships as essential to child's well being

This theme emphasised the view that the children were extremely responsive to the nature of the relationship and that if anything the children, because of their high levels of anxiety, needed extra reassurance of positive relationships. In school this could be indicated by anxieties for a child if a trusted teacher was unavailable:

"Mrs. R was off last month sick and [CWA] had a massive meltdown when she'd come home and then the next morning she was going, "Mum, my belly hurts. I feel really sick." I was like, "Okay," and we started walking to school and she wouldn't let go of my hand. When I walked her in Mrs. W was there. I was like, "Look, she'sthere," and she went straight over and let Mrs. R comfort her and she was all right then, and then she went off a few days later sick as well and the same thing happened" (Parent).

Both parents and teachers identified the importance of positive relationships and teachers were often recognised as attachment figures for the children as well as the family:

"Um, I mean me and [CWA] have a good relationship. I think I taught her when she was in Year 1 for a term, um, and then when I was off poorly, um, you could see that she–we get on really well and we had a good rela... because she wasn't quite right–when I wasn't at school, she was really anxious because I wasn't there, and change of routine and things. So I think me and [CWA] have a really good relationship and so, she feels comfortable I think" (Teacher).

"We have such a lovely teacher in year four and we did get to know her and she got to know [CWA], I think in that sense, I was a little bit more, "Huh, okay, she's got someone that she knows, she likes, she gets on with, and she can go to" (Parent).

Both parents and teachers highlighted that maintaining good relationships between home and school could be difficult especially due to lack of opportunities for communication and the potential for misunderstanding. Both recognized, however, the importance of good relationships between teachers and parents for the child's wellbeing:

"I think she sees me and mum talk and I don't know if that helps facilitate because she could see that we're getting on really well" (Teacher).

"I always worked closely with the parents, that's really important" (Teacher).

Linking with the previous theme, in some cases differences in behaviour at home and school and perceived misunderstandings led to the relationship being conflictual:

"What we have found is whilst we've had those successful interactions, um, the what I thought necessarily was successful within school when she went home [CWA] was still experiencing quite a high level of worry and anxiety" (Teacher).

"There's no such thing as coincidence with [CWA]. Time in school equals meltdowns at home without time in school, you don't get them at home" (Parent).

Emotional impacts of the autism

Both parents and teachers found coping challenging and many experienced stress and exhaustion:

"It's been really, really tough. It's been the most challenging and hair raising start to any year that I've experienced in my life this year... And um, there's times I've just felt really crushed by it all" (Parent).

"I'm going through the motions. Um but just before [CWAs] birthday ... I had a period where I just felt, it was like a couple of days where I just felt really, I just feltsuicidal actually. I went for a run and felt like I could throw myself off a bridge"(Parent).

For some teachers the child was seen to question their self-identity as a competent teacher:

"I felt like I was somebody who was excellent at forming relationships with children with autism. Then, [CWA] came along and he was very different from all of that. You know his behaviour and his profile were so, so different" (Teacher).

Nevertheless the relationship with the autistic child was also experienced by many of the parents and teachers as rewarding:

"It's the little things she comes out that made me laugh. So I could be teaching and she'll say, 'No Miss, it's supposed to be this,' she'll correct me and it just makes me laugh because I'm like, 'Actually, [CWA], you're right. I have said that, wrong.' (Laughter)" (Teacher).

Although other people within the family were sometimes supportive, parents also highlighted the impact on the child and other family members:

"We're in it together but it's still crisis, and then more family piles in with a, 'let's do something about it together then" (Parent).

"You know, the focusing on [CWA] as being sort of an identified person with a problem and not realising the dynamic for the whole family, the sort of the domino effect of that... and how that affected [sibling]" (Parent).

Parents also articulated the detrimental effect of issues such as poor sleeping patterns in their child and their own relationship as a couple:

"We don't have that time away to have adult discussions, and so that's why typically when they happen, we are stressed because it will be first thing in the morning when we're trying to get ready for work and school or you know, or just be like, when those things pop in your head and then we're tired so the communications is not clear either so we're like, reacting to each other again" (Parent).

Many parents communicated fear about the future, both for themselves and for their child:

"We're talking about basic life skills, survival as adult. I'm not going to be around forever, with my own health scare stuff that goes on, although I'm not at threat, I am you know scientifically considered more vulnerable in terms of my mortality, so Ithink well it's even more important that [CWA] is in a situation that helps him to be able to cope with the world because we're not going to be there for him forever, and if that happens sooner rather than later, he's going to anyway, it doesn't bear thinking about for him" (Parent).

Parents also felt isolated and that others did not understand their child and they were not supported in taking care of them and coping with the difficulties this might entail:

"I feel there is nobody else to look after them, and that's what's quite hard... And also like, I'll be too anxious to leave them with somebody else because people don't understand them" (Parent).

In conducting the interviews the researcher noted a sense of urgency and a need to tell their story from parents and some teachers including talking about the past and their own emotional journey with autism:

"It [diagnosis] was a terrible shock for me, [I: mm-hmm] I couldn't believe and I... oh when we have got uh meetings with teachers and uh with doctors I always cried at that time. It was, it was really very hard for me to speak about [CWA]" (Parent).

"It was really hard because I would take it all personally, but then that was because it was continually wearing, once he starts, he does not stop you know" (Teacher).

Bureaucracy as a barrier

Both parents and teachers shared the view that funding and support was inadequate in both contexts. Funding was an issue for both teachers and parents so much so that at times people had to spend their own money to get the resources they needed:

Teacher: *"Being a massive reader myself, we've got these clouds and if they read three times a week that they're supposed to they get a sticker and after six stickers, theycan win a–I give them a book, so I buy them books. It's costing me an arm and leg but it's really worth it because..."*

Interviewer: *"Do you buy that with your own money?"*

Teacher: *"Yes, I do. Yeah, because there's no money".*

Despite difficulties providing what was perceived to be appropriate support not all parents blamed the schools and there was some appreciation that both contexts were struggling to do their best to support the child in difficult and confusing circumstances:

"Whilst I am quite angry and critical about the way the school has behaved over the years, um I'm level headed enough to realise that it's not just them and it's not the individual people. There is a systemic failure going on at the moment and we've walked right into the middle of it. We walked into the deepest trough of the failings in the system" (Parent).

Both parents and teachers expressed being let down by services that didn't materialise or that the child's needs were passed from one service to another:

"We've had speech and language come in. They've worked with her for four weeks andthey're dropping her. They're giving her something to work on, prepositions basically uh and that's it. So she's doing under and on. She's been doing that for four weeks. They've moved her on to I don't know two more prepositions and then they've dropped her. And I can't believe that. Their view is that actually her needs are her autism. Her speech and language difficulties are a part of her autism therefore, it's not their place to support her" (Teacher).

Parents reported a long journey of being passed around and support not being available from the school and other services:

"It has been an uphill battle for us the entire way and even at the point of receiving diagnosis and acknowledgement there's something to be done it isn't done anyway. It'sstill not done, and there's a bunch of excuses, and it all came to a head before Christmas and meeting with the school" (Parent).

"We've been so incredibly let down by them and the system in general" (Parent).

Linking to the previous theme on the impacts of autism, lack of support from the system was seen to exacerbate stress and anxiety and sense of physical and psychological wellbeing:

"But it was all those things, well it was very stressful and I kept all my reports and everything...it finally did go to panel and then there was a delay because there were so many people going to panel, it took months, but at the end of the day we did finally get there, it just seemed to take such a long time, and when you're carrying a big child into school every day and you know, honestly I've had prolapse and everything" (Parent).

Feelings of control

Parents and teachers described that a sense of 'control' or having ability to influence their child was important. This related to their understandings and uncertainties about the nature of autism and specifically how it presented itself for their child. For parents they were shaped by a sense of how things had been in their own families and what to expect about their children and how to parent them. For teachers, likewise it related to historical factors such as their prior experience with children with the diagnosis and what training in autism they had received.For both of them there was a sense of a challenge to their identities in terms of what kind of a parent or teacher I am if I struggle to be able to control my child or to maintain order in the classroom. The sense of loss of control was experienced by some of them as quite a severe problem resulting in feeling depressed, tired and exhausted.

The sense of a loss of control was indicated in a sense of not knowing, not understanding or being able to predict what a child would do and how they would respond to their actions:

"There's always that conflict between how we think parenting should be and then when you have a child who doesn't respond to those things, it's kind of really allowing you know, really letting go and I have to say you know, now I do question everything that we ever taught about parenting, but it's so engrained that it's hard to completely let go of it you know, so this is where the weekend thing would come in, I felt that I was somehow not being a good parent if I will just- if we just did nothing completely, you know" (Parent).

At times this loss of control was also seen in adversarial terms such that the child started to be seen as 'attacking' the teacher below:

"So, when I was brought in and it was like, "Okay, get this class working," ... And, getting them to just not talk over each other... it was insane, yeah. And so, I had that to do and then with [CWA] sitting there. So, I'm trying to raise these standards and instill habits and routines and just literally just ordinary school behaviour where they can line up and walk somewhere and it doesn't take them 10 minutes and he was immensely unhelpful because he would always directly attack my efforts" (Teacher).

This sense of losing the ability to understand and influence also related to the help and support that parent sought. For example, below the mother describes how problems came to a head and seeking support from CAMHS was the only alternative. However, seeking such professional support also carried with it an implication of failure in not having been able to manage things themselves:

"I suppose we had a bit of a shock a couple of years ago because things were so bad, it really came to a big- you know, she was very, very distressed, and then she was diagnosed with the autism, she went through CAMHS and then after that I kind of lost my confidence a bit as a mother, I guess, so I just took a step back" (Parent).

