2023

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https://pearl.plymouth.ac.uk/handle/10026.1/21021

http://dx.doi.org/10.24382/5061
University of Plymouth

CHILDREN WITH WILLIAMS SYNDROME: EXPERIENCES OF MAINSTREAM PRIMARY SCHOOLS

By

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A thesis submitted to the University of Plymouth

in partial fulfilment for the degree of

DOCTOR OF PHILOSOPHY

Plymouth Institute of Education

JANUARY 2023

Acknowledgements

Many thanks to the children who welcomed me into their lives for one week and guided their own research projects about their school. Thank you to the families and schools for helping the research to take place.

I am grateful to the Williams Syndrome Foundation for travel funding towards fieldwork.

Thank you to Associate Professor Dr Jan Georgeson and Dr Emma Macleod-Johnstone for their fantastic supervision, care, and great humour. They are among an excellent network of support and encouragement in Plymouth Institute of Education.

To my family, friends and a special thanks to the proofreading team for all their support and advice.

For Tom the man, thank you for agreeing to be part of my writing. I am so proud to be your sister.

Author's Declaration

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee.

This thesis has been proofread by a third party; no factual changes or additions or amendments to the argument were made as a result of this process. A copy of the thesis prior to proofreading will be made available to the examiners upon request.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

Presentations at conferences:

Symposium 'Exploring young children's views through the Mosaic approach - examples from research practice' (online) at EECERA Monday 6th September 2021

Gibson, S and Gulliver, K. (2022) - Rethinking the meaning and place of Disability in education and society, workshop presented at annual PIoE ITE conference (BEd and PGCE)

'How to support children with WS in mainstream primary schools' at WSF Convention Sunday 17th July 2022

'Going at a different pace: supporting inclusion for children with disabilities' at EECERA August 2022

'More than listening: inclusion for young children with a rare developmental disability' at BERA September 2022

Word count of main body of thesis: 72,889

Signed: K.Gulliver

Date: 31.01.2023

Children with Williams Syndrome: experiences of mainstream primary schools

Katherine Gulliver

Abstract:

Four children with Williams Syndrome shared their daily experiences of attending a mainstream primary school in the South West of England, UK. Using an adaptation of the Mosaic approach (Clark, 2011), children shared their perceptions and experiences of belonging to a class, developing responsibility and learning to follow the rules. Children guided the researcher during a visit lasting one week in each school. Methods included videos, a child-led tour, photographs and interviews with staff. Informed consent was obtained by gatekeepers including children's parents, head teacher and school staff. Children were continually monitored for assent using a reflective, ethically conscious total communication approach. Findings show close relationships with practitioners were essential for supporting child centred inclusion for children with disabilities. Outside the classroom the space was more open and supportive for practitioners to recognize, respect and respond to children's own paces. Whilst children are included inside the classroom, practitioners provide a safe space that celebrates children's own priorities and paces outside of the classroom. This study highlights the need for settings to facilitate space based on Elkind's (2006) unhurried approach. Teaching assistants play a significant role in supporting children and staff, by developing knowledge of both the child and the disability through close, responsive working with children. Implications for practice indicate staff would benefit from WS specific knowledge and training as well as strategic school inclusion practices to enable staff to share their knowledge-from-experience with class teachers.

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Dark Orange – Sophie
Green – Orla
Yellow – Ryan
Blue – Wendy

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Data Key

Code	Description
Audio S1	Audio transcriptions are assigned to the child’s first initial, and number of transcriptions
Video S1	Videos are assigned to the child’s first initial, and number of videos
O3, p.4	Fieldnotes are attributed to the child’s first initial, the day of the fieldnotes, and page number. For example; Orla, day 3, page 4.
ST	Sophie’s teacher

STA	Sophie’s teaching assistant
OT	Orla’s teacher
OTA	Orla’s teaching assistant
RT	Ryan’s teacher
RTA	Ryan’s teaching assistant
WT1	Wendy’s first teacher
WT2	Wendy’s second teacher
WTA	Wendy’s teaching assistant

Glossary and acronyms

Hyperacusis	a type of sound sensitivity
Hypersociability	an over-eagerness to interact with others
PHSE	Personal, social, health and economic education
RRB	restricted and repetitive behaviours
SEN	special educational needs
SENCo	Special educational needs Co-ordinator (Sometimes referred to as SENDCo)
SEN/D	special educational needs and/or disabilities
SEN TA	Special educational needs teaching assistant
TA	Teaching Assistant
WS	Williams Syndrome
WSF	Williams Syndrome Foundation

1. Introduction

Children with special educational needs and/or disabilities (SEN/D) have the right to attend their local regular school (UNESCO, 1994). Inclusion literature emphasises several challenges in understanding how to support the inclusion of children with diverse learning needs in an education system that values performance and conformity. Education provision in England has traditionally comprised a two-track system with various pathways for children labelled as having a SEN/D who could attend a special school, mainstream school or unit for part of or all the week.

Working in a special school, I supported children with disabilities to access the local mainstream primary classroom for an Art lesson. During the lesson, the child I was supporting found it difficult to wait and began shouting. The strategy in place to help him process waiting was to take off the three Velcro buttons signalling the time that he needed to wait. Whilst I was guiding him, the class teacher looked over at me and asked us to leave. In that moment, I could see how the environment was not conducive to supporting children who needed different strategies. Although there were processes to support children, I questioned how inclusion could work without a radical shift in culture. I recognised how lucky I was to grow up with a sibling with a disability that meant I was keen to embrace different ways of working with disabilities and diversity.

Part of my discussions will include personal information about my brother, who has Williams Syndrome. I talked with him and our parents to discuss the potential implications for including these details. Although he was more than happy to be part of my ‘writing’, it was essential to discuss with our parents, who alongside myself act as gatekeepers in a consent network in order to keep his information safe and protected. Within my methodology I will discuss the ethics of the complications of informed consent. However, an important part of my research is raising the social justice issue of misrepresentation and underrepresentation of individuals with disabilities who are often not included in research. It is important to me that my brother is included in my writing, as he is at the heart of the research.

1.1. Introducing Tom

When my brother was born with a disability in 1990, my parents were told he would never read or write, might not walk, and that he would be so delayed that he would not be capable of working. The historic view of disability hit them as a tragedy, with a baby labelled as incapable and poorly. A grandparent commented that there were ‘homes for people like that’ which echoes the historical segregation of people with differences and disabilities that were deemed ineducable and separated from society. Today, Tom is taking orders at the café, using the till and coffee machines to serve customers with full support from a charitable organisation. He might not love writing, but he sends emails and texts phonetically using his laptop and loves receiving replies. Tom is a huge part of the local community, as demonstrated by the town fire brigade arriving at his birthday party to say hello, and us always meeting someone who knows him every time we walk through town.

A large part of having a sibling with a disability is developing knowledge of how to access support and funding. In order to have the right support for Tom, my parents had to collect evidence which proved his disability prevented him from living independently and affected him in all areas of his life. This demands a view of disability that highlights the challenges and difficulties rather than the joy and laughter that he brings.

I recognise the language behind dis/ability which might reinforce the positioning of someone as less able, and therefore less valued. However, I understand disability as a difference, with a positive, affirming identity that celebrates diversity (Swain and French, 2000) whilst acknowledging the real lived experience of physical and physiological differences that impact daily lives. Disability is a complex phenomenon, and families with a child with a disability must navigate through medical, physiological, social, cultural and physical environments (Bhaskar & Hartwig, 2010). For Tom, this includes the material reality of having a visible yet complex disability and how this is managed, shaped, ignored or avoided in society. A critical realism perspective (ibid, 2010) helps to highlight the real experiences of responding to and traversing through the journey of disability.

Traditionally, disability has been viewed through a medical model where disabilities were seen as deficits and individuals assumed to be less than able and therefore arguably less valued (Gibson & Blandford, 2005). On the other hand, the focus on individual physical impairments with a medical model has successfully advanced treatments and rehabilitations for individuals to access support. Through diagnosis and specialist support, individuals with disabilities can access high quality care and education that enables them to have equitable provision. Therefore, individuals with disabilities must evidence their deficits in order to receive the support needed to have the opportunities that others without disabilities have.

Fortunately, we belong to a large group of families with a diagnosis of Williams Syndrome (WS). Diagnosis enabled our family to connect with others who were also managing the complexity of this specific disability. It helped my parents to feel that they were not alone and could share experiences and advice with others. Within this network, we could celebrate our ‘norm’. Growing up as a member of the Williams Syndrome Foundation (WSF), I have spent many holidays, discos and summer barbecues playing with other siblings and children with Williams Syndrome. In the last three Williams Syndrome conventions where families from across the UK joined together to share experiences, connect and learn from research, I witnessed the joy and pride in belonging to the group. We wear t-shirts, bags and hats showing off our connection, and I walk arm in arm with Tom, proud to be members.

Tom spent the majority of his education and care in specialist provision. He attended the local special school for 19 years, before a placement at a specialist college where he continued to work on life skills. He currently lives in a shared house with 24-hour support between him and one other individual with Down Syndrome, and additional one-to-one hours for personal care, physiotherapy and going on trips out. Through the same organisation, he has support to volunteer in the charity shop, bakery, café and office during weekdays, as well as numerous directed activities such as arts, crafts and drama with important issues and life skills taught through role-play and discussion. Therefore, in relation to the argument for educating children with disabilities, I have observed in my own family the positive effects of specialised provision, which some researchers argue to be segregation (Greenstein, 2013; Nilholm & Alm, 2010).

Working in special schools, residential special schools and a children's home for young people with complex needs has consolidated the belief that specialist provision can support children with disabilities to have high quality, appropriate education and care. However, my experiences with children with disabilities have been only positive, accepting and interactive, which reflects the principles that launched the inclusive agenda nearly 30 years ago (UNESCO, 1994). Therefore, although I may present bias towards specialist education, I also advocate for equality and diversity.

1.2. Introducing me

My background as having a sibling with a disability plays a significant part in this research. The choice of methods as discussed in the Methodology (see 3) indicates this background as I am eager to emphasise the position of children with disabilities in qualitative research, their knowledge and potential involvement. It is hoped this piece of inclusive research encourages more collaborative and inclusive inquiries with children with or without disabilities, as co-researchers rather than subjects (Christensen & James, 2008). On the other hand, although my research explores children with WS's experiences, I am not a child with WS. I sit on the periphery, with acknowledgement that my background has influenced my desire for this particular topic for research.

Increasingly, more children with disabilities are attending their local mainstream primary schools. Over half the families in WSF have a child with WS in mainstream primary education (Gulliver, 2016), and therefore, I wanted to investigate the experiences of children with WS. Setting my study in mainstream primary schools has provided me with noteworthy comparisons from my own experience and knowledge of different educational provision. This has contributed to my position in the inclusion debate, and my understanding of how mainstream schools can successfully support children with disabilities. I hold a particular position as a sibling of a child with WS as my experiences enable me to observe, interpret and represent the views of children with WS from a close perspective.

Furthermore, from working with children and young people with different disabilities, I have insight into various resources and methods of communication for individuals with disabilities. However, although individuals may have similar diagnoses, for example WS, there are countless individual differences. The heterogeneity of individuals with WS has been widely highlighted in research over recent years (Lough *et al.*, 2016; Riby *et al.*, 2014). This means it is necessary to build a relationship with participants, to understand them as an individual rather than their diagnosis. Reflected in the medical model view of disability, any assumptions built from a diagnosis or label may prevent me from observing how different children experience mainstream primary school.

I have experience working as a teaching assistant in both mainstream and special provision supporting children from age 3-19 years. However, although I have taught children with different disabilities, I have not been involved in directly teaching a child with WS. WS guidelines suggest children with WS should be supported by a teaching assistant (TA) for at least part of the day (Tynan, Kye & Van Herwegen, 2021). This reflects the increase in numbers of TAs in primary schools that have been linked to the need for extra staffing to support children with SEN/D (Webster, 2014). The school staff therefore will have unique perspectives of working educationally with children with WS in their setting.

1.3. Introducing the inclusive context

Before the 1971 Education Act, many children with disabilities were deemed ‘ineducable’, either living in special care units, hospitals, or training centres that were then made into specialist schools when the responsibility of children with SEN/D was shifted from the area of health to education (Warnock, 1978). The broad umbrella term of SEN/D holds various definitions including specific learning difficulties such as dyslexia; speech, language and communication needs; cognition and learning; social, emotional and mental health difficulties and sensory or physical needs (DfE, 2015; Gibson & Blandford, 2005).

The notion of removing special schools began with the 1978 Warnock Report and 1981 Education Act encouraging mainstream schools to become more accessible to children with SEN/D (Hodkinson, 2012). Launching the concept of inclusion internationally, the Salamanca Statement (UNESCO, 1994, p.viii) stated “those with special educational needs must have access to regular schools which should accommodate them within a child-centred pedagogy capable of meeting these needs”. As well as attempting to address disablism in society, a social justice view of inclusion suggests that discrimination can be eradicated by removing segregation in the form of special schools (Norwich, 2008; Thomas & Loxley, 2007).

The following twenty years has seen a plethora of research and policies, including Mary Warnock's reconsideration in 2005 where she suggested there was still a place for specialist schools, which further highlights the uncertainty found in the inclusion debate (Warnock & Norwich, 2010). The SEND Code of Practice, reviewed in 2014 (DfE, 2015), details guidance for education settings to support individuals with disabilities aged 0 to 25 years. Furthermore, the Equality Act 2010 focused on employment rights and a clearer definition of disability to help form a more inclusive society (Florian, 2010).

Despite the surge in policies and guidelines, inclusion remains a difficult concept to define. Early use of the term was muddled with integration, which describes the practice of placing children with SEN/D into mainstream provision, rather than the principles behind accepting and including children with SEN/D (Rodriguez & Garro-Gil, 2015). Mainstream schools improved access by changing the physical environment, which provided access for children with certain types of SEN/D (Florian, 2010). However, children with SEN/D were not necessarily included as part of the class or whole school (Hodkinson, 2012). Practitioners have been left grappling with the consequences of ambiguous definitions and competing agendas.

Rather than view inclusion as a physical integration into a group or setting, other definitions suggest that inclusion needs a more nuanced understanding of being a valued member of the social community at different levels and degrees (Qvortrup and Qvortrup, 2018). Although a consensus of definition has not been reached, my own view of inclusion is based on the human rights principles of acceptance and a sense of belonging (Hodkinson, 2012). This means that inclusion can be achieved in all settings, regardless of mainstream or special provision. However, it is important that children's needs are met, differences are celebrated and opportunities are available that ensure every child has an equitable educational experience.

As inclusion became a legal obligation to educate all children with disabilities, the moral principles and values that legislation intended were at risk of being overshadowed by the challenges schools experienced in attempting an inclusive, quality education for all. With the added pressures of school league tables in England, tensions have grown between the inclusion of children with SEN/D in mainstream schools and the potential impact on reported academic achievement, affecting the school's overall score on school league tables (Broomhead, 2013). Despite suggestions that attendance of children with SEN/D would damage schools' positioning, research shows schools with a high inclusive ethos demonstrated a strong commitment to high achievement, showing inclusive practice to be beneficial to all learners (Farrell *et al.*, 2007). More recent research has suggested the high achievement of schools is directly linked with equity and the full participation of all children (Black-Hawkins, Florian & Rouse, 2016). Schools with high achievement might demonstrate inclusive values embedded throughout the school.

Research towards my masters' degree found that parents who chose a mainstream school for their child with WS focused on opportunities for their child to socialize and interact with same-aged peers (Gulliver, 2016). However, the particular socio-cognitive profile found in WS often results in difficulty making and maintaining friendships, leading to social isolation (Riby *et al.*, 2014). One of the purposes of my PhD study is to share with peers and school staff the collective considerations of interacting with a child with WS, resulting in better understandings of how to support a child with WS in a mainstream education setting.

1.4. Introducing the research

This research comprises case studies of four children with WS attending four different mainstream primary schools, in order to highlight individual experiences and insights. A case study approach helps to situate the participants' experiences in their schools. Settings were chosen based on parent's response to an invitation for research, in order to find schools being attended by a child with WS. The schools show a range of experiences which broadly reflects the support and experiences found among mainstream primary schools.

The main research question investigates "What are children with Williams Syndrome's experiences of mainstream primary schools?" The following sub questions then delve into more depth to understand the experiences of children with WS contributing to research, sharing their experiences of school, and the school's approach to supporting children with WS.

- What do children with Williams Syndrome show is important to them in their school?
- What do children with Williams Syndrome want to contribute to research about their experiences of school?
- How do children with Williams Syndrome interact with peers and staff?
- What do participants understand about supporting a child with WS in school?

- How do schools facilitate inclusion of children with WS?

It was important to me that the project captured the experiences of the children with WS in their setting. An adaptation of the Mosaic approach (Clark & Moss, 2011) was chosen for its strengths-based view of children, adaptability and opportunity to understand individuals' experiences of places and things. The Mosaic approach is a combination of methods including a guided tour of the location, picture taking and discussion, observations and interviews.

All the names of the schools and participants in the study are fictitious. I purposefully did not use initials or numbers, but full names to represent the very real people who shared their experiences within these four school communities. Therefore, the following study will explore the experiences of Sophie, Wendy, Ryan and Orla. All the school staff involved in the study were female, and therefore the titles for all the staff have been made Ms. Partly this is to protect the identifiable features of participants, but also because of the power assumptions that could be made between staff with different marital status and occupations.

My project explores whether mainstream primary schools need specific understanding and knowledge of Williams Syndrome to fully support children with WS and inclusion more generally. A review of the literature will discuss the complexity of conceptualising disability and introduce the field of Williams Syndrome research. My methodology will emphasise the strengths of using the Mosaic approach in enabling children with WS to share their individual experiences of four settings, respectively. The findings are divided into two sections, with the first highlighting children’s experiences and the second section underlining school’s experiences of managing the inclusion of these children. The headings and subheadings purposefully use active verbs to represent the process of investigating the field, learning from the children about their experiences, and thinking about how staff and schools encourage, guide and manage inclusion.

The discussion will highlight my reflections on supporting children with WS in mainstream primary schools. This will include both children’s and staff’s perspectives on their experiences of being part of a school community and understanding the subtle and complex ways children with WS communicate. The conclusion will emphasise how the study has contributed to the field with key findings and recommendations for further research.

2. Investigating the field

I will begin with a critical analysis of the concept of disability, to understand how disability is defined and viewed through different lenses. I will also position myself within the debate before introducing the current research field of Williams Syndrome (WS). The majority of research into WS comes from psychology and genetics studies, which I will use to explore the behaviour phenotype, cognitive and social profile of individuals with WS. It is also useful to contextualise this within my brother's life experiences, as well as some consideration for the type of research used, including cross-syndrome comparisons. There have been considerable developments in guidance for WS education and calls for wider research including children's views. I will then examine the inclusion agenda, discussing differences in staff roles and responsibilities in managing inclusion for children with SEN/D.

2.1. Conceptualising disability

Disability has been reconceptualised over the last century as advocates call for better representation and more equal opportunities (Series & Nilsson, 2018). However, there continues to be challenges and prejudices of a society built for and by neuro-typical people.

Having a label of disability can result in individuals being treated differently or discriminated against. For example, through stigma and discrimination, or the risk of a totalising approach which assumes all of a person's actions are as a result of their label (Arishi, Boyle & Lauchlan, 2017; McKenzie & Dallos, 2016). There is also a risk that their strengths or talents may be overlooked, and both stigma and being overlooked can become internalised by the child. Norwich

(2009) identifies this dilemma of identifying children with a disability or special educational need (SEN) in order to ensure access to educational resources. Parents interviewed from the United Kingdom, the United States of America and the Netherlands suggested reducing identification, but also improving the general education system to become more inclusive and positive about disability (Norwich, 2009). As argued previously, inclusion is a contentious area. One definition offered by Florian and Beaton (2018) is that inclusion can be viewed as a pedagogical approach that supports children's individual differences without marginalising individuals based on their needs.

Although this study focuses on the lives of children with Williams Syndrome, it is important not to ignore the intersectionality of disability, which includes a person's gender, sexuality, religion, ethnicity and more. As Goodley (2013, p.33) states, "disability is imbricated with other categories of difference, experiences of marginality and forms of political activism." A participant with a disability is also a participant with an age, gender, race and experience of the world. To understand how disability is seen as a disadvantage, it is important to contextualise other disadvantages such as poverty, gender and social class (Liasidou, 2012).

Case studies are a useful approach to explore the participant in particular contexts, which links to wider social, cultural and environmental influences (Stake, 2005; see 3.2). An important aspect of case study research is exploring intersectional factors, which embody each participant's situation. Looking through an intersectional lens helps to analyse and contextualise each case study with a greater depth. Furthermore, Liasidou (2012, p.170) argues that by drawing on intersectionality and disability, inclusive education debates can provide “alternative analytical lenses to challenge reductionist and neoliberal discourses of inclusive education, and discuss the extent to which educational structures and institutions create/perpetuate inequality.”

Marginalised groups and the ‘other’ have a substantial history of mistreatment and misrepresentation (Rieser, 2006), with the intersectionality of disability clearly entangling with race, class and gender (Goodley, 2013). From the genetics movement which interprets disability as an abnormality to be removed, to the dominating media portrayals of individuals needing help from a charity, individuals with disabilities have been represented as helpless and needy (Goodley & Runswick-Cole, 2011). Whilst disability studies focus on destabilising the traditional medical view of disability and highlighting socio-cultural influences, Goodley (2013) suggests critical disability studies extends this discourse to thinking about disability as a starting point for other complex debates encompassing the individual, for example, ethics of care, feminism and queer studies. In the same way queer theory rejects the binary of straight or gay, Goodley (2013) argues the importance of rejecting the dominant hegemonies of dis- and abled.

Noddings (2002) proposes ‘ethics of care’ as both the fundamental aspect and goal of education as caring and relating with others morally. Noddings (2002) also suggests that care is a basic need in that all people want to be cared for. Her distinctions between caring-for, and caring-about, builds a foundation for moral learning and justice. When an individual uses an ethics of care to care-about, they will action this to ensure the caring does occur. Noddings (2002) explains that those who experience being cared-for will have more desire to care for others. Based on my experiences of caring-for and caring-about, my study embeds a sensitive ethical approach which recognises moral principles and social justice. Individuals with disabilities are often seen as needing a level of care, through carers, support workers or teaching assistants. In Tom's organisation, there is a range of levels of care from support workers. Many of the individuals also express a desire to care-for, either through animal care, looking after others or caring for the environment. Using critical realism (Bhaskar & Danermark, 2006; see 3.2.2) enables me to consider caring-for and caring-about children with SEN/D as another starting point for exploring the relational experiences of children with WS in mainstream school.

Historical and political implications of labelling can perpetuate inequalities (Arishi, Boyle & Lauchlan, 2017). Therefore, advocates have been challenging the perpetuation of these inequalities through specific areas of discrimination; race, sexuality and gender. Schneider (2015) suggests that solutions for groups facing oppression can be helpful for promoting social participation for children with SEN/D. Alternatively, by considering the other through race, queer theory and Feminism, cultural theorists move away from the reductionist view which Shakespeare (2013) identifies as lacking theorisation and neglecting culture and identity. On the other hand, there is a clear distinction between disability and other oppressed groups (Shakespeare, 2006). If society achieved gender equality, feminism would no longer be needed because genders would be treated equally, thus removing the barriers to society. If individuals with disabilities no longer had social or physical barriers in society, they would still have the reality of their impairment.

2.1.1. *Models of disability*

People with disabilities were at significant risk of being socially oppressed, suffering from institutionalised discrimination (Barnes, 1996) when disability rights advocates and academics campaigned in the Disability Rights Movement of the 1970s. The success of the Union for the Physically Impaired Against Segregation (UPIAS) politicised disability and promoted the argument that learning difficulties could and should be catered for in mainstream schools. Instead of seeing disability as an impairment within children to fix or rehabilitate in a separate system, the Disability Rights Movement inspired change towards a needs model which understands that children have particular needs which could be provided for within a mainstream education.

The social justice and human rights agenda from the Disability Rights Movement promoted a change in view from individuals with impairments to disabling environments, discourse and attitudes (Barnes, 1996). The social model of disability argues that disability is a social construction, which is caused by the exclusion or restriction of activities from organisations that have not considered people with impairments. Instead of attempting to meet the needs of children with diverse learning needs, the social model of disability emphasised that the school is responsible for changing its environment and policy.

In the late 1990s, Tom experienced his first integration through a weekly physical education (PE) lesson at the local infant's school with children two years younger than him. My parents were overjoyed and emotional when the class teacher put Tom's name on a peg outside the classroom for his PE kit bag to hang with the rest of the class. However, conflating integration with inclusion meant that whilst mainstream schools may have improved the physical environment to enable children with disabilities to access provision (Florian, 2010), children may not have been included as part of the whole school (Avramidis & Norwich, 2002). Studies show parents are eager for their child to be more than physically present, but socially included and accepted into mainstream schools (Hess *et al.*, 2006; Slee, 2013; Gulliver, 2016).

A strong critique of the social model is the over-simplification of the real lives of people who have an impairment that is an important aspect of their life (Shakespeare, 2006). Individuals with WS have a micro-deletion on chromosome 7 that causes several challenges in learning difficulties and health. It is important to emphasise that the crucial work from disabled activists introducing the social model of disability were mainly people who had physical impairments. Therefore, people with intellectual impairments may not have been included or considered as carefully in the conceptualisation of this model. Similarly, Shakespeare (2006) argues that the UPIAS was a small group of activists who were predominantly white heterosexual men with physical impairments, and therefore not representative of different disabilities and experiences.

The concept of an intellectual disability can be defined through the medical diagnostic category of a cognitive abnormality and maladaptive behaviour (Schalock *et al.*, 2010). These two areas involve levels of intelligence and difficulties with social and daily life. Intellectual disabilities are then classified as mild, moderate, severe or profound and multiple learning disabilities. Identification of intellectual disability relies on categorising scores from IQ results of 25-39 as severe, 40-54 as moderate, and 55-69 as mild (Rapley, 2004).

Research has found the mean IQ of individuals with Williams Syndrome (WS) to range from 55 to 62 (Mervis & Klein-Tasman, 2000). My brother's full-scale IQ was 59 when tested in 2013. However, the IQ level measurement can mask large and important differences in ability such as visuospatial ability, which studies have found to be much lower in people with WS than their verbal ability (Bellugi *et al.*, 2000). This definition of intellectual disability focuses on the medical discourse of impairments, diagnosis, disorder and abnormality. However, "the conceptualisation of disability as a political-ethical-moral social status is central to the arguments of the theorists of the social model of disability" (Rapley, 2004, p.62). Therefore, although it can be useful to categorise the levels of an intellectual disability, this is only one aspect of how a cognitive disability could be measured or experienced.

It can be unhelpful to analyse the dominant medical and social models of disability as though they are the only two and contrasting views. Although literature views a paradox between the different models of disability, my family has clearly navigated a path between managing various models of disability with Tom. When the local authority suggested that Tom could attend the local town college, my parents had to fight for the funding for Tom to attend a specialist residential college further away. Tom would not have received the type of support at the local college that he did at his specialist college. To apply for funding meant viewing Tom in a deficit way, by highlighting his difficulties in comparison to typically developing peers. My family had to use different discourses when collecting evidence to support arguments for funding, as they negotiate different ways of thinking in order to benefit Tom. On the other hand, the affirmation model by Swain and French (2000) can be seen in our family as we enjoy the love and inspiration that he brings which is also part of his disability; my other brother talking about Tom at his interview to medical school, and myself now inspired to explore other children's experiences of WS in schools.

Although views towards disability have evolved, it remains a complex, political debate with individuals fighting for equal access to work, housing, education and status (Slee, 2013). The next section will explore the specific type of disability Tom has, and how it might be diagnosed and recognised in society.

2.2. Diagnosing Williams Syndrome

In the following section, I will identify a significant amount of research introducing Williams Syndrome, a rare intellectual disability that is diagnosed by medical professionals (Hillier *et al.*, 2003). I will link my own experiences with the literature to help contextualize the medical research. My brother Tom was diagnosed at 14 months by a paediatrician based at the local hospital, who recognized Tom's medical history and facial features. Individuals with WS share distinct facial features, which can include a wide mouth, upturned nose, high rounded cheeks, irregular and/or widely spaced teeth, a stellate pattern in the iris and a squint (Bellugi *et al.*, 2000). Years later, a simple blood test could determine a diagnosis using a FISH (fluorescence in situ hybridization) test of DNA (Hillier *et al.*, 2003) and recent anecdotal stories from parents show some diagnoses even before birth. With a diagnosis, my family had access to the charity Williams Syndrome Foundation (WSF), set up by parents of children with WS to share advice and information about the disability.

Williams Syndrome (WS) is a rare disability caused by a microdeletion on the 7th chromosome resulting in moderate to severe learning difficulties and a range of health problems (Karmiloff-Smith *et al.*, 1995). Population studies reveal different occurrence rates, from of 1 in 20,000 live births in the USA (Karmiloff-Smith *et al*., 1995) to a study in Norway stating the prevalence to be as many as 1 in 7,500 (Strømme, Bjømstad & Ramstad, 2002) but no other prevalence studies have been conducted to date. Research on genetics has refined a specific region with around 20 genes deleted on 7q11.23 (Mervis, 2003). Previously, diagnosis was extremely difficult, with very little information known about WS until 1988 when researchers became particularly interested in the relation between language abilities and cognitive deficits (Mervis, 2003). Two years later, Tom was born.

When comparing children with WS to typically developing children, there is an emphasis on a deficit view of disability. An array of health and mental health difficulties are common in individuals with WS. Infants and young children with WS have difficulty thriving, which often includes trouble sleeping, feeding and maintaining weight. Global developmental delay means children will be slower to hit key milestones such as walking or talking. Around 75% of individuals with WS have the congenital heart defect Aortic Pulmonary Stenosis (Donnai & Karmiloff-Smith, 2000). Hyperactivity and ADHD are common, as well as hypercalcaemia (abnormally high levels of calcium), hypertonia and texture intolerance (Donnai & Karmiloff-Smith, 2000). Often, there are reports of gastrointestinal difficulties, urinary tract and bladder problems. My parents had to become confident in working with a wide range of medical professionals such as cardiologists, anaesthetists, physiotherapists, occupational therapists and more, to help Tom to manage his disability.

2.2.1. *Physical needs*

One of the areas children with WS may experience difficulties is developing motor skills, strength and coordination (Bellugi *et al.*, 2000). This is particularly useful to know when supporting children with WS in school. Some research shows that individuals with WS have more difficulties with fine motor skills than they do with gross motor skills (Bellugi *et al*., 2000), although motor delays are common throughout childhood and adolescence compared to age matched typically developing peers. Individuals with WS have poor muscle strength and agility, performing worse than the group of age matched participants with Down Syndrome (Wuang & Tsai, 2017). Agility and movement are important for school-age children with WS to navigate daily activities.

Individuals with WS have specific cognitive difficulties in certain visuospatial perception and memory skills which has "implications for a variety of tasks requiring gross or fine motor control" (Wuang & Tsai, 2017, p.1048). Visual perception includes discriminating, memory and understanding the visual-spatial relationship, which will affect how an individual understands and interprets what they can see. Atkinson and Braddick (2011) suggest there are several difficulties with visual perception, spatial processing, task switching and motor control and planning which affects individuals with WS managing everyday tasks. For example, rotating an item to fit in a slot is a particular challenge as an individual must learn to grasp the item with their thumb in a position which will enable them to turn their wrist comfortably, or be able to leave their hand in a comfortable position after fitting the slot.

Individuals with WS may have difficulties with balance, tone, gait, and fine motor coordination, particularly in comparison with same age individuals without disabilities (Barozzi *et al*., 2013; Morris & Mervis, 2021). Barozzi *et al*. (2013) suggest that activities such as climbing stairs requires visual depth information. As a baby, when moving from the patio to the grass, although it was flat, Tom would stop, sit down and crawl across as if he was unsure of the depth of changing surfaces. However, Atkinson and Braddick (2011) argue that difficulties are due to a dorsal stream impairment through a combination or visual, motor, cognitive spatial and executive functioning impairments. Although hypertonia is observed in younger children, there is also differences in muscle tone and hyperreflexia in older children with WS. When he was older, I video recorded Tom walking towards me on a trip to the seaside when Mum spotted that he seemed to be walking with an awkward gait. This video was shown to medical professionals and subsequently hyperreflexia was suggested. Tom is now regularly accessing physiotherapy routines and daily stretches at home with support.

Furthermore, Harvey *et al.* (2020) has highlighted the probability that more than 50% of children with WS will have visual difficulties but that this may be overshadowed by their diagnosis and other visual-motor impairments. Harvey *et al*.'s (2020) results of their study showed children with WS had a range of complex vision difficulties that were not reported in their Educational, Health and Care plans (EHCP), a document which should outline the education, health and social care needs of children with SEN/D. This emphasises the difficulty in knowing how to support children with a specific rare disability.

2.2.2. *Sound sensitivities*

Hyperacusis has been associated with Williams Syndrome, often accompanied by cochlear hearing loss. Hyperacusis involves sensitivity to loudness, annoyance, fear, and pain which can result in anxiety and depression, and has been linked to social phobias and generalised anxiety disorders (Tyler *et al.*, 2014). Hypersensitivity to certain sounds, particularly machines, fireworks and balloons bursting occurred in 85-95% of individuals with WS in one study (Donnai & Karmiloff-Smith, 2000).

Research describes hyperacusis as an oversensitivity to 'normal environmental sounds' and phonophobia as an 'aversion to or morbid fear of normal sounds' in research using a Hyperacusis Screening Questionnaire and Audiologic testing (Gothelf *et al.*, 2006). Results highlighted cochlea hearing loss in WS could be linked to repeated exposure of high-level noise although no children were exposed to high-risk level noise. Findings state:

> The cochlear impairment in WS is due to repeated noise stimulation in the absence of the appropriate protection normally provided by the acoustic reflex. The hyperacusis could be the result of the combination of cochlear hearing loss and auditory nerve dysfunction, which probably alters the perception of loudness in the afferent auditory system (Gothelf et al., 2006, p.394).

Therefore, the authors propose standard support such as behavioural desensitization to noises through repeated exposure would be inappropriate for individuals with WS. This also raises concerns for how children manage normal environment noises that sound very loud.

Gothelf *et al.*'s (2006) findings are supported by recent guidelines that emphasise the use of very gentle and gradual exposure to sound, which is then shared by giving the child some control over the sound (Tynan, Kye & Van Herwegen, 2021). Furthermore, a recent study examining the acceptability and effectiveness of a play-informed and humour based gradual exposure therapy for children with WS suggests this could be a valuable intervention to engage with phobic stimuli (Klein-Tasman *et al.*, 2022).

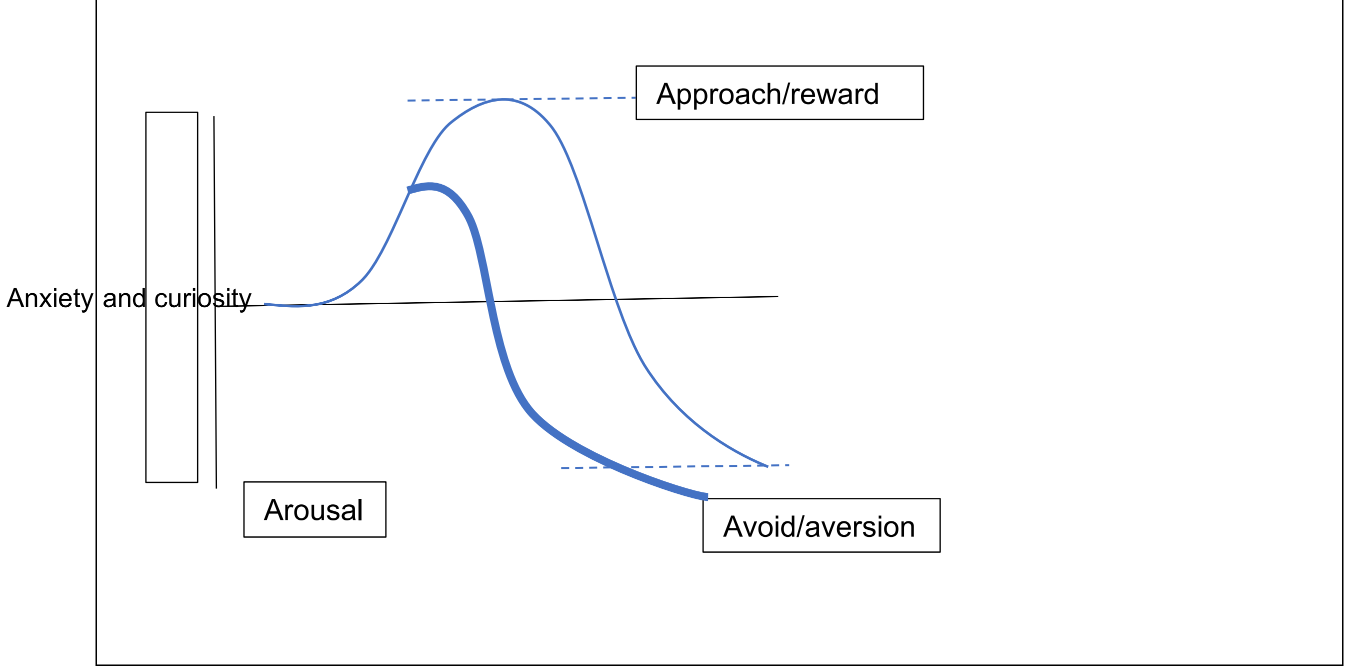
Glod, Riby and Rodgers' (2020) review on sensory processing issues such as hyperacusis confirmed sound sensitivity was often reported more in younger children with WS. Described as abnormal reactions to sounds, the authors also note hyperacusis as one of four categories of the unusual auditory phenotype; lowered hearing thresholds, lowered uncomfortable loudness level, fear of certain sounds and auditory fascinations (Glod, Riby & Rodgers, 2020, p.34). An interesting distinction here is there a difference between hyperacusis and a broader range of sensory processing difficulties associated with younger individuals with WS. Therefore, I have reflected this by labelling the section sound sensitivities rather than categorising them as a type of hyperacusis.

Anecdotally, familiar experiences at WSF networking events are asking the very popular disco to lower the volume, whilst children cover their ears and talk worriedly about the possibility of fireworks, balloons bursting or sudden noises. Every Bonfire Night my brother's building excitement is paired with his need to be safely inside a building watching from the window with a pair of ear defenders, worried about the noise. Research confirms this as an unusual auditory phenotype in WS, although Levitin *et al*.’s (2005) study found true hyperacusis and auditory fascinations were reported less than fearfulness to idiosyncratically particular sounds (80%) and lowered uncomfortable loudness levels, known as odynacusis (Levitin *et al*., 2005).

Families of children with WS have shared their child’s interests in hoovers or fire engines. These obsessional interests have also garnered some attention across the media, with ‘The boy who is obsessed with vacuum cleaners: Rare syndrome means that Lane, 9, just can't stop collecting Henrys’ and ‘An eight-year-old who has the rare disorder Williams Syndrome had a visit from #Sutton firefighters for his birthday. Ethan loves the emergency services but alarms make him anxious so crews went to him to donate old equipment for his new blue light themed bedroom’ (Innes, 2013; LondonFireBrigade, 2019). This helps indicate the complex relationship between sound sensitivity and sound fascinations.

To investigate this further, Wundt’s U shape curve shows levels of arousal when exposed to stimuli; examined by Berlyne (1960) who proposes there are stronger negative reinforcement of unpleasant (anxiety related) feelings than the positive reinforcement of the reward of the stimuli. For example, an individual experiences a reaction to an object or noise (stimuli) and may experience a stronger anxiety rather than the reward of the object or noise. Spielberger and Starr (2012) expand this to include an individual’s management of anxiety and curiosity, suggesting that individuals may experience heightened physiological arousal through specific curiosity. Similarly, Semel and Rosner (2003) highlight that individuals with WS can be very distracted by noise to the extent of leaving all activity to find the source of the sound, suggesting the need for exploratory behaviour as suggested by Berlyne (1960).

Figure 1: Adaptation of Wundt's U shape curved with Berlyne and Spielberger and Starr's curiosity.



Stimuli that exceed the optimal level may evoke specific curiosity and exploratory behaviour, flight or fear. For example, a loud, daily environmental sound that creates a larger reaction than usual, may cause individuals to need to find the location to explore this sound and experience the physiological reactions common with flight or fear. When searching for the stimuli, an individual's curiosity will be peaked, and curiosity encompasses some elements of anxiety (Spielberger & Starr, 2012). Individuals may be able to reduce their uncertainty and discomfort by exploring the stimuli. This may offer some explanation as to the fascination with certain sounds that many individuals with WS seem to display. However, the stronger negative reinforcement of anxiety related feelings causes the individual to avert, as reflected by the bolder blue line (Figure 1).

Perhaps an added complexity to sound sensitivity is the musical affinity many individuals with WS appear to show towards music listening and music making (Dunning, Martens & Jungers, 2015; Erasmus, 2014). The strong relationship between WS and music has been anecdotally known with minimal research reviews or publications until Thakur *et al.'s* (2018) systematic integrative review highlighting strengths in musicality, expressivity and heightened emotional responsiveness. Despite cognitive impairments, many individuals with WS have matched musical abilities to typically developing control groups (Erasmus, 2014; Thakur *et al.*, 2018). This is supported by Levitin *et al.'*s (2004) study who also showed individuals with WS displayed greater emotional responses to music, earlier interest in music and listened to more music per week. Both positive and negative effects of listening to music also lasted longer in the WS group (Levitin *et al.*, 2004) which supports the heightened emotional responsiveness to music.

The last 30 years of research into Williams Syndrome gives readers a detailed and informative picture of the genotype and phenotype typically found. This is useful as it depicts the various strengths and difficulties that children with WS may experience. The following section explores a range of common characteristics associated with individuals with Williams Syndrome.

2.3. Characterising Williams Syndrome

Individuals with WS are known for displaying charming and gregarious character. Described as an 'uneven' socio-cognitive profile with 'peaks and troughs' (Donnai & Karmiloff-Smith, 2000; Klein-

Tasman, Li-Barber & Magargee, 2011), research into Williams Syndrome tends to use the traditional deficit view of disability. This section will look further into the characteristics and behaviours often displayed by individuals with WS, such as hypersocial behaviours, social strengths and difficulties.

Previously called ‘cocktail party chatter’, individuals with WS can have significant strengths in expressive vocabulary (Brawn & Porter, 2017; Stojanovik, 2006). Despite their happy nature, individuals with WS can also experience anxiety, phobias and difficulty with concentration (Brawn & Porter, 2017). Described as an “undercurrent of anxiety,” Meyer-Lindenberg *et al.* (2005, p.991) found individuals with WS showed extremely high rates of excessive worrying (57%) and specific phobia (symptoms in 96%) whilst Riby *et al.* (2014) indicate individuals with WS struggle to understand the concept of stranger danger. It is therefore important that children with WS have opportunities to practise and develop their social skills and management of anxieties.

2.3.1. *Hypersociability*

Individuals with WS are described as over friendly or hypersociable, due to their eagerness to socially interact with others, including familiar and unfamiliar people (Fisher *et al.*, 2017; Klein-Tasman, Li-Barber & Magargee, 2011). Although this skill is arguably useful for socializing with others, welcoming the public and engaging with audiences, there are risks associated with individuals’ lack of discrimination between friends and strangers. Therefore, it is understandable why much of the research highlighting it focuses on the challenges.

Research has probed at the possibility of hypersociability being intentionally used to camouflage challenges in social-perceptual skills, social-cognition, communication, and maladaptive behaviours that impact daily living skills (Jarvinen, Ng & Bellugi, 2015). Similarly, Riby *et al.* (2014) questioned whether the WS social phenotype helps protect individuals from the development of anxiety, or acts as a mask. Examining the drive behind approach behaviours in individuals with WS compared to typically developing individuals, Jarvinen, Ng and Bellugi (2015) indicated that although both groups showed desire to talk to strangers, individuals with WS were more willing to befriend strangers than typically developing individuals. The authors suggest the typically developing individuals were able to understand social context whilst the individuals with WS demonstrated a reduced ability to socially evaluate others. Difficulty in understanding contextual cues may be related to individuals' lower cognitive abilities impacting on decision-making and trust judgements (Järvinen *et al.*, 2015).

Plesa Skwerer and Tager-Flusberg (2016, p.174) investigated "whether the heightened social motivation and empathy demonstrated by children with WS [would] lead to prosocial behaviours such as instrumental helping". However, although results showed higher empathic responsiveness to another's distress, individuals with WS were less likely to actively help. This indicates a difference between their desire to interact and the reasoning behind the interactions, or knowledge and understanding of what to do to support another person's distress.

High social motivation and eagerness to befriend others was also found by Weisman *et al.* (2017) in a task where individuals with WS chose to become friends with a person in a story regardless of how they perceived them, in positive and negative scenarios. When comparing groups of individuals with WS and individuals with the diagnosis of 22q11.2 deletion syndrome, individuals with developmental disabilities and typically developing individuals, the WS group experienced more difficulty with the false belief task than some but were better at labelling happy faces than others (Weisman *et al*., 2017). This indicates the unique socio-cognitive profile attributed to individuals with WS who display high social motivation, as well as cognitive difficulties such as perceptual and auditory processing, working memory and executive control which results in difficulty identifying others' concealed intentions and thoughts. Weisman *et al.* (2017) suggest stories may be an effective teaching strategy to help children with WS learn how to respond in different social situations, which could help reduce their social vulnerability.

2.3.2. *Social vulnerability*

Researchers suggest that hypersociability behaviours result from an inability to suppress high social motivation impulses (Jawaid *et al.*, 2012). Therefore, individuals with WS may have emotional understanding, but are unable to control their prosocial drive due to their differently functioning frontal lobe (Porter, Coltheart & Langdon, 2007). However, researchers have also linked an atypically enlarged amygdala volume with atypical social approach behaviours (Martens, Wilson & Reutens, 2008). In Haas *et al.* (2010)'s study, individuals with WS showed abnormal amygdala response to fearful expressions, paired with an increased tendency to approach strangers.

In their study on neural correlates of genetically abnormal social cognition, Meyer-Lindenberg *et* *al.* (2005) matched typically developing individuals to age and IQ of individuals with WS with a high functioning intellect. When shown threatening faces, amygdala activity was significantly lower in individuals with WS compared to the typically developing group. On the other hand, amygdala activity was abnormally increased for individuals with WS in the threatening scenes test, which is associated with specific phobias. This could explain the high non-social anxiety found in individuals with WS (Meyer-Lindenberg *et al.*, 2005). A decreased social fear would explain the social disinhibition found in individuals with WS, because the amygdala is not signalling to avoid the threat, for example a stranger. A combination of prosocial behaviour, and inappropriate reactions to threat or certain circumstances can lead to significant social vulnerability. Non-social anxiety may also cause challenges for children with WS in daily activities at schools.

Overall, research indicates the complexity of the social cognitive profile in individuals with WS and emphasises the social vulnerability of individuals with WS through social competence and approach behaviour. Several studies have investigated the social vulnerability of individuals with WS, where results show little appropriate awareness or knowledge of risks of interacting with unfamiliar adults compared to typically developing children (Lough *et al.*, 2016; Riby *et al.*, 2014). Brawn and Porter (2017, p.20) highlight "the presentation of individuals with WS, such as their friendliness and relatively good conversational abilities can mislead professionals and result in an underestimation of the amount of support required to enable participation within the community and increased independence". However, little research has investigated how this is managed through education, and how their social vulnerability may impact school life.

2.3.3. *Anxiety*

Research has suggested figures of up to one in five children experience mental health problems (Bor *et al.*, 2014) and the UK has been highlighted as one of the poorer countries for children's wellbeing (Innocenti, 2020). Individuals with WS have a higher risk of anxiety disorders such as generalised anxiety, separation anxiety and specific phobias as one of the most commonly reported anxiety disorders (Dykens, 2003), compared to the general population (Pitts *et al.*, 2016; Royston *et al.*, 2017). Moreover, there is a distinction to be made between anxiety disorders and anxiety.

The psychological symptoms of anxiety may include concentration difficulties, distractibility and memory difficulties, which are all also common among children with WS. Therefore, there is a risk of diagnosis overshadowing, where the characteristics of anxiety may be attributed to be part of the syndrome rather than a presentation of anxiety. Additionally, the traditional medical model view of disability proportions the blame of characteristics and behaviours onto WS as opposed to external factors such as environmental or societal barriers.

For education settings, Einfeld (2005) claims that 'emotional disturbances' can be difficult to manage in school, suggesting that children with WS require anti-anxiety medication rather than strategies to overcome the intense anxiety. This view echoes earlier medical perspectives of disability which attribute the problem to within the child which can be fixed, rather than a social perspective which questions how society can be fixed, for example in attitudes and knowledge of WS. A booklet produced by members of the North East Williams Syndrome Research group for WSF provides information and guidelines for primary school teachers of children with WS. Furthermore, an anxiety toolbox and resource leaflet have been produced in an effort to help parents manage and address their children's anxiety (Rogers, Riby and Hanley, *in preparation*). However, this is an intervention for parents at home, and it is not known how successfully this can be adopted in a school setting.

Higher anxiety is linked to difficulties with social functioning, suggesting that challenges navigating social situations may cause anxiety. Furthermore, impairments in executive functioning were linked to increased anxiety (poor inhibitory control, high impulsivity, and poor adaptive and attentional flexibility) (Ng-Cordell *et al.*, 2018) which is another measurement used to define disability. Therefore, it is unsurprising that children with WS may have an increased risk of anxiety because of their difficulties with executive functioning and difficulty managing social situations.

There is notable presence of anxiety disorders for people with WS; a high risk of experiencing anxiety compared to typically developing peers, which researchers continue to explore (Ng-Cordell *et al.*, 2018; Rodgers *et al.*, 2012; Royston *et al.*, 2017). However, research often uses standardised assessments and classification criteria developed primarily for the general population. Measurements rely on parent or carer reports of symptoms of anxiety disorders rather than symptoms of anxiety. For example, the Spence Children's Anxiety Scale—Parent Version (SCAS-P) is a 38-item parent-report measure that assesses symptoms of anxiety based on DSM-IV criteria for childhood anxiety disorders (Spence, 1998). Recently, this is beginning to be explored through interviews with parents who describe behaviours and strategies for managing anxiety (Royston *et al.*, 2021). Parents reported anxiety showing as physiological through trembling and sweating, and behaviours such as crying, repetitive behaviours, a worried look and increased vocalising or talking to others (Royston *et al.*, 2021). However, this relies again on parental report and contributes to the lack of research that involves children's own perceptions and experiences.

Despite the high number of hospital visits, medical appointments and blood tests that children with WS often experience, little research has investigated how families manage health anxiety. One case study revealed an increased risk of PTSD for individuals with WS, particularly with the high prevalence of anxiety pre-surgery, and the connection with PTSD for individuals following heart surgery (Alexander *et al.*, 2019). Therefore, although research continues to develop an understanding of reported behaviours and symptoms of anxiety disorders, there is a gap in understanding the reality of children with WS who may experience anxiety.

2.3.4. *Emotional sensitivities*

Earlier research has emphasised empathy as a distinctive personality trait amongst individuals with WS (Frigerio *et al.*, 2006; Klein-Tasman & Mervis, 2003; Mervis & Klein-Tasman, 2000). Recently updated educational guidelines for WS highlight empathy or emotional intelligence as a strength (Tynan, Kye & Van Herwegen, 2021). Parental reports using the Children's Behaviour Questionnaire and personality questionnaire suggests 96% of the children with WS showed empathic characteristics (Klein-Tasman and Mervis, 2003). Smith (2006) suggests that people with WS have a high emotional empathy sensitivity, but that this can impact their intellectual development, as they focus more on the emotions of the speaker than the content (Smith, 2006). Therefore, this leaves individuals with WS with several challenges in managing their own emotions and the emotions of others.

In previous research, young people with WS showed more verbal empathy (such as validation or comforting) and behaviours compared to those with other mild to moderate disabilities (Sullivan & Tager-Flusberg, 1999). Plesa Skwerer and Tager-Flusberg (2016) suggest this research shows enhanced empathy compared with age-matched children with and without developmental disabilities. However, research has highlighted individuals with WS have difficulty identifying others' concealed intentions and thoughts, (Weisman *et al.*, 2017) which would enable them to understand empathy.

The difficulty in defining empathy is distinguishing between connecting with a person's feelings, and responding to one's own distress. Rosner (2001) states that these are two very different experiences:

> However, one defines empathy and sympathy, both are thought to differ from personal distress, which is seen as a self-focused, aversive reaction to another's state that is experienced as anxiety or discomfort (Rosner, 2001, p.6).

Both types of experiences may lead to prosocial behaviours such as helping, although WS participants did not actively respond in a study examining helping behaviours by Plesa Skwerer and Tager-Flusberg (2016). The experimenter did not ask for help, or praise any help, and parental expectations or practices might account for the differences between WS and DS groups in whether they helped. Overall, the authors could not indicate whether individuals with WS showing concern reflect higher levels of empathy, or “increased behavioural expressiveness, more likely related to social disinhibition than to social competence” (Plesa Skwerer and Tager-Flusberg, 2016, p. 1016). Either way, individuals with WS may experience personal distress and anxiety when seeing another person’s emotional state.

Children with WS were also rated by parents as more anxious than comparison groups, although they did not show more behaviours reflecting personal distress during displays of emotion (Rosner, 2004). Therefore, this leads me to question how individuals with WS display anxiety, particularly if they experience emotions more acutely than other individuals. Results from the same author indicate that young people with WS with higher anxiety ratings were less likely to respond with empathy (Rosner, 2001). However, research has highlighted the complexity of affective and cognitive empathy, with Tone and Tully (2014) emphasising the link between empathy and an increased risk of internalising problems such as anxiety which particularly relate to the fear and arousal system (See figure 1).

Despite earlier reports emphasising empathic qualities, Laws and Bishop (2003) propose individuals with WS have pragmatic language impairments and poor social relationships. Social cognition comprises identifying facial emotions, reasoning, empathy, theory of mind and decision making (Serrano-Juárez *et al.*, 2021). Social cognitive areas have been highlighted as a social ‘dysfunction’ and difficulties for individuals with WS. Therefore, it is more likely that individuals with WS may experience emotional sensitivity or transference rather than empathy. Smith (2006) overcomes this argument by proposing that empathy can be divided into two abilities; cognitive empathy (theory of mind skills) and emotional empathy (sharing emotions).

Children with WS may experience more intense emotional reactions to seeing other people's emotions. They may experience difficulty with understanding and identifying the emotions of others, which includes what to do with their emotions. Researchers argue between highlighting a high emotional empathy, and a low social cognition, which is needed to really understand empathy. Therefore, I question whether children with WS are experiencing empathy, rather than a heightened sensitivity to emotions which requires support and education in knowing how to identify and respond to other's emotions.

2.4. Researching Williams Syndrome

Previous research into the social profile of individuals with WS has used various surveys and systems such as the SRS (social responsiveness scale), SSRS (social skills rating system) and Child Behaviour Checklist (Jarvinen, Ng & Bellugi, 2015; Klein-Tasman & Lee, 2017; Klein-Tasman, Li-Barber & Magargee, 2011; Riby *et al.*, 2014). Results are useful in highlighting different areas of strength and difficulty, for example, individuals with WS scored highly in social motivation, with lower scores in social awareness and social competence (Klein-Tasman & Lee, 2017; Klein-Tasman, Li-Barber & Magargee, 2011). This suggests that children with WS need specific social skill support in educational contexts, to develop their social cognition and competence.

Recent research of social functioning has used the SRS and Salk Institute Sociability Questionnaire (SISQ) to explore parents' perspectives of children aged 7-14 years with high-functioning Autism, WS or neurotypical development and their reported observed social traits (Lai, Ng & Bellugi, 2021). The SRS measures social competence, social awareness, social motivation, social cognition and social communication whereas the SSRS assesses behaviours including cooperation, assertion and self-control (Klein-Tasman & Lee, 2017). Klein-Tasman, Li-Barber and Magargee (2011) used multiple rating systems to increase validity, as well as comparing reports from both parent and teachers. Their results highlight differences in how adults perceive social behaviour, with teachers rating milder difficulties than parents. Furthermore, the study included children with WS in mainstream and special education settings. The experiences of children and parent and teacher interpretations of their social skills could vary depending on so many individual differences. Authors suggest that parents may have compared their child with typically developing siblings to perceive starker differences than teachers.

Another questionnaire often used is the Child Behaviour Checklist School Age Form. This tool is a 113- item rating questionnaire which measures behavioural, emotional, and social difficulties. Categories comprise of: anxious/depressed, withdrawn/depressed, somatic complaints, social problems, thought problems (including obsessions, compulsions, nose and skin picking, nervous movements, sleep difficulties, seeing or hearing things, and strange ideas or behaviour), attention problems, rule-breaking behaviour, and aggressive behaviour (Klein-Tasman *et al.*, 2015). A challenge with checklists are that participants are limited to pre-selected options, closed responses and no research into the possible indicators, triggers and reasons for the behaviours, or examples of real lived experiences.

Lough *et al.* (2016) used SRS and the Spence Children’s Anxiety Questionnaire – Parent Version to extract in-depth qualitative data through semi-structured parent interviews. Statistical analysis in their study found all individuals displayed ‘inappropriate’ social behaviour and naivety to danger, although this behaviour was influenced by different personality traits, the nature of social behaviour and how parents responded to the behaviour. Due to the heterogeneity of the group, Lough *et al.* (2016) suggest support for individuals with WS and their families must be tailored to account for individual differences.

Many of the research studies conducted with groups of individuals with WS compare their results with other groups of intellectual disabilities, and typically developing peers that could be age matched, or IQ matched. However, my study does not need to compare experiences of groups of individuals, because the research focuses on the experiences of those with Williams Syndrome to offer insights, rather than children with other types of disabilities.

2.4.1. *Mirror syndromes*

Social strengths and over-friendliness were often reported in direct contrast to individuals with other disabilities such as Autism Spectrum Disorder (ASD). Mervis and Becerra (2007) argue that although ASD has been viewed as the opposite of WS, they often overlap. Similarly, Laws and Bishop (2004) claims WS shares many characteristics of ASD. Parents and teachers completed the Children’s Communication Checklist (Laws & Bishop, 2004) which found that individuals with WS also had pragmatic language impairments, difficulty with social relationships and restricted interests that can often be found among characteristics of ASD.

Likewise, Riby *et al.* (2014) found over half of participants with WS scored highly on the subscale 'autism mannerisms' on the SRS including stereotypical behaviours and restrictive interests. Restricted and repetitive behaviours (RRB) are often seen in individuals with ASD, and researchers have questioned whether RRB are used to reduce anxiety, or could be a consequence of anxiety. In a cross-syndrome comparison of parent self-reports, research did not find a link between higher levels of RRB and anxiety for the WS group (Rodgers *et al.*, 2012). Similarly, Huston *et al.* (2021) found no link between the severity of individuals with WS's compulsions or stereotypies (repetitive thoughts and behaviours) although there was a link between higher anxiety and severity of obsessions.

Interestingly, it is becoming increasingly known that individuals with ASD, particularly females, can be good at masking their symptoms, either through compensating or camouflaging (Corbett *et al.*, 2021). Compensation "occurs when a person's observed behaviour appears more typical than what would be expected" based on their ability and symptoms (Corbett *et al.*, 2021, p.1). Therefore, individuals would have to understand and recognise the social behaviours, cognition and emotions of others using theory of mind. This would be more difficult for individuals with WS to do as research has shown significant difficulties among individuals with WS in theory of mind tests, which recognises the intentionality, beliefs and emotions of others (Karmiloff-Smith *et al.*, 1995; Serrano-Juárez *et al.*, 2021). For example, individuals with WS often do not understand metaphors, jokes or irony.

Camouflaging refers to individuals with ASD hiding or masking symptoms that “may be viewed as socially unacceptable… by imitating or memorizing the social behaviours of others” (Corbett *et al.*, 2021, p.2). As previously stated, hypersociabilitiy and the charming, sociable behaviours from individuals with WS could be used as an opportunity to mask their misunderstandings or anxiety. On the other hand, this could be unhelpful as individuals may be masking their difficulties or worries. I remember occasions where my family taught Tom to practise and rehearse social behaviours such as minimising staring at people and rocking on his feet. The difficulty with practice conversations is the unpredictability of the reciprocator. Similarly, although rocking on his feet would sometimes make my parents dizzy, it was a good way of him indicating that something might not be right, for example, needing to change activity or showing he was worried.

Although disability research can help stakeholders understand difficulties between groups of children with disabilities and those who are typically developing, there is a risk that research can over emphasise or oversimplify the lives of children with WS when compared to other syndrome groups. Furthermore, the clear gap of children’s voices may reflect the belief that individuals with disabilities lack the capability to conduct research about their own lives. Therefore, it is important to enable children with WS to take an active part in research about their lives to find out their own experiences.

2.5. Educating children with Williams Syndrome

Due to the rarity of Williams Syndrome, school staff may not recognise or have experience working with children with this disability. In their study, Reilly, Senior and Murtagh (2015, p.1) concluded:

> The majority of teachers of children with neurogenetic syndromes report limited knowledge of the syndromes, but also a lack of belief that the children's needs are different from the majority of children with intellectual disabilities.

Individuals with WS however do show specific areas of strengths and needs that are unique to the WS profile compared to other intellectual disabilities.

Palikara, Ashworth and Van Herwegen (2018) share their concern for the limited practical research and evidence-based interventions for individuals with WS who have a range of complex needs to be supported in education settings. Although a rare disability, the authors suggest interventions for children with Downs Syndrome and ASD may also be beneficial for children with WS in different ways. Research therefore needs to be conducted to evaluate evidence-based interventions for specific groups.

2.5.1. *Educational guidelines*

There has been a significant movement of research towards educational interventions and programmes for individuals with WS, with key individuals such as Dr Fionnuala Tynan, an educator in Ireland who also has a brother with WS. Tynan's (2018) book, Williams Syndrome Holistic Educational Strategies (WISHES) promotes a strength-based view of children with WS and presents educational strategies both in the classroom and at home, with a range of practical worksheets and toolboxes for reflecting on individuals’ needs and development.

Earlier guidelines for teachers of children with WS were written by experts in the field in the 1990s, although no research has evaluated the views, experiences or validity of these guidelines (Reilly, Murtagh & Senior, 2016). Recently, the teachers' guidelines have been updated by Tynan, Kye and Van Herwegen (2021) and a current study underway by the same authors seeks to develop Children’s guidelines with children and young people’s own perceptions.

In their study on behavioural phenotypes in the classroom, Reilly, Murtagh and Senior (2016) analysed parents’ and teachers’ views on key interventions for children with specific intellectual disabilities, including WS and Fragile X Syndrome, Prader-Willi Syndrome and Velo-cardio-facial Syndrome. Parents of children with WS reported the need for structure or routine and visual methods least, however these results were compared between the syndromes. Routines and visual methods are recommended in the WS Education guidelines and are very important strategies in the classroom (Tynan, Kye and Herwegen, 2021). Repetition and memory were reported most for both parents and teachers of children with WS, with a strong emphasis on the use of music in the classroom. Reilly, Murtagh and Senior (2016) found syndrome specific differences between the groups that could influence the classroom, competence and inclusion of children with WS. Their research suggests schools and staff lack knowledge and awareness of specific needs of children with intellectual disabilities (Reilly, 2012; Reilly, Murtagh & Senior, 2016). Although there are multiple differences between one person with WS than another, Reilly (2012) argues that specific knowledge of syndromes can be useful for staff, particularly regarding behaviour and cognition. Similarly, South *et al.* (2021) reflect this justification for comparing groups of people with WS with groups of people with ASD.

Other relevant research in WS education includes Fisher and Morin's (2017) social skills training programme for adults with WS. The authors worked with adults with WS and their parents in three studies examining social functioning of adults with WS. Focus group interviews with adults with WS provided insight into the adults' perceptions of friendships including the importance of friends, what they would like to do with friends, and barriers to friendships (Fisher & Morin, 2017). In the same study, parent reports suggested individuals with WS needed help initiating and maintaining conversations. Examination of performance on initial lesson plans showed an increase in knowledge after the two lessons. Participants were reportedly engaged in lessons and demonstrated understanding through role-play and completing the homework. However, the programme was piloted over two days, which is a short time to know whether participants' change in knowledge also effected a change in behaviour, or whether the knowledge they learnt remained with them. Therefore, further research is needed to investigate social skill programmes for individuals with WS, or how schools manage social skill development. If successful social skill interventions are implemented early and developed throughout education and daily life, this could impact significantly on the daily lives of individuals with WS (Fisher & Morin, 2017).

On the other hand, when analysing the social position and social skills of children with SEN/D in mainstream education, Frostad and Pijl (2007) argue that social skills training would not likely change the position of socially isolated pupils. They found that pupils without SEN/D could be accepted by their peers without having friendships, and that pupils could have a friendship without being a member of a subgroup, but that this was not the case for most pupils with special educational needs. Their suggestion was based on the significant low relation between social position and social skills, so if children developed social skills, their position in the educational community would not change due to other children's preconceived attitudes and perceptions of the child with SEN/D. Although this was a study with general special educational needs, research has highlighted feelings of social isolation among individuals with WS, as well as difficulty forming friendships and understanding the concept of friendship (Fisher & Morin, 2017; Plesa Skwerer & Tager-Flusberg, 2016).

2.5.2. *Friendships*

Whilst some studies suggest that difficulties with social communication and conversation with peers lead to friendship difficulty (Mervis & Klein-Tasman, 2000), other studies indicate difficulties understanding social context and picking up cues. Parents in the Fisher and Morin (2017) study shared their children's difficulties understanding the situation; individuals with WS would interrupt a conversation to start their interaction, unaware of when it is appropriate to join, interrupt or start a conversation. Furthermore, parents reported difficulties in processing gossip or arguments between others, which they linked to difficulties with friendships where individuals with WS were unsure how or when to get involved (Fisher & Morin, 2017).

For individuals with severe disabilities, learning disabilities and other types of SEN/D, numerous research studies have examined the absence of friendships and peer interactions in schools

(Lyons, Huber, Carter, Chen, & Asmus, 2016). A study of special education teachers showed that teachers responded to a wide range of difficulties related to students' social skills in school. These were mainly associated with forming and maintaining peer relationships, and the majority of teachers emphasised students' limited peer relations and lack of assertiveness, limited self-management and academic related skills (Vlachou, Stavroussi, & Didaskalou, 2016). In WS research, parent and teacher reports using the SSRS found over half the participants had below average skills in cooperation, assertion and self-control (Klein-Tasman, Li-Barber & Magargee, 2011).

Children with SEN/D often experience difficulty making and maintaining friendships, leading to social isolation. Research shows children with SEN/D interact with non-disabled peers less frequently (Carter & Hughes, 2005). This may be due to time spent outside the general classroom, working 1:1 with a teaching assistant or support worker rather than with their class peers. A lack of opportunities to interact with peers may mean children with SEN/D are less able to practise social skills, leading to lower social competency (Carter & Hughes, 2005; Cutts & Sigafoos, 2001; Evans *et al.*, 1992).

Social isolation can affect wellbeing, self-confidence, motivation and school performance (Frostad & Pijl, 2007). When individuals with WS experience rejection by peers, this could impact their educational experience. Difficulties with social interactions may prevent successful inclusion. Schools may use specific interventions and programmes to help personal social development and increase the quality and quantity of friendships in school. However, there is a risk that school staff over-estimate the abilities of individuals with WS due to their sociable nature.

2.6. The English mainstream primary school classroom

In England, children are entitled to free education at a state-maintained school which is funded by the local authority or government (DfE, 2020). Local authority-run schools must follow the national curriculum, whereas academies and free schools are run by not-for-profit academy trusts and have more freedom to follow a different curriculum. The five stages of education starts with the early years, followed by primary, secondary, further and higher education. Children generally start school in the September following their fourth birthday, although compulsory education begins in the term after a child's fifth birthday, but this usually means the child will go straight into Year 1 rather than experience a year in Reception class (DfE, 2020). Between each year, children experience a vertical transition which at certain times may be more significant; between different settings such as a nursery and primary school, or from one classroom to the next (González-Moreira, Ferreira & Vidal, 2021). With this change, children may leave a familiar environment and relationships with staff, which researchers have considered as important developmental moments (ibid).

Transitions can be good opportunities for children to develop social and academic skills; however, they could cause social and emotional turmoil. Experiencing change can lead to stress and anxiety, and children therefore may need more support to regulate their emotions (González-Moreira, Ferreira & Vidal, 2021). Additionally, horizontal transitions may occur daily for children moving from home to school, or leaving one activity to start another. On the other hand, systems can be put in place which remove the challenges associated with transitions. For example, a rolling snack which encourages children to access the snack at their own pace, rather than a rigid time implemented by staff (Hayes, O'Toole & Halpenny, 2022).

For children with Williams Syndrome, Palikara, Ashworth & Van Herwegen (2018) argue that transitions may be more problematic due to a higher level of anxiety experienced through changes in daily routines, structure, and familiarity of support staff. Furthermore, it is particularly important for children with SEN/D to be supported with transition to different settings, when professionals and families must ensure information is shared with the new staff and setting (DfE, 2015).

Support staff may be employed to work individually with a child in a ratio of 1:1, specifically when the child has secured an Education, Health and Care Plan (EHCP) that details the resources required to meet their needs, as well as the funding needed to implement the support (DfE, 2015). Schools work with local authorities to determine their local offer of resources for supporting pupils with SEN/D, with a budget which can be topped up with funding by the local authority generally where the child lives (ibid). Similarly, children and families with an EHC plan may have a personal budget with access to direct payments or funding arrangements managed by the local authority or school (ibid).

The English mainstream education system has seen an increase in of the number of support staff from the early 1980s to try to reduce teacher workloads, improve retention and raise standards of pupil achievement. In 1997, the number of full-time equivalent (FTE) support staff was 61,000 compared to 162,900 ten years later (O'Neill and Rose, 2008). This number has most recently increased by 3.9% from 2019/20 to 2021/22 to 275,812 teaching assistants (DfE, 2020). However, teaching assistant (TA) roles have been problematized as lacking clear responsibilities, inadequate training and shifting responsibilities (Sharma and Salend, 2016).

2.6.1. *Introducing the TA role*

In England, the role of TA was intended to release teachers from routine, care and administrative tasks to focus on pedagogy. However, the government also proposed that TAs could more directly impact pupil attainment through instructional roles, supervising classes or working with small groups. Therefore, TAs were tasked with taking on more of a pedagogical role, without training or professional development (Blatchford, Russell and Webster, 2012b). The government's response to this dilemma was to create a higher level teaching assistant (HLTA) job who were trained against a new higher level professional standards framework. HLTAs could supervise classes set work by class teachers.

The role of the TA and HLTA continued to be ambiguous when the National Agreement clarified that HLTAs should not be interchangeable with a qualified teacher (Blatchford, Russell and Webster, 2012b). Graves (2013, p.97) implores:

> For although a lack of deep professional knowledge and expertise may prevent the recognition of the HLTA/TA role in the hierarchy of the school, the development of

> specialist knowledge, perhaps around intervention strategies, specific learning difficulties, or with increased pastoral responsibilities and partnership with outside agencies and parents, may engender certain power shifts and provide a site for resistance in the day-to-day reality of the school.

On the other hand, the increase in teaching assistants occurred at a similar time to the increase in pupils with SEN attending mainstream provision. TAs became more important in promoting and facilitating inclusion, particularly as research highlighted the lack of confidence and knowledge about working with children with disabilities from teachers (Avramidis & Norwich, 2002). Therefore, TA roles have become more ambiguous as they support children with increasingly complex and varied SEN/D, including children with health needs, severe learning difficulties and physical disabilities (Lacey, 2001).