Similarly a teacher described the development of difficulties with a child which led to a questioning of their abilities to influence the child, but also of feeling no alternative but to bring in outside sources of support as a consequent sense of futility and failure:

"There were times when actually his behaviour became so disruptive that really I would have wanted him to just be carefully managed out of the

classroom and there was just nobody to do that here. It doesn't happen. And so, I exit the class. And, that really irked me because I thought, 'You can't really hand him the amount of power to make everyone go away.' And, I didn't like that" (Teacher).

Resorting to bringing in others to assist was indicated in these quotes to have a consequence for further fuelling the sense of a loss of control and failure.

This theme also related to what was experienced as imperatives of how they 'should' be acting with their children. For example, parents described a sense of a cultural norm that they 'should' be doing things with their child at certain times like weekends:

"But I still have this thing, and I don't know whether it's a cultural thing you know, what it is, that I need to be doing stuff with my children you know, and I think like I was saying to you before, weekends always been a bit of a problem because I feel like we should be doing something" (Parent).

This notion of what is normal and to be expected was also evident in a mothers' quote below of a sense of drifting from being a 'perfect' family to a dysfunctional one. Her sense of a collapse of being able to assert control and influence can be seen in her reference to becoming 'depressed':

"It went from us being this like, almost that perfect family that everyone, 'Oh, you know, you're such a lovely family', and everybody will always say that, to suddenly feeling like we were this dysfunctional family...but we were I mean, I was depressed and we were all like bouncing... and I can remember I dropped them off at school and I just think my heart will just be going and I'll just be thinking, 'Are we ever going to be carefree again you know, are ever going to be...' I just thought, "What's happened?' it's like just everything had just crashed, we're like this dysfunctional family" (Parent).

In a similar vein the teacher below describes how he experiences his attempts to have some control over the class, to make himself heard as being thwarted by a child and he likewise experienced a sense of helpless and hopelessness such that he wanted to 'cry all the time:

"He would discern that I was trying to get some order and routine... he would just do anything he could to stop that being able to happen and that's where he would talk over me, make silly jokes, try to make the other kids laugh and then escalate and then just be so noisy that they couldn't even hear me and I couldn't even hear them. So yeah, amazing, hard. I would feel tired and like I wanted to cry all the time. And, I would get up and dread coming in" (Teacher).

DISCUSSION

The analysis revealed the following shared themes between teachers and parent, Each Child is Unique, Behavioural Differences between Home and School, Building Positive relationships as Essential to Child's Wellbeing, Emotional Impacts of the Autism, Bureaucracy as a Barrier and Feelings of Control.

Less experienced teachers and parents tended to acknowledge the unique characteristics of the child and in some ways question the usefulness of the label in understanding and supporting the child. The abilities of the child were at times seen as surprising and the child was perceived to have areas of competence that could be built on. More experienced teachers appeared to have a more rigid, arguably pathologising perception of the child, based on beliefs about autism and what strategies had worked previously.

Ho [29] highlights the danger that over-emphasis on the diagnosis, rather than the unique qualities of the child, can lead to approaching all children in the same way regardless of their individual potential, strengths and interests. In such cases, the child as a unique person can be lost or become totalised by the label [30]. Whilst some can experience the label as liberating, in other cases the child becomes a list of deficiencies and is disempowered from constructing their own identity [31]. In our study this was also articulated by parents who felt their child was not understood. The more flexible approach of teachers relatively new to the profession may reflect an increasing move to embrace neurodiversity and question medical models of disability in favour of the concept of 'difference' [32]. Related to this, in our own sample understanding autism was important for teachers and parents, but this alone was not enough. Parents and some teachers felt it was also necessary to understand how autism influenced each individual child differently.

Within the theme Behavioural Differences between Home and School considerable emphasis was placed on anxiety as a feature of autism and resulting meltdowns as being problematic. Previous literature highlights the potential repetitive negative cycles of anxiety, meltdowns, exhaustion and helplessness experienced by families of autistic children [33]. In the current study, anxiety and distress were seen to be related to separation from important attachment figures and transitions between contexts. In addition, comfort and averting problems was characterised by warm relationships between families and teachers where the importance of key figures in each context was recognised. These findings echo discussions in the literature regarding the common co-occurrence of autism, anxiety and attachment difficulties and the need for attachment based interventions targeted at the system around the child [34,6].

In more problematic situations children were perceived to disguise or 'hold in' feelings at school resulting in emotional outbursts at home which could lead to mutual blaming and misunderstandings between home and school. These findings underline the heterogeneity of autism, the difficulties in identifying expression of anxiety from other behaviours and the need for teachers to be supported in understanding autism-related anxiety [35]. Existing research also confirms parent's perceptions of school as a potentially anxiety provoking context for autistic children linked to lack of understanding, sensory issues, academic expectations and social demands [36].

Both parents and teachers agreed that services were lacking and that more support was needed for those who care for and educate autistic children. Related to this, the school system was seen as inflexible and results-driven, not allowing teachers opportunities to adapt to individual needs or time to develop understanding of the autistic child. Both parents and teachers felt a pressure to maintain control and also at times a sense of not knowing how to support the child or manage difficult situations. Research mirrors these findings in identifying a lack of support for autistic children, their families and for schools, emphasising the need for collaboration, improved communication and mutual support between family, schools and available services [37,8].

Perhaps the most widely articulated concerns among parents and teachers were the emotional impact of autism and the pressing need for positive relationships around the child to promote wellbeing. There was a feeling that both teachers and parents had many demands on them and opportunities to talk and explore what happened in the other context would be welcome, but were currently very limited. The children were seen as very sensitive to and dependent on positive relationships with key people around them to maintain wellbeing and engagement.

Implicit in this was that everyone would be able to function more effectively if they felt connected and supported. The effect of perceived threat, anxiety and distress on all levels of cognitive function, including planning, memory, learning, attention and decision making, is well documented [38]. Many of the parents and some of the teachers in our study were experiencing stress and exhaustion. In addition, some parents reported fear concerning the future and a sense of isolation and resignation. They also reported distress and anxiety among other family members and the autistic child.

The importance of parents and schools working in partnership is well documented [39], with benefits reported for schools, parents, children and the local community [40, 27]. Indeed, some have argued that home-school collaboration is instrumental in a child's educational success [41]. From a systemic attachment-based perspective, positive relationships of key figures, both with the child and around the child, have long been known to foster a sense of security, confidence and wellbeing [42]. Systemic ideas have developed in parallel in clinical and educational contexts and current conceptualisations of the benefits of encouraging positive home-school systems around the child draw from both of these disciplines [43]. The findings reported here suggest that positive relationships between home and school were seen as very important not only for the child, but also for teacher and parent wellbeing, but this relationship was also seen as being difficult to maintain and foster. Issues such as lack of opportunities for communication and misunderstandings resulting from irregular contact were perceived to exacerbate difficulties. Where parents and teachers were able to maintain positive relationships, there was a sense that each understood the position of the other, not only in addressing challenges, but also that the teacher or parent was doing 'a good job' albeit sometimes in difficult circumstances.

IMPLICATIONS FOR PRACTICE

The findings of the current study add to the evidence for the benefits of positive home-school partnerships. Our findings add to a body of research which suggests that where positive home-school relationships exist, contextual understanding, sense of wellbeing and success is enhanced. The development of SAFE with Schools, as a systemic attachment-based intervention which supports teachers and parents to work collaboratively is a pressing need. Interventions which facilitate secure relationships with and around the autistic child, alongside shared understandings of autism and collaborative problem-solving, will benefit not only the child, but also those teachers and families who are experiencing distress, isolation, blame and sense of failure.

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SAFE with Schools Parent and Teacher leaflet & poster

The intervention / follow-up stage…

You may decide to continue with the study and go on to the *intervention & follow-up* stage.

This brings parents and teachers together to take part in the *SwiS* programme, where you work together on an autism related difficulty for your child.

If you decide to take part in the intervention stage, parents and teachers will need to:

1. Attend the *SwiS* programme.
2. Resume reflection logs
3. Try out ideas and strategies learnt during the *SwiS* programme.
4. Attend a follow-up interview after 8-12 weeks.

This completes participation in the *SwiS* study.

Find out more…

Contact us

You can contact us to find out more about the study, or to let us know that you are interested by email or telephone.

Telephone:
Tara Vassallo

01752 585433
07809 217271

Email

tara.vassallo@plymouth.ac.uk

For information about SAFE family therapy please visit www.safefamily.org.uk

SAFE with Schools

A study to support parents and teachers of children with a diagnosis of Autism Spectrum Disorder (ASD)

Invitation to take part

We want families and schools with children with a diagnosis of autism, to have more support, so we developed a new support package called *SAFE with Schools (SwiS)*.

This initial small study for parents and teachers of primary school-aged autistic children, is to find out if *SAFE with Schools* is helpful, before doing a larger study to include secondary schools.

You are invited to take part in this small study.

If you want to find out more, please contact us, we will be happy to help answer any questions you may have.

What is *SAFE with Schools (SwiS)*?

SAFE with Schools is for parents and teachers of autistic children.

SwiS has been created from the SAFE intervention; a family therapy support package for the whole family, based on well-known ways of helping families, and what we know of autism.

SwiS aims to help with difficult interactions you face as a parent or teacher of an autistic child by providing ideas and strategies to build on relationship strengths and tackle challenges.

In *SwiS* sessions you will be asked what things you find challenging when supporting your child and what things you cope well with.

SwiS is delivered by an experienced clinical team, and you will have ongoing input and support from the researcher.

SwiS is designed as a 2 full-day professional development programme.

What will taking part involve?

The study has 2 stages: an *exploration* stage and an *intervention/follow-up* stage.

You can choose to take part in just the *exploration* stage or both stages. Both stages require the participation of the parent/s and main teacher of the child with a diagnosis of autism

The exploration stage…

For the *exploration* stage, as the parent/s or teacher/s of the child, we will ask you to keep a separate reflective journal about key interactions with your child, including any meltdowns.

After four weeks, in separate, individual and confidential interviews, we will then ask you about your thoughts and ideas of autism and feelings about interaction experiences with your child.

This completes the *exploration* stage of the study.

SAFE with Schools

An invitation to parents and teachers of children with a diagnosis of autism. If your child is in mainstream primary school, we would like to invite you to take part in a research study exploring a new support package called **SAFE with Schools**

We are looking for parents and teachers of primary school aged autistic children to take part in this small study, to see if SAFE with Schools is helpful, before doing a larger study to include secondary schools.

What does taking part involve?

The study has 2 stages, an exploration stage and an intervention/follow-up stage. You can choose to take part in just the exploration stage or both stages, however both stages require parent and teacher participation.

The exploration stage involves keeping some notes about your interactions with your child/student and undertaking an interview.

The intervention/follow-up stage brings parents and teachers together for the intervention, delivered as a two day professional development programme, to develop strategies and strengthen communication. Parents and teachers will then resume brief notes and have a follow-up interview 8-12 weeks later.

What is SAFE with Schools?

We want parents and teachers of autistic children to have more support, so we developed SAFE for Schools.

SAFE with Schools is a therapeutic support package for parents and teachers, with a focus on improving interactions, strengthening relationships and tackling challenges, including meltdowns.

It has been created from the SAFE intervention, a family therapy support package for the whole family. SAFE is based on well-known ways of helping families, and what we know about autism.

What do I do now?

If you want to find out more or would like to take part, please contact:

Tara Vassallo
Email: tara.vassallo@plymouth.ac.uk
Tel: 01752 585433 / 07809 217271

Participant data

Parent Participant codes	Parent Mother (M) Father (F)	Teacher participants	Teacher Gender Male (M) Female (F)	Number of Years teaching
P01a P01b	M F	**T01a** **T01b** *(TA)*	**F** **F**	**>5** **>5**
P02a	M	**T02a**	**F**	**>5**
P03a - withdrew *P03b - withdrew*	*M* *F*	*T03a*	*M*	*>5*
P04a	M	T04a	F	<5
P05a	M	T05a	F	<5
P06a *P06b - withdrew*	M *F*	**T06a**	**F**	**>5**
P07a	M	**T07a**	**F**	**>5**
P08a P08b	M F	**T08c** *T08a withdrew left teaching* *T08b (TA) withdrew*	**M** *M* *F*	**>5** *<5* *>5*
P09a	M	**T09a**	**F**	**>5**
P10a *P10b - withdrew*	M *F*	T10a	F	<5
P11a P11b	M F	T11a	M	<5
P12a P12b	M F	T12a	M	<5
P13a *P13b - withdrew*	M *F*	T13a	F	<5
P14a P14b	M F	T14a	F	<5
13 P-T units	*13 Mothers* *5 Fathers*	*7 Teachers >5 Yrs teaching* *7 Teachers <5 Yrs teaching*	*11 F* *3M*	

Appendix J

Data Summary

Formal session number	Session type	Purpose	Present	Activity
1. Exploration	Introduction meeting - joint	Confirm genuine interest. Informed consent. Get to know you – P/T dynamic, contextual understanding, and study fitness.	Teacher/s AND Parent/s together	Discuss study purpose and commitment. Q&A. Arrange individual meetings with parents and teachers.
2. Exploration	Individual meeting/s	Get to know you – individual family/professional contextual understanding – continued wellbeing	Parent and Teacher separately	Discuss study in more depth, answer any questions and issue reflective journal. Arrange interview
3. Exploration	Interview	Conduct interview of experience of autism Collect informed consent for Stage-2	Parent and Teacher separately	Record narrative and collect journal
4. Intervention	SwiS Day 1	SwiS programme - recorded	Multiple Parents and Teachers together	Deliver SwiS content - observations
5. Intervention	SwiS Day 2	SwiS programme - recorded	Multiple Parents and Teachers together	Deliver SwiS content - observations. Issue new reflective journal
6. Post Intervention	Focus groups / Meetings *(between 1 and 3)*	Catch-up and ensure wellbeing.	Parent/s and Teacher/s together	Discuss initial experience, any questions, use of array of SwiS activities and strategies.
7. Post Intervention	Final Interview	Conduct interview of experience of SwiS	Parent and Teacher separately	Record narrative experience of SwiS and collect reflective journal

Appendix K

Exploration Stage Consent Form

University of Plymouth

Faculty of Arts and Humanities – Plymouth Institute of Education

CONSENT TO PARTICIPATE IN RESEARCH STUDY – Exploration stage.

UNIVERSITY OF
PLYMOUTH
Plymouth Institute
of Education

Research Area: An exploration of the nature and alleviation of 'meltdown' episodes among children with autism across family and school contexts

Principle Investigator: Tara Vassallo tara.vassallo@plymouth.ac.uk Telephone 01752 585433

Participant Number: __ __ __

Purpose of study: The aim of this research, is to better understand triggers, processes and identify potential intervention opportunities associated with 'meltdowns', among children with a diagnosis of mild to moderate autism attending mainstream school. The intended applications include, developing more effective forms of support and intervention for these children and those who care for and educate them, across home and school contexts.

Please initial each box

1	I confirm that I have read and discussed with the researcher, the participant information sheet for the above study and I understand the objectives of this research, the interview process and meltdown data I will be recording.	
2	I confirm I have considered and understood the information detailed on the participant information sheet, have asked any questions and have received satisfactory answers.	
3	The two stages of the study have been explained to me and I understand that I may choose to take part in one or both stages. I understand my participation is voluntary and will not affect my participation in the exploratory stage should I decide not to participate in the intervention/follow-up stage.	
4	I understand that the interview I give will be audio recorded and transcribed verbatim. Every effort will be made to keep my information confidential, with all identifying details from the interview and meltdown logs changed, to protect my anonymity as far as possible.	
5	I understand that all data relating to me will be kept securely for a 10-year period once the study has been completed and destroyed once that period has passed.	
6	I understand my participation in the study is entirely voluntary and I can withdraw without giving a reason and without negative consequences. My right to withdraw myself and my data, up to when the data has been anonymised, has been fully explained to me.	
7	A clear explanation of the complaints procedure has been given to me and I have contact details of the researcher and their director of studies.	
8	All potential benefits, risks or inconveniences have been explained to me and I have been given a copy of this information in writing to retain for future reference, including contact details of where and from whom I can access support should I need it.	
9	I agree to take part in the exploratory stage of this study.	

Full name of participant:	Signature:	Date:
....	....	....
Full name of person taking consent:	Signature:	Date:
....	....	....

Appendix L

Exploration Stage Reflective Journal

Blank example pages 1-3 of 10 (pages 4-10 identical to page 3)

SAFE with Schools

Interaction Reflection Log

Participant ID:

Date of issue:

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Additional Participant Notes

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Interaction Reflection Log

Participant ID: ....

Date: ....

Reflection on successful/positive interaction/s (what went well and why)

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Reflection on where meltdown/challenging behaviour has been averted (what happened and how/why did it stop)

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Reflection on a meltdown/challenging behaviour episode (and use the boxes below to measure the episode)

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Intensity/severity rating of each challenging behaviour/meltdown episode (circle one)	Approx. duration of episode	Confidence rating to manage each episode (1 = not at all confident, 7 = very confident)						
Minor ..... Mild ..... Moderate ..... Severe ..... Extreme		1	2	3	4	5	6	7
Minor ..... Mild ..... Moderate ..... Severe ..... Extreme		1	2	3	4	5	6	7
Minor ..... Mild ..... Moderate ..... Severe ..... Extreme		1	2	3	4	5	6	7

Appendix M

Stage 1 - Interview Schedule – Parents

UNIVERSITY OF
PLYMOUTH
Plymouth Institute
of Education

An exploration of the nature and alleviation of challenging behaviour [CB] including 'meltdown'

episodes among children with a diagnosis of autism in family and school contexts

Exploring parents and teachers experiences of CB and meltdowns, to understand triggers and processes and to identify potential new interventions and forms of support across home and school contexts.

Stage 1 Interview Schedule - Parents

Research interest 1 - Relationships

Exploring the effect of CB on family and home life, from the perspective of a parent of a child with a diagnosis of autism and influence on attachment.

Topic areas 1-3, participant questions *(and researcher notes for question direction)*:

1. **Explore a little into family background to understand their particular dynamic and how that dynamic might impact on family management of autism.**
   a. Could you tell me a bit about who makes up your family? *(Explore whether it is traditional nuclear / blended / single / extended / other)*
   b. How would you describe your family? *(Explore whether perhaps harmonious, organised, calm or chaotic, reactive, noisy etc., explore whether it has it evolved around autism)*

2. **Background information about [child's] autism diagnosis – (exploring the parent's history with, and feelings about, autism)**
   a. What did you know and understand about autism prior to receiving the diagnosis? *(Explore whether only media portrayal or deeper more formal knowledge prior to personal experience)*
   b. How did you 'feel' when you received [child's] diagnosis? *(Enable exploration of response to diagnosis, such as feelings of relief and validation, after years of fighting for recognition that something is different; or perhaps a sense of loss or bereavement, shock and fear of the unknown)*
   c. When [child] was diagnosed, what did you understand about the diagnosis? *(Enable exploration of parent's understanding around implications and expectations of [child's] development)*
   d. What are your thoughts about what the diagnosis means for [child] and for you and your family? *(Exploration of parent's thoughts and feelings around the impact on education, social development and future independence of [child]).*

3. **Exploring a little about [child] and life as their parent...**
   a. How old is [child]?
   b. When was [child] diagnosed?

    c. Tell me a bit about [child]. What does s/he like to do? Does s/he have a special interest?

    d. How would you describe your relationship overall?
- i. Give me some examples of things you and [child] like to do together?
- ii. What does [child] especially like doing with you?
- iii. How often do you get the opportunity to do that?
- iv. Does anything get in the way of that?

    e. Describe a time in the last week or so, you and [child] really *'clicked'*?
- i. Tel me more about this time?
- ii. How did you feel?

    f. Can you describe a time in the last week or so when you and [child] were really not *'clicking'*
- i. How did you feel?
- ii. How do you think [child] felt?

    g. Can you think of a time recently when [child] was upset or angry.
- i. What did they do?
- ii. How did you feel and what did you do?

    h. Can you tell me about a time recently where you have been upset, anxious or frustrated as a parent.
- i. How did you express that?
- ii. What impact do you think these feelings have on you and [child]?

    i. How has autism influenced your relationship with [child]?
- i. What support does [child] need from you and how do you feel when this happens?

    j. Think of a time when you and [child] were separated.
- i. Can you describe it to me and its effect on you and [child]?

    k. Tell me something that's wonderful about being mum/dad to [child]?
- i. Anything else? *(list if necessary)*

    l. Tell me something you find challenging about being mum/dad to [child]?
- **i.** What do you feel makes this aspect of parenting a particular challenge? *(Explore impact of others, needing more knowledge, fear, not connecting, behaviour)*

    m. Do you think autism has impacted your own mental health and wellbeing? If so, how?