An international systematic review on the role of support staff found TAs work more often with children with SEN/D than with children without SEN/D, although some Tas educated peers about how to help support children with disabilities (Sharma and Salend, 2016). Outside of England, the role of support staff may seem to be more explicitly linked to inclusive practice as the terms used to describe TAs cover responsibilities that support children with SEN/D. For example, integration aides supporting the learning of pupils with disabilities in Australia (Sharma and Salend, 2016), or assistants in Finland are hired to help children with SEN/D in their studies and to manage various situations in school (Takala, 2007). Special needs assistants provide personal care support to enable students with additional needs to attend schools in Ireland (Zhao, Rose and Shevlin, 2021). However, literature has raised similar challenges in the lack of clarity in the role and how support staff are positioned within the classroom and wider school (ibid). Therefore, the lack of a universal recognised term for support staff (such as paraprofessionals, teacher aides, classroom assistants, learning support assistants and paraeducators) suggests that similar issues may occur across the international context of roles outside the profession of class teacher.

Policy change in Italy reflected a move towards inclusive education by closing the special schools and creating a role of support teacher responsible for supporting classroom teachers to manage the inclusion of children with disabilities (Devecchi *et al*., 2012). The intention of a qualified special education support teacher was to support the facilitation of inclusion whereas in practice this position brought low status and insecurity that led to problems with retention and redeployment (ibid). In comparison with England, the deployment of support staff shows similar challenges of how support staff are positioned, valued, and managed. Contracts can be problematic if teaching assistants are specifically allocated to work with a child with SEN/D as funded by an EHCP. This work may be to help promote independence and peer support which would effectively mean the TA may no longer be needed and their contracts reduced, or even redundancy (Balshaw, 2013). Therefore, contracts may rely on a child's level of need and schools may be wary to emphasise the child's progress in EHCP annual reviews. These issues demand a clear system of management and collaboration amongst teachers and support staff.

England's approach to TA deployment remains the responsibility of the local school, with special educational needs co-ordinators (SENCOs) responsible for strategic decision making which may include specific training and professional deployment of TAs to support children with SEN/D (DfE, 2015; Wedell, 2006). The SEND Code of Practice (DfE, 2015, p.99) states that pupils may access support from “teaching assistants of specialist staff” which suggests an enhanced level of knowledge of SEN, although the term TA is used only three times in the whole document. Accountability of how children with SEND are supported in mainstream schools is through Ofsted inspections and the annual review where families and professionals meet to review and comment on children’s progress.

2.6.2. *Agendas and tensions*

Wilkins (2015) argues that the performative frameworks comprising data driven management of individual teachers and schools are particularly intensive in England. Education reforms emphasise individual responsibility for improving standards through performance and competition (Ball, 2012). As teachers are held accountable for results and learners with learning disabilities may not achieve these results, this impacts the performance of the whole school (Glazzard, 2011). This is because the education system measures norm-related standards by focussing on narrowing the attainment gap rather than accepting and embracing diversity (Glazzard, 2011). Therefore, the standards agenda and marketization of schools may prevent practitioners implementing inclusion. This focus continues to perpetuate marginalisation of those unable to reach the standards deemed ‘the norm’ which is based on another assumption that with the right support, children with disabilities can achieve the norm rather than meeting them at their level and working with them at their own pace. This narrative may influence practitioners’ understanding of how to support children with SEN/D if they are viewed as being ‘behind’ their peers, particularly in contention with the neoliberal education system that emphasises competition between schools, and choice for parents (Roberts-Holmes and Moss, 2021; Wilkins, Gobby & Keddie, 2021). Measuring the performances of children, teachers and schools illustrates a shift away from values of creativity, integrity and the moral principles behind what it means to be a teacher (Ball, 2012). Practitioners therefore balance their need to be seen and judged by ‘playing the game’ for educational reform, with their own identity and commitment to teaching. Wyse & Torrance (2009) suggest that the high stakes national assessment system in England should be replaced in order to better evaluate educational progress. They argue “the current intense focus on testing and test results in the core subjects of English, maths and science is narrowing the curriculum and driving teaching in exactly the opposite direction to that which other research indicates will improve teaching, learning and attainment” (Wyse & Torrance, 2009, p.224). Ball (2000) labels these responses and resistance as a form of fabrication where schools may manage a portrayal of inclusion, yet children have very different experiences of inclusion. Similarly, schools may manage to meet the standards agenda whilst also providing a quality inclusive pedagogy for all children. In this way, practitioners find ways to manage both inclusion for the narrative of performativity and inclusion for the rights of children. This reflects current ‘pockets of resistance’ highlighted among Early Childhood practitioners in the different ways they react to discursive policy (Archer, 2022).

Teachers have varied experiences in supporting and teaching children with different levels of SEN/D through their own background experiences and interests. An international review of policy and practice found training and development in SEN/D was either an additional or specialist area through initial teacher education or a postgraduate qualification (Rix *et al.*, 2013). This suggests that practitioners commit to this area through a self-identified need, value or interest in the area. Therefore, staff with more knowledge of SEN/D are those who have actively sought this particular area rather than as part of their teacher education programme.

The Code of Practice (DfE, 2015) details the legal requirements and provides guidance for schools to be able to support children with SEN/D. From this, 'quality first teaching' recognised all teachers are teachers of children with SEN/D who should use a variety of learning strategies to effectively meet each individual's needs. However, with the ambiguous role of TAs in supporting children with SEN/D, Radford *et al.'s* (2011) analysis of instructional activities found significant differences in quality of instructions between teachers and TAs, raising issues of training of TAs and the challenges of children with SEN/D spending less time with a qualified teacher. Other criticisms of the 'quality first teaching' initiative are that it is a common-sense approach, where teachers are positioned as being at fault for not meeting children's needs, (Done & Andrews, 2020). Moreover, the increased demands on educators to know whether they are doing enough and the best they can, may cause problems in professional identity and responsibilisation (Hellawell, 2018).

I also question whether knowledge of SEN/D and special education would support teachers to implement inclusive education. Lewis and Norwich (2004) question whether there needs to be a specialist SEN pedagogy. Although reductionist, Mintz and Wyse (2015) distinguish between a sociological focus on experiential knowledge of getting to know children as individuals compared to the starting point of a psychological position of understanding disabilities through categories of deficit. However, both views understand the importance of seeing the individual. Similarly, Ridgway (2019, p.2) argues:

> Guidance for teachers and those preparing future teachers is inherently contradictory, claiming to take a ‘social model’ stance on inclusion while simultaneously prescribing a diagnostic medical typology to conceptualise different learner needs.

Therefore, class teachers may learn about inclusion in teacher education, and then learn to adopt a medical typology to talk to different professionals in order to support children with a diagnosis to get funding for example.

In his review of pre-service teacher education for children with SEN/D, Hodkinson (2009) proposes a lack of established tradition of special education in the UK. One study has shown student teachers who undertake programmes on inclusive and special education are likely to hold views that are more aligned to the social model view of disability (Cameron & Jortveit, 2014). Furthermore, in their study of an international postgraduate cohort, Kamenopoulou, Buli-Holmberg and Siska (2016) assert that student teachers must have opportunities to explore theoretical concepts and reflect on the complexities of inclusive education. Similarly, Passy (2013) describes a government centralised pedagogy focussed on National Curriculum and regulations, which prevents student teachers from spending time considering and reflecting on theory.

Continuous professional development (CPD) in teaching has been problematized recently as lacking the continuous progression from initial teacher education to career-long provision, with questions about how to identify individual needs, how to employ methods of CPD and evaluate the effectiveness (Campbell-Barr, Bamsey & Gulliver, 2022). CPD opportunities occurring as short-term experiences such as courses, workshops and conferences are often linked to school agendas on curriculum reform or assessment exercises rather than the task of teaching and learning (Darling-Hammond, Hyler & Gardner, 2017).

Challenges with education performativity and continuous professional development highlight difficulties in managing inclusion for individuals with SEN/D. Furthermore, the role of teaching assistants has become increasingly complex and varied to help support the inclusion of children with SEN/D (Saddler, 2014; Ravalier *et al.*, 2021).

2.6.3. *Differences in roles and positions*

Teaching assistant roles have shifted considerably so that their responsibilities can overlap with the class teachers, including planning and teaching (Mackenzie, 2011). A key role for TAs is to raise pupil attainment, particularly in core subjects such as literacy and numeracy. They can be responsible for general class work, whole school work, administrative tasks and teaching groups of children in targeted sessions (Saddler, 2014).

Some research suggests TAs working 1:1 with children with SEN/D lower children's achievement, or that the children show little to no progress (Blatchford, Webster & Russell, 2012a; Farrell *et al.*, 2010). However, Saddler (2014) argued against this, exploring their impact on facilitating communication and fostering social inclusion. Many children with SEN/D have difficulties with social communication, and these difficulties affected their ability to form relationships. Saddler (2014) found children were able to follow TA's modelling of good social communication. Her investigations also found a link between social inclusion and academic achievement, suggesting that the use of a TA can really assist children with SEN/D to be included effectively in mainstream. On the other hand, Fox, Farrell and Davis (2004) reported adults with Down syndrome had felt different or isolated during their school years, and many had viewed their TA as their best friend. Therefore, it is important that staff facilitate interaction between pupils.

One of the risks associated with working as a 1:1 TA is in over-supporting the child. Termed 'SEN Velcro-syndrome', the child may become more reliant on their TA rather than learning to work independently (Vincett, Cremin & Thomas, 2005). Similarly, children who become more reliant on TAs are at risk of developing learned helplessness unless staff know and understand how to scaffold learning and support children's growing independence (Radford *et al.*, 2015). Therefore, it is important for schools to facilitate training and collaboration between the class teacher and teaching assistants that enable them to communicate about how to support each child's needs.

TAs have an increasingly complex job which can be divided into several different roles according to Blatchford, Webster and Russell (2012a), including prompting, scaffolding, facilitating interactions with peers, and implementing interventions. An Australian study revealed challenges in role confusion and identifying the type of skills required to perform the role of TA (Butt & Lowe, 2012). On the other hand, Alborz *et al.'s* (2009) study showed TAs who were supported and monitored throughout their role felt clearer on what they were doing for the children.

However, it is the class teacher that is responsible for the children in their class. Fox *et al.*, (2004) suggest that teachers sometimes viewed the TA as the expert and would hold them responsible for children’s learning, which can prevent the child from being seen as the school’s responsibility. Furthermore, the different status and pay for TAs can sometimes result in them being excluded from important discussions and meetings (Mackenzie, 2011) and their limited time directed to supporting the child.

The whole school should hold the responsibility for each child to be fully included (Fox, Farrell & Davis, 2004). When children move class, key strategies and knowledge of how to support the child must move with them to prevent staff from starting again, sometimes with different expectations. On the other hand, changing staff can be beneficial if staff have higher expectations or new ideas of supporting children. Additionally, it is the schools’ responsibility to manage resources for children with SEN/D, and ensure appropriate training for TAs to fulfil their role (DfE, 2015). The SEND Code of Practice (DfE, 2015) highlights the need for schools to utilise their TAs effectively.

Whilst the class teacher has the responsibility for the children in their class, the Special Educational Needs Co-ordinator (SENCo) is in charge of provision supporting children with SEN/D, including the deployment of TAs (DfE, 2015; Wedell, 2006). Although TAs are appointed to work with class-teachers, the SENCo is still responsible for the professional development of the TA, but this varies throughout different schools as interpretations of the SENCo role differ, creating challenges. There is also criticism regarding the amount of work expected from SENCOs and research has questioned whether one SENCo can hold the responsibility for all children with SEN/D in their school (Pearson & Ralph, 2007). This reinforces the need for a whole school approach to supporting inclusion.

A large survey by Moss *et al.* (2021) calling TAs the 'unsung heroes' found TAs played a pivotal role in pupil's learning and the running of the school during the global pandemic. Their research recommends schools draw on the knowledge and understanding of TAs who have "a unique understanding and a clear view of what matters most within their community and for their pupils" (Moss *et al.*, 2021, p.29). TAs are usually local members of the community and therefore have a wealth of local knowledge and experience that can be used to "identify the priorities and needs of pupils" (Groom, 2006, p.200).

Similarly, research including parents and carers' voices show there is an important focus on schools as a way of enabling children with SEN/D to be a part of the local community (Hess *et al.* 2006; Resch *et al.* 2010). Schools have the opportunity to demonstrate and contribute towards an inclusive community that values every individual. Therefore, schools could be the foundation for developing inclusive perceptions within the community, or used to ensure an inclusive society.

2.6.4. *Including children with disabilities*

Inclusion for many relies on a sense of belonging and acceptance (Florian & Beaton, 2017). Parents of children with disabilities emphasise this in their desire for their children to belong to the school community (Haines *et al.*, 2015). However, Vandenbussche and De Schauwer (2017) question the depth of belonging as children with SEN/D participate in the school in different ways; as a school pupil, or through connecting with others. This relies on being able to participate relationally with others, and be accepted by peers (Bossaert *et al.*, 2013). Arguably, children with

SEN/D who have difficulty interacting with others and forming relationships will require more support to develop and build relationships in order to be fully included.

In practice, inclusion is a term full of contradictions and tensions, termed illusionary (Hodkinson, 2012) a struggle (Allan, 2006) and exclusionary (Slee, 2011) in education policy that undermines inclusive practice (Runswick-Cole, 2011). The full inclusion vision was attempted in other countries such as Norway (Cameron, 2017) when they closed all special schools. Over 90% of children with special educational needs are in mainstream classrooms (Cameron, 2017). However, my visit to a school in Oslo, Norway revealed whole classes of children with SEN/D or small units for children who chose to attend a separate class to work as it was quieter. Importantly, some of the children were able to share their own choice and the staff respected their decision. Additionally, my observation was for one morning visit to a school in January 2016. On the other hand, I observed similar experiences in mainstream primary schools I worked in, in the South West of England, where children with SEN/D spent varying amounts of time in separate classrooms.

Norwich (2008) describes the continuum approach which provides a range of different provision for children with SEN/D from full time in a residential special provision across to full time in a mainstream setting, with varying levels of support. In the late 1990s to early 2000s, Tom first experienced integration through PE lessons, and then joined the local junior school for one day a week; the same school that his brothers and I attended. Tom was a popular member of the class, wore the same school uniform, and occasionally joined in games of football with his peers at lunch times. However, Tom was supported throughout the day with a 1:1 TA from the special school, as none of the work the rest of the class did was differentiated or adapted for him by the class teacher. Instead, his TA adapted the work for him to join in. Perhaps this was because the special school remained fully responsible for him, and because it was quite new for the junior school to be including children with disabilities. Traditional dominant views of disabilities and lack of knowledge or training meant that class teachers might not have known how to include Tom in their lesson planning, and this is reported as a problem for integration/inclusion in research (Avramidis & Norwich, 2002).

Further challenges to defining inclusion, are the practice of meeting all children's needs in the classroom. Difficulties include staff perceptions of disability, knowledge, awareness, and confidence in teaching children with various SEN/D (Avramidis & Norwich, 2002; Fox, Farrell & Davis, 2004; Reilly, Murtagh & Senior, 2016). In their review of the literature, Avramidis and Norwich (2002) found that teachers held different attitudes to students with mild, physical, sensory and more complex disabilities. They suggest teachers are more accepting of children with physical disabilities rather than cognitive disabilities. Although teachers seemed positive about inclusive education, this was based more on the philosophy than the practice. On the other hand, the literature review from Avramidis and Norwich (2002) dates back 20 years when inclusive education was emerging from integration. Research highlights other challenges for inclusive education in mainstream schools such as lack of funding, resources, deployment and management of teaching assistants supporting children with SEN/D (Mackenzie, 2011; Richardson, 2019; Saddler, 2014).

Inclusion also means recognizing and meeting children's diverse learning needs. Allan (2006) argues that the exclusionary process of providing children with SEN/D with individual work which can be very different to the rest of the class can isolate them. Differentiation was suggested as a means to diversifying teaching strategies and approaches, but Florian and Rouse (2017) contend this could marginalise children. In contrast, the Universal Design for Learning (UDL) framework promotes an inclusive philosophy to embedding the social model and inclusive pedagogies proactively within classrooms (Rose and Meyer, 2006). The UDL approach opposes the view of additional supports or integrated activities, and instead advocates for planning and consideration of participation for all learners from the very start (Lieberman, Lytle & Clarcq, 2008).

In summary, İnclusion has become an overused term full of challenges and complexities that contradict competing discourses. English mainstream schools have competing tensions between the performance agenda and inclusion agenda. In order to fully include children with SEN/D, the school system must compete against the marketization of schools that assess their performance on academic achievement only. Teachers are caught in the tensions between the moral principles of inclusion, and the practicalities of managing diverse learning needs, which may result in a fabrication that does not represent the real experiences of children with SEN/D, for example in order to get a diagnosis or funding. Furthermore, preconceived attitudes and experiences of different disabilities may influence teachers' confidence in their abilities to support inclusion (Black-Hawkins & Florian, 2012). Teaching assistants have increasingly complex roles and shifting responsibilities that demand significant knowledge and training to understand how to support children with varying levels of SEN/D.

2.7. Summary of the field

The traditional medical view of disability can be detrimental when used to marginalise groups, but important for understanding in–depth knowledge of specific disabilities. My parents experienced the historical view of disability as a tragedy when Tom was diagnosed with a disability. Our family navigated different models of disability in order to help support Tom, and enjoy his quirks, interests and connections with the community.

Williams Syndrome has a complex profile, which has largely been researched through the disciplines of psychology and biology that explore the phenotype and genotype. Through this, it has been useful to understand how an individual with WS may have strengths and difficulties in social behaviour, cognitive and physical learning. Research has highlighted difficulties in developing fine and gross motor skills, visuospatial awareness and perception, as well as risks of sound sensitivities such as hyperacusis.

The characteristics found among many individuals with WS include a high social motivation, and eagerness to interact with others. However, challenges in understanding and interpreting social cues and cognition can make communication difficult for individuals. There is a significant risk of vulnerability and isolation, as well as feelings of anxiety. Individuals may have generalised anxiety disorder, phobias and non-social anxiety that are often everyday objects that cause sudden and loud noise. Once described as empathy, individuals with WS show comforting and caring behaviours but this is problematized as their difficulties in understanding another person's perception mean they are more likely to share intense emotions without understanding why. This emphasises the importance in understanding how children with WS can be supported in a mainstream education setting.

Inclusion has evolved over the last thirty years, from troubling definitions of integration and physical placements, towards a social model understanding of participation and belonging. This is challenging for schools who are managing the tensions of performativity and standardisations and the principles behind inclusion. However, staff also have various access to resources and training in understanding different ways of supporting the inclusion of children with disabilities. Often, this might rely on staff's own interests and initiative to find professional development that focuses on supporting children with SEN/D.

School staff roles and responsibilities have changed so that teaching assistants are increasingly used as support staff for working directly with children with SEN/D. Challenges include differences in status and training, as well as the tensions of a non-teaching role that has evolved to include pedagogical activities, and social and emotional development. Literature indicates that children working closely with a TA in a 1:1 ratio or small group may prevent them from being involved in interactions amongst peers, as well as direct teaching from a qualified teacher. However, literature is building a picture of the essential role that TAs can play in contributing to the running of a whole school (Moss *et al*., 2021; Takala, 2007).

In summary, the inclusion of children with SEN/D in mainstream primary schools has been fraught with challenges in competing tensions, understanding what inclusion means and how to fully support different children. Research suggests staff need to have specific knowledge of WS and different types of intellectual disabilities in order to understand how to support their education. There is also a significant research base into the characteristics of WS, but a lack of children's voice in research. Therefore, in order to better understand how schools support children with WS, it is important to understand how children with WS experience their education.

3. Methodology

3.1. Research question

This research comprises case studies of four children with WS attending four different mainstream primary schools, in order to highlight individual experiences and insights. The main research question investigates “What are children with Williams Syndrome’s experiences of mainstream primary schools?” The following sub questions then delve into more depth to understand the experiences of children with WS contributing to research, sharing their experiences of school, and the school’s approach to supporting children with WS.

- What do children with Williams Syndrome show as important to them in their school?
- What do children with Williams Syndrome want to contribute to research about them?
- How do children with Williams Syndrome interact with peers and staff?
- What do participants understand about supporting a child with Williams Syndrome in school?
- How do schools facilitate inclusion of children with Williams Syndrome?

Questions were addressed through an adaptation of the Mosaic approach (Clark, 2008; Clark, 2017), an assemblage of tools that can be used to listen to research participants of all ages and abilities. The Mosaic approach was originally developed when researching early childhood settings which enabled very young children to evaluate their environment (Clark, 2008; Clark & Moss, 2011). The multi-method approach features children's own photographs, tours and maps combined with discussion and observations to gain deeper understanding of children's perspectives (Clark, 2008; Clark & Moss, 2011). The Mosaic approach was specifically developed to be inclusive and adaptable for all children and adults, using a 'strength-based view of the child' (Clark *et al.*, 2014, p.207). The framework encourages children to communicate their thoughts, feelings, information and ideas in their preferred style. This suggests that the methods within the approach can be adapted to help children with SEN/D share their experiences and knowledge (see 3.5).

The fundamental principle of this research was to be inclusive in theory and action, which meant enabling each child to be an active participant, rather than being objectified or not heard (Christensen & James, 2008). Limited research exists which includes the perspectives of children with intellectual disabilities (Palikara, Ashworth & Van Herwegen, 2018). In this study, children with WS were the primary stakeholders, and it was therefore important that I worked alongside children with WS to highlight their own perceptions and experiences. Research suggests that children with WS display hypersocial behaviour and high social motivation whilst experiencing social difficulties due to low cognitive ability (Jarvinen, Ng & Bellugi, 2015). To enable children with WS to participate in research, an array of methods inspired by the Mosaic approach were used that did not rely solely on verbal speech or cognitive ability.

In the international drive towards inclusive education, arguments continue from a human rights perspective to consider schooling all children together instead of separate schools such as special schools (Florian, 2012; UNESCO, 1994; Unicef, 1989). In practice, more children with intellectual disabilities such as Williams Syndrome are being educated in mainstream primary schools (Riby and Hanley, in preparation; Palikara, Ashworth and Herwegen, in preparation). However, the inclusion agenda continues to raise several challenges for children, families and staff. It was therefore important to investigate the experiences of children with WS in mainstream primary schools.

3.2. Design

The study was set across four mainstream primary schools where a child with WS attended.

Sophie, age 5 years, attended Ridgeview school, located in an urban town on the edge of a city with a population of around 10,000. Ridgeview school was divided across two sites, with one class from each year group on the site that Sophie attended.

Orla, age 5 years, attended Littlewood school, a faith school in a small rural village with a population of under 2,000.

Ryan, age 6 years, attended Golden Oak primary school, in a suburban town on the edge of a city with a population of over 20,000.

Wendy, age 5 years, attended Edgewater primary school, in a large seaside village of over 10,000 people.

A case study approach enabled me to conduct in-depth explorations in real-life settings, using an array of methods (Kumar, 2019; Stake, 2005). There is uncertainty around defining case studies, which reflects the differences between researcher's choice of methodology and epistemology (Bassey, 1999; Stake, 2005). For some researchers, case studies are used for an initial study before either generalising to larger populations, or deeper study using statistical analysis (Flyvbjerg, 2011; Kumar, 2019). As the post-positivist movement evolves, increasing numbers of researchers are trained in handling different types of data in order to use the methods best suited to answer the research question, rather than driven by methodology (Flyvbjerg, 2011; Tashakkori & Creswell, 2016).

This discourse suggests case studies are generalisable, but my study does not aim to generalise or investigate causality in relationships. Instead, my study recognises individual differences between participants, settings and contexts in real life situations. The case study does not aim to prove or disprove a hypothesis, rather to learn about a situation, and understand the complexities of children with Williams Syndrome learning in a mainstream school. Similarly, Stake (2005) emphasises the design of the study as being beneficial to understanding the case rather than generalising from it. Findings can then be used to highlight experiences of children with other intellectual disabilities, different types of special educational needs and disabilities, and the way schools can support them.

A case study approach tends to focus on analysis of one, or a small number, of cases (Bassey, 1999). In my study, the children's experiences form a case study, and the schools provide the settings for each case. Thomas (2015) argues case studies require a boundary from the start, to provide researchers with the frame within which they conduct their research. However, the type of research I have conducted is a participatory, adaptable and flexible study, which is more processual than fixed. Whilst some researchers suggest the case is a fixed object rather than a process (Thomas, 2015), my case study emphasises and reflects the participant's growth and movement as cases progress and develop over time (Flyvbjerg, 2011).

A significant part of a case study is setting the context (Thomas, 2015), which includes understanding the type of school, culture and community in which each child with WS, their peers and staff, are situated. Stake (2005, p.120) suggests that "for the qualitative research community, a case study concentrates on experiential knowledge of the case and close attention to the influence of its social, political, and other contexts". Therefore, it is important to understand the politicisation of inclusion and disabilities (see 2.1.1), as well as the different social contexts of the schools. Additionally, case studies enable researchers to analyse at different levels such as classroom, school and system level which is useful for inclusion literature (Nilholm, 2021).

The case study approach does not require large numbers of participants, which would be needed in large-scale research designed for generalisations (Cohen, Manion & Morrison, 2007). Instead, the methods used have produced large quantities of data, including video footage, photographs, transcriptions of conversations with children and staff, and daily observations in fieldnotes. Additional data such as the ethics log in my reflective diary details the context of the school, as well as documentation such as school policies.

Central to a case study approach is a methodological flexibility that can provide a large volume of data and can be a little overwhelming to the novice researcher (Flick, 2018). Structuring the methods through the Mosaic approach helped to increase my confidence conducting this type of fieldwork, which closely aligns to my epistemology.

3.2.1. *Qualitative inquiry*

My own position as a qualitative, interpretivist researcher recognises that there is not one fixed reality, but several interpretations of reality. For families of a child with WS, research about different experiences of primary schools can highlight ways in which children are supported well and what could be helpful to know more about. It is also therefore important to understand the context of the school where the study will highlight experiences through rich narratives.

The research questions demand a qualitative style of inquiry featuring open interviews and observations. Previous research into the socio-cognitive profile of WS has predominantly used quantitative inquiry, mirroring assumptions that research conducted effectively uses designs based on a positivist positionality (Donnai & Karmiloff-Smith, 2000; Jarvinen, Ng & Bellugi, 2015; Martens, Wilson & Reutens, 2008; Stojanovik, 2006). This has benefited my brother as he has visited psychology laboratories for cognition, memory and developmental assessment measures, providing evidence to show the level of age he is cognitively functioning in contrast to his chronological age. For example, at age 23 years he performed at an age equivalent level of 7 years 10 months on the British Picture Vocabulary Scale-III and 9 years 6 months on the Verbal IQ (his highest score). He scored below the range of ages measured by the Performance IQ Block Design test, below 6 years 2 months, whilst his nonverbal fluid reasoning was 6 years 10 months. These results shown to various professionals and care services have secured him additional 1:1 hours to help him attend work placements and live in supported living accommodation.

Whilst acknowledging the benefits of important quantitative research into WS through neuroscience, psychology and genetics, it is useful to understand the differences between research based on quantitative and qualitative data. Debates between researchers date back several decades when research was primarily handling quantitative or qualitative data (Denzin, 2009). Positivist researchers often investigate causal relationships through direct investigations and experiments, where they can offer generalizable findings that can be tested and replicated.

However, the type of research question I wanted to ask required a different type of research, which focussed on experience, events, processes and individual narratives (Cohen, Manion & Morrison, 2007). Additionally, qualitative research emphasises the importance of context, meaning and process (Denzin, 2009) which does not seek to investigate a relationship between variables or experiment. Instead, my research centred on the schools and lives of four children with Williams Syndrome, incorporating their experiences and own narratives, which relies on rich detailed context.

Researchers have begun to question the gap in qualitative explorative research, particularly from perspectives of key stakeholders and education in Williams Syndrome (Palikara, Ashworth, & Van Herwegen, 2018). As an interpretivist researcher, I believe that research conducted by the positivist paradigm often views participants as subjects of research. By looking objectively at individuals with disabilities, their lives, experiences and interests are at risk of being overlooked. This is highly problematic, as research that continues to overlook or not listen to the voices of individuals with disabilities, will perpetuate the view that it is too difficult to conduct research with people with SEN/D (Aldridge, 2007). The primary stakeholders in my study are children with WS, their peers and school staff. It is therefore important that the chosen methodology enables them to reflect their own perspectives, and share their views. My methodology ensures children with WS are invited as active participants, through an adaptation of the Mosaic approach (Clark & Moss, 2011) which views children through a strength-based approach.

Using participatory methods was vital for exploring the personal lived experiences of children with WS in the classroom, and the perceptions of school staff. In line with my interpretivist position, I value the multiple realities from children with WS and school staff (Cohen, Manion &

Morrison, 2007). In parallel, by adapting the Mosaic approach (Clark, 2008) the research helped to create a picture of participants' experiences using several methods. Thick descriptions help represent the complexity of each situation and context (Cohen, Manion & Morrison, 2007).

With the inclusive ethos behind the research, I was keen that participants were actively involved in the study, which emphasises and contributes to the values of equality and diversity. I was also keen to encourage participants to explore their own understanding and experiences, with the knowledge and agency that they can influence their situations. Similarly, social justice issues are intrinsically linked to the inclusion debate, directly when using the human rights approach to argue for the inclusion of children with disabilities into local mainstream schools (Booth & Ainscow, 2002; UNESCO, 1994).

The particular research methods chosen helps to address the issues of power, as children take a significant role in contributing to the research, sharing their knowledge and experiences through a tour of their school, a place they know well and that the researcher does not know. As an outsider to the children and schools, I am able to reflect on my own position and work towards understanding the participants' own definitions of their situations. The presence of the researcher may influence the participants, for example the children may want to impress or distract the researcher. Similarly, adults may wish to avoid or re direct the researcher. Therefore, it is important that participants understand the aims of the research, the ethical considerations behind the research, and my position as an open, honest researcher (see 1.2.).

Overall, the widespread use of naturalistic research supports the justification that it is a valid style of research and can produce important data and analysis.

3.2.2. *Critical Realism*

I adopted a critical realist approach to disability studies, which moves beyond reductionism to a system that acknowledges different levels of reality such as the physical, medical, psychological, but also psycho-social, socio-economic, cultural and normative (Bhaskar & Danermark, 2006). Bhaskar (1974, p. 250) states, “things exist and act independently of our descriptions, but we can only know them under particular descriptions”. Critical realism is flexible in that making sense of the world is open and fluid in the different ways categories and relationships are ordered (Scott, 2005).

Impairments are a reality that cannot be deconstructed through materialism (Shakespeare, 2013). Similar to Craig and Bigby’s (2015) study, all the children in my study had intellectual difficulties which were more than part of their narrative and had a real impact on their daily life. Disability is more complex than being reduced to the disability versus impairment dichotomy. Social and medical models fail to understand and resolve structural issues of experiencing disability. I understand disability to be more relational between an embodied individual and the social, cultural, physical environment (Shakespeare & Watson, 2010).

Shakespeare (2013) highlights how critical disability studies moves away from the simplistic binaries of medical and social model views, or medical sociologists and disability studies. Furthermore, the critical element is important for questioning underlying assumptions, and highlighting issues with social oppression. This mirrors other arguments of social oppression from feminist and race thinkers (Goodley, 2013). However, Critical realism extends this to acknowledge the many different levels of a disabled person's life including the physical, medical and psychological. As Shakespeare and Watson (2010) adeptly argue, an individual still has an impairment when society removes all disabling barriers, whereas a female would no longer be oppressed when all socio-economic and cultural barriers are removed.

Another part of critical realism is the emphasis that individuals are active constructors of their world, which is why it was important in my study that all participants were respected and supported to actively participate in meaning-making (Craig & Bigby, 2015). Similarly, the capability approach highlights individuals' strengths and resources, both internally and externally. Individual (skill, talent, interests) and social factors (wealth, community, family, income) will affect a person's capability (Vehmas & Watson, 2014). Williams Syndrome is a type of impairment with various levels of severity which exist independently of how society understands and views disability. It is therefore important to understand experiences of disability through different levels of context. The interplay between physiological impairment, structural conditioning and socio-cultural interaction provides a richer understanding of disabled people's lives than solely biological or cultural reductionism (Shakespeare, 2013). Therefore, disability as a very complex phenomenon should be analysed through different levels ranging from medical to physical, psychological, social, political and cultural (Shakespeare & Watson, 2010).

3.2.3. *Positionality*

My background as having a sibling with a disability plays a significant part in my ontology, epistemology and methodology. It is important to acknowledge these unique life experiences and thinking which have guided the research process, analysis and conclusions.

In respect to positionality, I hold the distinct position as a sibling of an individual with WS. As a child, I attended activities, trips and conferences alongside families and children with WS through the Williams Syndrome Foundation, a charity led by parents and families. My personal involvement with WS and the Williams Syndrome Foundation may have encouraged parents to participate or feel more comfortable. This insider perspective may have helped me access the sample, and build rapport with participants (Chavez, 2008). My experiences also enable me to observe, interpret and represent the views of children with WS from a close perspective. Furthermore, from working with children and young people with different disabilities, I have insight into various communication styles and behaviours of individuals with disabilities. However, although individuals may have similar diagnoses, e.g. WS, there are countless individual differences. The heterogeneity of individuals with WS has been widely highlighted in research over recent years (Lough *et al.*, 2016; Riby *et al.*, 2014). This means it is vital to build a relationship with participants, to understand them as an individual rather than their diagnosis. Reflected in the medical model view of disability, any assumptions built from a diagnosis or label may prevent me from observing how different children experience mainstream primary school.

Using the Mosaic approach ensured perceived power is shifted from the researcher as an adult and outsider who holds knowledge and authority, to the children who take on the role as teacher, information gatherer and collaborator (Clark, 2017). Therefore, it was possible for situations to be examined through the eyes of participants rather than the researcher. My choices of methods highlight my eagerness to emphasise the position of children with disabilities in qualitative research, their knowledge and potential involvement. My background experiences and knowledge of working with children with various disabilities helped me to feel confident in offering different opportunities for children to engage in the research.

It is hoped this piece of inclusive research encourages more collaborative and inclusive research projects with children with or without disabilities, as co-researchers rather than subjects (Christensen & James, 2008). On the other hand, I am not a child with WS, and I have not educated a child with WS. Although I will have some knowledge and understanding of working in different schools, the teaching staff show unique perspectives of working with the specific sample of children.

Qualitative researchers have examined the concept of power between researchers and participants, particularly when those participants are children (Cocks, 2006; Kellett, 2005; Punch, 2002). Children shared their knowledge of a place they were very familiar with, and were able to guide the study through their own choices (3.8). Teaching staff were continually given choices as to when, where and how to discuss their own knowledge and experiences.

3.2.4. *Hearing the child*

My background and experiences have given me a deep passion for 'tuning in' or listening to young people, further than verbal cues. This echoes Mason's theory, known as the discipline of noticing, which suggests we need to notice and "be sensitive to the experiences of pupils" and "sensitive to notice opportunities in the moment" (Mason, 2002, p.61). Working closely with individuals with disabilities encourages me to focus on moments such as the following example, where my work continually requires me to interpret individuals' signals, behaviours and communication, below the surface.