Research interest 2 – Challenging Behaviour [CB] (including Meltdowns)

Understanding parents' feelings of coping and competency to manage meltdowns at home, in public and with friends, exploring frustrations and anxieties.

Topic areas 4-6, participant questions *(and researcher notes for question direction)*:

4. **Exploring the parent's day to day experience of meltdowns and CB**
    a. When was [child's] last meltdown/CB episode?
- i. Can you remember what was it about?
- ii. How did it affect family function/routine?
- iii. Did it affect anyone else in the family – if so 'who' and 'how'?

      b. Are you experiencing any change to [child's] meltdowns over time? *(Explore any increase/decrease – getting harder/easier with maturation and growth)*

      c. How do you feel about the responses of others to the meltdown? *(Prompt exploration around partner, siblings, family, friends, strangers and whether/how feelings change depending on who is responding)*

5. **Looking at meltdowns/CB within family life.**

      a. How do you feel toward [child] when they have a meltdown or display CB? *(Explore feelings of parental perception and their feelings of competency and coping to manage meltdowns)*

      b. Do you anticipate meltdowns/episodes of CB? Do you know when they are going to happen? *(Explore any anticipatory tension – including maintenance of known triggers and negative cycles of interaction)*

      c. When meltdowns/CBs happen, are you ready for them - do you feel able to cope? *(Explore preparedness and parent's own management strategies)*

      d. Have meltdowns/CB changed daily life for your family? *(Explore restrictive activity, acquisition of knowledge, changes to home environment, child's education or parental employment).*

6. **Meltdowns in the present and the future**

      e. Do [child's] meltdowns give you any particular cause for concern about the future? *(Enable discussion around fear for their child or even own safety, future, CJS, reaction of 'others' finding friends/partner/independence).*

Research interest 3 - School

What parents understand about the teacher's context? Exploring their perceptions, opinions and relationships.

Topic area 7, participant questions *(and researcher notes for question direction):*

7. **Thinking about when [child] is in school**

      a. What do you think the teacher sees from [child]? *(Explore whether at odds with teacher view, challenging student/good child or vice-versa).*

      b. What kind of relationship does [child] have with his/her teacher? *(Explore parent perception of whether it supports or impacts [child's] autism and whether this has an effect at home)*

      c. What kind of relationship do you have with [child's] teacher? *(Explore levels of communication, collaboration, blame, responsibility)*

      d. What does the teacher do to support [child] and is there a perceived impact on [child] and the wider family?

      e. Does [child] have meltdowns at school?

          i. What do you think triggers [child's] meltdowns in school

         ii. Or does [child] hold it together at school and explode at home

      f. Is there anything else you would like to say today?

Appendix N

Stage 1 - Interview Schedule – Teachers

UNIVERSITY OF PLYMOUTH
Plymouth Institute
of Education

An exploration of the nature and alleviation of challenging behaviour [CB] including 'meltdown' episodes among children with a diagnosis of autism in family and school contexts

Exploring teacher experience of CB and meltdowns, to understand triggers and processes and to identify potential new interventions and forms of support across home and school contexts.

Stage 1 Interview Schedule - Teachers

Research interest 1 - Relationships

Exploring the effect of meltdowns on classroom and school life, from the perspective of a teacher educating a child with a diagnosis of autism.

Topic areas 1-2, participant questions *(and researcher notes for question direction):*

1. **Explore a little about [child] and what it is like teaching him/her.**
   a. What year/grade is [child] in?
   b. What do you understand about [child's] diagnosis?
   c. What subjects do you think [child] excels in and struggles with?
   d. How much time do you estimate you spend with [child] compared with the average time spent with the rest of your students?
   e. How would you describe [child's] social position in the class? *(Exploration around [child's] experience of bullying, conflict, tolerance, [child's] social development)*
   f. A strong teacher-student relationship is important for development and learning. Describe your relationship with [child]. Is it a close teacher-student relationship?
      i. If so, what is it that facilitates that positive relationship?
      ii. If not, what are the barriers for developing a good relationship?
   g. Tell me something that's wonderful about teaching [child].
      i. Anything else? Does [child] have a special talent or interest?
   h. Tell me something you find really challenging about teaching [child].
      i. What do you feel, makes this aspect of teaching a particular challenge? *(Explore potential for lack of knowledge, lack of support, lack of connection with child/family).*
   i. Describe a time in the last couple of weeks where you and [child] really *'clicked'*
      i. How did you feel
   j. Can you describe a time recently where you and [child] were not *'clicking'*
      i. How did you feel about that
      ii. How do you think [child] was feeling
   k. Can you think of a time recently when [child] was upset or angry?
      i. What did [child] do?
      ii. What did you do?
   l. How has autism influenced your relationship with [child]
   m. Do you think teaching [child] has had or will have an impact on you professionally and personally, particularly in terms of your mental health and wellbeing?

Research interest 2 – Challenging Behaviour [CB] (including meltdowns)

Exploring teacher's feelings of coping and competency to manage meltdown behaviour in the classroom and across the school context

Topic areas 2-4, participant questions *(and researcher notes for question direction):*

2. **Exploring the teacher's day to day experience of meltdowns in school**
   a. When was [child's] last meltdown?
   b. Was it in class or elsewhere?
   c. Can you remember and/or pinpoint what it was about?
   d. How did it affect everyone around [child]? *(Consider peers, staff and the child themselves).*
   e. Are you experiencing any changes to [child's] meltdowns over time? *(Explore whether an increase/decrease is being seen – if it is getting harder/easier with maturation and growth).*

3. **Looking at CB including meltdowns within school life**
   a. When [child] has CB goes into meltdown, what's your immediate reaction and how do you feel towards [child] *(Explore teacher's sense of protection/duty of care, feelings of competency and coping ability to manage meltdowns)*
   b. Do you anticipate CB/meltdowns? Can you predict it occurring? *(Explore any anticipatory tension – including maintenance of known triggers and negative cycles of interaction).*
   c. When CB/meltdowns occur, are you ready for them – do you feel able to cope? *(Explore preparedness and teacher's management strategies).*
      i. Do you feel your ability to cope changes depending on the situation, for example, would you find it easier to manage the meltdown in the classroom, but less so outside, when on trips or during sporting events).
   d. Have CBs/meltdowns changed classroom life for you as a teacher? *(Explore whether using restricted activity, have they undertaken additional professional development, made adjustments to environment to support [child] in school, do they have a plan, and one that involves the parents)?*

4. **Meltdowns in the present and the future**
   e. Do [child's] CBs/meltdowns give you any cause for concern for the future? *(Enable discussion around fear for their student and own safety, future independence, CJS, relationships – peers, authority)*
   f. What, if anything, would you like to do about them?

Research interest 3 - Home

What teachers understand about the parent's context. Exploring their perceptions, opinions and relationships.

Topic area 5, participant questions *(and researcher notes for question direction):*

5. **Thinking about when [child] is home**

Page **2** of **3**

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a. What do you think [child's] parents' experience on a daily basis? *(Explore whether at odds with parent view, good student/challenging child or vice versa).*
b. What kind of relationship do you think [child] has with their parents? *(Explore teacher perception of parental relationship supports or impacts [child's] autism and whether this has an effect at school).*
c. What kind of relationship do you have with [child's] parent/s? *(Explore levels of communication, collaboration, blame, responsibility)*
d. What does the parent do to support [child's] education and is there a perceived impact on their schooling?
e. Does [child] have meltdowns at home that you know of?
    i. What do you think triggers [child's] meltdowns at home?
    ii. Or does [child] hold it together at home and explode at school?

Appendix O

Intervention Stage Consent Form

University of Plymouth

Faculty of Arts and Humanities – Plymouth Institute of Education

CONSENT TO PARTICIPATE IN RESEARCH STUDY – Intervention/follow-up stage

Research Title: An exploration of the nature and alleviation of 'meltdown' episodes among children with a diagnosis of autism across family and school contexts

Principle Investigator: Tara Vassallo tara.vassallo@plymouth.ac.uk Telephone 01752 585433

Participant Number: __ __ __

Purpose of study: The aim of this research, is to better understand triggers, processes and identify potential intervention opportunities associated with 'meltdowns', among children with a diagnosis of mild to moderate autism attending mainstream school. The intended applications include, developing more effective forms of support and intervention for these children and those who care for and educate them, across home and school contexts.