> *Working in a residential home for young people with complex needs, I came across a situation where a girl was visibly distressed, crying and displaying self-injurious behaviour. I called her name, encouraged her to stop hitting herself, and immediately heard the song playing in the background. Another member of staff appeared behind the cupboard door, where she was finding some new trousers. I mouthed to her that this song was triggering the girl; "she asked for it" was the reply. I had experienced the girl's behaviours before which suggested she was escalating [increasingly distressed] and needed support straight away. I guided the girl to her rocking chair; with just over 30minutes of reassurance, rocking, a weighted blanket and 'shh' or whispering repeated phrases back to her. Having worked with the girl for a few months, I knew the song she was asking for repeatedly was a trigger, which could cause her to escalate. In this case, she was saying one thing, but meaning something else, requiring support to manage her behaviour when the song did play. In my experience when working closely with her, I need to give her options of changing the song playing; paying close attention to her body language, speed and pitch of voice. It is also important to know whether something is different or unfamiliar, to suggest reasons for displaying behaviour that tells me something is wrong. Perhaps, when repeatedly asking for her 'trigger' song, she is telling others that she is uncomfortable, hot or in pain. It is therefore important to assess the whole situation before playing the song or encouraging a different song.*

My eagerness to listen closely to young people with disabilities reflects my chosen methodology. The Mosaic approach (Clark & Moss, 2011) uses an array of methods that does not rely solely on verbal speech or cognitive ability, as opposed to other methods such as questionnaire surveys or individual interviews.

My research question directly involves children with WS. In order to research about children, methodology must involve them in ways to show they are listened to and understood. Although as adults we have memories and experiences of being children, we are very different to children (Punch, 2002). Adults dominate our society, but instead of seeing children as 'lacking' or 'less valid' than adults, children are capable participants in their own lives. Differences between adults and children reflect the need for me to ensure children have opportunities to share their knowledge in appropriate ways. For example, children may have less or different vocabulary, shorter attention spans and less experience of the world (Punch, 2002).

In meetings with my supervisors, we discussed the possibility of having a group of adults with WS to analyse or comment upon the data and my findings, as a way of adding validation to the data. This would also further contribute to inclusive research (Nind, 2017), and exploration into individuals with WS own experiences. However, I do not believe that this would be beneficial for the adults with WS, who are often eager to talk about their own topics of interest but not necessarily my research project. Furthermore, it is not necessary for participants to contribute to all stages of the research process, but it is important to discuss and reflect on their active participation. In his reflections on the ladder of participation, Hart (2008, p.24) later stated:

> Adult facilitators of projects should not be made to feel that they must always support their child participants to operate on the 'highest' rungs of the ladder, but they must manage to communicate to children that they have the option to operate with these 'higher' degrees of engagement.

Indeed, one of the purposes of this research is towards fulfilling a PhD in Education, and I chose the research questions, aims, methods and design. However, I chose this particular research because I found a need for the study, which will also help address the gap in the literature. In addition, contributing to inclusive and participatory research may encourage more collaborative and inclusive research projects with children with or without disabilities, as co-researchers rather than subjects of research (Clark, 2010; Harcourt & Einarsdottir, 2011; Kellett, 2005).

3.3. Methods

As previously mentioned, Williams Syndrome is a rare syndrome, with an occurrence of between 1 in 7,500 and 1 in 20,000 live births (Mervis & Klein-Tasman, 2000; Strømme, Bjømstad & Ramstad, 2002). When focussing on primary school aged children with WS in the UK, the population is then reduced to less than 150 (figures obtained from WSF in Gulliver, 2016). Not all parents of children with WS become a member of the charity Williams Syndrome Foundation (WSF), which means my sample only included parents and children who are members of the charity. Therefore, they may be more confident with participating in research or sharing their experiences, and there may be more children with WS attending mainstream primary schools that are not members of WSF.

Due to the rarity of WS, it was not feasible for me to contact schools first before inviting parents and families of primary aged children with WS. From feedback from the Plymouth University Education Research sub-committee, it was important to manage expectations so parents understood that the schools had to give their permission first before children and parents could consider participation. Therefore, I sent an initial letter and pack of information to parents and families of primary aged children with WS in the WSF regions in the South West of England (Appendix 2). In contact with the social media Officer for WSF, I created a short poster advertising the research, which they shared on social media and gathered some interest. Parents who were interested in the study then contacted me with details of their child's school, from which I contacted the headteacher for permission (Appendix 2). In this research, both the headteachers of the schools, and the parents of the children, were gatekeepers.

Four children with WS, their parents and schools agreed to take part in the study. In July 2019 I visited three children in the schools with a view to starting the study the following Autumn term. I had two more parents interested, and an opportunity through a colleague to approach a special school with at least three children with a diagnosis of WS. Although this would have been an excellent opportunity to work with children with WS in a special school and offer a slightly different interpretation to my study, the school was concerned with teacher workload pressures and declined to be involved.

I was very aware that although I wanted to spend time within schools to develop a relationship with the children and staff, schools and staff have significant time constraints. Furthermore, schools may feel unwilling to facilitate the research if they feel at risk of criticism. Therefore, it was vital that documentation to the schools explicitly described the impact and importance of research, the aims, methodology and ethical considerations such as prevention of harm and protection of data (Cohen *et al.*, 2007).

The sampling technique used combined homogenous purposive sampling (Cohen, Manion, & Morrison, 2007). Participants were purposely recruited due to their potential similar backgrounds and experiences, because children with WS have been known to exhibit hypersocial behaviours, as well as several social difficulties due to their intellectual disabilities. It was not possible to recruit via random sampling because I was limited to participants, willing schools and children diagnosed with the rare disability.

I initially planned to recruit up to six schools and participants within the South West of England. Other qualitative phenomenology researchers recommend a sample of between 2 and 25 (Alase, 2017; Tashakkori & Creswell, 2016). Considering the context, I aimed for more than 2 to explore different schools and experiences of the professionals and families involved in having a child with WS. However, due to time, travel and cost I was limited to involve a certain number of primary-age children with WS. This is a common difficulty with qualitative research, but the smaller size sample enabled me to maintain and appropriately manage a good quality study. Furthermore, the type of research did not require large numbers of children or schools, but an in-depth exploration of a select number of children who met specific criteria, for example having a diagnosis of WS and attending a mainstream primary school.

It took several months to recruit the four children’s schools with the relevant consent. I also realised there was a significant amount of data gathered in each school, which meant that I no longer advertised the study after my fourth participant. The methods used with each participant produced large quantities of data including interviews with children and school staff, which produced over 30 transcripts to analyse. Additional data included videos, photographs, observations and fieldnotes.

Poster 1: Posters shared on social media and through WSF

Research Opportunity

I am a PhD student at Plymouth University, conducting a research study investigating **how children with Williams Syndrome socially interact with others in mainstream primary schools.**

I am eager to work alongside children with WS who attend **a mainstream primary school** in the **South West of England.** I will spend time visiting the children in their schools, enabling them to share their experiences through photos, art and voice. I look forward to working with families and gaining the **support of your child's school**, to enable me to do this research.

Please contact me at katherine.gulliver@plymouth.ac.uk for more information

Happy Williams Syndrome Awareness Month!

3.3.1. *Initial school visits*

Initial school visits occurred with three schools, whilst I was still recruiting children. One school did not want to be involved due to heavy staff workload, whilst another school did not respond to my email. All participants and names of schools have been given pseudonyms to protect their identity as much as possible.

Initial visits helped to introduce me to the children and settings, enabling me to start building rapport before research began. I met with each of the children to introduce myself, and I had a conversation with each of them. As part of the conditions for obtaining funding from the WSF for travel, I shared the research proposal in the WSF magazine which is sent regularly to members twice a year.

Golden Oak primary school

I arrived at Golden Oak primary school which looked newly built and renovated. I noticed a lot of support staff, and there was a friendly and professional atmosphere. Ryan was in his class, and *looked up to see who the visitor was as I popped my head around the door. Ryan's TA brought him and his friend out to talk to me on the table outside the classroom. Ryan seemed excited to talk to me, through his repetition of asking my name. The TA, who had been supporting him for the first two years of his school, encouraged him to ask a question to continue the conversation.*

> *Ryan: What's your name?*
> *K: Katherine*
> *Ryan: What's your name Katherine? What's your name? What's your name name?*
> *TA: Let's try and ask Katherine a different question, like what is your favourite colour?*
> *Ryan: What's your favourite colour?*

Ridgeview School

I parked at Ridgeview School and noticed it seemed to be in the middle of a large secondary school campus, with teenagers walking around. This is a smaller school, with only one class per year because the school is divided across two sites. It has less room to move around, with lots of furniture and resources visible. The playground is filled with loose parts, objects, chairs, cardboard, tyres and I am excited to see the children's imaginations in play. The staff are very friendly, and I meet Sophie who seems very shy. Our conversation is minimal, and I am unsure whether we have made as strong a connection as I did with Ryan. Sophie's parents later shared with me that she found my picture in the WSF magazine and pointed to me as the lady that visited her.

> *Sophie: Dress, dress, dress*
> *Sophie: coming to play?*

Littlewood School

I drove through a quiet, quaint village with rich history and beautiful landscapes. It is starkly different from the other two schools I visited which were in busy towns. It is a friendly village, with a strong sense of community. The school is on the edge of a woodland, and the class has access to a large outdoor space with big sand boxes and mud kitchens. The children are keen to explore and befriend insects and bugs. Forest school is a large part of their week. Staff are friendly and welcoming. I meet Orla and her TA, who helps her to focus on my conversation with her. It is nearly home time:

> *TA: Tell Katherine what you do at forest school*
> *Katherine: What do you do in forest school?*
> *Orla: We have forest school this afternoon and I have forest school, and I do forest school and see Mum. I do forest school this afternoon and have milk. I do forest school this afternoon and come back and get my home things then see Emily and Mum. Emily is always there.*

I recorded my observations of the schools and my first conversations with the children in my fieldnotes book. This gave me a sense of what the children liked to talk about, and already how they might be supported to have a conversation. From these meetings, it emphasised the importance of the research methods I had chosen which did not rely on verbal communication but enabled children to share their perceptions in different ways. I did not visit Edgewater School for an initial visit before the study, because it took several months to advertise the study, gain informed consent and organise the fieldwork. Co-incidentally, although I did not know Wendy very well, I had met her and her parents at previous WSF events whereas I had not met the other children in the study before.

3.4. Fieldwork

I spent one week in each setting, and each morning I ensured that I arrived before the children so that I could offer assistance to staff in either preparing workbooks, tidying the setting or offering a cup of tea. This gave staff the opportunity to discuss the research, ask any questions or share things that had occurred to them from the day before. For example, if they had borrowed Tynan's (2018) WISHES book, then the teaching assistants would sometimes reflect on their own ideas, the children's needs or ask for my own experiences about my brother.

3.4.1. *Information about each school*

The following table illustrates the schools attended by the 4 children in the research study. The highest percentage of pupils with SEN support (20.7) occurred at Golden Oak School where Ms Jacobs was given more responsibility as a specific SEN TA. She had time to plan and resource activities, frequent training and appeared more confident in working with children with SEN/D.

It is important to highlight information about the schools to show the differences in size, socio-economic backgrounds and number of children with SEN. These factors are often associated with disadvantage (Goodley, 2013; Liasidou, 2012) and can highlight a difference in funding, support and differences in community. Factors such as persistent absence and percentage of SEN support or percentage of pupils with free school meals can indicate these differences in funding within the local community. Whilst the Local Authority may choose to provide all primary school children with free school meals, all children in Reception, Year 1 and Year 2 in state funded schools were entitled to a school meal as of September 2014. Eligibility for free school meals for children in other year groups was based on numerous factors such as whether parents and guardians are receiving a type of income support. Therefore, the number of free school meals received in primary schools can suggest the area is of a lower socio-economic status.

Ridgeview School had the highest percentage of pupils with English as an Additional Language (32.3) and free school meals (31.9). However, the school was split across two sites and Sophie attended the one class entry form site, which meant her experience was in a much smaller setting, similar to Orla’s class in Littlewood School. The ratio of boys to girls are about half, which is as expected.

Table 1: Schools Information Table

Information about schools	Golden Oak	Littlewood	Edgewater	Ridgeview
Total pupils	621	207	434	724
% of Girls	47% girls	50.7% girls	44% girls	49.6% girls
% Free School Meals	6.8	6.8	6.1	31.9
% English as an Additional Language	1.9	0.5	1.8	32.3
% Persistent Absence	4.2	6.1	12.4	11
% SEN Support	20.7	14.8	10.3	14
Pupils to Teacher ratio	23.6	25	23	17
OFSTED rating	2012 Outstanding	2016 Outstanding	2012 Good	2018 Requires Improvement

3.4.2. *Information about children and staff*

Sophie, age 5 years, attended Ridgeview School, located in an urban town on the edge of a city. Ms Hughes, the class teacher, had taught Year 1 for just over a year after 6 years working in a tuition centre for children from 4 to 16 years where she had some experience teaching children with global developmental delay. Ms Watts had been working 1:1 with Sophie in the previous year, and her role shifted to working in an enhanced ratio, so she supports Sophie along with 5 other children who sit on her table in the classroom. Although Ridgeview School has four classes per year, Sophie was in the smaller site of 1 class per year.

Orla, age 5 years, attended Littlewood School, a faith school in a small rural village. Ms Roberts was in her third year of teaching, and as a small part of her teacher education had experience working in a special school for children with complex disabilities. Ms Turner was a teaching assistant for nine years, working as a 1:1 with a boy with Down Syndrome from pre-school through to Year 6 before working with Orla when she joined the school in Reception class.

Ryan, age 6 years, attended Golden Oak primary school, in a suburban town on the edge of a city. This school had a two-form entry. Ms Dill, the class teacher, was helping prepare the class for Year 2 Statutory Assessment Tests (SATs) with a practice paper. Ms Jacobs worked 1:1 with Ryan and has worked as an SEN TA for four years. Prior to this, she worked at the school for a few years doing lunchtime cover. Ms Jacobs and Ryan also work with another child called Emily who has some difficulties with learning. Emily works together with Ryan in the mornings, and then joins her class next door in the afternoons. A third child who is a year younger, Rose, has joined Ms Jacobs temporarily as she was having difficulties staying in her class and focussing. The school was gathering evidence to secure funding for her own SEN TA.

Wendy, age 5 years, attended Edgewater primary school, set in a large seaside village. Edgewater School has two classes per year, and Wendy’s class has two class teachers sharing the job. The first three days was Ms Pennywell. The last two days the class teacher was Ms Lock who had been teaching for eight years, and at Edgewater for a year and a half. Her experience in the previous school was supporting children with emotional and behavioural issues, and Autism spectrum disorder. Ms Dot has been Wendy’s 1:1 TA since nursery, which is why she was known by her first name by all the children. Ms Dot has been at the school for ten years, as lunchtime cover and then providing interventions before moving to full time as a 1:1 for the last four years. Ms Dot was working 1:1 with a boy with a different syndrome prior to working with Wendy.

Orla, Sophie and Wendy were in Year 1 classes whilst Ryan was in a Year 2 class. All four children were in the same class as their chronologically aged peers. The following details the dates and time spent there. All visits occurred before the national lockdown, with the last visit ending the week before the global pandemic heavily impacted Britain.

7th October 2019 – child was absent due to illness
One week beginning 11th November 2019
One week beginning 25th November 2019
One week beginning 27th January 2020
One week beginning 9th March 2020

I decided to include the photographs of children in this thesis to help show their vibrant personalities visually. Taking photographs of the children helped to show them what the research looked like, for example a picture of them with the audio recorder or looking through photos. These became more important with the creation of research photobooks (Appendix 1) which were sent to the children to keep a record of what participating in research looked like.

My decision to include copies of photographs of the children and that the children had taken evolved after my first visit. Concerned with autonomy, I emphasised the ownership of the photos of the children so much so that I did not have many to analyse when I came away. Many of the photos Sophie had taken included children or staff in her class, and without their consent I would not use them. I was more interested in the activity itself and how that could provide Sophie with an opportunity to share her thoughts. However, I realised that I did need to somehow capture their photographs so that I could look back on what they had taken or to remind me of our tour. Therefore, I became more comfortable with asking for a copy of their photographs as it would impact how I was able to analyse and complete the study.

Although the audio recorder was a handy size to keep in my pocket, I always felt it important to make its presence known if being used. This meant that conversations that were recorded with staff were more formal interviews whereas ad hoc conversations could equally give me an abundance of information, which required me to write in note form after. Similarly, the presence of the audio recorder and video camera were clear when working with the children and staff.

3.5. The Mosaic approach with children with WS

Clark and Moss (2011) developed the Mosaic approach to listen to very young children using an array of methods and tools such as photographs, drawings, guided tours and maps. As children with WS are generally very sociable, but are at risk of having non-social anxiety, it is particularly important that the Mosaic approach enables participants to share their perceptions of the spaces they use.

The values behind the Mosaic approach are particularly appropriate for working with children with WS, as ‘experts in their own lives’ (Clark, 2017, p.22) who hold a very different perspective of their own experiences and perspectives, to that of an adult’s perspective. In an adult dominated society, children are at risk of being viewed as ‘less than’ an adult, which suggests their perspectives are not as valued (Punch, 2002).

Viewing children as skilful communicators relies on practitioners providing a variety of resources, environments, opportunities and tools to enable young children to communicate (Clark, 2017). Although children with WS may be eager to communicate in research, this can depend on how the researcher is able to provide the right type of support for children to understand and share their perceptions. Another underpinning value of the Mosaic approach is the view that children are meaning-makers (Clark, 2017) which aligns with my intentions to invite children with WS to be active participants in the research.

Drawing on key articles form the United Nations Convention of the Rights of the Child (UNCRC), young children are viewed as rights-holders and active citizens. Clark (2017) points out Articles 12 and 13 declares that children have the right to express their views in matters that affect them, and that communication of information should be through a multiplicity of media of the child's choice. Similarly, a wide range of policies including the 2014 Children and Families Act highlights children with disabilities' views, wishes and feelings, and the importance of their participation as fully as possible in decisions (Department for Education, 2014). This is key to informing individual day-to-day interactions as well as service design and review. Furthermore, the SEND Code of Practice (DfE, 2015) promotes the self-advocacy of children with disabilities and their families.

3.5.1. *Guided Tour*

I had previously contacted families and staff with accessible documentation featuring symbols and language to explain my visit. Children were invited to show me around their school in the first couple of days of my visit. The guided tour was intended to establish their role as co-researcher. I wanted children to introduce me to their school, which would help them to develop their role as researcher as they could guide, direct and teach me whilst physically moving around the spaces within their school. Alike other tour guides, by showing me their school the children were encouraged to observe, listen, discuss and learn about their space through walking and showing me (Clark, 2008).

This enabled me to begin to build rapport with children, as well as encouraged the children with WS to take an active role in the research. Traditionally, children may not be familiar or comfortable with having an active role, particularly in the educational environment where they are taught to listen and follow instructions more often than actively choosing or directing the activity (Punch, 2002). However, significant social strengths found among individuals with WS are their sociability and eagerness to interact with others (Brawn & Porter, 2017). This was found in the study where some of the children were animatedly excited to meet me, while others seemed to accept my presence in the class. All children agreed to help show me their school, either with their TA or another child in their class.

3.5.2. *Photographs*

Children were invited to take photos of their school during the guided tour. This resulted in pictures of anything the child chose as a significant part of their school space, such as parts of the playground, coats, toys or rooms.

Taking photographs allows participants to continue actively controlling the tour and contributing to their own research of their school. During the tour, I hoped to ask children where they were taking me, and what happens there. The first tour needed considerably more of my prompts and guidance, which highlighted how different the task was to children's usual experience of school. This in itself is important to highlight as the impact of my research inevitably influenced my visit. Fieldnotes written after the tour helped me to consider and reflect on the areas of the schools children highlighted, and the spaces they did not show.

Cameras are generally accessible, fast capturing and fun to use (Poveda *et al.*, 2018). Unlike sole drawings or words, photographs enable participants to capture an instant image which can also include a sense of the ambience, place and context (Poveda *et al.*, 2018). Whilst photographs provide a physical and visual entry into the participants' world (Aldridge, 2007), it is important to understand the meaning behind the photo, or the researcher risks misrepresenting the image.

Halfway through my week-long visit, I printed photographs from the tour, and found a convenient time where I asked children to discuss what was in the photographs. Through reflecting on the tour and choice of photographs, children were encouraged to process their thoughts, giving them order and showing importance to ensure a meaning-making experience (Aldridge, 2007; Poveda *et al.*, 2018). I hoped that this activity would help corroborate the interpretation and analysis of children's experience and educational environment. However, this activity became more important as an opportunity for the children to guide the research through what they wanted to do with the photos.

Photographs can act as a stimulus to encourage conversation (Aldridge, 2007). Discussion about the photographs were important to give context to the content. Children with WS usually have a good grasp of expressive language, with varied vocabulary (Alfieri *et al.*, 2017). However, the young age of participants and individual differences resulted in varied verbal ability. Many were working with speech and language therapy interventions. Considering an individualistic approach, it was important that the research tools enabled children with and without verbal speech to participate in discussions around why they took the photo, or what it may mean to them.

Remaining flexible and adaptable, I offered opportunities for children to add drawings, words, pictures or labels to their photographs to attempt to capture their experience and perceptions of school. This helped to highlight children's experiences of taking photographs, and what they were interested in. For example, Sophie enjoyed taking photos of friends, and I wrote this next to her photograph booklet. On the other hand, Orla enjoyed mark making with the pink pen, and she chose her favourite photographs to create a poster that she decorated with the pen.

3.5.3. *Observations*

A trial observation in a local special school allowed me to experiment with different types of observation techniques and develop my preferred style. Initially I designed a focussed observation through a pro forma to focus the goal of the observation, but too much structure in a pro forma may limit or restrict my attention to the observation (Flick, 2018). Writing detailed notes also took time away from the children, whereas I wanted to be more involved in their activities. Therefore, observations in my research took place frequently throughout the day. Descriptive observations provide rich detailed context of the classroom, children and staff. Certain moments felt important, such as the whole class PE lesson, or a small group phonics session which I recorded during the activities. Other times I recorded observations at lunch time and after school in a journal.

Observations took place at various times throughout the usual school routine. Although I hoped to observe naturally occurring events and behaviours, there was a risk of my presence influencing the behaviour and experiences of pupils and staff (Cohen, Manion & Morrison, 2007; Flick, 2018). However, these observations form one part of the Mosaic approach (Clark, 2008), adding depth to the research, rather than being the only method I rely upon. Furthermore, observations are a recognised method within listening to young children with SEN/D (Nind, Flewitt & Payler, 2010; Parry, 2014).

My position of being unfamiliar with the setting was useful so that I could closely observe the children and staff. Participants may not notice their behaviours as they have become familiar to them, whereas my position as researcher enables me to pose questions. A regularly written reflective diary was used to detail observations, conversations and activities. During data analysis, I found that the fieldnotes were detailed enough to remind me vividly of my own experience during the school visits.

3.5.4. *Videography*

Videography as a research method is valuable in documenting exactly what is happening in a scenario and interaction. It has been used increasingly in various areas of research including “psychology, conversation analysis, ethnography, education studies and child studies” (Sparrman, 2005, p.241). Written observations rely on what I see, and how clearly I document them. By extending participant observation and digital voice recording, a video can capture non-verbal parts of an interaction, for example eye gaze and gestures (Sparrman, 2005). This is important in social interactions, as verbal speech only comprise a small percentage of the interaction. Written and voice recorded observations rely on rich and detailed descriptions. Videos can be repeatedly viewed, capturing more aspects of a situation and reducing the possibility of researcher selectivity (Flick, 2018).

There are several practical challenges to using videography, video representation and analysis (Goldman *et al.*, 2014). Videos may not capture the whole space or activity, where a written report could (Sparrman, 2005). Therefore, it is important to emphasise that using a video is one part to the Mosaic approach, which will help address the research questions. Assumptions made watching videos may affect audience or viewers’ response (Tobin & Hsueh, 2007). For example, a video of one misunderstanding does not mean all children will have this misunderstanding. Similarly, the methodology of the study is not intended to be generalisable but a specific example to draw insights from. Therefore, video analysis also needs to be reflective and considered as a moment in time during my visit which I could re-watch.

Descriptive observations helped to provide detailed context. I introduced the children to the camera for them to take photographs early in my visit. I discussed with the class teacher and teaching assistant to organise a suitable time to record a video. After a couple of days, I organised with the teaching assistant to take a video of them working with the child. I did not have consent for other children in the video, which meant we took the opportunity to film when the TA and child were working in another room or space. I hoped to record natural social situations such as a spontaneous conversation, but the presence of technology can still affect how participants behave (Flick, 2018). One member of staff preferred not to have her face filmed, so I stayed with the camera to point the lens towards the child and away from the adult. The observation may also be affected by whether the participants move in and out of the video shot (Flick, 2018). At times, children from other classes would walk past the activity, which meant the video footage could not be used. This also highlighted the possibility of distractions for children who are working outside the classroom, in corridors or other areas of school.

3.5.5. *School Staff Interview*

I offered teaching staff individual interviews, which could have been more comfortable for them to discuss their experiences of supporting a child with WS. On the other hand, a focus group interview might have been more appealing to school staff with limited time. However, group interviews can be compromised if some participants dominate or influence the conversation more than others (Cohen, Manion & Morrison, 2007). All interviews lasted between 20 and 50 minutes. All but one of the school staff participated in interviews, and although I emailed a smaller set of questions to one class teacher, they were too limited on time to respond.

Interviews explored teaching staff's experience of supporting individuals with disabilities, knowledge of WS, and their experience supporting children with WS. This type of data cannot be sought through observation, and would be limited by survey or questionnaires, which often use closed questions (Seidman, 2006). Other limitations to surveys include the willingness of participations to complete answers in full, whereas interviews feature a researcher who is often able to use active listening skills to show they are interested in what the participants have to share. Furthermore, "interviewing provides access to the context of people's behaviour and thereby provides a way for researchers to understand the meaning of that behaviour" (Seidman, 2006, p.10). People cannot know the perceptions of another person, so we rely on asking them to explain their own subjective understanding. An effective way of asking is through a conversation or interview. Whilst observations provide access to someone's behaviour, an interview allows researchers to put the behaviour in context in an attempt to understand the persons' actions (Seidman, 2006). Interviews took place with staff after I had spent time working alongside the class. With their consent, children's photographs and the video of the child and teaching assistant could have been a useful stimulus to "prompt discussion, stimulate recall or provide a basis for reflection" (Jewitt, 2012, p.3). However, most interviews were conducted ad hoc, during class teacher's PPA time, or when there was enough adult supervision in the room for the teaching assistant to leave.

3.5.6. *Photobooks*

Photobooks have been used in research, therapy and education where children choose a theme for thematic photobooks, take photos, and create a book (Veksler, Reed & Ranish, 2008). Other research recognises through the social practices of co-creating research children can become co-authors of photobooks (Stetsenko & Ho, 2015).

Sophie, Orla, Ryan and Wendy each received a personalised photobook (Appendix 1) to represent their research output. Based on the socio-cultural perspective that children are not passive recipients of culture, but co-contributors together as researchers, the children, and staff and I were co-creating the research, both responsible and responsive to each other and our surroundings. In this way, although I made the photobooks myself, it narrates the process of the research that the children and staff participated in.

Each photobook followed the same template; a picture of myself saying I visited their class; pictures and short sentences describing the research process, what children did and what I was going to do next. The photobooks included photos of the children speaking into the audio recorder, looking at their photographs, and many of their own photographs of their school. The last few pages showed a photograph of me at my desk on the computer, and writing books as I described sharing the research with others. This was another useful aspect of the Photobook as it showed participants what I actually do with the data we gathered, for example, writing it up and sharing it to help others. In a handwritten note to each child, I thanked them for their help in the study, and encouraged them to share the book with their family, friends and teachers. I asked Wendy's family if I could have a copy of the photobook for my own research (see Appendix). Her note asked her if I could have a copy to share with my friends/teachers at

University, and I explained this to her parents, as well as re-iterating the research aims.

I had intended to visit the children in the schools again, where they could reflect on the research and share it with their friends, family and teachers. When this became less of a possibility, I looked to making the photobooks. During the government advised lockdown, my participants may have been isolating with their families, as they will have been classed as vulnerable. With this in mind, I contacted each of the families via email or message to explain the photobook idea, ask for their address and ask after the family. Parents replied enthusiastically, mirroring my assumption that this may be a nice surprise in the post during a difficult time, where children can be reminded of their school, learning and research.

The photobooks were a good way of debriefing without face-to-face contact or reliance on participants' availability, access and technology. It was not possible to learn how the materiality of this book affected participants – what they could smell, feel and notice when they looked at the pages. The sensory experience may have evoked memories, feelings and thoughts. Therefore, contact with parents during this time was helpful to indicate how the children and families experienced the book. Parents shared their feedback through photos, messages and videos from the children to say thank you. Sophie's family shared that she proudly took it into school to show everyone, and Wendy reportedly looked at it over and over again.

The photobooks had several functions. Not only did they provide children with a debriefing of the research, they also reiterated the research aims, their participation and output. The photobook meant that parents and families could share in children's meaning making and participation in research. Children and parents both seemed proud of their creation. Another strength of the photobooks was enabling children to view themselves as authors, helping them to understand the value of books and reading, as well as emphasising how books are a form of communication rather than a challenging task. All the children were learning to read, which emphasises the importance of the research material being meaningful. Ms Turner had emphasised the importance of finding something that Orla was passionate about, so that she could tailor the reading to be more meaningful for Orla.

Similarly, children may be more motivated to read or share this book with the photos they took themselves. Edwards *et al.* (2002) suggests self-made materials can be very motivating for children, as they were involved in the creation of the artefact. They could also present it to the class, and it could be used as a stimulus for discussion and further learning or participation.

3.6. Ethics

The Plymouth University Education Research sub-committee approved the research. Ethical considerations are rooted into the Mosaic approach, where participants continuously display their right to withdraw by choosing to participate in an activity, change the activity or move away. By choosing this approach, I embedded an ethical framework into all stages of the research. I created documents for children, parents and school staff to explain the purpose, benefits and reasons behind the research. If an ethical dilemma or decision occurred during fieldwork, I noted this down in an Ethics log and could talk to my supervisors or the school staff (further ethical entanglements are discussed in 3.2.) Additionally, I requested permission to approach the Plymouth University Ethics Committee throughout my research for amendments or further ethical concerns not previously considered. Furthermore, this project met the requirements of university research degree regulations and Plymouth University and BERA (British Educational Research Association) ethical guidelines for research involving human participants.

All participants had pseudonyms explained to them in terms they could understand. Any information was kept confidential and shared only with my supervisors. I followed school safeguarding policies and knew to notify safeguarding leads of schools if necessary. All identifiable information about participants was anonymized, encrypted and password protected, kept for the period of the PhD, after which it will be securely destroyed. Anonymised data may be used in future studies, and in keeping with ethical protocol stored securely for 10 years.

3.6.1. *Consent*

Parents and head teachers of schools were gatekeepers whom I sought for permission and consent, similar to a consent network (Nind, 2008) whilst the children were specifically asked and continually monitored throughout the visit for assent. I supported children to communicate in their preferred style, for example using a total communication approach with Makaton sign language and simple speech, and no children in the study used a communication aid. Children with WS typically show highly motivated social behaviour (Klein-Tasman, Li-Barber & Magargee, 2011), so I anticipated that children would not feel excluded or ostracised from the class, with the option of leading the tour with a friend/s. Indeed, children in the study all welcomed me warmly, and often it was the children with WS who were the most interested in my visit to their class.

Regarding participants giving informed consent, the Mental Capacity Act of 2005 ensures an assumption that adults with learning disabilities have the capacity to consent. Although capacity may be impaired by cognitive difficulties, researchers can increase capacity by presenting information in an accessible way (Nind, 2008). For example, I used simplified language, signing and picture aids to increase participants' understanding. Similarly, in the legal system to be 'Gillick-competent' is the ability to understand a choice and the possible consequences, rather than for consent to be deemed by age (Nind, 2008). Therefore, presenting information in a participant-accessible way allows participants (in this case, children with WS) to make the choice to participate or withdraw from the study. My study does not rely on testing a child's intellectual ability; the more appropriate test is their ability to understand their own lives and be able to share that with others through research. However, children's ability to weigh up the consequences of participating in research is a difficult concept to measure. The ethically sensitive approach ensures that I protect the children in the study from harm, and increase their capacity to understand in order to assent.

Seale *et al.* (2015) suggests that data analysis and reporting are difficult aspects of researching with children and adults with disabilities. However, I contend that this is the most important part. Sharing photobooks detailing the research process adds to the authenticity of the consent process. Children used cameras to take photos and later these photos appeared in an activity when I printed and showed them. Some time later, these same photos appeared within a photobook which can be shared with others, increasing their understanding of what they have said and done. This process of consent enables children to connect to the process. However, consent is more complex in school situations, where children are usually less able to opt in and out of participating due to the expectation of following adult instructions.

3.6.2. *Right to withdraw*

All participants were advised verbally and in writing about their right to withdraw from this research. I used the total communication approach (a combination of Makaton sign language, clear verbal language and visual aids) for children. Initially I intended to introduce the children to a system of a green card and red card to physically show assent and right to withdraw. However, I felt that this was unnecessary as children had their own system for participating or withdrawing from activities. My communication with staff was important in being able to understand when a child was showing assent without feeling pressured to follow authority, which would usually take place in a school setting where adults have more agency over children. My extensive experience with children with WS also helped inform me of their willingness to participate, although it is acknowledged that all children are different. Children and families had my contact details if they wished to withdraw their video and or any photos shared with me as data for the research study. My frequent articles in the WSF Spring and Summer magazines also reminded families of my contact details.

Participants could withdraw from the research at any time until the data analysis stage, at which point all identifiable information was anonymised. Participants were informed of this clearly in information sheets and verbally.

3.6.3. *Ethics Log*

The Ethics Log, complementing my reflective diary featuring narrative descriptions rich in context and observations, enabled me to reflect on ongoing ethical considerations. The Ethics Log could be shared with supervisors, and schools if needed. In-depth reviews of various literature highlighting the challenges of researching with children ensured that I remained aware and careful to avoid harm, exploitation, and keep children’s privacy and autonomy (Cocks, 2006; Harcourt & Einarsdottir, 2011). Researching with children is unpredictable. Children experience the world differently to adults, as well as using different or less vocabulary, having a shorter attention span and fewer experiences of the world (Punch, 2002). Therefore, it was impossible to imagine every possible outcome or potential problem when working alongside children. Using common sense and my extensive background experience in working with children with disabilities, I strived towards embedding assent and reflexivity into the whole research.

3.7. Data tables

The following tables show each of the data recorded from the weeks spent in each school.

Individual School data plans

Figure 2: Data collected from Ridgeview School

Guided tour	Recorded on the first afternoon in daily summary, observation and photos taken					
Photos	All taken by Sophie kept on school iPad, mostly of other children	Photos cut by Sophie and I put together in a Photobook	7 x the photobook making activity	10 x taken by me of Sophie cutting, writing, exploring recorder	6 x written work	4 x general classroom and timetable
Observations	Written throughout daily summary	Conversations with Ms Watts	Time spent with Sophie and peers on Table	Phonics session		
Videos	3 x interventions	3 x photobook and recorder exploration	2 x conversations			
Audio Recordings	Ms Hughes interview	Ms Watts interview	7 x S exploring recorder	5 x making photobook	3 x interventions	3 x conversations
Daily summary	Written at the end of each day, including section for Ethics Log					
Overall school summary	Written at the end of the week					

Figure 3: Data collected from Littlewood School

Guided tour	In small periods across two days, recorded in daily summaries, observation and photographs taken

Photos	26 x taken by Orla on camera	2 x chosen to stick on paper	6 x taken by me of photo activity			
Observations	Written throughout daily summaries	Speech and Language Therapist assessment	Time spent with Orla during Busy Time	P.E (Physical Education) session		
Videos	1 x interventions	1 x short statement	1 x conversation and photo/bag exploration			
Audio Recordings	6 x Orla exploring recorder	Interview with Ms Turner	Interview with Ms Roberts	2 x making Photobook		
Daily summary	Written at the end of each day, including section for Ethics Log					
Overall school summary	Written at the end of the week					

Figure 4: Data collected from Golden Oak primary school

Guided tour	On the afternoon of the third day, written in daily evaluation and captured in some recordings and photos					
Photos	3 x by Ryan	5 x by me				
Observations	Written throughout daily summaries	Bucket game, Space day, Playground	Time spent with Ryan on table outside			
Videos	1 x during 1:1 Literacy					
Audio Recordings	6 x Ryan exploring recorder	4 x Guided tour	2 x general conversation with Ryan	Interview with Ms Jacobs	Photomap	
Daily summary	Written at the end of each day, Ethics Log become intertwined					

Overall school summary	Written at the end of the week

Figure 5: Data collected from Edgewater School

Guided tour	On the afternoon of the first day, the tour was given by W and a friend picked from the class by the staff who was “good at showing people round”					
Photos	15 x by Wendy	4 x by me				
Observations	Written throughout daily summaries	Carpet time, Read Write Inc, Maths, play	Time spent with Wendy in the class			
Videos	3 x during 1:1 Literacy					
Audio Recordings	2 x Teachers interview	1 x Ms Dot interview	1 x Photo tour interview with Wendy	1 x talking about camera	4 x Hellos	
Daily summary	Written at the end of each day, Ethics Log become intertwined					
Overall school summary	Written at the end of the week					

The first school visit has a significantly higher number of videos, audio recordings and photographs. One interpretation is that as my first school visit, I was more directive with the research. As the visits continued, I focused more on enabling others to direct the research. Another possible reason is that the type of school setting and work that Sophie was doing lent itself to co-researching with me over several different times of the week, including her 1:1

intervention time outside of the classroom and her reluctance to attend assembly.