Please initial each box

1	I confirm that I have read and discussed with the researcher, the participant information sheet for the above study and I understand the objectives of this research, the training I will receive, the meltdown data I will be recording and the follow-up interview process.	
2	I confirm I have considered and understood the information detailed on the participant information sheet, have asked any questions and have received satisfactory answers.	
3	The two stages of the study have been explained to me. I understand that I have self-selected to take part in both the exploratory and intervention/follow-up stages of the study, that my participation is voluntary and I am free to withdraw at any time prior to anonymisation.	
4	I understand that the interview I give will be audio recorded and transcribed verbatim. Every effort will be made to keep my information confidential, with all identifying details from the interview and meltdown logs changed, to protect my anonymity as far as possible.	
5	I understand that all data relating to me will be kept securely for a 10 year period once the study has been completed and destroyed once that period has passed.	
6	I understand my participation in this study is entirely voluntary and I can withdraw without giving a reason and without negative consequences. My right to withdraw myself and my data, up to when the data has been anonymised, has been fully explained to me.	
7	A clear explanation of the complaint's procedure has been given to me and I have contact details of the researcher and her director of studies.	
8	All potential benefits, risks or inconveniences have been explained to me and I have been given a copy of this information in writing to retain for future reference, including contact details of where and from whom I can access support should I need it.	
9	I agree to take part in the intervention/follow-up stage of this study.	

Full name of participant:	Signature:	Date:
Full name of person taking consent:	Signature:	Date:

Appendix P

Stage 2 – Interview Schedule – Parents

UNIVERSITY OF
PLYMOUTH
Plymouth Institute
of Education

An exploration of the nature and alleviation of 'meltdown' episodes among children with a diagnosis of autism in family and school contexts

Exploring parents and teachers experiences of meltdowns to understand triggers and processes and to identify potential new interventions and forms of support across home and school contexts.

Stage 2 INDICATIVE Interview Schedule – Parents

INDICATIVE sample interview questions to guide discussion:

Exploring the individual experience and impact of parent and teacher partnership working. Identifying individual changes in coping and competency when navigating meltdowns.

Topic areas 1-3, participant questions *(and researcher notes for question direction):*

1. **Experience of working together**
   a. How did you find the experience? (+/-)
      i. Tell me something you found helpful
      ii. Tell me something you found difficult
   b. How do you think this experience has changed your relationship with your child's teacher?
      i. How has contact with [child's] teacher changed since the joint working? *(Explore frequency, style, efficacy understanding)*
   c. How has this experience of working with your child's teacher impacted your understanding of your child, their behaviour and needs both in the home and particularly in the school context?

2. **New Strategies**
   a. Did you gain any new strategies for meltdown management, either from the intervention, from your child's teacher, or from shared experience?
   b. Did you offer/share your strategies with your child's teacher?

3. **Meltdown behaviours**
   a. Have there been any changes in meltdown behaviour? *(Explore frequency, intensity, duration and impact on others)*
   b. What would be your overall 'perception' of your child's meltdown behaviour now? Do you view it any differently?
   c. How would you rate your competency levels and ability to cope when faced with a meltdown situation? *(Rate by drawing).*
   d. What changes have you experienced, in terms of your feelings of coping and competency to manage meltdowns and how do you think these changes have come about?

Appendix Q

Stage 2 - Interview Schedule – Teachers

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An exploration of the nature and alleviation of 'meltdown' episodes among children with a diagnosis of autism in family and school contexts

Exploring parents and teachers experiences of meltdowns to understand triggers and processes and to identify potential new interventions and forms of support across home and school contexts.

Stage 2 INDICATIVE Interview Schedule – Teachers

INDICATIVE sample interview questions to guide discussion:

Exploring the individual experience and impact of parent and teacher partnership working. Identifying individual changes in coping and competency when navigating meltdowns.

Topic areas 1-3, participant questions *(and researcher notes for question direction):*

1. **Experience of working together**
   a. How did you find the experience? (+/-)
      i. Tell me something you found helpful
      ii. Tell me something you found difficult
   b. How do you think this experience has changed your relationship with your student's parent?
      i. How has contact with [child's] parents changed since the joint working? *(Explore frequency, style, efficacy, understanding)*
   c. How has this experience of working with your student's parent impacted your understanding of your student, their behaviour and needs, both in school and particularly in the home context?

2. **New strategies**
   a. Did you gain any new strategies for meltdown management, either from the intervention, your student's parent or from shared experience?
   b. Did you offer/share your strategies with your student's parent?

3. **Meltdown behaviours**
   a. Have there been any changes in meltdown behaviour? *(Explore frequency, intensity and duration)*
   b. What would be your overall 'perception' of your student's meltdown behaviour? Do you view it any differently?
   c. How would you rate your own competency levels and ability to cope with a meltdown situation? *(Rate by drawing).*
   d. What changes have you experienced, in terms of your feelings of coping and competency to manage meltdowns and how do you think these changes have come about?

Appendix R

Ethical reflection and justification of the research:
The 'when, what, why, how, and who'.

When discovering and framing a research methodology, one must undergo a process of ongoing ethical justification, not only for the research subject being explored, but also for what has taken place across the research both before and during the project, and importantly, in consideration of the *after*, that of future applications and the **'when'** of these questions (Clough & Nutbrown, 2012). Underpinning my methodological decisions was an aim to create a logical and appropriate research design that responded flexibly to the main research questions which in turn supported the voice of my participants.

The context of autism, which itself is a wholly diverse and eclectic perspective. This was to ensure that meaning might be made from the contrast, and even chaos, that naturally emerges when uniting autistic and non-autistic worlds. Methodology goes beyond the simple explanation of *what one did* and *why one did it*, to more of a philosophical process; a cogent rationalisation, and an evolving narrative (the emerging story) of the critical pathway of conscious and unconscious decision-making by the researcher, that can often begin long before the research ever took shape, as it was in this case.

Justification for conducting a particular piece of research, the **'what'**, may seem easy, especially when one looks at it for example, from the position of how disadvantaged a specific population is and how little attention is being paid to resolving their situation. It is easy to become convinced that any research that might result in improvement for a particular community, must be justifiable, particularly when a gap in the literature also appears to exist (Spain *et al.*, 2017). Whilst research for a PhD should make an original contribution to the development of knowledge and theory, it should also be pragmatic and consider whether there is a *reason* for this gap. It should not be research for *research's sake*; for example Khun (1962) argues that science proceeds through paradigms which make assumptions about what is important or irrelevant in terms of what topics are researched. Likewise, social constructionists suggest that issues of power are involved in research, such as what research is funded, and by whom. A case in point in relation to mental health (*and this includes autism*), there is considerable investment in biological/ neurological orientations to it since these can

promote the use of medications to treat various conditions. This can be extremely financially rewarding for pharmaceutical companies, which in turn generate income and opportunity for governments such as tax revenue and exports. Hence the direction and nature of scientific investigation is far from a neutral purely science-based approach; for example, there may be an underlying economic motive.   So, to answer the question '*are there potential cultural or 'other' demographic reasons for the lack of addressment of a particular problem within the social world for a particular community?'*, the answer is *'Yes'*.   In addition, we can (and should) go further and ask, indeed, is the *problem* that frames the research question even a problem for the population in question, or are we just creating one when viewed from particular social positions and though our own social lens? In relation to autism, it is not just commercial interests that drive and influence research, but also those of other interest groups, including education, parent/family rights movements, and groups of adults with an autism diagnosis; though as is typically the case with children, self-advocates usually hold less power and have less influence than adults who claim to speak for them. Therefore, before undertaking this study, careful consideration of this was embedded within the research formulation process, and reflected upon throughout, shaping not only my ongoing methodology, but also how I reached the decision, (my justification), to pursue this inquiry in the first place.

To justify conducting ethically sensitive research such as this, prior to beginning this research journey, I asked myself many questions about the *who, when, how,* and *why* of undertaking this study *(the 'what')*. This reflective process was an iterative one, as I went back and forth, considering the potential impact on my participants, the autism community, the autistic culture, and on myself.

The **'*why*'** of doing it, for me, was always clear. I would conduct this because outcomes for autistic people are unnecessarily poor, resulting in unfulfilled potential and early death of a population living in a twenty-first century developed country; a country with full access to free education, healthcare and opportunity, none of which is equitably distributed or accessible for autistic people (All Party Parliamentary Group on Autism, 2019). I would conduct it because the autistic community desire change; because without exception, every autistic person, parent, and teacher I consulted with before, during, and throughout this research process, wants better for this community, because what continues to be experienced, are unacceptable outcomes that begin in childhood with the school experience and the culture of '*othering*', resulting in isolation

and exclusion, proliferating and compounding throughout the person's lifespan. For the wider community, I wanted to give parents and teachers a voice, something deeply rooted in my own experience and my ongoing work within the community, and because this type of approach to autistic children in mainstream education was demonstrably absent from the literature.

Although there are many ways to collect data in qualitative research, the *'how'* of conducting this research, realistically, was set years ago and underpinned by personal experience. From the moment I left Australia and stepped into the autism community as a parent of an autistic child here in the UK, a lack of voice for autistic children, adults, and their families was a recurring theme across the autism community. Parents had often suffered years of being ignored or not believed by practitioners about their child's difficulties. Many have been accused of Fabricated and Induced Illness [FII], previously Munchausen's by Proxy [MbP] (Clements, 2021), which has received little or no attention within academic research, but has a high profile within the grey literature, as is a significant proportion of sociocultural writing around aspects of autism, that are beyond the medical and clinical.

Becoming *unsilenced*, having the opportunity to tell their story, by writing it down through *journal entry,* talking to someone who would actively listen and not judge or accuse, through *interview* or *face-to-face meeting,* or being in the company of similar others, *sharing experience*, *connecting,* and *offering support,* are understood as positive experiences both for autistic children and their caregivers (Fleischmann, 2004; Fleischmann, 2005; Huws, Jones & Ingledew, 2001; Solomon & Chung, 2012). Therefore, parent and teacher *voice* were gathered using this eclectic mix of methods, augmented by observation, which when combined, captured the richness of the participants' narratives and helped reveal their stories.