The next school visit had a completely different structure with the continuous provision approach, which although lent itself to co-researching opportunities within the class, it was also a busy, open environment. The more time I spent visiting schools, the more confident I became with working flexibly alongside the children and staff to find suitable times for audio recordings, videos and photographs that would capture their school day, but not take them away too much from their daily routine.

Whilst all the guided tours aimed to be in the first couple of days, Ryan's school visit was slightly different as the Monday was 'Space Day' which was especially different to his usual daily routine. Although this enabled us to spend time within the class doing various activities that showed a cross-curricular topic, it meant that the week began with predominantly my own observations.

3.8. Methodological achievements and challenges

This research in itself was a route to self-advocacy by providing time, space and materials for children to share their perceptions. With the view that children are capable of conducting research, and sharing their perception, there were several challenges to asking young children with disabilities to take control of the research. In the first school visit, Sophie seemed unsure where to take me on a tour around the school. Ms Watts joined us, and we both encouraged her to show me her school, whilst I asked questions such as 'Where do you go for assembly?' and 'where else do you go?' or 'what do you do here?'

It was useful for the children to spend some time with the camera, learning the purpose of the different buttons. Many pictures did not necessarily show what the child was aiming to take a photo of, because the button to press to take the photo demanded a lot of force, which pointed the camera down. For Sophie, I swapped the digital camera for an iPad as the camera's buttons seemed difficult for her to press.

> *Sophie attempted to use the digital camera. She took a few photos, although it looked difficult for her to manage holding and pressing the button. All photos were up close, pointed away from the potential intended subject, and mostly were of the table in front of her. We then swapped to use the iPad. Again, Sophie took some time to explore taking photos which framed the intended subject. With practice, Sophie seemed more confident and independently taught herself to hold the iPad slightly higher to capture what she wanted* (S1, p.1).

In conversation, staff disclosed that children were not usually given the opportunity to take photographs, and suggested this was a good opportunity for them to develop an additional skill. Often the children would be photographed next to an activity, or have their work photographed to show what they had been working on that day. These photographs were taken by the teacher and either shared with family via a platform or kept as a record of evidence. This could be an opportunity for children with WS to have agency over their work, by capturing it themselves and offering opportunities to discuss with teachers or family the activities they had participated in that day. On the other hand, taking photographs of their work may also separate children from their peers who do not often have photographs of their work which highlights the dilemmas of differences as discussed previously (2.1.1.).

3.8.1. *Respecting children as capable researchers*

In order to listen to young children with disabilities, it is important to respond to children's needs and interests. However, there were distinct moments of tension within the research. A part of understanding their feelings, thoughts and experiences is respecting that children also have their own goals, desires and wishes. This may mean that the participatory research initially designed does not happen as expected. In contrast to the well-conceived, minutely timed and considered planned activity, young children have the ability to bring the unexpected and unpredictable.

Examples from the analysis highlight the children's roles as co-researchers. Although the research aims and purpose were my own decision, and my presence influenced the participants, children were still able to confidently direct the research in their own way, either by glueing or cutting (Audio S3). Their decision to talk to me showed what they wanted to share with me or not. Very young children with disabilities have their own desires and goals. It is our responsibility as reflective and responsive researchers to carefully listen to children, and not override the opportunities or remove spaces that encourage agency and voice. The children's rights movement emphasises this as well as an increasing focus on enabling children with SEN/D to contribute to decision making as reflected in the SEND Code of Practice (DfE, 2015).

The following example begins with a section of transcript from an audio recording where Sophie is looking at the photographs she took of her school. Photographs may represent something important to children, and looking at the photographs with the children, practitioners can listen to reasons why children took the photographs and what they intended to show. It is part of an approach designed as a reflective process for children to consider meanings, make sense of experiences, make new connections and express understandings (Clark, 2010). This requires researchers to use multiple methods of listening to the children, which might appear different from researchers' intended aims.

3.8.2. *Cutting up the research*

Katherine: What's inside?
Sophie: I need some….
Katherine: Are you going to do some colouring?
Sophie colours and
Sophie: let me write *sounds out F* T*photos
Katherine sounds out f o t o
Katherine shows S the photobook
Sophie: we need to put the
Sophie: writing
Sophie: h e lo
Sophie: can I do some cutting?
Sophie: I cut it
Sophie: I want to cut this
Sophie: and write it
Katherine: what else can we write?
Sophie draws
Katherine: what have you drawn?
Sophie does dots
Sophie: can I cut it now?

My eagerness for the children to explain to me about the photos, nearly stopped me from listening to what Sophie wanted to do. Instead of cutting the photographs, I was hoping Sophie would like to add drawings and colouring to help explain or make meaning from the photographs. Fortunately, she was very clear in telling me that she wanted to cut the photos, and this was a significant moment where I recognised that I wanted her to lead the research, even if it was against my initial desire. Whilst cutting through the photos could appear as a form of resistance to the research, her love and interest of using the scissors was more evident as part of her recognition that she was able to share her own interests, strengths and guide participation in the research. Cutting around the photos helped us to make a draft photobook of her pictures. This emphasises the importance of following children's interests, as a way of enabling children to communicate, share their perceptions and guide the research.

3.8.3. *School staff as researchers*

Whilst the children showed their consent by either photo taking, cutting or moving to a different activity, school staff were more aware of wanting to give me as much information as possible. Recorded conversations sometimes felt like a barrier because I needed to present the audio recorder and switch it on, whereas informal chats often gave me rich information on the spot, but required me to digest this information before summarising in notes in a notepad later.

Teachers on the other hand, did not have as much time or space to give to the research. Five out of six teachers participated in audio recorded interviews, although the sixth teacher was originally happy to email questions and answers, my emails remained unanswered and I was deeply aware of the pressures she was under to prepare the class for SATs, and maintain their 2012 Outstanding Ofsted rating.

3.8.4. *Researcher as school staff*

Whilst I observed many things in the class, and spent time with peers and staff, most of the research tasks were done outside of the classroom. I considered that doing the activities in the classroom could distract others, as well as emphasising the children's differences, or contributing to children feeling ostracised or singled out. Coincidentally, I was also keen not to disrupt the children's timetable and usual routines, although my presence was already a distinct difference for their school days. I was keen to minimise the intent focus I had on one particular child, so when I was in the classroom, I would listen to other children read, talk to them, and learn a few of their names. On the other hand, spending a lot of time with one child outside of the classroom also could emphasise my focus, and this was more evident in Golden Oak primary school when Ryan spent much more of his time outside of the classroom.

I found my role as researcher merging among the school staff who during Tidy up Time had a distinct lead in directing children to sort, tidy and put away the abundance of objects. At one point I was asked to use the Class iPad to take photos of children to add to their evidence linking their learning to the National Curriculum levels. Other times I volunteered to hear children read their books. These were TA responsibilities and I when I found myself taking this role, I felt able to become a part of the class. This meant that I was not focussing on only one child which could have ostracised them, and that I was able to provide additional support and help to the children and staff. On the other hand, this meant my position as an adult in the class was reinforced, so children would recognise me as a figure of authority and therefore someone who they had to listen to, rather than someone they could choose to listen to. This was important for me to reflect on in my ethics diary as I remained sensitive to the responsively ethical research process.

3.9. Engaging with stakeholders

I attended the Williams Syndrome UK Researcher Network in Durham in September 2019, where

I shared my research in an academic poster and discussion. Through conversations with other researchers, I disseminated information about my project as well as justifying my reasons for the methodology and aims. I was asked which group of children I would compare my results to, for example, children with Down Syndrome or Autism, or typically developing peers. This experience emphasised the importance of my positionality and methodology to contributing to research about, for, and with children with WS.

My contact with the Williams Syndrome Foundation (WSF) provided me with connections to the social media and Communications Officer who was keen to share my research on social media platforms, as well as the bi-annual magazine. I also produced a short biography for the charity's website, as a Researcher involved with Williams Syndrome. I produced regular short articles in the Williams Syndrome Foundation bi-annual Magazine, which updated members on the research as well as advertising what I was doing and why. A parent of a child with WS reached out to discuss their child's education, and I have met again with them at the most recent WSF conference. I attended the WSF Butlins Conference in Summer 2022 with my brother and parents, as a member and presenter where I presented to a group of parents and carers of children with WS. This was a particularly important moment as parents and children were the main stakeholders of my study, and discussions emphasised the continuous challenges that parents face in choosing educational provision, and ensuring children are supported fully, whilst considering how children with WS may experience school.

3.10. Data analysis

There were moments within the research process where conversations crossed with consultancy, as I sought from staff further clarification about my data, and staff asked about my own opinions and views. Analysis therefore took an active and iterative form throughout fieldwork, data immersion and reflecting. The children themselves reviewed the photos they had taken when I showed them a selection of printed photographs which removed duplicates. The children then returned to the same photos within the photobook, which helped them to make meaning from their experiences of school and the research process. Seeing how the research was captured through photos, videos and words, the photobooks became part of the consent process of understanding how research can be shared with others, and making sense of the research. The interviews with staff were transcribed through a transcription service, whilst all recordings of conversations with children were transcribed verbatim by myself, enabling me to process thoughts and reflections through note taking.

Information from schools, such as size, locality and a description, was useful to understand the context. For example, differences in school size, socio-economic background and number of children with SEN/D can indicate differences in communities such as funding and support. Interviews included information from school staff such as length in post, previous occupations and experience of working with children with SEN/D. This was to highlight the variation between people and schools in my study, which helps to broadly reflect the range of primary schools that can be found in England. Information also provides context to the type of school and staff's previous experiences and understanding of supporting children with SEN/D.

I spent several months looking through and making sense of my findings, before writing them. This included re-reading fieldnotes, summarising my thoughts and making detailed notes from watching and re-watching the videos. My decision to use active verbs as the headings of the findings represents the ongoing dynamic nature of experiencing, learning and thinking for children and staff working in schools. After this choice, I realised that the active verbs also reflect Braun and Clarke's (2019, p.4) suggestion that "the final analysis is the product of deep and prolonged data immersion, thoughtfulness and reflection, something that is active and generative". Returning to thematic analysis, Braun and Clarke (2019) emphasise the importance of the researcher recognising and understanding their ontologies and epistemologies. The authors introduced the phrase 'reflexive thematic analysis' to represent the significance of the researcher in the process of telling the stories. I recognised this in my own approach to this research project from bringing my experiences and knowledge of WS, my brother Tom and my deepening understanding of critical disability studies together to make sense of the data. Reflexive thematic analysis helps to create and interpret stories from the data, and demands a "reflexive and thoughtful engagement with the analytic process" (Braun & Clarke, 2019, p.594).

Looking at the photographs and videos, I was keen to explore a narrative approach to help tell the stories of Orla, Wendy, Ryan and Sophie. Analysing the videos was an initial challenge, and after investigating Laban's Movement Analysis, and attempting to code interactive spaces influenced by the work of Nind, Flewitt and Payler (2010), I re-watched each of the videos and noted my observations. I often found something that I wanted to share with an audience, that showed something about how children were using the space, what they were looking at or distracted by, and how they were supported in their work. For example, how Ms Watts was physically supporting Sophie, or how Orla reacted to a sound during our conversation. Often these moments reflected encounters of responsive 'withness'-thinking from Shotter (2006), an important element of understanding and listening to children, particularly children with disabilities. I also drew on Mason's (2002) 'noticing' to find moments which were important because they *showed* something (Mason, 2002).

After reading through the transcriptions of school staff interviews, I generated initial themes using NVivo, the qualitative data analysis package (Appendix 3). I assigned quotes from staff interviews under different categories, including:

- WS specific information
- Inclusion in practice
- School support
- SEN experience
- Child focus
- Peers
- Social skills
- Training
- Transition or change
- Teacher and TA differences

However, this brief analysis was only formed from the teacher and TA interviews, and so only captured one dimension of children's experiences, without any of the children's data. I felt it was important to start the analysis with each of the children's experiences of research. I began to present the findings in an overall story that showed each child's unique characters, likes, dislikes and experiences of primary school. I created an analysis framework which told the story in different layers, starting with the children’s experience of being a pupil. Children’s experiences underpinned the study, so there is less focus on school settings than the reader may anticipate. This is because central to exploring children’s experiences was my closeness to their perception of school to give a more nuanced view of education. The school itself was not the case in which I compared experiences between provisions. Instead, the schools were the settings within the case study of children’s experiences of attending a primary school. I drew on these insights to highlight the wider, ongoing challenges of supporting children with WS and other diverse learning needs in mainstream primary schools.

Beginning the findings with the initial guided tour helped to situate the study within the place of school, and therefore seemed a good opportunity to introduce children’s research into sharing their school and experiences within it. In this way, the Mosaic approach helped me to formulate and structure my analysis. Additionally, my previous knowledge and experience of Williams Syndrome and education influenced how I approached the analysis and subsequent chapters. Children’s experiences included a significant part of what having Williams Syndrome may be like from different perspectives. The way each of the children guided the research enabled me to focus on different key characteristics that are often researched from behaviour and psychologist approaches, for example, having anxiety or sensitivities to sounds. It seemed appropriate to then explore how children with WS were supported by either staff or their peers, and how this was experienced.

The second layer of the analysis framework positioned the data from the view of managing inclusion in different primary schools. This analysis looked at the position of schools, class teachers and opportunities for professional development in order to help facilitate inclusive educational practice. My analysis considered the staff perspectives and experiences of managing the competing tensions of inclusion. This included thinking about the spaces used both inside and outside of the classroom, and the opportunities for staff to talk with each other to share their knowledge and experiences.

The next section begins telling the stories of Orla, Wendy, Sophie and Ryan’s experiences of being a primary school pupil.

4. Experiences of being in a primary school

The following chapter addresses the first three research questions which ask: What do children with Williams Syndrome show as important to them in their school? What do children with Williams Syndrome want to contribute to research about them? And how do children with Williams Syndrome interact with peers and staff?

The following sections help to share the experiences of the four children in their schools, starting with the theme 'being a primary school pupil'. The use of verbs in the titles of themes deliberately highlights the nature of the research, and the real day to day life of children experiencing school, which is a continuous, dynamic process. The next theme 'going at a different pace' investigates time and pace for children with WS, their peers and staff, and looks at Elkind's (1987) 'Unhurried approach'. An important theme for research with children with a rare disability is 'knowing and understanding WS' and for the school staff and peers, how to encourage and assist a child with WS.

4.1. Being a primary school pupil

The children showed me around the school during a guided tour which aimed to help establish their role as co-researcher. Introducing me to the spaces they use in school would encourage them to develop their role as researcher as they could guide, direct and teach me whilst physically moving around the spaces that they use within their school.

Sophie guided me around Ridgeview School with Ms Watts, her TA, whilst taking photos. Some of Sophie's photos focussed on the door of her classroom and the door of her old classroom. In conversations about the photos, Sophie repeatedly told me the name of her previous classroom. I discussed this with teaching staff who then considered whether Sophie was still experiencing the transition from her old class. As it was the first week of the second half of the Autumn term, Sophie had attended her new class for several weeks.

S1

Ms Hughes, Sophie's class teacher, highlighted the transition:

> She'd always look at my door but never come in. So, she was aware that that's the door she had to go into. She was like, "Cherry class," but she'd never go into it (ST, p.16).

In conversations with Ms Hughes, these photos supported my interpretations that Sophie was still experiencing a transition period from the classroom she had spent the previous year in. Staff explained that preparation for joining Year 1 took place mostly outside of the classroom, so Sophie only saw where to hang her coat or play outside, rather than the inside of the classroom. Ms Hughes noted that:

> I think if I were to have another child like that, I'd probably change it and go, "Let's have a conversation about this. You're coming into my class." I know a transition book was sent home for mum so then she could show her during the half term, go, "This is your class" There was a picture of me and the coat racks and the outside bit but not the inside (ST, p.16).

In Sophie's research into her experiences of school, she was able to highlight her sense of transition by taking photos and telling me the name of her previous class. This enabled Ms Watts to reiterate to her that 'Strawberry class' was no longer her classroom (S1, p2).

Orla showed me around the school in several stages, either with Ms Turner or on her own. This took place over three days, to coincide with the rest of her timetable as I was eager not to withdraw her from the class. She took photos of toys, play areas, staff, coats, the hall and the entrance area. Orla took two photos of teaching staff who were not in her own class but other teachers in the school as she showed the other classrooms. Orla was reminded to knock on a classroom door and ask the teacher if she could take a photo of them.


O1

When talking about the photos, Orla enjoyed exploring the glue, so we worked together to glue them on the paper and then she coloured over them with a pink pen (Audio O1). Similarly, when discussing with Sophie the photos she took on her tour, she guided the research into cutting the photos (Audio S3). These examples help highlight the children's roles as co-researchers who had agency over the research, despite my own attempts to guide them towards talking about, drawing or marking the pictures (Audio S3). This emphasises the capability that some very young children have to share their desires and goals when carefully listened to, and given the opportunity. An important aspect of working with children with SEND is enabling them to contribute to decision making as reflected in the SEND

Code of Practice (2015).

Ryan showed me around his school on his own. Ms Jacobs, Ryan's TA, suggested he could do it independently, and was surprised when we later discussed the spaces he showed me, which did not include many areas such as the outside playgrounds where he enjoys riding the bikes. Instead, Ryan took me out of the class, pointed out the small playground, and showed me the hall for assembly, and the area outside his classroom where he often worked. The school was considerably bigger than what Ryan's photographs showed, including several different buildings for different year groups, and other play areas which he used such as the bikes area, woodland and fields. When asked what to call the space outside the classroom where he worked, Ryan replied 'our school!' (Audio R2 Guided Tour).

Clark (2012, p.337) states a map is another way of "children making their environment visible, a tangible form of meaning making" but as Sophie and Orla had done different things with the photographs, I was keen to be guided by the children. When sat next to Ryan talking about where he took me on the tour, I drew some shapes to represent his class, the playground and assembly. Upon reflection, asking the children to map out their school is a significant task, particularly children with WS who may have challenges with visuospatial awareness (Atkinson & Braddick, 2011). We could have worked together to create a map of their own classroom, but this would have required us to work inside the classroom.

When I talked to Ms Dot and Ms Pennywell about asking Wendy to take me on a tour of the school, they were both unsure that Wendy would be capable of doing this on her own. They chose a peer they considered very able to show a guest around the school, and who could help Wendy to complete the task. We went without Ms Dot, and Wendy was mostly led and encouraged by her peer to show me their school. I invited Wendy to take photos, which mostly showed different areas of the two outside playgrounds, the hand dryer from the girls' toilets, and the coats outside of her classroom. On a later occasion Wendy took pictures of my shoe, the camera case and my bag. This was useful in capturing what 'doing research' looked like, and were included in her photobook (Appendix 1). When looking through the photos, Wendy was most excited to see the hand dryer (Audio W1) which had become a significant part of her experience at school, as detailed in 4.3.v.

4.1.1. *Following the rules*

As a primary school pupil, children must follow a range of classroom rules, including to listen to the teacher or adult, raise their hand to answer a question, or sit in a certain seat. Ms Jacobs emphasised the classroom rules when comparing supporting Ryan outside of the classroom to inside the classroom. She suggests that although Ryan may not be learning the same materials as his peers, when he is in the classroom with them, he is learning the classroom rules:

> He's learning that when somebody's talking you need to listen. Out here he can rabbit on [talk] as much as he likes, but when Mr Abraham is talking you can't talk, you can't just get up and walk out the classroom. You need to sit there and pay attention (RTA, p.4).

Observations emphasised this through teaching assistants' prompts to listen and look towards the class teacher (R2, p.1). Similarly, children were often distracted or overwhelmed with the lively activity within the classrooms which would prevent them concentrating on listening to the class teacher (R1, p.1; O2, p.1).

Observations of the children in their classes showed that often children with WS had more reminders than other children to sit down in their seat, sit correctly and remain seated in order to help them focus on the task (Video R1; Video W1). Furthermore, when seated, children needed to adjust themselves physically into the correct position before working with their TA to complete a task such as reading or writing (Video R1; Video W1). Ryan was asked to sit up and place his helping hand (with physical guidance) onto the table before starting to write. It is recognised that occupational therapists recommend developing postural control, balance and stability for handwriting (Weintraub *et al.*, 2009) but this physical posture also may have encouraged Ryan to focus on the task.

Figure 6: Video R1 screenshots	
	
Ms Jacobs is using her pen to point to the page so that Ryan knows where to look	Ms Jacobs helps Ryan put a guiding hand down onto the table
	
While Ms Jacobs writes the next word to copy, Ryan plays with bouncing the pencil	Ryan copies the word into his book, remembering how to form the letters as Ms Jacobs points to the spacing

Figure 6 displays an extract from a video where Ryan is keen to complete the writing task so that he can play (Video R1). The video shows Ryan resting his head on his arms before being reminded to sit up in his chair. Ms Jacobs shows Ryan that he will be writing next to the number 5, which Ryan seems to use as a basis to work out that he will need to do “number 6 then number 7” before “we can go back and play!” (Video R1). In Ryan’s eagerness to finish the writing task, he shows his comprehension of the number sequence needed to follow instructions. Children with WS often experience difficulty with mathematics tasks that require working memory (Van

Herwegen & Simms, 2020) and so it is interesting to consider this opportunity for a child-led practice of skills such as counting onwards and backwards.

However, Ms Jacobs seems focussed on what she needs Ryan to be able to complete. Ms Jacobs brings Ryan's focus back to the task of working out instructions for his recipe, and copying the words written in front of him. In Ryan's experience of school, he needs to complete a task before doing something he enjoys. On this occasion, Ryan spent 20 minutes sitting and working on his writing task with prompts and encouragement from Ms Jacobs. After completing his writing task, he was able to join his two peers next door to play with the marble run.

Alternatively, children also showed they could manipulate the rules of being a primary school pupil to their advantage. For example, during 'Tidy up' Time, Orla emptied the pencil pot on the table she was near and spent the whole of Tidy up Time slowly putting each object back into the pot (O2, p.2). This could suggest Orla knew she had to tidy up something, but wanted to control the tidying to the area she was already in. Although it shows she can follow the classroom rules of tidying up time, it raises some questions as to how Orla experiences this time of transition that signifies the end of one activity and the start of another.

In discussion with Orla's TA, Ms Turner, she commented that she always supported Orla to get ready to leave the class at the end of the day earlier than the rest of the children. This was intended to avoid overwhelming Orla with a busy, noisy atmosphere, and anxiety at a time of transition between school and home.

Tidy up Time was often a significant part of the school day for Orla, as the children spent the majority of their day in ‘busy time’ which encouraged a guided independence approach using continuous provision. Within busy time, there were opportunities to access arts, crafts, hand sawing wood, glue, mud, marble runs and wooden blocks around the classroom. This echoes early childhood philosophy and pedagogy such as the Montessori approach which encourages practitioners to facilitate child-led learning (Isaacs, 2018). Therefore, tidy up time was one of the key times for children to follow the directions of adults rather than their own choices of activity.

4.1.2. *Taking responsibility*

Children were guided to take responsibility as primary school pupils. This included taking responsibility for their possessions, to help promote and develop their independence. Children were prompted to put away their bags and coats, including taking ownership of hanging their coats up when they fell on the floor (R3, p2).

Ms Jacobs expressed concern over the need for Ryan to take responsibility rather than rely on adult support:

> He is so reliant on someone telling him what to do. Even things like in the morning it’s taken me three months to get him to hang his coat up and to get his bottle out of his bag. His bag, well you can see it there, it’s on the floor. That’s not where his bag [should be], but that’s close enough for me, it can stay there. He used to just hand it to me and things like putting his coat on. He would just ask someone. You’ve seen that he’s struggled, and he’s gone to the next adult and said will you help me, he just wants someone to do it for him. I think with[out] me or any 1:1 I think he would do very little (RTA, p.6).

Whilst Sophie, Orla and Wendy were being encouraged to ask for help, Ryan was able to ask for help. However, sometimes Ryan would do this with a task that he could do himself, but when asking another adult for help there was a chance that they would assume he could not do it, or that they should do it for him rather than prompt him to learn himself. Instead, Ms Jacobs recognised this as an opportunity for Ryan to increase his independence and responsibility.


O2


W1

In photo tours, two of the children decided to take photos of the coats which suggests this could be a key aspect of their school experience. For Sophie, she was learning to put on her coat independently, and Ms Watts was focussed on enabling her to develop her fine motor skills so that she could fasten her own coat poppers. The coat area was also one of the areas shown to Sophie before she moved classrooms.

When arriving at school, all children were encouraged to take responsibility for taking their coats off and hang them on a specific peg, before starting the day. In Orla's class, children would also change their shoes as they had often arrived in outdoor shoes. The two pictures, taken by Orla and Wendy, contribute to the narrative of being a primary school pupil.

School staff suggested that children needed to learn to follow directions and understand classroom routines such as sitting at certain tables or carpet spaces. This was more emphasised for Sophie who had a seat on a specific table, and had spent the previous year working outside of her classroom with Ms Watts:

> If we give you an instruction, try and do it without looking back at us for approval. You're going to have to get that point. We felt like bringing her into the classroom rather than going outside, it was very difficult at first because again, her attention was just all over the place… But I think now we've drummed it in, "You need to go to your seat." She's really clicked on to it (ST, p.3).

This reiterates the work needed in supporting children to learn the classroom routines, structure and instructions. Sophie's TA emphasised the concept of being a primary school pupil as following the classroom routines like her peers:

> For her to be more independent and getting used to being inside the classroom with everybody else, following a structure, like everybody else (STA, p.4).

A key aspect of being a primary school pupil was knowing where to go. Some of the children were drawn to other areas of their classroom, or in the corridors, often watching other children and adults (O4, p.1; O5, p.1). Ms Turner echoed this in her interview:

> I've caught her sometimes, just standing and watching other people milling around school (OTA, p.4).

The phrase "where should you be?" was often heard during my visits, for example, when Wendy was found standing in a different place in her class's queue, or in a completely different line. At times Wendy was still sitting at the table or on the carpet whilst the rest of the class had moved. Reminders to Wendy helped her to move with everyone else, otherwise she was distracted, sometimes focussing on watching or listening to something else (W2, p.2; W3, p.2). Similarly, there was an occasion where Ryan was distracted by a younger peer with SEN. They were both stood in front of each other, pulling faces whilst the rest of the class followed the instruction to take their coats to the hall. Ms Jacobs asked them "what should you be doing?" to prompt them (R2, p.1).

The need to facilitate independence was also emphasised by Ms Roberts:

> Her curriculum is so different to the other children there's a real danger that she becomes completely reliant on [Ms Turner] or another adult for all of her learning. The great thing about a set up like this [continuous provision] is that she can be independent (OT, p.3).

4.1.3. *Friends*

Spending time with Orla in her class, it was clear that she was developing key social skills in sharing and taking turns, which would support her in making and maintaining friendships. As previously stated, research into children with disabilities has traditionally highlighted difficulties in making and maintaining friendships (Vlachou, Karadimou & Koutsogeorgou, 2016). This has been reflected in research with children with Williams Syndrome, despite an eagerness to interact with others (Jawaid et al., 2012; Plesa Skwerer & Tager-Flusberg, 2016). During the school day, there were many opportunities for teaching staff to help guide children in social situations such as sharing or problem solving (O5, p.2). This occurred more often because Orla's classroom was modelling a continuous provision approach which allowed children more flexibility to choose their own activities, and therefore come across each other in the classroom during different activities.

Often, school staff would role model appropriate turn taking, sharing and talking to peers for Orla (O1, p.1; O3, p.1). For example:

> [Ms Jones calls Orla's name twice, but Orla is still not looking at her]. Orla, look at me when I'm talking to you. Kerry gave you the ice cream when you wanted it, which was very nice, so now it would be nice if you could give Kerry the truck (O3, p.1).

Although role modelling and narrating the process, Ms Jones uses several words to describe the instruction. The suggestion that it would be nice to share the truck could be complex for Orla to understand.

Other children in her class also became upset and possessive of toys or objects that were near to them, but it was more noticeable for Orla who would need support to resolve the situation with 'kind hands' (O5, p.2; O3, p.1). Despite her difficulties with sharing, on two occasions Orla became very distressed when she could not see her peers. This happened when she arrived early in the classroom one morning and exclaimed "Oh no! I've lost my school friends!" On another occasion, Orla was visibly upset when going to the after-school club and again mentioned losing her school friends (O5, p.1). This could suggest that Orla values the peers in her class, or that her usual experience of the classroom is full of others which meant she may have been unsettled when she noticed their absence.

Sophie expressed a specific interest in her peers when given the camera and looking at the pictures she took:

> *Sophie sees her photos and she is excited, especially about the pictures of the children in her class. She wants to take them home* (S3, p.3).

Sophie focussed on the children in the photographs, and refers to them as her friends, saying:

> *"I like my friends" and describing the photographs as "my classes and all my friends and um... there's Olive, there's James…" before continuing to list the children's names* (Audio S1).

Interestingly, my observations had not seen her speak to, or spend much time with these children whilst I had been there, but this class of children had remained the same for Reception and now into Year 1, suggesting Sophie relates to her peers as friends. Research on peer relationships for children with WS have so far only explored parent and teacher insights (Gillooly *et al.*, 2021). Moreover, practitioners and families may use the term 'friends' for all peers in a class, often when teaching children to be kind to each other, take-turns or listen, without the true meaning of a reciprocal friendship.

When asked about friends, children often listed a range of people that they could see, including the staff and me:

> *"Who are your best friends?" Ryan lists everyone currently in the room, including me and Ms Jacobs* (R4, p.2).

Studies suggest that difficulties with social communication and conversation with peers lead to friendship difficulty for children with WS (Mervis & Klein-Tasman, 2000; Fisher and Morin, 2007). This was highlighted in Sophie's experience in the classroom when she attempted to join in her peers' conversation about fish (S3, p.1; see 4.2.i). Similarly, children seemed to initiate conversations with a child with WS by taking on a protective, nurturing or teaching role, asking them a question or telling them where to sit (see 4.4.i. for more discussion).

A further challenge for friendships for children with SEN/D is often that their peers will be overly mothering towards them. This was apparent with Wendy when her peers would tickle her, play peek-a-boo, pull faces and want to hold her hand (W2, p.1; W3, p.1). At times, other children physically guided Wendy around the classroom, and encouraged her to stand up or sit down. Although this can be considered helpful and friendly, Wendy could become reliant on her peers to show her where to go, rather than practising developing skills such as listening to the instructions and navigating the classroom independently.

For example:

> *On the carpet, the girls sit next to Wendy, holding her hand, shuffling her forward, turning her round to face the right way and leading her back to her chair and tucking her in* (W1, p.1).
>
> *Sitting on the carpet this afternoon, Fiona holds Wendy's hands. Pulling at her back to sit her down, Fiona keeps hold of Wendy's finger and then Wendy lets go* (W2, p1).

Staff seemed very aware of the tendency for some children to be more protective of Wendy, with Ms Lock explaining:

> They can be quite mothering to her. Particularly the girls, boys not so much, but a few of the girls that can be quite mothering, and we have tried to say to her: "Give her a bit of space" (WT2, p.3).

This quote suggests the girls in the class demonstrated care and nurture, which is a traditionally feminine performativity of gender compared to boys (Butler, 2020). However, staff expectations of gender performativity meant that they might notice the girls more. I had observed that some boys showed more care towards Wendy than others, and similarly some girls more than others. Their actions towards Wendy reinforces her social position in the class which Frostad and Pijl (2007) claim will not change due to children's preconceived attitudes and perceptions towards children with SEN/D.

Observations showed Wendy becoming irritated with being over-protected, at times choosing to walk with Ms Dot or to let go of her peers' hands. Children who were eager to help Wendy to put an object away were encouraged to step back and let her do it herself (W4, p.1).

During my visit with Ryan, I noticed that as soon as he exited a building, he ran around screaming, wailing his voice and roaring at other children. School staff repeatedly asked Ryan not to scream, as his difficulties with spatial awareness means that he can get very close to children without realising their personal space. In observations in the playground, Ryan's peer talked to him after two peers had asked him to be quiet by signing and saying shh. The girl crouched down towards him slightly and asked, "and what sound do dinosaurs make?" to which he animatedly replied with a roar (R3, p.2). In my conversations with staff, I wondered if Ryan was mimicking what he could hear on the playground, combined with his passion for dinosaurs roaring.

After my conversations, Ms Jacobs then asked him why he usually screams outside:


R1

> I asked him earlier why he was screaming outside, [and he said] "because I do, I like it, that's what children do" … I think he just thinks that's what children do… he said, "because that's what children do". Then he'll say my throat hurts, so I don't know why he does it to be honest… so lining up in the morning, we're trying to get him to stop, first thing in the morning screaming in someone's face, or roaring in their face (RTA, p.7).

When I thought about the noises I heard on the school playground, there was an overwhelming sound of children shouting, laughing and screaming. From the staff and other children's perspectives, the noise is an unpleasant behaviour that they want to stop, but Ryan perhaps sees it as joining in or attempting to manage the growing background noise. Therefore, Ryan is audibly sharing his experience of being a primary school pupil through children screaming, laughing and shouting.

An observation from my fieldnotes supports this interpretation:

> *When the class's noise levels increase at the end of talking, he begins to make the beginnings of a quiet roar, and I think this is his reaction to the noise similar to the playground* (R4, p.3).

4.2. Going at a different pace

The following section links to David Orr's (1996) concept of slow knowledge, highlighted by Clark (2020) in her blog on Slow Knowledge and the unhurried child. Under pressure from neoliberalism (Roberts-Holmes & Moss, 2021), education increasingly focuses on the use of standardised tests to measure performance and accountability, which promotes and values a fast knowledge that can be measured. Using this viewpoint, children with SEN/D are often perceived as being behind their peers, and therefore under a 'catch up' narrative which adds further pressure to valuing fast knowledge and marginalising others, in a perpetual cycle of inequalities.

In contrast, my research draws on the concept of the unhurried child, and the need for schools to allow for and accept different paces. A slow pedagogy favours time for both educators and children to slow down and think deeply. Consistent with my positionality, learning is valued as a process of being a primary school pupil, which is a development and building of experiences as opposed to a race to an end, measurable product (Gillespie & Adams, 2014). Pinar *et al.* (1995) extend this perspective of education as more than a bounded process, but an action of social practice (Pinar *et al.*, 1995) which highlights the importance of the socio-cultural context.

4.2.1. *Using the Unhurried approach*

The following section draws on David Elkind's (1987, p.8-9) unhurried approach which:

> Advocates providing young children with a rich and stimulating environment that is, at the same time, warm, loving, and supportive of the child's own learning priorities and pacing. It is within this supportive, non-pressured environment that infants and young

> children acquire a solid sense of security, positive self-esteem, and a long-term enthusiasm for learning.

This stimulating and supporting environment was distinguishable in the responsive actions of TAs (4.4.2) in providing children with support and security. Sophie's class was a busy environment where children were faster than her in both their movements around the classroom or the playground, and in their speech to one another. Children with WS have slightly different growth trajectories than non-disabled peers (Martin *et al.*, 2007) and Sophie and Wendy were noticeably smaller and slower than their peers, which contributed to their experiences in school. One observation captured Sophie's difference in being smaller and moving slower than her peers:

Superheroes

Wet play lunch time, and a lot of the class is gathered around the Role Play area, excitedly pulling on superhero costumes. Ms Watts encourages Sophie to go to the role play area.

She cautiously eases herself over.

I am talking to Ms Watts about Sophie while Sophie stands and watches the children. She doesn't talk to them much, very rarely, because they all talk so fast, by the time she starts to talk… her voice is very quiet, and her speech is slow. She's so slow, in her actions too. Another girl has already gone to get the superhero costume that she seemed to be drawn to… Sophie is a head and shoulders below the rest of the class. Everyone else moves so fast, and she bobs in between them, gazing up at the children as they swap superhero costumes excitedly. Sophie moves cautiously, unsteady of the space around her, almost bracing herself against potentially being bumped into.

After a while, Sophie returns to Ms Watts from the busy role play area.

Ms Watts: What have you been doing?

Sophie: (shrugs) I don't know

Ms Watts: You don't know?

Sophie: The children

Ms Watts: The children?

Sophie: yes

Ms Watts: The children is or are (holds up two fingers to show plural, from speech and language interventions)

Sophie: are

Ms Watts: yes

Sophie: The children are playing superheroes.

This is a great moment for Sophie because she has been able to speak a whole, clear sentence to Ms Watts, which they have been working on in their speech and language intervention sessions (S4, p.2).

There was a distinct contrast between the speed of the children moving around the role play area, Sophie's small stature and movements and her success in creating a sentence which described her peers. Although Sophie's learning pace was starkly different than her peers, Ms Watts was able to prioritise her needs at her pace by linking her speech and language learning with her experience in the classroom.

Similarly, school staff noted Wendy's small stature and their concern for her when moving with the rest of the class:

> It is hard because we're conscious as well, so when we're coming out of assembly or coming here to get the coats, you are worried because physically she moves a bit slower than everybody else, you are worried she will get knocked over (WT2, p.3).

Children were often able to go at their own pace outside the classroom, away from their peers. This is echoed by Ms Pennywell who explained:

> [Ms Dot will take] Wendy out to have a read of it after we've read it as a class and work through it like that at Wendy's pace (WT1, p.2).

Similarly, observations of Orla during singing assembly (O4, p.2), noted pace again when Orla joined in the last word of the line of music that Ms Appleby repeated for the younger reception class. The rest of the music was taught at a faster pace, and as she fiddled with her blu tack, sat on the bench next to the Year 6s, Orla was more focussed at looking across the large number of children in the hall. Orla's increased height from sitting on the benches could suggest that there were too many distractions for her to focus on learning the song, until the reception class were given a more specific, deeper input of one line to repeat.

In conversations with Ms Turner, she discussed how the class were taught to support Orla. Whilst discussing how to address an issue, Ms Turner explained that staff would explain in a slow manner:

> The SENCo [special educational needs co-ordinator], who was Reception teacher, basically told the whole class that we need to educate Orla and if she's done something that we felt that needed addressing, we would talk to her, we would talk to the child that was concerned and we would explain the whole thing to everybody, quite slowly and in an quite a slow manner that actually Orla is learning and make eye contact. Eventually, Orla … she realised that … she did learn, she realised that you couldn't just go and snatch something and then she got used to her friends (OTA, p.2).

Similarly, observations of Wendy outside on the playground emphasised the need for more time, as before she was able to find the right child to stand behind, the queue had already moved:

> *The line is in alphabetical order, and Joyce is in front of Wendy in the alphabet, which is why Ms Dot always encouraged Wendy to find Joyce, hold her hand and walk next to her. However, Ms Dot has been thinking recently of moving a step forwards so that she could show Wendy a picture of her standing in the line, and she find the right position to stand in. I later overheard her asking Wendy to find Joyce in the line and stand behind her, but by the time they had walked towards the line, it was already moving into class* (W3, p.2).

As well as understanding the need for an unhurried approach, being outside the classroom enabled staff and children to work in a quieter environment. Sophie had previously spent her first year of school spending the majority of time working with Ms Watts outside the classroom. This was noted in the following fieldnotes after conversations with Ms Watts:

> *Sophie seems very focussed. Ms Watts says that at first it was difficult for her to cope in the classroom, being distracted and overwhelmed. In Reception [last year], Sophie spent a lot of time outside the classroom with Ms Watts. She started school being very frightened and easily upset. Ms Watts worked a lot on increasing her confidence, trying new things, both academically and physically, including jumping in the playground. In the class, Sophie would join in the input, and then go straight outside with Ms Watts for 1:1 support at her table* (S2, p.1).

By being outside the classroom, Ms Watts also claimed how much more focus and attention she could give to Sophie, compared to being inside the classroom. For example, Ms Watts' change in TA role meant working on a table with 5 children alongside Sophie:

> I'm working with four or five extra on the table. It can be challenging because every single one of them… It's quite hard to work with all the children at the same time. For Sophie the hope is like last year I used to work with her totally one to one. I'd bring her out of the classroom, just me and her doing the work (STA, p.4).

On this particular table, there were children with a range of high needs such as English as an additional language, elective mutism, and severe speech and language difficulties. Although the whole group could perhaps work at a similar slower pace than other children in the class, this again is based on the assumption that children will work at the same pace as each other rather than their own unique pace. The variation in needs meant that the Ms Watts was managing a highly complex role of keeping children on task, interpreting their needs and scaffolding support in up to 6 different ways.

Additionally, being able to go at a different pace outside the classroom meant that children could have other needs met, such as having frequent breaks, toilet trips, drinks and snacks. Ms Jacobs also used the time to listen to what Ryan and his two peers were saying to each other, encouraging important skills in social communication. Ryan's class was distinctly different to the other classes I had visited as they were in Year 2 and so focussed on preparing for Statutory Assessment Tests (SATs):

> *Inside the class, children work very quietly, and on different activities, including arithmetic, english and maths using practice questions to work towards SATs in May (R3, p.1).*

Therefore, there was more time for Ms Jacobs to work with her small group on their activities in different areas of the school, because they would not be participating in SATs papers. These activities included the bucket game, cake making, speech and language interventions and writing (R4, p.1). The bucket game was noted in two schools, although Ryan was the only one of my participants who took part. Using similar principles found in Attention Autism, the bucket game aimed to develop shared enjoyment, increase attention and improve joint attention (Buckingham, 2012).

4.3. Learning with Williams Syndrome

The following sections highlight aspects of children's experience of having Williams Syndrome. Williams Syndrome is a rare disability, and over half of the children with WS in the UK who are members of WSF, attend a mainstream primary school (Gulliver, 2016). Research into WS describes a distinct profile, whilst researchers also emphasise the heterogeneity of the syndrome, and variations within WS (Porter & Coltheart, 2005). The children in this study showed their different personalities, characters and interests that shaped their experiences of school, such as determination, passion and fun.

Although it is an important part of knowing and understanding WS, difficulties with approaching strangers (Doyle *et al.*, 2004; Fisher, 2014; Frigerio *et al.*, 2006) were not apparent during fieldwork. It is worth highlighting that schools have a strict policy on who is allowed to visit the children. When visiting, I gave identification and a Disclosure and Barring Service certificate which declared me safe to work with children and vulnerable young people. Therefore, it is difficult to appreciate how children with WS are supported to interact/not interact with strangers if new adults in schools are always classed as safe to approach.

4.3.1. *Anxiety*

There is a significant concern for heightened anxiety in WS (Woodruff-Borden *et al.*, 2010), which was described more anecdotally by parents in the study rather than school staff. Ms Jacobs mentioned Mum's worry about anxiety, and explained how she had few concerns herself due to Ryan's happy character:

The Robot Dance

At school, in the six hours of the day at school I do not see him anxious at all. His mum is very concerned about his levels of anxiety. On his educational health care plan a lot of his targets are based around anxiety but we have got no evidence of him being anxious in the school. The only thing he will get worried about is if the fire alarm goes off… Some of the children we do like to tell them in advance, sometimes we tell them ten minutes before because it saves a whole day of worry. Sometimes we don't tell them at all. We have this thing called lockdown [emergency drill] and that went off the other day and he was fine, he was absolutely fine.

Sometimes, he does the robot dance, he dances to the alarm. Sometimes it goes off and he'll go home and that's all he'll talk about that it went off. In school he's like, oh this is fun. We don't know what he's saying at home that's made him anxious in the day because during the day he doesn't seem worried about

> anything.
>
> Even today there was a change of timetable, he was like, yeah, that's okay… Space day, yeah, space day, he's not worried about it. Mum thinks he's got really high levels of anxiety. He does a lot of bed wetting and Mum, I think links that to anxiety as opposed to anything else. We've got no reason at school that we know of unless he's really good at hiding it. That is genuinely he is holding it in and then letting it out when he gets home.
>
> We can't pinpoint anything that we think is causing him really bad anxiety. It's hard because I don't doubt for one second that he's feeling stressed at home but we don't know what it is because at school he's portraying perfectly I've had a lovely day. It's hard. (RTA, p.8)

The time and space between Ryan's experiences in school and at home may provide him with opportunities to reflect from a distance. Summa (2015) uses Wordsworth's poetry as 'emotion recollected in tranquillity' to offer a relation between emotional responses and memory that could indicate why Ryan responds differently at home to school. When Ryan is talking about it at home, it suggests that he is processing the events of the day when he is ready.

An important note to draw attention to is the individual differences between WS which means not all children will experience anxiety, or an anxiety disorder. However, in the example above, Ms Jacobs begins by describing not seeing any anxiety, and starts to reflect on how Ryan talking about it at home could be showing anxiety. Talking repeatedly about something could be a presentation of anxiety, such as repetitive questioning (Tynan et al, 2021). When an individual is processing an event that may have caused anxiety, it is often useful to talk about it. Ms Jacobs then shares the issue of bed wetting at home, which is a more commonly known result of anxiety. This suggests that she is aware of Ryan experiencing some anxiety, but not how it is being presented in school. As Ms Jacobs indicated, "*unless he's really good at hiding it*" is one of the issues raised by researchers that children with WS may use hypersociability to protect themselves or perhaps mask their anxiety (Dodd, Schniering & Porter, 2009; Ng-Cordell *et al.*, 2018; Rodgers *et al.*, 2012).

A child seemingly dancing to a fire alarm might not necessarily show a frightened child, but this movement could be a release of energy that Ryan uses to either show his emotions, or to manage them. Similarly, physical movements such as drumming fingers, nail biting or swinging feet can be signs of internal agitation when anxiety is embodied (McGrath, Reavey & Brown, 2008). It is not known whether this dance is a way of Ryan managing anxiety by making himself feel better, or physically moving to cope with the situation. It is interesting that Ms Jacobs shared the 'robot dance' as an example of him coping with anxiety, because as she describes the event, she begins to reflect on whether he is hiding anxiety.

Similarly, an observation with Sophie at her school showed anxiety through repeatedly talking about the hall. A few weeks prior to my visit, two boys played the drums in the hall during Assembly (S4, p1):

> *Having driven to school through the snow, it has turned to rain and so it will be wet play, which means going into the hall at break time. Sophie says "we're going in the hall" x 5 times whilst Ms Hughes continues to talk to the whole class. Sophie has her hand up and Ms Hughes chooses her, "We're going in the hall and doing wake and shake" says Sophie, and Ms Hughes replies yes.*
> *Next, we are in a small classroom for Phonics, focussing on special friends NG 'thing on a string'. Ms Watts is teaching the new sound NG, practicing how to say it, what it looks like and thinking of other words that end in -ng. She asks the group; Any questions?*
> *Sophie: We're doing Wake and shake in the hall*

> *Ms Watts: We're not talking about that right now*
> *Sophie: back in class*
> *Ms Watts: No, we're not talking about that*

In this example, when Sophie is talking about doing Wake and Shake in the hall, there is a different meaning behind her words. I interpreted this to suggest she is worried that if she went into the hall, there could be children playing the drums loudly. However, staff who are focussed on teaching phonics or giving instructions to the whole class are not necessarily aware of this second meaning behind her words.

Persistent questioning has been linked to a demonstration of anxiety for individuals with WS (Semel & Rosner, 2003). This example may show that Sophie's anxiety has not been noticed, or particularly managed. However, some of the guidance for children with WS who have obsessive topics suggests giving them clear boundaries to stop them from talking about the same thing, particularly if it has been answered (Udwin, Yule & Howlin, 2007). On the other hand, this does not directly help Sophie to develop skills to manage her anxiety. Through repeating the question, Sophie could be indicating that there is a different issue that needs addressing rather than the literal question being answered.

However, Ms Watts seemed to become more aware of this on another occasion where Sophie was worried that a video would feature live music such as the drums. Ms Watts took Sophie's hands in reassurance, and clearly explained where the music will come through the speakers:

> *There is a buzz in the classroom as everyone has non-school uniform. Getting ready for Children in Need's [charity] Wake and Shake: Sophie shows when she is worried by dropping her head down. Ms Watts says she used to do this in Reception all the time, and*

> *does it less now. Sophie will not follow an instruction, put her head down, and show a sad face. Ms Watts hold's Sophie's hands and reassures "no one is playing the drums" Sophie thinks the new Wake and Shake video will have live music i.e. drums. Sophie says "no instruments" and Ms Watts describes that the music will come from the computer like usual, with no instruments* (S5, p.1).

Another significant example of Sophie's anxiety linked to the drums was noted in further observations when Ms Watts encouraged Sophie to show me the drums upstairs in school. Despite her fear of drums, she was very eager and excited to ask for a drum set for her upcoming birthday. Whilst looking at a magazine, she pointed to a toy drum saying, "that's a baby drum" and so Ms Watts asked her to find the one she wanted. Ms Watts finds the page for musical instruments and Sophie immediately points to the biggest looking drum kit.

> *"That one" Sophie immediately points to a bigger looking drum kit.*
> *"You want a drum for your birthday?" asks Ms Watts and Sophie nods. "There's a drum upstairs, we can go and see it." Sophie nods.*
> *"Shall we go upstairs and show Katherine?" Very quiet, head bowed, Sophie replies "Um, um. I don't know"*
> *"Shall we show Katherine the drums?"*
> *"um, um, but not play them".*
> *Ms Watts then offers Sophie [house] points, and Sophie negotiates showing drums to me but not playing them* (S5, p.1).

In the following transcript, Sophie is encouraged to touch the drums for a reward of house points, although she protests frequently that she would prefer to just look at them (Audio S2):

> *Ms Watts: Sophie, do you like the drums?*
> *Sophie: yeah. But I didn't want to play the drums*
> *Ms Watts: Okay, what do you like about the drum*
> *Sophie: (a little louder) I just want to look at the drum*
> *Ms Watts: okay. You're going to have a drum for your birthday. What are you going to do with it?*
> *Interruption*
> *Ms Watts: show off the drum. Go on then*

> *Sophie: I just want to look at it*
> *[…a little later]*
> *Ms Watts: You didn't like it. Why?*
> *Sophie: because it's so loud*
> *Ms Watts: it's so loud. So tell me about the drum you're going to get for your birthday*
> *Sophie: A big one*
> *Ms Watts: like this? This big? Wow. And what are you going to do with it?*
> *Sophie: just look at it.*
> *Ms Watts: Just look at it? Are you going to go tap on it? Just gentle tap? Like this?*
> *Sophie: Mmm*
> *Ms Watts: Yeah you've done that before. Why don't you show Katherine you can actually do it?*
> *Sophie: I just want to look at it*
> *Ms Watts: just one?*
> *Bang*
> *Ms Watts and me: Oh wow! Yay!*
> *[…a little later]*
> *Sophie: just the same like, a bang, like something like, um, it's like, it's something like bang bang*
> *Ms Watts: Yeah, a drum goes bang bang doesn't it*
> *Sophie: Yeah And a firework*
> *Ms Watts: And a firework does bang bang and you don't like that.*

This particular incident reminds me of my brother's fascination and fear of fireworks, and the extremely useful pair of ear defenders that enabled him to enjoy bonfire nights from inside buildings.

The audio recording demonstrates Sophie's agency in not wanting to touch the drums. Ms Watts encourages her, with the reward of a house system point, to overcome her fear. The full transcript indicates that Sophie is getting clearer and more confident in stating that she just wants to look at the drum. She also begins to describe why she might not want to touch it; "*because it's so loud*" and Ms Watts guides Sophie to completing an explanation.

In regard to managing Sophie's anxiety, Ms Watts gradually guides Sophie towards touching the drums with support, encouragement and praise. Without specific WS knowledge, for example a recent trial using humour and play-infused therapy to help children with WS overcome fear (Klein-Tasman *et al.*, 2022), Ms Watts used her knowledge-from-experience and understanding of Sophie's wishes and worries combined with gradual desensitisation. Ms Watt's acceptance of Sophie no longer joining assemblies in the hall for the week I visited also echoes her understanding that Sophie's issue with the drums is important to manage and support. Ms Watts helps to frame Sophie's feelings about the noise, comparing the drum to the firework. Sophie's fascination with the drums is shown through wanting to have a drum kit for her birthday. I also wondered if this would enable her to vary the dynamics of the drum herself, and therefore put her in the position of control over the object that is causing her anxiety.

Orla similarly showed an awareness and apparent sensitivity to noise when during my visits a small beeping noise was coming from the door:

> *Orla is very distracted and seems anxious about the small beeping noise coming from the door. Stands by the door numerous times, repeating "that noise" and wanting to know where it comes from* (O2, p.1).

This example is supported by Semel and Rosner (2003, p.173) who state that individuals with WS "typically cease all activity and seem compelled to identify the source of the sound."

Being tested by an external visitor to the school can cause some anxiety, and by complimenting the lady's lipstick (see below) Orla was able to avoid answering the questions. Tynan (2018, p.125) confirms "if they are anxious about a task, they are likely to avoid it by engaging the adult in a conversation". Categorised in research as an example of restricted and repetitive behaviours

(RRB), lip picking occurs in the following observation when Orla was visited by a speech and language therapist to be assessed (O4, p.1):

> *Orla is getting more and more restless. Orla avoids answering a question by exclaiming, "I like the lipstick you are wearing!" Orla needs more work on prepositions and building up to more than one instruction. She prefers to say what is happening in a picture to pointing out which of the pictures show a certain thing. Has begun lip picking. I wonder if her concentration is really affecting her level of understanding. Orla notices that Amy has a sheet with smaller pictures on which she is marking. Orla tries to look at it, but Amy covers the part of the sheet she is currently using [as it has the answers]. More lip picking until she finally picks the skin off.*

Repetitive behaviours such as lip picking, obsessions and picking skin was reported amongst parents and teachers of children with WS (Klein-Tasman *et al.*, 2015). Similarly, obsessions have been noted in WS research that uses the Social Responsiveness Scale of which one of five domains measures autism mannerisms/restricted interests and repetitive behaviour (Gillooly *et al.*, 2021). The earlier WS guidelines for teachers propose 'intense fascination and preoccupations' with certain objects, toys, people or topics (Udwin, Yule & Howlin, 2007). However, research links many obsessional traits in WS to obsessive-compulsive disorders (Ng-Cordell *et al.*, 2018; Riby *et al.*, 2014; Switaj, 2000).

4.3.2. *Sound sensitivities*

Hyperacusis, a sound sensitivity, is often reported more in younger children with WS (Glod, Riby & Rodgers, 2020). On several occasions, Sophie hovered her hands over or near her ears when she was near another child who sometimes had outbursts of emotion:

> *Ms Watts supports Michael who is climbing on the table, and Sophie puts her hands over her ears in preparation for a potential outburst* (S3, p.3).
>
> *Sophie has her hands half raised up, poised below her ears ready to cover them at any moment. Ms Watts explains that she is near Michael, who might start shouting and*

> *screaming* (S4, p.2).
>
> *Sophie watches Michael closely, with her hands over her ears at times* (S5, p.1).

Orla also had her hands near her ears ready to cover them if she was near the school repair person, who was more likely to be using noisy machinery around the school. Observations and discussions with Ms Turner suggested Orla experienced anxiety around the person she named the 'leaf blower man' because of the leaf blower machine. Ms Turner was very aware of the link between the noise and anxiety:

> She's got better but any noise from a long way away, she will say, "what's that noise, what's that noise." So, her anxiety levels start straightaway. We would just reassure her that if we were in the forest, that we don't worry, that's a long way away, it's not coming any closer, it's not going to get any louder, you don't need to worry about it but she still stood there and she's still listening to hear that noise (OTA, p.7).

Ms Turner suggested that Orla's sensitivity to noise was improving, and a range of techniques were used to help Orla manage her anxiety, such as ear defenders, reassurance, social stories or removing the cause of the issue.

Similarly, Ms Roberts emphasised the issue of noise with the hand dryers in the toilets:

> We tried all sorts of things and in the end, we just turned them off. They are so loud it was completely prohibitive… In the end we just unplugged it… They tried social stories and things like that but in the end, noise was a huge issue for [her]. I think it is for a lot of children with WS isn't it? It was really becoming a massive barrier (OT, p.6).

During my visit, the door into the corridor started beeping to indicate an issue. This was significant for Orla and she asked several others where the noise was coming from. The following Figure 7 indicates an example during Video O3 of Orla's fascination with finding the source of a noise.

Figure 7: Video O3 screenshots	
	
Orla interrupts a question to ask “what’s that noise?” Looking up at me with a worried face. She is flicking through some sticky notes. Orla: What’s that noise? I: I don’t know. Is it the fan? (pointing behind Orla at the computer tower) on the computer?	Orla: (staring at me, then slowly turns around to where I am pointing) I: there’s a (shows finger and thumb close together) tiny fan inside Orla: is that the fan that…
	
I: What else can you tell me about your school? Orla: (gets up from the chair) I: are there any fun things you like doing? Orla: (moves towards the shelves next to the computer) I: Oh! You have a sticker on your arm! Orla: (looking up at the shelves) what fan? This fan?	I: We don’t touch it, but it’s on the… inside the computer Orla: what ‘puter? I: Okay, (gets up and gestures towards the computer tower) this is a big computer, and there’s a tiny (shows finger and thumb close together) fan right inside that you can’t see (waggles finger) because it’s inside (pointing) Orla: can I look? I: you can look but you mustn’t touch, you must look a little bit away from it because this is a really important computer with lots of work (gestures) Orla: I’m going to go to the toilet before we go to more schools

I had attempted to draw Orla back into my conversation about school, and also pointing out the sticker on her arm which could have been a distraction. However, her need to know the origin of the noise enabled me to help her explore where it was coming from. When given an answer that Orla appear satisfied with, she moves away from the computer and states that she is going to go to the toilet before carrying on with our work on her school.

Wendy also expressed anxiety particularly over the sound of the hand dryer from the girl's bathroom. Wendy showed her anxiety through telling me about the hand dryer on the first day of my visit. Wendy introduced me to Ms Dot's "*friendly hand dryer*" (W1, p.3) who had nicknamed the hand dryer in an effort to encourage Wendy to use it with her. Wendy looked worried, frightened and did not want to use it, although Ms Dot talked her through each stage of washing hands and approaching the hand dryer, explaining that it will turn on with her hands underneath, and turn off when she moves her hands. When visiting another school during the week, Wendy also wanted to know if there was a hand dryer in the toilets, which fortunately there was not. The angle of the photo taken by Wendy shows that the hand dryer is much higher than her, which means the air will blow directly down on to her.

My own fieldnotes expand:


W2

Ms Dot thought it was getting better but seems more of a problem this week, but it can vary. Perhaps because I have asked her about her school, and this is a significant part of her school day. Other girls in her class have picked up on her issue and encouraged her to join them as they all dried their hands together, and Ms Dot held her.
Wendy talks a lot about the hand dryer, and started

> *asking passers-by. Asked Liam, a child in her class "do you use the hand dryer?" to which the children looked confused and did not reply. Ms Dot encouraged her to repeat the question. "Do you use the hand dryer?" said Wendy very clearly. Again, Liam looks confused. Ms Dot prompts that Wendy asked a question, and wants to know the answer. Liam smiles, puzzled, "yes!" and walks on.*
> *Ms Dot is keen to make a social story, and I encouraged her to use the photo that Wendy had taken* (W3, p.2)

Interestingly, Ms Pennywell did not recognise it as anxiety, but an issue that many children learn to outgrow. When asked about Wendy's 'hand dryer fear or worry' she replied:

> I think a lot of children have hand dryer phobia. It's just so loud, isn't it? It turns on and it's like: "Oh!" Especially now because they're quite strong. My little boy used to be… I think she will outgrow that, I don't know. Maybe (WT1, p.5).

Figure 8 illustrates Wendy looking through the different photos that she had taken on the tour with her peer. The audio emphasises how she was most excited about the hand dryer (Audio W1):

> *Wendy: Yeah. And this is where the hand dryer is*
>
> *I: Yeah. So these are all the photos you took of your school*
>
> *Wendy: That's when I… Ms Dot used the hand dryer.*
>
> *I: We could keep these photos, and maybe Ms Dot can work with you with them*
>
> *Wendy: Yeah. Ooh. There's the hand dryer*

Figure 8: W1 Audio Photo discussion	
	
I: What's your favourite photo? Wendy: I'm going to see the hand dryer one	I: You did really good taking these photos with Jenny.

The perceived excitement to see the hand dryer does not appear to directly suggest that Wendy is experiencing anxiety, until she is next to the hand dryer and visibly worried or upset. This emphasises the problem with others such as school staff or peers misunderstanding the children's eagerness and repetitive talking about an object or sound. This supports the fascination with certain sounds as described in the review of sensory processing issues such as hyperacusis (Glod, Riby & Rodgers, 2020).

4.3.3. *Emotional sensitivities*

Researchers argue as to whether individuals with WS have enhanced empathy (Plesa Skwere and

Tager-Flusberg, 2016), verbal empathy (Sullivan & Tager-Flusberg, 1999), or emotional empathy (Smith, 2006). Rosner (2001) argues that empathy derives from a personal discomfort or distress when reacting to another person. My previous discussion shows the difficulty using the term empathy for individuals with WS without the cognitive understanding of theory of mind. Moreover, individuals with WS may experience intense emotional reactions which could be from personal distress and anxiety when seeing another person's emotional state.

Children showed experiences of sensitivity to another person's distress that were connected to illness. For example, when visiting Ryan I had a cold sore on my lip, which he seemed concerned about, asking what was on my lip. Ryan had much more experience with hospital appointments than the other children I visited, and therefore this could have been more of a significant experience for him. However, another example of medical concern occurred during a conversation between Orla and a TA who was absent the previous week:

> *Orla: did you scream?*
> *Orla: did you cry? (overlapping TA talking about being ill last week)*
> *Ms Shepherd: Yes I probably did cry a couple of times*
> *Orla: Don't cry*
> (O3, p.2)

Often, children with WS will have many medical appointments. It has been suggested in older research that medical appointments are potentially anxiety-provoking (Semel & Rosner, 2003) but this has not been a focus in WS anxiety research. Families talking together at conventions have shared the challenges and fears individuals with WS face when going to the doctors, dentists, hospitals and clinics. One case study following a 9-year-old after cardiovascular surgery highlighted the increased risk of PTSD which has not been investigated in WS research (Alexander *et al.*, 2019).

Anxiety has been recently linked to empathy in individuals with WS by Royston *et al.* (2021) who used a formulation framework approach to their study on anxiety. In their interviews, parents reported that anxiety related to the negative emotions of others.

Ms Hughes also commented on this reaction, but interpreted it as part of Sophie's caring nature:

> She's very good at recognising when people are upset as well. I think I'll just be sat there, my angry teacher face and she'll come up to me and be like, "Are you sad?" and I'm like, "No, I'm fine. I just look angry but thank you." Then she'll give me a little pat and walk off. It's really sweet that she's either… she's just a very caring child but she's clearly picked that up of going I know that's not normal. I know that's not how I'm used to seeing you so there's something not quite right, let me go and check. It's just like that caring nature inside her (ST, p.11).

Ms Turner also mentioned this on another occasion when describing the situation of a peer whose brother was having cancer treatment:

> On that particular day, I think I might have said to Sam, do you want to come and play playdoh and she was like, yes please. Yes, [Sam is] very wobbly at the moment but Orla, I think she senses those things, she's really, really perceptive, if somebody is sad, she'll go up to them and she's really caring in that way, with adults and children (OTA, p.6).

The following observation expands the idea of caring for another person in another situation:

> *Cara was ringing the bell after lunch whilst all the children were on the carpet. A teacher takes bell away as it is time to listen. Cara cries loudly [she is usually in the corridor and not her Year 4 class. Her SEN TA Ms Cox is with her in Orla's class to help cover Ms Turner's lunch break]. Orla hears this and immediately stands up, gazing at her. Orla moves slowly towards her, and asks what is wrong. Ms Cox explains that Cara wanted the bell but it is time to listen to Teacher and she can have the bell later. Teacher calls Orla to carpet space. Orla walks up to her, stood very closely. Teacher directs Orla to carpet space. Orla stands on carpet space, staring at teacher. Teacher signs sitting and Orla sits down, saying "Cara*

> *wants her bell back." Teacher explains it is not her bell and that she can have it later (O3, p.2).*

Focussing on Orla's movements, she is drawn to Cara when she cries loudly, and would like to give Cara the bell back. Orla moves slowly, eyes gazing at the teacher, and tells her what she wants which would help stop Cara crying. Orla was fixated on the situation of a distressed peer in the class, and perhaps would have responded well to some reassurance before moving onto another task.

Emotional sensitivities were noted in other experiences where children picked up on their peers' sad feelings, which would distract them from their work as they needed to find out what was wrong:

> *Working outside the classroom with Ms Watts whilst this rest of the class was in Assembly. Molly screamed and shouted nearby. Sophie asked after her by repeating her name several times over 30 minutes. Ms Watts explained to Sophie that Molly was upset, and then talked about going to find her to ask, "Why Molly sad" (Video S9).*

Figure 9: Video S9 screenshots	
	
Ms: You want to see her? Are you going to say something to her? What are you going to say to her?	*Sophie: Don’t feel sad*
	
Ms: Shall we go and see her? But do you know what? For Molly, sometimes when she is sad, she doesn’t want to see anybody, okay? So, we can go and talk to her, but if she listens to you, okay.	Ms: But if she says Sophie go away, we need to come back. Sophie nods Ms: Okay? *Sophie: Yeah*

Figure 9 shows the skills by Ms Watts in recognising Sophie’s worry, reassuring her whilst holding her hands. Ms Watts also discusses possible social interactions with Molly, and what they will do for different scenarios, for example if Molly asks them to go away, they will leave (Video S9).

> *We went upstairs to Molly's classroom. Sophie squatted in front of her whilst Molly explained how upset and cross she was about not getting a golden ticket and therefore not liking the rest of the class. Sophie then asked about Paw Patrol and Molly showed her a toy from her bag. When asked, Sophie said that Molly felt happier, and that Sophie now feels happier* (S5, p.3).

In this example, Sophie directs her peer to showing her something positive such as a television programme toy which seems to help her feel better. When asked, Sophie said that her peer's happiness has helped her own happiness.

It is unclear whether Sophie's experience of empathy is based on connecting with her peer's feelings, or responding to her own distress at seeing someone upset. Rosner (2001) suggests that empathy and sympathy are both derived from a person's distress, although results indicated that young people with WS with higher anxiety ratings were less likely to respond with empathy. Whilst some research showed children with WS perform well at emotion recognition on non-verbal tests (Ibernon, Touchet & Pochon, 2018), there is a concern echoed by Smith (2006) that high emotional empathy sensitivity can impact individuals' intellectual development, as they could focus more on the emotions of the speaker than the content (Smith, 2006).

The following example indicates the "heightened level of sensitivity to the emotional reactions of others" described in individuals with WS (Klein-Tasman, Li-Barber & Magargee, 2011). Ryan became visibly upset when a play rehearsal meant his peer showed him a sad face:

> *During a rehearsal for the class assembly, Ryan became very upset and distressed. The story was the boy and the alien saying goodbye, and the girl he was paired with pouted*

> *her lips into a sad face. Ms Jacobs called over to him, "it's pretend, it's not real, it's pretend!" and Ryan cried. Ms Jacobs had to talk him through some calm, deep breathing to help stop crying. Ms Jacobs explained that they were saying goodbye but that is okay, and it could be a happy thing. She then asked the girl if she could put a happier face on, because the goodbye could be a nice happy goodbye. Ryan recovered and re-joined the class.* (R1, p.2).

This rehearsal was also to music. Research indicates that many individuals with WS have an affinity to music, and some may have very powerful and emotive reactions to music (Thakur *et al.*, 2018). This suggests there is a connection between a powerful reaction and fascination towards something which may be difficult to process. For example, the children are eager to talk about and show me the thing they are scared of, in the same way that they can be very sensitive to sound but also share an affinity with music.

4.3.4. *Social skills*

Often, children would finish the sentences spoken by adults. In the following transcript, Ms Jacobs is completing a short summary of Ryan's day to take home. After I ask Ms Jacobs whether she completes it with him, she doesn't usually but asked for his input about something he has enjoyed today:

> *"Enjoyed it…*
> *I have enjoyed…*
> *some…*
> *some writing…"*
> *Ryan replies with several pauses, and long, slow, drawn out words*
> *"And doing some…*
> *playing with um…*
> *Katherine…*
> *And…*
> *Now…*
> *I want…*

> *To say…*
> *Bonjour comment ca va…!"*
> *he finishes with a flourish. Ms Jacobs and I are both surprised, asking "you enjoyed writing? Hang on, what were we writing? …In…."*
> *"Instructions" Ryan completes the sentence* (Audio R1).

We were surprised that Ryan's favourite activity of the day was writing, considering his reluctance to complete the writing task and his enjoyment at other activities such as the marble run. This could suggest that Ryan wishes to 'give the right answer,' or he is working out what he needs to say was something he enjoyed at school. School, for him, might be the writing tasks. However, this also mirrors the answers given in Tynan's (2014) study which she suggests may link to the subjects that staff give more focus and praise to children as they find the work difficult.

Similarly, in Video R1 there were many instances where Ryan finished sentences, which may have been based on guessing what he needs to say rather than making sense of the sentence. However, using guesswork can result in missing cues or misunderstanding directions (S3, p.3). In observations, all the staff would ask where children needed to be, or what they should be doing. For example, when Sophie was asked about her coat, she goes to sit back on the carpet, looking unsure (S3, p.3). Combine this with hyperactivity, difficulties with concentration and attention, children can both miss and misunderstand instructions.

Interestingly, the following example demonstrates Sophie's confusion with the teacher's instruction for the class to make a circle:

> *Everyone is in their carpet spaces, whilst Sophie is sat on her chair.*
> *James: "excuse me, move back Sophie."*
> *Sophie looks down, tries to shuffle back.*

> *Teacher: everyone make a circle (signs circle; everyone starts to move into a big circle)*
> *Sophie: "I can't make a circle."*
> *She is in front of the teacher now, looking up at her.*
> *Teacher: "move back, move back."*
> *Sophie moves back tentatively, seemingly confused.*
> *Everyone else moves into a circle, and Sophie then seems to understand when she sees. She stands up, and goes to the other side of the room to sit in a space in the circle* (S4, p.2).

These examples reflect some of the difficulties with relation and conceptual language (Mervis & Klein-Tasman, 2000) and understanding social cues (Godbee & Porter, 2013). On the other hand, research has emphasised people with WS as having social strengths, particularly seen in their high motivation to interact with others. Their social strengths include specific verbal abilities such as receptive vocabulary and verbal short-term memory (Brawn & Porter, 2017; Klein-Tasman, Li-Barber & Magargee, 2011). Ms Dot discussed the need for repetition over time when Wendy and I were playing a board game and she seemed to mix the names of colours. However, research highlights expressive language as a real strength, and this could be reflected in staff's perceptions of children with WS being caring and thoughtful. In contrast, children in one study showed little understanding of how to help a person beyond expressing verbal empathy (Plesa Skwerer & Tager-Flusberg, 2016).