Reflecting on my own experience, I can concur, having experienced this first-hand as a parent, an advocate, and ally within the voluntary and community sector, and during my psychological studies conducting my first significant piece of independent research (Vassallo, 2016). Being heard is vitally important to parents of autistic children. However, this was not restricted to parents of autistic children, but also reflected and reinforced within my work in inclusive education, where teachers felt equally stymied and silenced and in need of professional development and social support, as they negotiated a SEND system unfit for purpose (Cooc, 2019; Rodríguez, Saldana & Moreno, 2012). *Talking, writing, connecting*, were so important to parents

and teachers, yet so often these elements were entirely missing from their day-to-day personal and professional interactions, as well as with each other (Miretzky, 2004). Therefore, my research project needed to reflect and provide the opportunity for all three elements to be available to my participants, to meet the needs of those taking part in a way that would not add unnecessarily to their load. Consequently, combining *interviews, journals, focus groups*, and *meetings*, and providing a safe and neutral place to *'be'* and *share* together, was the clear and best choice of methods.

Probably the question that caused me to pause the most however, was, 'if I do this research, **'who'** might it help?' Unlike the previous two questions, this one did not have a straightforward answer. Beyond the highlighted reasons for this study (*that of providing an opportunity to explore the systemic relationship between parents and teachers, by enabling those missing elements of talking, writing, and connecting*), and addressing a gap in the literature (*to better understand the experiences of parents, teachers and the autistic child they share in the context of systemic intervention*), I could not get away from the fact that the answer to this question could include myself; this research could help '*me*'.

Continual reflection and re-examination of research is an ethical necessity and a stance that pervades my approach to this and any study I undertake. Therefore, to gain anything from it personally, for me felt unethical. Yet in conducting this project, I might benefit in all kinds of ways. My own knowledge and learning about autism would be greatly extended. My experience and voice would have an outlet. Professionally I could fully immerse myself in my area of *'special interest'*, a place where I am most content. I could gain my doctorate and with it the opportunity to do further research. Personally, it might offer me the opportunity to reflect on, or share, some of my own experience with my participants. This in turn might increase my own feelings of wellbeing, as it is shown that shared experience is valuable in terms of connection, self-esteem, and overcoming feelings of isolation and *othering* (Cortland *et al.*, 2017). All these thoughts and concerns formed part of the ongoing reflexive process embedded within my research approach. (Cortland *et al.*, 2017)

I then asked the inverse question, *'who' might it hurt?* The answer was again, not straightforward. Firstly, I sit with the knowledge that the population I am researching, the parents and teachers of autistic children who are struggling, or in difficult circumstances, are often fragile, living between states of crisis and coping (Gray, 1994; Gray, 2002; Ilias *et al.*, 2018; Solomon & Chung, 2012). Is it fair then, to

ask something of them, when they already exist with limited resources at their disposal? Could this additional demand cascade to impact their child - the very children I want to effect change for? Moreover, what about the autistic community themselves, from whom I also needed permission and guidance, both before and throughout my research? Is it fair to ask them for their help? Does this constitute a demand too far for a community who have been answering questions for decades about the strengths and talents found in their differences, only to have their voice ignored, and their perspective of the world pathologised? Would this be too patronising and insulting? I was not sure, but I knew I could not, and would not, do anything without them, which presented me with the dilemma of whether I should I even start down this road.

These questions raised some ethical issues for me, as finding ways to work with vulnerable and '*vulnerabilised*' groups (Macdonald *et al.*, 2021) is an ethical minefield, and one researchers often feel is best avoided. However, avoidance of hard questions is equally ethically precarious, as such avoidance effectively silences the very voice that needs to be heard the most (Leeson, 2014). Thankfully, my answers came unexpectedly through sensitive and continued engagement with the community. As a member of a neurodiverse family and an autistic ally, connected to the autistic community, I had been engaging with autistic people, as well as their families, friends, and the parents and teachers of autistic children and young people, for many years, providing emotional and practical peer support for parents, amplifying both the autistic and parental voice within education and statutory services, and on occasion, providing support with parent-teacher relationships. I had access to many forums across the country and indeed across the world, including my Australian network, so one day began a series of conversations, asking the question, '*should I do this?*' The answer that kept coming back was a resounding '*Yes! ...But please do get on with it*'. The rest, as they say, is history!

Appendix S

Reflection on cyclical attitudes – do teachers' opinions of and attitudes toward parents, shape their expectations of children, or is it vice-versa?

A cyclical relationship

From a systemic perspective, this question illuminates the importance of teacher perceptions of parents and children; where ideas about one, potentially shape attitudes about the other. However, what was less clear within this research was *which influenced which the most*, or were they *mutually dependent*? Did the teachers' view of the child, shape their expectation of and attitude toward the parent, or did the teachers' view of the parent, influence the teachers' attitude toward and expectations of the child?

I questioned whether my own experience of a positive teacher relationship in Australia might have been similarly influenced. I enjoyed a positive relationship with my son's school and the school had high expectations of my son. However, were these expectations of my son from the school inherently high? Did they genuinely see his potential, which then lifted their expectation of us, his parents, opening the door to that positive relationship and creating the environment within which he flourished? Or was it because as parents, we were empowered and proactive, which made our contribution to our son's education more acceptable to the school, who then adopted that information about him and his potential from us, lifting their expectations of him? I could not be sure. Although, as I saw no evidence of a less favourable attitudes toward children whose parents were not so empowered or engaged, the former felt more likely. However, if the latter was true, this might explain why my positive Australian experience did not immediately transfer to the UK context. We did not immediately have the opportunity to establish a relationship with the teacher and the school, therefore *they* did not know about *us* and consequently their default position, given the challenges and barriers to parental engagement in the UK at the time and attitudes toward autism, was one of low expectations of parents, and also of the child.

As our early encounter with such teacher preconceptions in the UK had confirmed, we were indeed '*just another autism family'*. Despite some significant parental effort and investment in the school by us to improve this position (*parent driven meetings, written communication detailing ways to support, volunteering in school, running school-based parent support group*), our time in the UK education

system never did reach the same depth or sincerity of relations we experienced in our Australian setting, suggesting a possible cultural difference toward autism between the antipodean and UK contexts.

Perhaps because Australian expectations of children were inherently high, parental input was not only welcomed but expected to support this. This was a different approach to the parent-teacher relationship in the UK, which has a long history of assumed deficit in autism and parental blame for children's difficulties, perpetuating a legacy attitude toward families of autistic children that is embedded within social narrative, and difficult to change (Jacobs *et al.*, 2020; Osborne & Reed, 2008; Wood & Olivier, 2011; Woodgate, Ateah & Secco, 2008).

Example scenario - Combining SwiS activities to explore problems.

This example demonstrates how a combination of the '*day in the life of*' and '*tracking*' activities were needed to unpack a difficulty for a child and find a solution to the problem.

A parent depicted a problem that had been going on for most of the term. Getting their child to school was straight forward most days, but on Thursdays their child would now refuse. The parent had no idea why, except that the child would become distressed and uncommunicative every Thursday morning, describing feeling nauseous (*the child had a general phobia of vomiting*). They became pale, clammy and feverish, and although not sick, experienced an upset stomach and diarrhoea. No reason could be found by the GP, who suggested a passing stomach bug, which resulted in the child staying home Thursdays and then most Fridays for much of the term. As this was impacting the child's attendance, it resulted in stressful communications from the school t the parents, reminding them of their legal obligations to send their child to school and the consequences facing them should they fail to do so. This elevated parental stress as they still did not know what the problem was and had no relationship with the school to explore it further. They feared their child might be experiencing a bullying scenario with another child, or worse, with a staff member, and were under pressure from the school to '*resolve*' things. In this case, whilst time spent with the teacher exploring the '*day in the life*' scenario elicited understanding for the situation, did not immediately illuminate the problem further, except confirmation from the teacher that there was no change of staff, the child's routine was stable, with no bullying they could establish. Both caregivers even with their combined knowledge of the child could not explain the problem with Thursdays. However, the indirect participation of the child using the complementary '*tracking*' activity revealed the source of the problem and the newly strengthened parent-teacher relationship resulted in a quick and easy solution.

The parent '*tracked*' the '*day in the life scenario*' with their child as part of their SwiS '*homework*'. Using it to explore the Thursday morning *anxiety-based school avoidance* cycle, the parent was able to break down what was happening and how their child was feeling. This revealed an environmental barrier for the child; the school had a

recent menu change for school lunches, and the smell of Thursday's menu was so sensorially challenging, it made the child feel physically sick in school. Although they were not *actually* sick, this was enough for the child who was already emetophobic, to avoid school on Thursdays.

Sharing this new information with the teacher enabled the teacher to make the necessary adjustments in school to ensure the child had fresh air and did not have to navigate that area of the school on a Thursday until the next menu rotation could be tested with the child, helping them stay away from the strong smells of the canteen. It also highlighted to the teacher the extent of sensory sensitivity being experienced by the child, making them more aware of potential sensorial barriers across other aspects of school life.

The extended circle of security

HOME: Parent/carer – family relationships and demands, safe place.

FAMILY RULES: Familiar and predictable.

Preferred attachment strategies of parents.

PARENT Secure-base

TEACHER Safe-haven

SCHOOL: Teacher/TA – educational demands, social relationships, attachments.

SCHOOL RULES: Formal and informal, explicit and implicit.

Teachers' preferred attachment strategies.