Although not unsurprising, some of the children in my study would respond to a question with what I could consider as a silly answer. However, answers tended to be focussed on a particular interest of theirs, such as a favourite song or princesses. Ms Jacobs explained that she has been prompting Sophie to ask for help or to say "I don't know" instead of saying 'princess' (S2, p.2).

Listening to my own conversation with Orla from our audio recording, I was talking to her about a photo she had taken of chocolate oranges. I seem to use a lot of statements that encourage her to finish my sentence, as a way of supporting her to have a conversation with me. This does not necessarily help her to show me what she thinks of the photo, and could lead her to guessing rather than understanding the situation. Communication is based on sharing a common theme with another individual, which means having the comprehension of the topic we are talking about, as well as an interest in each other's responses. However, offering sentences for children to guess the finish does not help develop specific communication skills.

> *Katherine: chocolate orange, that's right. What are they for?*
> *Orla: for eating.*
> *Katherine: yeah that's right! Children have been bringing chocolate oranges in, instead of…*
> *Orla: chocolate!*
> *Katherine: instead of Christmas cards. And we're giving those chocolates to…*
> *Orla: sick people*
> *Katherine: Yes, well, people who are hungry, at the Food Bank (O1 Audio).*

Whilst the chocolates are known for eating, the children in the school were donating a tower of chocolate oranges for the food bank instead of writing Christmas cards to each other. Orla's guesses can work well as sentence finishers, but does not demonstrate her understanding of the purpose of the chocolates, or our conversation.

Similarly, observations showed challenges practising conversations with peers. In the following example, a group of 6 children sit around the table in a small intervention room with Ms Watts for their Phonics session. As Ms Watts prepares the resources, the children break out into spontaneous conversation:

> *Wilfred, sat on the corner of the table: Why does no one believe me that I was born*

> *underwater, I'm a fish…*
> *Sophie: I, I, I (immediately looks up at him, leaning slightly towards him across the table)*
> *Wilfred: …that I can live underwater, and breathe underwater and…*
> *Sophie: I, I, I, I…*
> *Wilfred continues talking about being a fish*
> *Sophie: I, I*
> *Jane sat opposite, looking at Sophie: I've got a pencil like Sophie. You see that pencil with the holes on it? I have a pencil like that.*
> *Sophie stares at Jane for approximately 5 seconds.*
> *Jane smiles*
> *Sophie copies the smile*
> *Ms Watts calls the group, ready to begin*
> (S3, p.1).

On this occasion, I was interested to hear what Sophie heard in her peers' story of being a fish that caught her attention and eagerness to join the conversation. It seemed that she was unable to find the time to coordinate her sentence as he continued to talk animatedly, and then her attention was brought towards the girl opposite her for a different topic. We can draw comparisons with research that examines individuals with WS's difficulty joining in conversations (Fisher & Morin, 2017) as well as the sustained eye contact which supports research showing children with WS have typically longer eye gaze (Lai, 2020). I also noted that Jane talks towards Sophie in the third person, rather than talking to her. Jane may have been talking to another peer, or myself, but this also may stem from an assumption that Sophie was less able to carry out a conversation with her. When Sophie was unsure how to respond, she seemed to copy Jane's smile.

One of the strengths of individuals with WS has been highlighted as learning by memory, rhymes, songs or short phrases. Mervis and Becerra (2007) suggest that individuals with WS rely on their strengths in verbal working memory to be able to comprehend complex sentences. Likewise, Dunning, Martens and Jungers (2015) found that individuals with WS had better short term verbal memory when the phrase was sung compared to spoken. Their data also suggests that formal music lessons also increased short term verbal memory. Although most staff had read about links between WS and musicality or musical affinity, there were no examples of singing or musical phrases. On the other hand, Ryan was repeating short phrases to himself "*start from the bottom, one. Curly C then round*" as he formed letters. Phonics had stopped the previous year, and so Ms Jacobs had created her own messages for Ryan to make sense of how his pencil marks were forming letters (R4, p.1).

Similarly, most school staff used a variety of short, repeated phrases to enforce classroom rules and behaviour:

> *Orla finishes off sentences from memorised phrases.*
> *Sitting with Ms Cox and her 1:1 in the corridor where there is a small area for her to stay most of the time*
> *Ms Cox: and what's the rule for play dough?*
> *Orla: sit down*
> *Ms Cox: so that it doesn't go on the…..*
> *Orla: floor!*
> (O3, p.1)

This type of call and response enables children to rote learn rules such as sitting down when handling play dough so that it stays on the table. These memorised phrases are helpful in learning school behaviour, but not necessarily for deeper learning.

On the last day of my visit with Wendy, the class were sitting on the carpet discussing a story. Wendy put her hand up to answer a question:

> *Ms Lock asked "What you would do to get the objects down?"*
> *A collection of children hold their hands up.*
> *Ms Lock chooses Wendy who has her hand up.*
> *Wendy says "the lighthouse, the lighthouse, step in the lighthouse."*
> *Ms Lock replies "yes, there are steps inside the lighthouse. How would you get the shoe down?"*
> *There is a pause, and Ms Lock asks the question a couple more times, which prompts Wendy to put her hand up again whilst she is still answering.*
> *Ms Lock is still looking at her, and verbally prompts "Yes Wendy" who says "My Daddy would get a saw and my Mummy would get a saw and cut it down" [a real wow moment!]*
>
> *Ms Lock then uses Wendy's answer as a great example for everyone else, as the children in the class were contributing more ideas about the problems rather than the solution to getting the shoe down from the tree.*
> *As the observation continues… Ms Lock writes the sentence on the whiteboard for everyone.*
> *"I would ask my Mummy and Daddy to get a saw and cut the tree down"*
> *Wendy then says "My Mummy and my Daddy, I go downstairs and have breakfast and then milk and I hurt my knee and my leg."*
> *Ms Dot nods understandably and enthusiastically, "we've been doing sequencing so she may be thinking about that. Well done Wendy, good sequencing!"*
> *It felt as if Wendy had found her voice and was confident to share more, she was on a roll!* (W5, p.1)

The observation reveals Wendy's agency as she sees her sentence example written on the whiteboard for the rest of the class. This might have prompted her to continue answering, which is when her topic changed to talking about her morning routine. It was useful that Ms Dot worked closely with her to understand that Wendy might be sharing her sequencing with the class. Most importantly, Wendy's confidence seemed to grow as she actively contributed to the class discussion of the book, which could foster a sense of belonging.

4.3.5. *Hyperactivity*

Part of being a primary school pupil was learning to build attention and follow classroom rules, such as sitting still on the carpet or sitting correctly on a chair (see 3.1.i). However, for individuals with WS, research asserts higher risk of hyper activity and distractibility (Mervis & Klein-Tasman, 2000; Reilly, Senior & Murtagh, 2015).

Ms Jacobs described the need to prompt Ryan to ensure he stayed on task:

> He needs that constant, come on, come on… I think the class teacher wouldn't be able to do it because they've got 28, 29 other kids to worry about as well. Even with the class TA, there's so many children that need their help. I think he'd sit there all day. He's not got the incentive to do anything if he doesn't need to it. If he's not been told to do it, like you need to do this, I don't think he would do it (RTA, p.6).

As well as staying on task, Ms Jacobs was eager for Ryan to develop personal responsibility, as suggested earlier in being a primary school pupil. Observations also showed that TAs would understand how much time a child could spend on an activity before needing a break or change of pace. For example:

> Ms Jacobs *recognises when the children need a change of movement or break. They lose attention or focus, and she knows when to push for handwriting and when to give them the option of a break (R4, p.3; Video R1).*

Difficulties with hyperactivity were also noticed during my visit with Orla. Ms Turner explained;

> [sometimes] if you're trying to say something to her, she won't make eye contact, she'll try and run away. So, you have to just literally hold her by her shoulders and stop her, slow her down. I kneel down on the floor and look at her and say, right Orla look at me, listen to the instruction. Then you need her to calm before you then carry on (OTA, p.8).

Orla had many opportunities to explore the classroom through a child-led approach. Staff-assisted or instructed activities were often very short and focussed for approximately 10 minutes, as she found it difficult to stay sitting still. The continuous provision approach meant that Orla did not need to stay sitting for long periods of time, although it also meant that she did not practice this skill. Ms Turner was working on extending the amount of time Orla could focus on an activity, with the view that the continuous provision approach would end when Orla moved into the next classroom to begin Year 2.

4.3.6. *Physical skills*

Children were given different opportunities to practice their fine and gross motor skills, another area highlighted as a difficulty for children with WS (Wuang & Tsai, 2017). WS research has revealed challenges in fine motor skill development, strength and coordination (Bellugi *et al.*, 2000) as well as difficulties with gross motor skills, jumping, running and balancing (Elliott & Bunn, 2004).

Fieldnotes describe Orla's unsteadiness in the classroom, navigating around tables and bookshelves, often bumping into furniture. Interestingly, Orla was discharged from the occupational therapist (OT) team the year before, after she had 'settled well' and therefore it was only through the teacher reading WISHES (Tynan, 2014), the book about educational strategies for children with Williams Syndrome, before my visit that highlighted it as an area that may be useful for Orla to work on (O1, p.3). Ms Roberts shared:

> Reading the book made me think that's the bit we're not meeting, that's the needs of her that we're not meeting. Everything else I feel like we've not set about doing it all, but we've got an area in each of the… In each of the areas that it talked about we're doing something in each of those apart from physical issues. That was the one thing that jumped out at me to say that we should be doing something for this. Ideally, you'd have an OT in to do a proper assessment, but I think it's pretty obvious what her areas of need are around balance and coordination and proprioception and hopefully we can make a difference (OT, p. 3).

Similarly, Sophie's parents were keen for her to work on fine and gross motor skills, and Ms Watts made some games but would have preferred to be given tasks or training in order to know how to help develop skills. Ms Watts identified Sophie was experiencing difficulty with fastening poppers on her coat and so made some resources for Sophie to practice developing strength in her fingers, the pincer movement and turning her hand.

Ms Watts also focused on developing gross motor skills outside on the playground using the obstacle course and teaching Sophie how to jump from a wall. The occupational therapist had recommended chunky pencils and most of the support in place for her was focussed on aiding her visual impairment through the use of a writing stand and the position of her carpet space:

> *The OT's assessment of Sophie suggested she needed to use chunky pencils and to send staff on a specific handwriting course, which the SENCo casually informed me they recommend this course for everyone* (S3, p.1).

These fieldnotes indicate a gap in knowledge of WS specific difficulties such as fine and gross motor skill development, balance, coordination and spatial awareness. Generalised support for children with SEN/D such as a handwriting course or the use of chunky pencils could be useful when combined with a responsive practitioner who learn from their experience. Ms Hughes offered Sophie the chunky pencils but encouraged Sophie to choose whether she wanted to use them, which she declined.

In Ridgeview School, Ms Jacobs showed the book she used to follow exercises and assess the level of support Ryan needed to progress with his gross motor skills, balance and coordination:

> *There are Interventions such as colouring, painting etc. for Ryan's fine motor skills. The Stepping Stones Curriculum by Rachel White – "Helping Children to Improve Their Gross Motor Skills." Originally from a TA a couple of years ago, and now used for children 'like Ryan.' Ms Jacobs does an assessment, and chooses which areas to work on from that e.g. balancing and ball skills. Ryan is visibly enjoying it, showing more energy, running around, smiling* (R2, p.1).

The activities Ryan showed me in balancing and ball skills were similar to Wendy's Fun Fit sessions. Wendy was identified as part of a small group of children who needed some extra support. The group met in the hall with two TAs to practice and develop these skills:

> That's just children who have come through Reception and have come out of Reception and it's been noted that their coordination is not great… Over the years, there's been lots of people that do that from time to time with groups of children that need it. So, sometimes it's running in the school, sometimes it isn't, it just depends on who needs it and who is free to do it as well, so that's how that came about. I have a baseline which is done, on the first week you tick off all these things, whether they can do them or not and then after something like twelve weeks of doing the activities that are suggested you then go back to the baseline assessment and tick off what they can do and what they can't do and see the improvement (WTA, p. 9).

Furthermore, Wendy had a specific chair from her occupational therapist which was recommended to help enable Wendy to sit correctly. Without the chair, my observations showed Wendy would stand up a lot more, rock on her feet and so had more reminders to sit on her bottom and try not to wiggle (W1, p. 1). It was a solid, heavy chair which Wendy needed help to move back in order to stand up from seating, so Wendy had to stay where she was until Ms Dot or her peers helped to move it back for her (W1, p. 1). Whilst this equipment helped Wendy with her posture, it also highlights her need for support which differs from the rest of the class, and means Wendy relies on others to physically support her out of the chair. This challenge for Wendy helps to indicate the differences in priorities between the occupational therapist and education staff, who must work together to navigate solutions for support.

4.4. Encouraging and assisting

The varied school settings, families, background experiences and knowledge created such individual differences that the line often blurred between needing knowledge about WS, and knowing the children. Confidence in working with children with WS varied between staff and schools. Ms Turner and Ms Roberts asked about accessing a WS course (O5, p.2), Ms Watts asked about specific resources (STA, p.2) whilst Ms Jacobs noted the uniqueness of each child in my fieldnotes:

> *Talking to Ms Jacobs, there is a Handbook for Autism you can get, which gives you information about dealing with sensory needs, and emotional coaching. But she's not sure if she'd want one for Williams Syndrome, because that's just about the condition, and not everyone is the same. "That's just Ryan"… Ms Jacobs is an SEN TA, with regular access to training and resources, and support from the class teacher and SENCo etc. She is also very passionate when she talks about children with SEN, and she is very interested in the area* (R3, p.2).

It was clear that my presence at the schools prompted school staff to reflect on their understanding and knowledge of how to support children with WS. Many teaching assistants borrowed the WISHES book (Tynan, 2018), or parents had lent it to staff, and they discussed with me their thoughts. Ms Roberts found the book useful in identifying gross motor skills as another area of development to focus on. Having a primary school pupil with WS in their class meant peers and staff developed understanding about the specific syndrome through their experiences.

4.4.1. *Peers*

Children who attend a mainstream primary class have a range of different needs and backgrounds. Therefore, there are various opportunities for children to develop supportive peer roles and helpful attitudes. On the other hand, children may need support to prevent them being over-helpful (See 4.1.3).

The following observation shows an example of one of Orla's peers wanting to interact and support her. However, I felt a tension within these moments when the children seemed to be presenting themselves to me as a role model, which illustrated the different way they responded and valued children with SEN/D.

> *Orla is sat next to me at her workstation ready to open her book to read to me. She has identified the sounds and blended the words for Duck Socks and has opened the first page to the Adult Guides showing the sounds.*
> *Chris comes over and asks Orla "what is that, I like that" pointing at a monster she made which is on her display board in front of her. Orla does not respond.*
> *Chris asks Orla another question, calling her name but she does not respond.*
> *I say to Chris, "I think Orla wants to do her reading."*
> *Chris says "Orla, I don't know what this is, can you tell me?" pointing to the ck sound in her book.*
> *Orla has been reading out the sounds, and finds the place in the book that Chris is pointing to, and reads ck.*
> *Chris looks at me as he says "yes." He seems to be modelling, showing me that he did know what the sound was but that he wanted to share a supportive moment with Orla* (O1, p.2)

This example also indicates the children with WS benefit from interpreting and scaffolding, as Orla was unsure how to respond to Chris, or perhaps deliberately chose not to because she was busy. Likewise, Chris may not have understood the context of Orla wanting to read with me rather than answering his questions.

Similarly, when another peer asked Ryan to do a dinosaur impression, it was something that the children in his class knew he could do, rather than an exchange of conversation (4.1.3). The following observation shows the difference in roles between Ms Dot and Wendy's peers. Ms Dot uses signing and prompts to help Wendy manage wiping her nose, whilst her peers' reaction was to manage it themselves (W1, p.2).

Don't lick it!

Ms Dot prompts Wendy to wipe her nose with a tissue, reminding her that using her sleeve will spread germs, and that they talked about that before. Wendy then uses a tissue on her nose, and Ms Dot signs to her to rub her nose, and throw it in the bin. She then prompts her to wash her hands, and because the classroom sink is broken, she is sent next door to the other Year 1 class to use their sink.

In contrast, when on the carpet next to a peer, Wendy sneezes and needs a tissue. She does not move, and soon her peers have seen that she needs a tissue to wipe her nose.
"Don't lick it!" the girl in front cries several times, whilst Wendy remains frozen to the carpet, looking around with a helpless gaze. The girl next to her runs to get a tissue, and returns, holding it to Wendy's face. Wendy wipes once, but does not take the tissue, so the girl remains holding it, and wipes Wendy's nose several times. The girl tries to give it to Wendy, but without saying anything. Without the verbal prompts, Wendy does not seem to know to take the tissue, and the girl therefore has to keep it. The girl eventually puts it in the bin.

This example reveals different perspectives of support for Wendy. The first interpretation is that Wendy does not know how to participate within this social exchange. There is a significant amount of nonverbal communication that Wendy either does not process, or is struggling to know how to respond. This could demonstrate that the children did not know how to teach Wendy the next step of the task, and so they supported Wendy by doing the task for her rather than using it as a teaching moment to promote independence. Secondly, the only verbal instruction is to not do something, "don't lick it!" and there are no follow up instructions telling Wendy what to do, which leaves her stuck.

On the other hand, Wendy is showing a frozen response which could suggest an internal panic, ‘what do I do’? Using Norwich’s (2009) dilemma of difference from the child’s perspective, there may be a tension for Wendy between wanting the help to know what to do to complete the task, and wanting to be treated like the rest of the children. Wendy’s dilemma could suggest that by giving so much focus on her, the children emphasised the differences between them that made her stand out. It would be interesting to know how Wendy would be able to respond to a similar situation outside of the classroom, with a smaller group of peers.

Children in Wendy’s class were very keen to help and support Wendy in their own way. Children were often very keen to sit next to Wendy in the hall for lunch, so that Ms Dot had to make sure they all took turns. My observations noted the large amount of physical support that peers gave to Wendy such as moving her around the carpet, leading her to her chair and tucking her in, or holding her hand (W1, p2). Perhaps these gestures are mirrored from adult physical prompts such as seen in the video observations, but in this case the staff were very aware that this was less helpful for Wendy’s independence as well as it was annoying her. This was clear on the last day of my visit when Ms Lock exclaimed to the class:

> We don’t need everyone to help, let Wendy do it herself! (W5, p.2)

Similarly, Ms Pennywell described to me:

> We’ve got to tell them to “Stop picking her up, stop pulling her arms out of their sockets” (WT1, p.1).

To further highlight Wendy’s own attitude towards her popularity in the class, Wendy hid behind

Ms Dot's leg before being given a choice of either holding the two children's hands, or waiting for Ms Dot:

> *At end of play time, Poppy and James are desperately clinging to Wendy in the hope of holding her hand to help her towards the line, and Wendy hides behind Ms Dot's leg. Ms Dot asks "do you want to hold their hand, or wait for me?" and Wendy replies "wait for you" so Ms Dot informs the other children that Wendy wants to walk with her, and thanks them for the kind offer* (W3, p1).

Ms Dot's verbal input enabled Wendy to make her choice known, and let the other children know why she was hiding behind Ms Dot's leg.

4.4.2. *Staff*

Staff who worked closely with children with WS were highly skilled and recognised the need for a range of prompts and encouragement. For example, Ms Watts was working with Sophie to develop her speech and language:

> She needs a lot of encouragement [to] tell me, [so I] keep asking her questions, what are they doing… If you don't, she will point and say two words, even though I do understand what she's saying but you've got to ask her to verbalise the sentence (ST, p.9).

This was shown in several observations, for example:

> *Sophie has had a lot of input from her 1:1. This includes prompts such as "I know it's hard, but try again," or "have another go," and pushing Sophie to keep going. Ms Watts built this up over time. Sophie does not seem to get frustrated or upset. Ms Watts explained that other children would refuse to do the work, give up, lash out, but Sophie does not. However, Ms Watts uses prompts, scaffolding and reassurance in a way that encourages Sophie (S2, p.1).*

In the following video S2 example, Ms Watts uses several physical prompts and gestures to help Sophie develop her fine motor skills. Ms Watts had found that Sophie was struggling with strength in her fingers to fasten her coat poppers, and therefore had made several of her own resources such as the task in Figure 10 where Sophie pushes the blocks through the lid of the box using only her fingers rather than her whole hand:

Figure 10: Video S2 screenshots

	
Ms Watts holds Sophie's hand to ensure she is focussing on what she is saying	Ms Watts signs and gestures to Sophie to show her how to shape her hand so that her fingers are pushing the block
	
Ms Watts uses hand over hand approach to help Sophie to use the correct hand technique	Ms Watts claps and cheers Sophie who has finished putting all the blocks in the box

Sophie seems to value the input from Ms Watts in showing her how to shape her hands to complete the task. From a total communication approach, Ms Watts combines multiple methods of communication to support Sophie such as verbal instruction, gesturing and physical support.

Noted further in fieldnotes, Ms Watts demonstrates a scaffolding approach by telling Sophie what she must do, helps her to do the task, and then gradually takes away the levels of support. In the following observation, Ms Watts also uses a reward system to encourage Sophie to complete the course herself:

> *This was seen outside on the obstacle course. Ms Watts will hold Sophie's hand and go through the whole course, then Sophie must do it on her own. Sophie asks for her hand continuously, but Ms Watts is consistent. She begins the course, and halfway through stops for a cuddle, where Ms Watts explains Sophie will get a [house] point if she completes the course herself. Sophie completes the course, and is visibly proud (S2, p.1).*

Figure 11 illustrates a section of video which shows the different types of prompts Ms Dot uses to help Wendy overcome distractions and develop attention skills. Prompts include saying her name, touching her arm, and waiting for Wendy to look at her.

Figure 11: W2 Video screenshots	
	
Ms Dot taps Wendy’s arm and says her name as she relates the action in the story to an example that includes Wendy. Wendy immediately looks at her, nodding.	Wendy asks to repeat the sentences herself, with praise. Ms Dot encourages Wendy to pretend to throw, to mimic the action from the story.
	
Wendy points and names each of the pictures in the story. Ms Dot asks a question, and Wendy repeats pointing and naming the objects. “Answer the question, look at Ms Dot” Wendy looks at her, guesses the end of a sentence and then answers the question correctly	Ms Dot looks through the book for another word, as Wendy turns to look at the burst of noise as children open the classroom door for lunch.

School staff commented on the important relationship between children and the TA. It was also apparent that support staff spent a considerably longer amount of time working closely with children than the class teachers:

> It makes it easier when you get to know the child as well which is why I think with the first term, I feel bad saying it but I told [Ms Watts] to just do what she needs to do with Sophie so then I can kind of get to know her and see what she can do, see what she can't do and build up from that because I didn't want to give her something and then it kind of knocks her confidence down (ST, p.2).

In this example, Ms Watts had worked with Sophie the year before, so Ms Hughes was keen for that work to continue. Her worry about supporting Sophie is shown through suggesting that the work might not be set at the right level, and this can have repercussions, such as losing confidence. Similarly, Ms Lock suggested:

> Having the one-to-one support is something I'm used to as a teacher like when you have children that need that additional support and I think that's really helpful, that relationship. Ms Dot knows so much more about Wendy than I would ever know just because the amount of time that they've spent and the fact that she's carried on [supporting her from earlier years] (WT2, p.1).

My study suggests that as TAs spend more time with the children than other staff, they are seen as more knowledgeable about the individual child and their needs. The downside of this was highlighted in my visit to Orla when Ms Turner was absent due to sickness, and staff were unsure what tasks she was working on, and less confident of what their expectations should be (O5, p.1).

Ms Roberts suggested that there was risk associated with over reliance on the same TA when commenting on Orla's enjoyment spending time with the other TAs and children in the class:

> She's equally happy just playing with other children and I think for me that's the exciting thing about this child led approach. It allows all children to be included. If we were a formal Year 1 classroom, she would spend all her time with [Ms Turner], which I think is the most depressing thought ever really (OT, p.2).

Over reliance on a TA can lead to less opportunity to practice socialising with peers or working with a qualified teacher (Mackenzie, 2011; Radford *et al.*, 2015). However, there is a clear challenge when the teaching assistant becomes highly skilled in working with a child with WS based on their experience; this is not transferred to other school staff and is therefore lost when they leave or are absent.

Ms Jacobs described the need for her input in annual reviews because of her close work with Ryan compared to the teacher:

> We go to all of those, the annual reviews. They want to hear your thoughts. Obviously, Ms Dill is his teacher. I'm outside. There's a lot of things she doesn't know about him and there's things that I do, that she might not even realise that we do together or didn't know he could or couldn't do that. It's good to have me in those meetings just to get my perspective on it. (RTA, p.2)

Ms Jacobs talked about being 'outside' which is explored further in the next section. Being outside could indicate the physical position of outside the classroom with Ryan, or outside of the meeting. However, it does suggest a marked difference in the status or position between teacher and teaching assistant. Working very closely with a child enables the TAs to understand them as individuals. However, does the diagnosis of WS prevent other staff from feeling as confident or secure in knowing the children? It is important to share the knowledge and understanding of WS with others (See 5.4). Although this should not stop staff getting to know the children as individuals, the challenges in supporting children with WS suggests a lot of time is needed to build a trusting, responsive relationship between staff and children who recognise each child's unique pace.

4.5. Summary of experiences of primary school

Children shared rich in-depth examples of their experiences attending a mainstream primary school, from learning where to find their seat in the classroom, to taking responsibility for hanging up their coats and identifying their class. Children showed their daily routines, and shared their difficulties in listening to and responding to instructions from adults in the classroom. Both Sophie and Orla commented about their friends when looking through the photos, or looking for their peers. Often, when asked about their friends, the children would list the names of the peers in their class, and their TA, which indicates the challenges of labelling all peers as friends without understanding the complexities of friendships.

Sophie and Wendy were particularly smaller than their peers; and moved slower which sometimes meant they found it difficult to find their peers on the playground, or to join in conversations and play. As well as being easily distracted or looking the other way, children also benefitted from an unhurried approach to education which recognised their own learning priorities. Findings highlighted how the children with WS were going at a different pace to the children in their class. This often occurred outside of the classroom which will be explored further in the next section.

Part of experiencing education with Williams Syndrome included managing worries or areas of anxiety, which were often linked to a sound sensitivity and heightened emotions. Orla and Wendy expressed their worry about the hand dryers, whilst Sophie did not go to assembly after the boys had played drums loudly in an assembly a few weeks before my visit. Children shared different experiences in physically negotiating the classroom, developing their physical skills, social skills and managing distractions and sounds in the classroom.

Children were encouraged and supported by a range of peers and staff, in different ways. Many children in the class were keen to help children with WS navigate the classroom or find their seat, although at times their eagerness to assist prevented children with WS from practising independence and asserting themselves. Staff employed a variety of strategies including encouragements, prompts and scaffolding to help build children’s confidence in developing their skills.

The next section will take a step back from the children’s perspectives to consider how staff managed the inclusion of a child with WS in the four different schools. This will address research questions exploring how schools can facilitate inclusion, and what staff understand about supporting a child with WS.

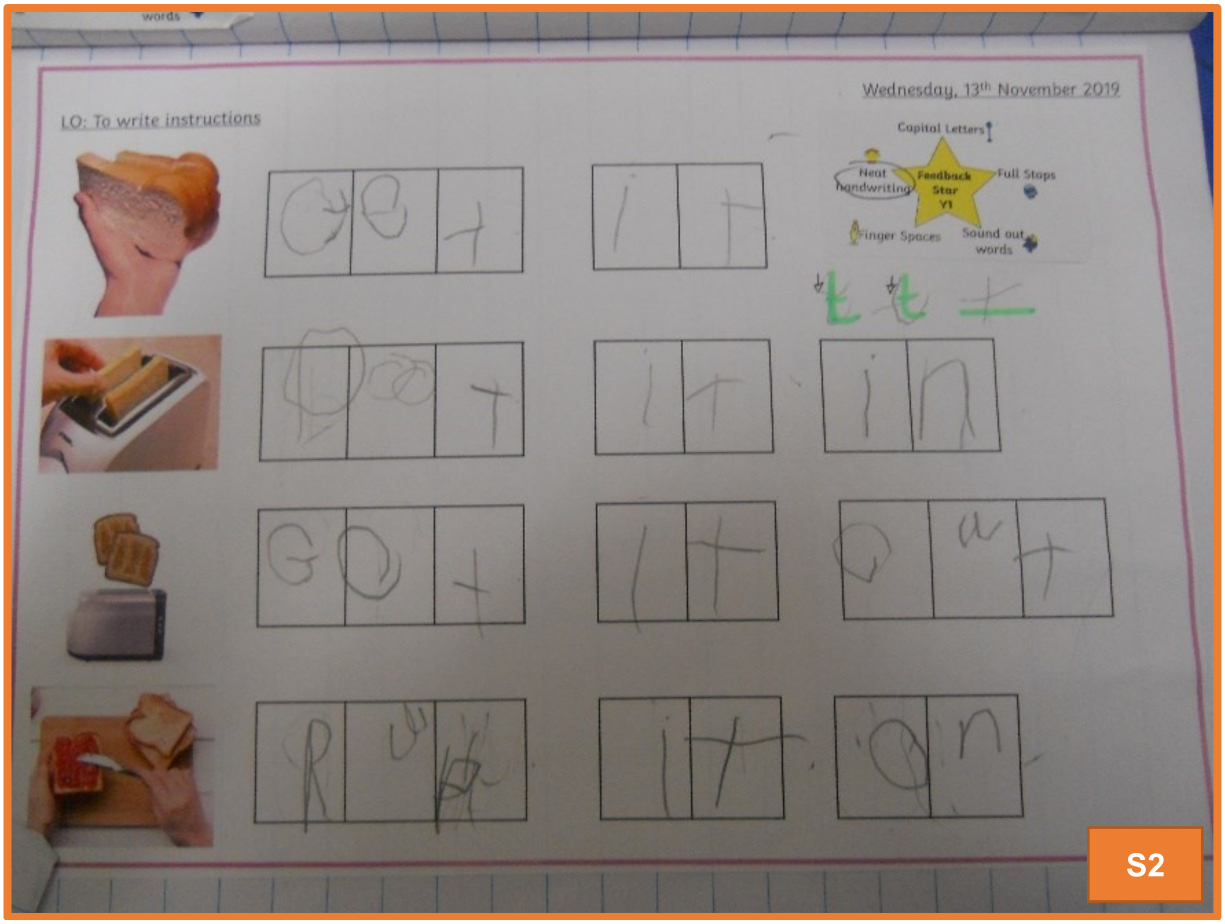
5. Managing inclusion in the primary school

Each school supported children with a range of diverse learning needs. The following section will explore how the staff used opportunities for pedagogical conversations and communities of practice to develop their knowledge and understanding of supporting children with WS. I will also look at the different areas of the classroom that staff used to work with Sophie, Wendy, Orla and Ryan, as well as the way the curriculum was designed and managed.

Children with WS generally have a mild to moderate learning disability, which often results in them accessing a different level of schoolwork to their peers. Sophie, Wendy, Orla and Ryan all had an Education, Health and Care plan (EHCP) with goals connected to the Early Years Foundation Stage (EYFS) curriculum.

5.1. Curriculum

Sophie's work during the week I visited shows the frame given to her group to complete their task (S2). Whilst other children in the class used full stops, capital letters and thought of creative words to form their instructions, others had different levels of support.



Ms Hughes pointed out the difference in Sophie's learning and assessments:

> I don't know if it's just too abstract for her at the moment…. even if there's not as much in terms of her writing, we can still take the pictures and have that in the book and go, "This is what she can do." So that by the end of Year 1 she has, not that she won't do but she's able to hit certain targets. She's done it in her own way. I didn't want to say that we can't assess her because she can't do it the same way as everyone else (ST, p.7).

This quote indicates Ms Hughes' accountability as she is telling someone "this is what she can do" to a third body which is outside of our interview. Perhaps her intention is to show Sophie's achievements to the school leadership, or the school inspection body such as Ofsted. However, Ms Hughes' quote shows she wants to help Sophie achieve at her own pace, which may mean using assessment in a different way. Therefore, rather than a focus on the performative nature of hitting certain targets (Ball, 2003), this example also illustrates the way Ms Hughes can navigate expectations of being able to provide evidence of Sophie's learning, with a genuine desire to enable Sophie to show what she has achieved.

Moreover, Ms Hughes was conscious of providing the right amount of support at the right competency level, so that Sophie could feel a sense of achievement:

> I didn't want to give her something and then it kind of knocks her confidence down. But equally I don't want to give her something that I think she could do and actually she did it quite quickly and then was bored (ST, p.2).

Ms Lock also mentioned the difference in targets for Wendy to the rest of the class:

> Because Wendy's targets are very different, the children in here their targets are to use capital letters and full stops in sentences, one of the most common ones, that's not what Wendy is working towards so we try and do something that would suit (WT2, p.2).

Year 1 in Littlewood School had one table named the 'tutor table' where Ms Roberts would invite a group of children to sit for a 20 minute teacher-led session. Apart from whole class carpet input, the rest of the time was chosen by the children. Orla did not join the tutor table, although in the interview Ms Roberts suggested Orla was becoming interested in what they did, and she had plans to work with her at another time. The continuous provision approach enabled staff to further children's learning through questioning, and they would record this on an iPad which would connect a task to an objective under the National Curriculum. Through my observations, I did not see Orla complete the tasks set in the week, although she had her own tasks at her own table with Ms Turner.

This different type of approach to education seemed to work well for Orla in that there were always children doing different activities in the classroom. Similarly, Ms Roberts suggested:

> The great thing about a set up like this [continuous provision] is that she can be independent. When we had clay outside, so she was able to access that, at her own level. She wasn't making the incredible creations that some of the other children were making but she was being independent working alongside her peers which I think is really important (OT, p.3).

An observation at Littlewood School shows how Ms Roberts recognized children's own learning priorities:

> *Ms Roberts sits at the front of children and asks for children's sentences that they have or are planning to write. A few children share the ideas they have written. The picture shows a ladder leaning against the house.*
> *Orla is looking around...*
> *Ms Roberts starts to wrap up the small lesson and Orla calls out that she hasn't said her sentence.*
> *Ms Roberts asks for her sentence.*
> *Orla starts "the ladder is.." as Ms Roberts stretches her hands wide to sign high, "very high."*
> *Ms Roberts "now say the sentence"*
> *"The ladder is really high." Orla has shared and shown her learning to the teacher and the whole class, using speech which is one of her strengths. Ms Roberts does not focus on the handwriting element of the task, and Orla seems to feel a sense of achievement* (O2, p.1).

Similarly, Ms Roberts comments on the different expectations for Orla as she recognizes her difficulty sitting for long periods. Ms Roberts therefore uses her increasing familiarity with Orla to shape her teaching:

> I think for me this feels so inclusive. I don't think she's capable and nor should she be at her age sitting down for 15 minutes with [Ms Turner] three times a day, and that's what it said in her [Support Action Plan]. The idea is for her to concentrate for 10 to 15 minutes three times a day and target things that are in plan. For a five-year-old that's enough as far as I'm concerned (OT, p.7).

Varied activities during the school day help children to develop a range of skills. For example, when children were talking to each other over play dough, Orla's favourite activity, she was developing fine motor skills as well as communication, sharing, and relating to each other through playing a game.

Littlewood School also had a forest school area which gave the class the opportunity to learn outside of the classroom. Ms Turner described:

> It's on a slope like this and when it's really slippy, they all struggle, they all slip over but she loves it, she goes right to the top of the bank, she'll climb up, she'll go along the top, along the edge, she loves joining in with all the activities, there's hammocks up there, she absolutely adores being in a hammock, with a friend. I can let her … I'm always a few steps behind in case she falls but I think you need, on a weekly basis, you need something like that, just to say, right actually we're out of the classroom, it's something different otherwise it can be quite hard work (OTA, p.6).