Child must navigate two sets of rules and attachment systems. Especially demanding for an autistic child. Important for family/teachers to communicate, similar to the need for parents and grandparents to be consistent and in agreement

The extended secure circle includes both the parent and the teacher / home and school
(Source: Personal collection)

Sculpt activity - example

| Child Sculpt | Parent Sculpt |

Child sculpt with key figures positioned and parental sculpt positioning the key figures as identified by the child and parental assumptions (Source – personal collection)

In this example of the *sculpting* activity, the parent (mum) and child 'C' agreed (mostly) about who was important within his system, and the relative position of some of the members. However, 'C' and his mum differed in terms of *'who'* 'C' was *'closest'* to, particularly in relation to 'C's' Nan, with whom he did not feel close, but was spending considerable time with. In this instance, the parent did not know about Jack at all, and positioned *'friends'* as being unknown, peripheral to 'C's' system as the parent assumed their child did not have any close friendship bonds but had only acquaintances at school. Differences about the importance of Nan, Jack, and the family dog to 'C', became quickly apparent, and consequently, visits to nan were made more on 'C's' terms, the dog was allowed to *'keep 'C' company'* at night, and the parents were able to support the friendship with Jack, through sharing this with 'C's' teacher who helped facilitate the friendship at school and connected both parents who went on to arrange playdates. The positive impacts on family dynamics and on 'C's' wellbeing were immediate, with 'C' more relaxed at home, experiencing less anxiety.

This exercise was shared with 'C's' teacher in the context of school, where the teacher felt he had *'significant support'*. She suggested positioning a system of fellow students and support staff around 'C' in quite close proximity, based on her observations of how he *'seemed'* to be in the classroom. However, this was not

matched at all by 'C's' representation, where he showed he felt isolated, without any friends, except for Jack, who was in another class and sometimes inaccessible to 'C' at school. With this knowledge the teacher was able to facilitate this friendship (which was mutual for Jack) within school.

When it was revealed that 'C' felt connected to only one other person in school (a mealtime assistant), who was not even on the teacher's radar as being important to 'C', but who in fact had formed a strong connection with 'C' and was providing regular and considerable pastoral support to him, the teacher was able to make arrangements for 'C' to have access to her in school as part of his daily routine, something 'C' looked forward to and increased his feelings of security.

In this exercise, we can see how relational dynamics can look and feel very different from a child's perspective compared to what is observed from the adult perspective. Without playful and safe exploration, both the parents and teacher would have had no idea about 'C's' experiences at home, or at school, remaining powerless to help.

Appendix W

A reflective overview of participants' general experience and engagement with SwiS

An overview of general experience

Positive aspects

Almost all participants expressed they found the experience interesting and enjoyable, finding *something* from the study that was helpful in their day to day lives and with the children they care for.

> *the main reason why absolutely I had to be here today was to put across how incredibly important I think this programme is … because of all the other stuff that's just failing everywhere, this is a fantastic opportunity* (Parent interview)

This expression of urgency was common across many parents, revealing their anguish in terms of **wasted time** and **fear for the future** in their narratives, desperate for '*something to change*' for their children; for someone to help them. Whilst teachers may have only recently come to experience problems recently, for the parent, they have often endured years of feeling isolated, hopeless and *in the dark.*

> *It's (SwiS) been a bit of light you know, against the really dark place we've been living, with this battleground of a system* (Parent meeting)

Many teachers who found elements to help them in their day-to-day practice, shared feelings of relief and often surprise at their discoveries, after previous approaches had failed.

> *it's been really useful … I've got some new strategies that I've used with [child], which have actually worked!* (Teacher interview)

Consistent with the heterogenous nature of autism and individual needs of people, participants gained different things from the experience, to differing degrees, and for a variety of reasons, with no two profiles of participant experience the same.

> *as a parent of an autistic child, you do anything to understand it (autism) more … it just helps to have whatever info we can have as parents and support and guidance so whatever [child] needs, if I can do something, I would do it. And it (SwiS) was a big help. This was a big help for me and I think [teacher] this time around* (Parent interview)
>
> *the two days, that was really very useful in terms of bringing—relating it to theory, and building more of a rapport with [parent]* (Teacher interview)

Observations of both parents and teachers during the programme days identified a hunger for information and opportunity to discover more about their child and about autism in general, Comments such as *'I'm looking forward to this'* and *'you can't get this from a book'* demonstrated a level of anticipation and expectation across the group. The value of gaining new ***knowledge and understanding*** was a strong theme, essential to both parents and teachers, fed by a willingness to share experience, which also connected to the alleviation of isolation and increased ***confidence.*** As such, participants were keen to pass on as well as receive *collective wisdom* about their children and about autism. Incidental conversations between participants when allowed to flourish, were littered with phrases and exchanges such as *'how do you handle…'*, *'I don't know how to…'*, *'I've found it helps if…'* and *'I hadn't thought of that'*. An interesting observation was the increased enthusiasm of parents in particular, which for some seemed a little subdued on arrival. This quicky grew in line with unrestricted interaction, and a majority of parents and teachers approached the programme with excitement and a sense of purpose.

Challenging aspects

It must be acknowledged, not every participant engaged with the research in such a dynamic way. A small proportion of teachers who were openly disinclined to the research during the exploration stage, remained so throughout. The corresponding parents picked up on this, expressing that they felt their teacher was less committed. One parent described their teacher as a '*reluctant participant*' feeling they had been '*persuaded*' to take part by their headteacher. This resulted in the parent feeling there was insincere engagement from the teacher, that they were just '*going through the motions'*, something borne out by the corresponding teachers' narratives.

> *I'll be honest, this is not really my 'thing'. I've been teaching too long to get much from this kind of training. I just don't need it, but if it helps [parent] then that's fine.* (Teacher comment SPD)

Interestingly, none of the teachers felt any disinterest from their corresponding parents, feeling parents were universally engaged, wanting to take part even when the teacher was less enthusiastic.

> *I didn't want to go back on the second day. And then [parent] said, (demonstrates parent pleading) 'Can we just go?'.* (Teacher interview)

Of note, was that follow-up with participants revealed the few teachers who were less engaged, subsequently either changed their setting and role within education or left teaching altogether soon after. This suggests they may have been in the throes of

making significant career decisions prior to and during participation, which likely impacted their engagement. One teacher who left education, had expressed disillusionment with their role, therefore perhaps could not *see the point* in participation, taking the view instead that it was a bit of a break.

It's a change and gets me out of the classroom for a bit (Teacher comment SPD) This was echoed by their similarly disinterested participant teachers, which is interesting because it draws an important parallel between teachers and children, that like their students, teachers also have needs that must be met to flourish within education. They too need to feel secure and invested in their role before deeper engagement can take place and new knowledge acquired and applied. Simply being present is not enough.

Closer analysis of these teachers also uncovered what appeared to be an inclusion bias that was deeply entrenched and hard to conceal. Dissatisfaction with the wider education system and inclusion agenda, as well as frustration at having such diversity in their classrooms, was revealed in their narratives.

Catering for so many different needs is nigh-on impossible. (Teacher comment SPD).

It's too distracting and there's no training (Teacher comment SPD)

Every class has got at least one (autistic student) now (Teacher comment SPD)

Their disillusionment and frustration did not point directly to schools' lack of commitment to, or investment in autistic students, rather, again revealing **bureaucracy as a barrier** and **negative time pressures,** describing the difficulty and pressure they felt from blending wider inclusion policy more generally, in a performance-based culture; an approach which was not for them. Their dissatisfaction did reveal an entrenched bias that *'different'* children should be educated separately, which may have been fed by this dissonant position between performance and inclusion.

> *I have been teaching long enough to see children with special needs who perhaps traditionally would have been in a special school- and I have kind of like— so I just sort of reflect on like the ups and downs of that ... I sometimes think that it's a valid point that you have to balance the best wishes of the child with special needs with the best wishes of the other children in class* (Teacher interview)

> *Teaching isn't what it was you know. Years ago, children like [child] wouldn't be in our school ... this 'full inclusion' agenda they've got going isn't working ... society's just not ready for that.* (Teacher meeting)

> *I don't believe all children should be in mainstream. No.* (Teacher meeting)

> *You do have to defend the rights of the other children to be educated* (Teacher interview)

Robinson and Goodey (2018) describe this as '*inclusion phobia*'. A '*condition of pathological anxiety*' of difference, or '*fear of the unknown*', which over time has contributed not only to the construction and definition of labels such as autism or learning disability (which in themselves are '*not natural scientific entities*' rather their '*very existence has been contingent upon the historically shifting anxieties of dominant in-groups*'), but also to maintaining exclusionary attitudes towards minority out-group children, with the impact on *other* children used to justify exclusion.

> *you have to balance the best wishes of the child with special needs with the best wishes of the other children in class. And, the effect let's say of three or four children with emotional and behavioural problems on a class is profound. And, there is even research to say that it will affect the life chances of those children. And. I'm alive to that*. (Teacher interview)

Some teacher narratives described a similar school ethos of '*exclusion by inclusion*', where autistic children were enrolled at the school, but often educated separately, in corridors by teaching assistants, or away from the rest of the class, '*managed*' as opposed to included and developed; a common approach employed by mainstream schools in the UK.

> *I found it quite difficult because as the class teacher, I have less interaction with [child] than my TAs do. [Child] is largely 'managed' by the TAs.* (Teacher interview)

> *what's it like to teach [them]? (Chuckles) I'm not sure because I don't get to do it very much* (Teacher interview)

In an interesting twist, despite the apparent disinterest from these small proportion of teachers, their participation in SwiS, however unenthusiastic, still resulted in an improved parent-teacher relationship for all but one of them.

> *the positive (from SwiS) that we've got is, we (parent and teacher) have developed a better relationship, which is what it (SwiS) was all about (laughs ironically).* (Teacher interview)

All parents and teachers gained something from this experience, however how parents and teachers perceived and constructed this, varied. The impact of time investment resulted in different outcomes for participants, revealed in the mix of subthemes, suggesting participants drew different things from the experience, composed from their own unique constellation of SwiS elements.

For the one parent-teacher unit where time with the teacher did not result in an improved relationship, time with other teachers and parents meant their experience of SwiS helped in other ways, offering hope for their child's outcome even if the school experience failed them at an institutional level.

> *if there's another tranche of this programme and we're still here and we've got another teacher to work with, I kind of want to start again because, what we saw in the intervention workshops was fantastic and, you know, it gave me a real buzz that there's hope and with the right people together and pulling together, you can overcome the obstacles of an institution such as this that maybe failing at management level but if you've got a couple of people who're willing to do what needs to be done, then it would be an entirely different outcome* (Parent interview)

This narrative was a powerful indicator of parental resolve to secure a better future for their children, their belief in the impact of *doing the right thing* and reflective of an indomitable optimism displayed by many parents.

Appendix X

Example working together, problem-solving.

An example of a negative cycle of interaction, highlighting the need for parents and teachers to problem-solve together was revealed by a teacher sharing their exasperation about how their child got upset regularly in class for no apparent reason. They had noticed it seemed to coincide with whenever it rained, but initially put that down to coincidence. The teacher was at a loss of how to navigate the child's distress which became increasingly worse as the weather deteriorated. Finally considering the weather as a causal link, the teacher thought perhaps the child was upset because they could not play outside. However, this presented a contradiction because the child often resisted going outside to play regardless of the weather, preferring to be indoors. This problem persisted until the teacher *tracked* the problem with the parent which revealed both the answer and the solution. A phobia of the dark underpinned the child's distress, a connection that was not immediately obvious. Prior experience had taught the child that bad weather, particularly wind and rain, might mean a storm might be coming. Their previous experience of storms had resulted in power cuts. Without power, there would be no lights. It did not matter that it was daytime, it would get dark and the anticipation of this was anxiety inducing. This association and activated anxiety led to feelings of insecurity making it impossible to engage with learning. This was frustrating for their teacher who had no idea of the root of their disengagement, eliciting sanctions at school when the child required comfort and reassurance. This resulted in them being upset at home having been upset during the day and when facing a return to school the next day, resulted in an understandable resistance to go. This was a cyclical but common scenario. Another child who was thought to have significant attentional problems for any activity, had difficulty prioritising the teacher's voice from extraneous noise such as background chatter, external sounds (*for example other children, the caretaker's lawnmower, or traffic*), giving the appearance of them *not paying attention*. Again, this had resulted in frustration from the teacher and on occasion a '*telling-off*' having been repeatedly brought back to task, but from the teacher's perspective say them '*drift off*' again. Being '*in trouble*' was difficult for the child to process as they did not understand what they did wrong and had no mechanism to explore the difficulty with anyone, increasing their distress, which they then took home. In these examples, increasing their communication and tracking incidents as a team, teachers, parents, and

on occasion the child, were able to interject, offer explanations, and find solutions together (*such as ensuring access to a torch in bad weather, and noise cancelling headphones during periods of high concentration*).

Beechwood School Testimonial

Beechwood Primary Academy

DISCOVERY

Chief Executive Officer – Mrs A Nettleship

Head of School: Mrs Lisa Evans
Assistant Head of School: Tamsin Bailey

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Beechwood Primary Academy
Rockfield Avenue, Southway, Plymouth,
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March 16th, 2020

To whom it may concern

As the SENCO of Beechwood Primary Academy, I would like to confirm our ongoing participation in the SAFE project. We supported teacher and parent pairs to attend the initial SAFE for Schools study and the outcomes were very beneficial. The teacher and parent were able to use the SAFE training to collaborate more effectively to meet the needs of the child and we also saw improvements in educational practice associated with autism.

One member of staff made huge strides in supporting a pupil with a diagnosis of ASD.

At the start of the programme she was very much of the opinion the pupil should just "get on with it" and that she didn't need anything different. However, her mind set changed over the course of the study and through working collaboratively with the parent she gained a much better understanding of the pupils needs and how she could make a big difference with very small changes to her practice. The outcome of that was that the pupil concerned then had the most effective transition to Yr 6 and settled without distress and the parents reported a calmer homelife.

It also impacted on her ability to support other SEN pupils and she is now a role model to other staff having adapted her teaching to meet the needs of all pupils in her class.

Safe for Schools has been a revelation and the impact it has had on the pupils and staff at our school is immeasurable. Understanding the importance of building a relationship with the parents in order to work together to support children with ASD has been the greatest impact on staff. The staff involved are constantly talking to each other about the study and how they are enjoying it. The feedback I have had from all of them has been incredibly positive.

Parents having the opportunity to share their difficulties and for teachers to hear some of these things has made them more sensitive in how they talk to parents and has given them a better understanding of how what they see in school is not always

a reflection of how a child is managing. They have become more observant and astute to a child's behaviours.

As a result of our involvement and the impact of this study, we decided that we would like to employ SAFE for Schools as an approach across our School for parents and teachers of children with a diagnosis of autism. The SAFE for Schools team have provided training at our school and a member of their staff has worked with teachers in the classroom to observe and advise. This phase of our involvement is still ongoing but we are already seeing improvements in the relationships and practice around the child. We will be sharing our experiences with other schools and support the development of this much needed approach, which has the potential to improve the care and education of these children.


Yours Sincerely

Jackie Daw

SENCO
Beechwood Primary Academy

Sample transcription analysis

Left margin notes:

Not yet okay with the situation

Has friends but they are busy with work etc.

Has a disabled mother so physical resources divided to support her – mother is a good source of emotional support

No time for ▬ as a couple

Despite having lots of people who care about them, ▬ acknowledges that they are functioning well as a family despite little practical help or any kind of outlet for stress – they operate in isolation for that.

Cannot recall last time she relaxed properly

Not ever being able to relax is part of managing autism

Can't take eye off the ball at all and can't trust that to anyone else

▬ doesn't sleep, nor does Dad – all 'running on empty'

Overthinking everything – never switching off – anxious and stressed

Tries to let go of things she can't impact such as the system – has to 'go along' with thing – tick the boxes

Transcript:

```
360  trying to find a place of, um, like a level with it but
361  I wouldn't say I was there yet. (Chuckles) I do have
362  some good friends, uh, peop- everybody's life seems to
363  be busy with work and other commitments, so I probably
364  don't do enough for myself to support myself in all
365  honestly. (Clears throat) I'm working on it. (Chuckles)
366  Yeah. (Chuckles)
367  I  Okay.  I mean do you- what about family?
368  P  Uh, my mum is close by, she's- she's wonderful but
369     she's also disabled.  [I:  Okay.]  Um, (clears throat)
370     so, she can't look after the boys as such, but she's a
371     very good source of emotional support. [I:  Yeah.]  She
372     loves me dearly and she wants things to be better for
373     all of us and to be honest with you, that's as good as
374     it gets sometimes, just knowing that people care is,
375     um, yeah, it's a big deal.  It's not like we're
376     completely on our own, there's a lot of people that do
377     really love us.  I think they find it frustrating
378     because they don't know what they can do.  So we don't-
379     I think it's really tricky because we don't ever get
380     any time away, ▬ and I don't get any time to go out
381     or anything like that.  So sometimes I think I feel
382     that we could- we can congratulate ourselves on how
383     well we're doing because we don't have that.  Some
384     people have an outlet where they have parents that come
385     and take them away and support them like that; we don't
386     have any of that.  I suspect we probably need to look
387     into having more time together, um, but we're just
388     muddling through and doing the best we can right now.
389     [I:  Yeah.]  Yeah.
390  I  Okay.  When's the last time do you think that you truly
391     relaxed?
392  P  Hmm, very good question.  I honestly don't know.
393     (Pause) You set me off again. (Chuckles)
394  I  You can't think when?
395  P  No.
396  I  Okay.
397  P  I think that's part and parcel with this stuff
398     sometimes.  As much as we probably all try, it's really
399     really hard just to let go because, you know, if we're
400     quite proactive with this stuff, your mind's always
401     kind of ticking over, what if this, what if that, what
402     am I going to do tomorrow, da-da-da-da, and it's not a
403     good way to live because it is exhausting, you know, it
404     impacts on my sleep.  [I:  Yeah.]  Um, ▬ doesn't
405     sleep very well, ▬ doesn't sleep very well, so I
406     think we're all running on empty a bit to be honest.
407  I  Would you say that you ruminate on all the…?
408  P  Oh yeah.  Yeah definitely, I do.  I absolutely
409     completely over analyse things and I sort of say to
410     myself a bit like a mantra now, "just breathe in and
411     let go".  And I know (chuckles) it's very simplistic
412     but just get myself through the day and then when
413     things start to rise up again, okay breathe, let it go,
414     let it go.  Because some stuff I can do absolutely
415     nothing about, you know, like being in the system with
416     schools and things like that, we just have to go along,
417     tick the boxes and follow the path.  If we shout or we-
418     you know?  It's- it's a funny one, it sort of feels
419     like, um, I'm not- yeah, I don't feel completely in
```

Right comment panel:

Tara Vassallo
Considers ▬ disabled – 'also'
@mention or reply

Tara Vassallo
Emotional support is critical
@mention or reply

Tara Vassallo
Reflective
@mention or reply

Tara Vassallo
THEME - Muddling through – doing the best they can with what they have
@mention or reply

Tara Vassallo
No relaxation – always on duty
@mention or reply

Tara Vassallo
Hypervigilance - stress
@mention or reply

Tara Vassallo
THEME – sleep deprivation and depleted personal resources
@mention or reply

Tara Vassallo
Rumination- stress
@mention or reply

Tara Vassallo
Strategy to manage own anxiety
@mention or reply

Tara Vassallo
Stuck in system – powerless, just a number 'a tick box' loss of identity

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