Ms Turner suggested that it was positive for children to understand that children worked differently:

> I hope that she stays in mainstream until Year 6 because I see that she's benefiting from it, she's getting so much from it and the other children are getting so much from her, they're learning that people are different (OTA, p.14).

Similarly, Ms Jacobs recognised the importance of having different learning opportunities, whilst also navigating the expectations of target-led teaching:

> Although they're having a break when they're playing Lego, that's ticking so many targets off. Even just little bits of conversation or problem solving like she's got the piece I want, what can I do? How can I figure this out? We were playing with the beads earlier and the tub was there and he was like I can't reach. I was saying what do you do now, how are you going to get the tub, it's little things like that. It looks like we're having a jolly most of the day but we're not (RTA, p.10).

Considering the differences in attainment, there is a risk that children are seen in the deficit view of disability of being less able, or unable to participate in the classroom. Ms Jacobs acknowledged the negativity that can surround the child with SEN/D when needing to understand what the child can and cannot do:

> It's hard, because whenever you talk about their child, if you're being honest there's quite a lot of negativity. There's a lot of he can't do this, he struggles with this and he can't do that. You try and put a positive spin on it but at the same time you want to be realistic, you don't want to lead them into false hope. (RTA, p.2)

The term 'false hope' seems to suggest that the parents are looking for hope in that Ryan does make more progress, or experiences fewer struggles. In this way, Ms Jacobs seems to view it as realistic to explain where Ryan is in relation to children his chronological age, or in relation to the expectations of school curriculum and age-related targets.

Working with both Ms Dill and the SENCo at Golden Oak primary school, Ms Jacobs points out:

> It's a joint effort, yes. We'll come up with an idea that we can do this, this, and this and then we'll just, I've got a copy of his EYFS targets and then I can just look through that and pick something out of that… He's got his individual planning sheet, all of his personal targets and they get picked by the SENCo, and then she will say you need to put this, and this for the annual review, that's what you need to work on next (RTA, p.10).

School staff made constant decisions about whether children could join in with the rest of the class, or use the time to focus on their own targets. Ms Jacobs explained:

> Ms Dill likes it when he's in class in the afternoons. She said to me before she went earlier, she was like he can stay in this afternoon because we've got this and this. She'll know which lessons are not worth it. History it's not worth him staying in but ICT, he can stay in for that one (RTA, p.4).

Similarly, Ms Dot shared:

> I usually let her sit on the carpet and listen to them because you don't know how much she's taking in. So, I usually let her just sit there and take in the first bit and when they go to tables, if it's something that I know is way, way beyond her we will just work on her corresponding one to eight or one to ten, that's usually our daily task to work on that (WTA, p. 5).

There seems to be a difficulty in knowing when children with WS benefit from being in the classroom, with some teachers prioritising English and Maths for whole class working, and others considering different subjects such as ICT or PE. This is explored further in the next section which looks at where children spend their time.

Overall, teachers have forms of accountability through league tables and inspections, as education has moved towards target and performativity (Ball, 2003). The children with WS usually worked on different tasks to the rest of their peers, or in a small group using different resources. Quotes from staff help illustrate the complexities of managing inclusion for children with a range of learning priorities and paces, as well as the pressures of accountability and educational policy. Passy (2013) describes the National curriculum, regulations and a government centralised pedagogy as an issue for student teachers who may have less time to consider and reflect on theory.

5.2. Working areas

Firstly, no consent was gained for the rest of the class to be included in the research. Therefore, when children took photos of others, they were not kept or used in the study, other than as a stimulus for children to talk about. This also allowed children to learn the value of asking for permission from both staff and peers to have their photo taken.

The nature of the research may have taken the children outside of the classroom in order to direct the tour, take photographs and videos and spend time looking through them. However, over the week spent with the class and in conversations with staff and children, it was clear that spending time away from the class was not an unusual experience.

O3

Illustration O3 shows a screenshot from Video O1 where Orla was very interested in the new leaflet given to Ms Turner by Ms Roberts to work on her gross motor skills, coordinate and balance. This photo shows the photocopying and materials room which had a table and chairs for small group work. Fieldnotes and observations showed Orla spent varied time at different stations around the classroom including by the Moon landing with the shiny marbles (tough tray), playdough at her 1:1 table, and outside by the mud kitchen, tyres and milk crates.

O4

Photograph O4 taken by Orla shows part of the classroom that has space for a train track, and some of the wooden blocks that other children would use to build ramps and towers for their marbles to run down.

S3

S3 and S4 photographs of Sophie were taken when she had chosen to stay inside the class whilst the rest of the class were in assembly (See 4.3.1 and 4.3.2). Sophie is at her chair which is among a table of a group of children, near the carpet. Ms Watts would often sit perpendicular to Sophie on her right-hand side, where the picture shows Sophie's writing board.

S4

Outside of the classroom, a table with two seats shows a visual timetable which was not explicitly used during my week there. Ms Hughes explained the day's timetable to the whole class whilst everyone was on the carpet, which is a useful strategy to aid all children. Sophie's table just outside the class is used in the afternoons when she is working with Ms Jacobs on her specific interventions such as speech and language or developing fine motor skills.

W3

As seen in photograph W3, Wendy is outside of the main class, on a large table which is also in the cloakroom. This meant that at times, Wendy may be completing her work whilst the rest of the class has finished and is entering the cloakroom to get ready for a break time. This area is between two full classrooms, which can sound very noisy with the doors open.

Both Sophie and Wendy had a physical writing frame provided which helped bring their work closer, and keep their book positioned, as opposed to Ryan in Video R1 who had to learn how to position his hand on the book.

R2

R3

Golden Oak primary school had a large hall at the centre of 4 classrooms comprising two year 1 classes and two year 2 classes. This hall was once used for an assembly, but most often has a range of tables outside corresponding classes for small groups and 1:1 working. Ryan regularly sat here in the mornings with his two peers. The photographs of Ryan (R2, R3) show two of the areas he worked in whilst I visited that week. As seen in the photograph, the hall also serves as the cloakroom for all four classes around the outside.

The other area was chosen after Ryan's class was practising a SATS paper, and so he and the two children he usually works with were taken to a small room next to the Family liaison officer room. This room was also used for the 'Bucket game' and comprised of a small table and set of chairs where he sat to complete his literacy work with Ms Jacobs.

When visiting Ryan, I noticed in my fieldnotes that I spent more time outside of the classroom:

> *I haven't been able to get to know the class as well this time. The last two weeks in schools I learnt lots of names, and spoke more to the children, listening to them read or talk about shapes.* (R3, p.1).

However, outside of the classroom, Ms Jacobs taught the three children a very different set of work to the rest of the class which was made relevant to them. For example, the children were writing instructions, so Ms Jacobs explained that her son wanted to make the cakes they had made previously, and therefore the children needed to write instructions for him to read.

I also noticed that within the class, without Ms Jacobs, Ryan preferred to avoid the task the rest of the children were working on. As it was a handwriting task, this may have been too daunting for him as this requires a lot of concentration and support (Video R1). Ms Dill offered him paper to draw a picture instead, but Ryan did not seem interested:

> *Within the class, without Ms Jacob's support, Ryan sits on the table, plays with stationery, putting the rubber in the bowl, and asking Ms Dill questions about using different colours and colouring in.*
> *The children are handwriting their letters to Ms Thomas who is leaving to work on a boat.*

> *Eventually, Ms Dill finds paper for Ryan to draw a picture for Ms Thomas.*
> *Asking what he will draw, Ryan replies "Gangnam" (his favourite song)*
> *Ms Dill says "No, a picture for Ms Thomas. She is going on a boat so you could draw a boat" and sits with him to direct his drawing.*
> *Without constant prompts Ryan remained sitting, making faces or noises, and talking whilst the rest of the class are silent and working. I notice the gap between Ryan and his peers a lot more than the others.* (R2, p.2)

During a Maths lessons, Ryan joins his peers in 'co location.' Ms Jacobs facilitated Ryan's participation by drawing an arrow which helped Ryan to understand which direction to turn when the rest of the class were turning 180 or 90 degrees anti-clockwise or clockwise.

> *Ryan manages to identify "a" for anti-clockwise and "c" for clockwise. Ms Jacobs has drawn a large arrow underneath, telling them which way to turn* (R3, p.1).

Ryan and Jane (a Year 1 pupil who was working with Ryan and Ms Jacobs) did not have seats at the tables in this class, because there was not enough room on the tables. Although a lack of seating plan may have ostracised the two children from the rest of the class, working on the carpet meant that they were able to use more space to move around and use an array of resources. On the other hand, even though the children were physically present, the children's work was very different to the rest of the class, which Allan (2006) argues can isolate children with disabilities from the rest of the class.

Talking about the realities of managing inclusion for Ryan, Ms Jacobs' words echo Norwich's (2009) dilemma of difference when she suggests:

> That's not inclusion if we treat him differently because he's got [a diagnosis]. I think this school tries really hard to be inclusive as much as we realistically can. Ideally we would be in a classroom, but realistically we're too loud. We stop all the time, he's eating, one needs the toilet, it's chaos. We need to be realistic for the rest of the class as well as these lot, but that's not practical (RTA, p.3).

Teaching staff talk about “bringing her [Sophie] into the classroom” in interviews, focussing on physically being inside or outside the classroom. Videos were all taken outside the classroom which meant that I would be less likely to capture other children in the background. When another child joined Sophie in a task during filming, I confirmed with Ms Watts that I would cut the video so it would stop before the child arrived. However, it did not seem unusual for staff to work outside of the classroom in quieter spaces where it was thought that children would be able to focus. For Ryan, Ms Jacobs felt more comfortable offering him snacks, having frequent breaks and being louder than the rest of the class, who were noticeably quiet if not silent when working.

There were differences in staff’s views on when children with WS would benefit being with the rest of the class. Ms Jacobs suggested:

> …in the afternoon he’s in there because it’s not as structured. It’s not English and Maths, it’s not the foundation subjects, it’s more your extras, so you’ve got things like art and they’re doing science at the minute and history. Yes, it’s going over his head, but he’s sat in a classroom environment. He comes to mainstream school so he needs to be part of the mainstream classroom. Let’s say for Maths, he’s gone in there now. We don’t have space at the table and we have to sit on the carpet but we’re still part of that class (RTA, p. 4)

Whereas Ms Hughes described:

> Maths and English is quite driven. I would rather her be in the classroom at that point. Then towards the afternoon it’s more investigation enquiry work which even though she would love, and I do feel bad not getting around to it, I would rather her focus on the interventions for herself, so going, “Actually you love to look around the classroom however, if you need to go and do your sounds, you need to go and do your quick words and you’re reading, that’s the time I’d prefer you to do it,” because it then helps her build on to her literacy stuff (ST, p.5).

Staff commented on the importance of being with peers, doing the same thing or joining a similar activity alongside peers:

> She’s joining the classroom like everybody else to encourage her to be more independent. It’s got a downside, that means she might not progress as well as she did last year, but the positive side is for her to be more independent and getting used to being inside the classroom with everybody else, following a structure, like everybody else. (STA, p. 4)
>
> So even PE, she changes with them in there, snack times, lining up times, we try and keep her in as much as we can because there is a lot of time when she is out with Ms Dot. When they’re all together on the carpet and doing things all together we try and keep her in that and then when they go off to do their own learning at the table that’s when Wendy goes off and does her jobs (WT1, p.2).

Ms Dot expressed some concern moving to Year 2 that with more tables in the room, Orla may find it difficult to navigate the classroom. However, her concern was that she did not want her to have to move away from the classroom to work in another space:

> Also, spatially because they’ve got a classroom full of tables, I know we’ve got lots in our room but there are lots of gaps in between, whereas the Year 2 classroom is much smaller and it’s very much a classroom environment. So, that will be the test, but I don’t want to feel that she has to … I don’t want to then have to find another space for her to learn, I don’t want that to happen (OTA, p.9).

Again, the physical placement of whether children were inside or outside of the classroom suggests that staff are aware of the tensions of inclusion. This could stem from the early focus on integration which did focus primarily on whether children were physically present. Moreover, this indicates the challenge in prioritising certain types of SEN/D support for different subjects. Staff thought some children would benefit for being within whole class discussions for the core subjects whereas other staff used this time for children to focus on individual tasks.

The example in the maths classroom brings debate as to whether children can have a sense of belonging, an important element of inclusion, when they do not have an assigned seat in a class.

On the other hand, the benefits of using the space on the carpet helped Ms Jacobs to demonstrate mathematical language to Ryan with a range of resources that were not as readily accessible on the tables. However, inclusive pedagogues would argue that the space and resources should have been accessible to all children, particularly as it is known all children have diverse learning needs and strengths that a UDL approach would help meet.

5.3. Opportunities for pedagogical conversations

Most teachers had limited time to talk to the TAs about the work due to differences in work hours. Teachers' pay and working conditions meant many of the class teachers started earlier and finished later than the school day, which was an expectation in Golden Oak primary school and varied with teachers' own responsibilities such as having children in the same school. On the other hand, TAs' hourly wages meant that they often started and finished the day at the same time as the children. Many of the TAs also worked extra hours at the after-school clubs. Therefore, there were few opportunities for the staff to talk to each other without the presence and responsibilities of children in their care. Staff navigated this through a range of different approaches using trial and error, TA flexibility and adaptation of work for children to be able to access the work:

> Ms Dot is brilliant with it, I'll try and explain to her in the morning what we're doing in our learning and we'll discuss how we could make that to meet Wendy's (targets)… (WT2, p. 2).

Staff found time to give continuous feedback between teachers and TAs, even if it was a very quick few minutes in between lessons. However, all the TAs had different breaks and commitments which meant they often had their lunch or morning break at other times to other staff.

Ms Lock explained:

> The only thing I'd possibly say is the time to feel like we're really planning effectively for her because it's having to be conversations in the moment. And obviously Ms Dot's hours and our school hours, although officially she starts at quarter-to-nine and officially she finishes at quarter-past three, she's with Wendy at lunchtime her breaks are not the same time as us.
>
> So, physically as a team, as teachers and support staff, we can't get together and say: "Right, this is what's coming up next week, this is what plans we'd have in place," so, it has to be conversational in the moment of each day because there is no time for us to sit down and say: "This is what's coming up, how would that fit with Wendy's targets? Let's make a personalised plan for the week." I don't necessarily know that it needs to be because sometimes people make work for themselves, it becomes a bit of a paperwork trail just to say: "We've done it," whereas verbally we do do it every day but I would say is just time to be able to spend time with Ms Dot and say: "Right, this is the plan for the week," but, like I say, because of her hours and our hours it just can't happen for a long length of time. So, we take the minutes in the morning at the end of every day and even within the school day we feedback, so it does happen, but not as a proper we're going to sit down and talk about Wendy now (WT2, p.5-6).

An alternative model was in place at Golden Oak school, as Ms Jacobs was employed as an SEN TA who had specific time for planning, preparation and had opportunities to talk to other staff whilst Ryan was in assembly.

Working in the space outside the two Year 1 classrooms, Ms Dot was able to ask for advice from next door's TA, Ms King, who was a Higher-Level Teaching Assistant (HLTA). Ms Dot asked her if she was using the right vocabulary to teach Wendy about weighing more and less:

> *Ms King sticks her arms out straight to demonstrate balance and encourages Wendy to do the same. Ms King reassures Ms Dot that she is using all the right words, same as, more*

> *than etc. and to use the arms as a visual aid.* (W4, p.1).

Some staff recognised the importance of creating time for pedagogical conversations, although this was problematic for class teachers and teaching assistants on different schedules and working conditions. TAs developed knowledge-from-experience of working closely with children with WS, but lack of time or opportunities meant that this knowledge is at risk of staying with the TAs.

5.4. Communities of practice

Staff supported each other in ways similar to Lave and Wenger's (1991) Communities of Practice, working towards a shared goal with a mutual understanding of each other's experiences.

Ms Jacobs described working together with Ms Dill in a joint effort:

> I can say to [Ms Dill] I think we should really try this, I think he can do this. She'll then come up with ideas of how to do it or vice versa. We're going to do this, why don't you try this version of it. It's a bit of a joint effort. Like I said you've got to come up with stuff on the spot quickly, sometimes you're doing something and that's not working and you need something else… sometimes you're like right let's try something completely different. It's a joint effort, yes (RTA, p.10).

Teachers recognised that TAs worked very closely with the children and therefore had more knowledge of them. Ms Turner described how the class teacher ensured she was involved:

> Yes, I think [Ms Roberts] likes to get me involved really because I spend most of my time with her and as much as [Ms Roberts] does spend time with her, she's not working with her, she's not seeing what she's doing, although I do keep her updated and I just say, we've had a breakthrough, we've done this, we've done that. Yes, so we're quite a close-knit team, the three of us which is really good, they are lovely ladies to work with, so I'm really fortunate in that respect because I know a lot of schools struggle and they don't get

> that support network (OTA, p.16).

Ms Hughes recognized Ms Watt's knowledge about whether the sheet was helpful or needed adjusting:

> So, like today, [Ms Watts] said that the sheet was quite difficult. Tomorrow I'll be like, "Okay, just do it on a practical base thing, take a picture of it and we'll have that instead. You tried it, it's not the best thing. We're going to go back to practical stuff and have that instead but at least you can see that we have tried (STA, p.17).

The implicit need for evidence of the work comes through this quote as Ms Hughes may be talking to an external body by saying 'you can see that we have tried' when describing the challenges between trialling a worksheet or photographing a practical activity.

TAs varied in their confidence talking to me about the support they needed to provide. However, my presence emphasised the diagnosis of Williams Syndrome, which might have influenced how they thought about it that week. Ms Jacobs wondered if she should be more lenient with Ryan, if he is finding it challenging to sit still on the carpet. Ms Turner was interested to hear about other staff and children's experiences.

Ms Dot showed her continuous thinking and reflection on how to keep progressing with Wendy:

> In this job, it's ongoing thinking all the time about what can I do to get that right, what can I do to get that right? … it was only last night that I started thinking: "She's not queuing up correctly, we've been doing this for a year now." So, I thought: "What can I do?" I thought if I get a photo, I might put it on the wall next to where we queue and one on the other doors, both doors, and just point to it every time we queue up and see how that goes. I used to have things on here but that didn't go so well, so I might just try it with them on the wall and point to it. It's like a process all the time, you're constantly thinking:

“How can I get round that? (WTA, p.6).

This quote indicates the process of inclusion as a struggle (Allan, 2006) as Ms Dot seems to have a pedagogical conversation with herself to support Wendy. My presence undoubtedly influenced staff’s focus on specific support for children with WS in education. However, a significant aspect of this support was the developing community of practice between staff who recognised the importance of communicating with each other to work towards a shared understanding.

5.5. Summary of managing inclusion

Overall, staff emphasised the need to work together to ensure children with WS are developing, working towards their goals, or accessing similar activities to their peers. Although the children had different targets to work towards, their age meant that this difference was less than when they progress through the school. This suggests that schools must ensure they manage the balance between meeting individuals’ needs and remaining a member of the class.

Staff would sometimes prefer quieter areas to work closely with 1:1 or small groups. Finding these working areas were sometimes difficult, and TAs were aware that being outside of the classroom does take time away from the class and their peers.

The difference in status and pay between teachers and teaching assistants reflects challenges in how schools manage inclusion. Ravalier, Walsh and Hoult (2021) point out the disparity between hours contracted and hours worked in their large-scale survey on TAs, and the lack of research considering the working conditions of TAs compared to teachers.

Without time to share lesson planning, resourcing and communication about assessment or progress, TAs hold more knowledge and experience than the teachers who have overall responsibility for the child. This emphasises the importance of having a Community of Practice which promotes sharing the knowledge and experience of supporting children with WS, and holds the whole school responsible for inclusion.

6. Mosaic moments and meanings: bringing the pieces together

The previous two chapters describe what children and practitioners showed me during the research project. These findings were shaped by the research questions so that chapter 4 included what children with WS showed as important to them in their school, how they interacted with peers and staff, and what they wanted to contribute to research. Chapter 5 then outlined what participants understood about supporting children with WS in school and how schools managed inclusion. The following sections will build upon these findings, as 6.1 and 6.2 brings the pieces of the Mosaic together to discuss children's experiences of being a primary school pupil. I will consider wider implications for children with WS experiencing the mainstream primary school system, belonging to a community and managing their differences. This section also builds on taking different perspectives and what I have learned about the experiences of children with WS in school. I draw on previous literature and my own experiences with my sibling Tom, who I have seen grow up to develop independence and manage different parts of his disability.

The next sections (6.3; 6.4) discuss how schools manage inclusion for children with WS. This involves considering how to develop an understanding and knowledge of what to look for in order to support children with WS, as well as considering the roles of peers and how they position support for children with WS. An important aim of my PhD was to share my findings with the schools, families and children, so that others can learn different ways of supporting inclusion for children with WS. Therefore, parts of this chapter will blend children's experiences and adults' intent in order to understand, reflect and point to implications for practice.

6.1. Being part of a community

Children with WS shared their experiences of being a primary school pupil, which required them to learn classroom rules, routines and responsibility. The children needed to be directly supported to learn the classroom rules, daily routines and develop responsibility: responsibility for their possessions, knowing to hang their coat and bag on a particular hook, and responsibility for themselves, such as knowing where to sit at the table or on the carpet.

6.1.1. *"It's my turn to talk"*

A significant part of children's school experience was learning to be a part of the school community. All of the children had prompts and support to sit in a chair when completing a task, or on the carpet with the rest of their class. The children had to learn to sit still and follow the rules, such as not to talk when the teacher is talking. This highlights some challenges for both the children and staff supporting inclusion.

> *Orla starts talking at Ms Roberts whilst she is talking to the whole class. Ms Roberts says, "it's my turn to talk" and continues giving whole class instruction. Orla continues to talk to Ms Roberts. Ms Roberts repeats "my turn to talk" two or three more times* (O5, p.1).

Learning classroom rules could be seen as problematic if children with WS could instead be focussing on their fine and gross motor skill development or speech and language skills which was often taught 1:1 with their teaching assistant. On the other hand, understanding classroom rules such as listening to the teacher could lay the foundation for important social communication skills such as sharing, turn-taking and listening, by building attention. The September 2021 revision of the EYFS Early Learning Goals encourages children to learn self-regulation, managing self and building relationships under the ‘Personal Social and Emotional Development’ prime strand (DfE, 2021). Emotional and behavioural self-regulation are known as ‘internal mental processes’ that are linked with capacity and motivation for cognition and learning (Whitebread, 2013). It is therefore important for children to learn self-regulation, to enable them to actively participate in learning processes.

Emphasis by staff was on increasing responsibility and independence for children to follow the structure and routine of a classroom. TA prompts of ‘where should you be?’ and ‘what should you be doing?’ encouraged children to be independent in their self-responsibility. Increased independence is a focus for many children with disabilities, but also shows the ability of peers to know the classroom routines, structures, and to follow instructions. Distractibility and hypersociability associated with children with WS (Klein-Tasman & Lee, 2017) helps explain why children may be drawn to watching and listening to other children and adults, which impacts on their ability to listen to and follow classroom instructions.

Ms Turner explains:

> Nine times out of ten, she’ll just be wondering and looking at the people walking past, and we get there eventually. She just takes a long time to do things - much longer - but I think that’s purely because if she was focused, I think she’s able to do it. She’s able to do her Velcro but she will just sit and dilly- dally and look around and do other things (OTA, p.8).

For children with WS, it is important to be able to build attention by learning to be in control, limit distractions and increase their concentration. The ‘bucket game’ with Ryan (see 4.2.1) specifically builds on children’s ability to increase attention and regulate their behaviour

(Buckingham, 2012). From these executive skills, children can begin to develop their ability to self-regulate by being able to handle strong feelings, focus their thinking and build resilience. From my observations, it became apparent just how these activities encouraged the development of self-regulation. I would argue it is important to include specific adult-directed tasks which enables adults to assess and evaluate progress, and help children with WS build their attention and concentration.

On the other hand, the appropriateness of many aspects of mainstream education contexts has been debated extensively. If children are learning to sit still and be quiet when an adult is talking, this could create an impassive, docile audience (Foucault, 1977) rather than promoting the participatory and democratic education that many key philosophers have highlighted as important for an inclusive, socially just society (Freire, 2005; hooks, 1994). In contrast with Freire's (2005) critical pedagogy which calls for open dialogic spaces and democratic teacher-student relationships, the mainstream education system in English schools requires children to learn the right time and place to share their views and understandings.

This relies on schools enabling children to learn when to self-advocate, rather than learning not to share. Interestingly, the children in the study had significantly more opportunities than their peers to share their thoughts with staff because of their increased 1:1 contact time with a TA. However, opportunities to share their thoughts would not necessarily arise without structuring or prompts, due to children's difficulty understanding and managing social communication (Mervis & Becerra, 2007). In contrast, Eriksson *et al.* (2007) suggest that continuous support from a teaching assistant may result in children not needing to initiate or ask for support and therefore having less autonomy, particularly when the teaching assistant is not there. Therefore, it is important that staff learn to recognise the agency children can have, and ensure opportunities are sought to develop these skills.

6.1.2. *Transitions*

Sophie's experience highlighted the importance of managing transitions. Sophie was one of the first children in the study to be visited. Whilst Sophie participated in the middle of the autumn term, Orla participated later in the term, Ryan in the winter and Wendy in the summer term. Researching her experiences enabled Sophie to begin to share her views by pointing out her previous class. This enabled practitioners to reflect on their transition processes and guide Sophie to recognising the difference between her previous and current class.

Ms Hughes suggested that Sophie was really helpful towards a new member of the class:

> She's made a really good friend in one of the new girls who has just started as well. She started a couple of weeks ago and Sophie came up to me and goes, "Can I show her where the toilet is?" (ST, p.5).

This is particularly interesting because in her photos and conversations, Sophie repeatedly pointed out the name of her old class. Therefore, Sophie might have been in a favourable position to understand and assist a new child to transition into the class, as she could relate to the experience of moving classrooms. By showing the new girl the location of the toilets, she was also taking an active role in helping with her transition.

In what I initially considered to be a rebellious act, Orla's manipulation of tidy-up time caused me to consider this as another moment of transition which could be difficult. This moment occurred in a lunch-time club which was a different space to the usual classroom which employed continuous provision. By emptying the pot of pencils and tidying them one at a time, she was able to remain in the same space and take responsibility for the pot in front of her. On the other hand, her actions could have mirrored what she saw other people doing around her without necessarily understanding the purpose of tidying up. She joined in by putting things into containers, but this did not allow her the experience of working together towards a common goal that would help foster a sense of belonging among the group.

Many early childhood settings employ techniques such as songs and chants to signal a change in activity, which can help children to experience a smoother transition (Izumi-Taylor & Lin, 2017). I did not observe any music or rhymes for tidy up time, although adults often verbally shared a time such as '5 minutes' which may not represent time the way that children with WS can relate or understand. Instead, the children experienced a series of shifts in activities. If children have a different sense of time, or are unaware of what 5 minutes feels like, then this might not be as helpful as practitioners intend as a mark of transition. Alternative transition signals such as using a sand timer or digital countdown may assist children's understanding of time.

Izumi-Taylor and Lin (2017) found interviewing American and Taiwanese children, responses suggested that children knew Tidy up time signalled the end of current activities before moving to another. Additionally, it was considered work which separated tidy up time from play (Izumi-

Taylor & Lin, 2017). This could also emphasise the difference between Orla's self-directed activities and tasks required from adults. Tidying up the classroom is another task which is directed and chosen by the adults in the class rather than children.

Furthermore, Ms Hughes suggested that Sophie:

> …might not necessarily understand social cues. So, when it's tidy up time, she'll come and just give you a hug (ST, p.10).

This could be interpreted as a moment where Sophie is navigating away from having to tidy up, to avoid a work task, or needing reassurance during a time of transition. Therefore, children with WS may find transitions challenging (Tynan, Kye & Van Herwegen, 2021), even if they do not directly show this. As a result, it may be useful for staff to reflect on the ways they support and manage transitions.

Two of the children took and shared photographs of coats hanging on pegs outside the classroom. Children's coats are an important personal belonging that are often used to signal transitions, either between home and school, or worn outside on the playground for play times. On the other hand, the focus on coats could contribute to their experience of being a primary school pupil who has ownership and responsibility of caring for and hanging up their coat. Ms Jacobs shared:

> He used to just hand it to me and things like putting his coat on: he would just ask someone… he just wants someone to do it for him (RTA, p.6).

This suggests that part of being a primary school pupil was developing independence and responsibility, such as Ryan hanging up his coat on the correct named peg. Other children such as Sophie needed encouragement to ask for help, whereas Ryan perhaps knew how to ask someone to help him, and Ms Jacobs recognised that he could use this to his advantage by having someone do the task for him. This relies on an in-depth and complex knowledge of relational agency and the sociability often linked with children with WS that could prevent staff from knowing the expectations or amount of support needed.

6.1.3. *"Oh no! I've lost my school friends!"*

Inclusion literature has questioned the extent and full meaning of participation, acceptance and belonging for children with SEN/D (Freer, 2021; Vandenbussche & De Schauwer, 2017). Parents have emphasised that children must feel a sense of belonging and acceptance to be a part of the school community (Haines *et al.*, 2015; Hess, Molina & Kozleski, 2006). Schneider (2015) questions a sense of belonging by highlighting through interviews with children with SEN/D that spending time with others who have similar challenges and experiences can be helpful. If classes had more children with SEN/D than without, this could perhaps help trouble the 'norm' (Goodley & Runswick-Cole, 2016) and emphasise diversity positively.

Participation could be through societal involvement (children with SEN/D being a school pupil) or more relational participation through relationships, interactions and connections with peers, TAs, teachers and families in different spaces, social contexts, in and outside of the classroom (Vandenbussche & De Schauwer, 2017). Social participation however relies on relationships, interactions with others, perceptions of children with SEN/D and acceptance from peers (Bossaert *et al.*, 2013). When children with WS have difficulties interacting with others and forming relationships, this can therefore impact their social participation.

From observations during the week, Orla varied between playing on her own and with others. This included playing with children from her class on the playground. It was interesting to notice the challenges Orla experienced in learning to share and take turns with others yet become distressed when she could not see the rest of her class: “Oh no! Where are my school friends?” (O5, p.1). This could reflect her eagerness to interact with others and the difficulties children with WS experience with friendships (Mervis & Klein-Tasman, 2000; Fisher & Morin, 2007). The first occasion was when Orla arrived early at school with her Dad, and the rest of her peers had not arrived yet. In conversations with Ms Turner, I learnt that Orla’s Mum had had a medical procedure which meant that Orla’s Dad would be dropping her off. This is important background context as Orla’s day is different to usual, and it is not known how she felt about her Mum’s procedure; she never mentioned it and I did not ask.

Two days later, Orla was going to an after-school club and again mentioned losing her school friends (O5, p1). Other children’s parents who were at the school and helping to lead the after-school club seemed to expect Orla’s reaction, and reassured both her and me that this does happen. Both events showed a transition between one part of the day to another, suggesting that this could be difficult for Orla. On the contrary, the usual activities of the classroom and Orla’s various interactions with peers may connect her with a strong sense of school community. When her peers are not present, it signifies a potentially distressing change for Orla.

Similarly, Sophie seemed drawn to her peers when I invited her to take photos, and again when she looked through the pictures. Although I did not observe Sophie spend time talking to or playing with her peers, she focussed on the children in the photographs, naming them as her friends. The classroom layout meant that children were grouped on tables, and Sophie also had a specific place to sit on the carpet, which was on a chair at the back, to help her to see the board. Due to the nature of the research and the working areas Sophie used outside of the classroom, there were fewer opportunities for me to see her with her peers. When she was near children in the role play area, or on the playground, Sophie would watch them or need prompts from them or others to join in.

Research has examined the absence of friendships and peer interactions for children with SEN/D in mainstream education (Carter & Hughes, 2005; Lyons *et al.*, 2016). Opportunities to interact with others can sometimes be inhibited by a constant adult support such as 1:1 TA, and work outside of the classroom which physically takes place away from the rest of the children (Radford et al, 2015). On the other hand, staff can play a significant part in facilitating interactions with non-disabled peers.

Both Wendy and Sophie's TAs mentioned targeted support for being a part of the school community. Wendy's target was to approach a peer on the playground and ask them to play, so Ms Dot prompted her to approach a named peer. On the other hand, Ms Watts preferred to prompt Sophie in a more responsive and less measured style, encouraging her to interact with others on the playground through sharing games and turn-taking or by moving away to encourage independence. Ms Dot explained:

> On the support plan I think her last target for social was just to… encourage her to go up to someone in the playground and ask them to play. I think that's her target actually just to make sure that we're progressing with that and I'm daily reminding her of that: 'How about playing with Jackie?' and trying to get her to initiate it because most of the time someone else initiates it (WTA, p.3-4).

Staff commented on children's likeability, for example, peers showed concern for when the children with WS were ill or absent. The children's experiences suggest they value being with their peers and may feel a sense of community and belonging by being a member of the class. However, as part of their experience of being a class member, children with SEN/D should be recognised as able to share ideas, make choices and decisions (Nind, Flewitt & Payler, 2010). Findings indicate that children position children with WS differently (See 6.4.1) and therefore it would be difficult to ascertain whether peers recognise children with WS as able to make decisions and share ideas within the scope of this study.

6.2. Children go at different paces

All the children in the study were working towards goals from the EYFS curriculum, which emphasises the difference between children in classes who were working towards goals under the national curriculum level Key Stage One. Historically, the introduction of the national curriculum was allowed to be taught at a slower pace to children with disabilities in special schools (Education Reform Act, 1988). However, when translating this across to mainstream schools, practitioners are at risk of viewing children with additional needs as 'falling behind' their peers, especially when they do not meet expected targets compared to chronological age. This perpetuates the assumptions that individuals with SEN/D are missing something or unable to do something, because they are being compared to neurotypical individuals (Vandenbussche & De Schauwer, 2017). Furthermore, the addition of resources, interventions and additional adults in the classroom does not necessarily mean teaching children at a slower or different pace, but arguably could increase the pressure to develop and practice a wide range of skills whilst still valuing fast knowledge (Orr, 1996). Clark (2022) describes the opposite of teaching children slowly as tuning into children’s own speeds.

Research continues to challenge the increasing focus of ‘school readiness’ as a way of preparing children for formal learning, without considering clear individual differences between children such as summer and winter birthdates, various socio-economic backgrounds and additional needs (Kay, 2018). Meyer (2001, p.10) states:

> We say inclusion does not work because children have not changed enough. We may say the reason it is not working is because children are not yet ready. It seems to me that it is the adults who cannot seem to get ready, so children spend an entire lifetime –another entire generation- waiting until everyone is ready for them.

Similarly, Roberts-Holmes and Moss (2021) challenge the discourse of testing, assessments and readiness as a feature of neoliberalism and marketization of education in early childhood education and care. The argument for marketization seeks to improve school quality as well as value for money, but Furedi (2010, p.16) argues ‘it is not always clear what is being bought and sold’. Whilst it may be useful to measure the success of a school through academic achievement (Farrell *et al.*, 2007), the league tables which embody performativity culture starkly contrast with the principles behind inclusion. Elkind (2006) describes the issue of high expectations and increasing pressure on children to hurry them towards adulthood. Rushing children into always achieving the next stage contributes towards the discourse of valuing adulthood more than childhood. This echoes the sociology of childhood movement calling out against the traditional view of children as not-yet adults, less able and less valued in society (Punch, 2002).

Learning takes time. Orr (1996) succinctly describes the many limitations of fast knowledge, and the underlying assumptions it brings when it is valued above all else, suggesting “we are playing catch-up, but falling farther and farther behind” (Orr, 1996, p.700). Focusing on infant and toddler development, Gillespie and Adams (2014) highlight the importance of adults waiting and watching before identifying, engaging and extending opportunities of learning based on responding to individual development. Similarly, the TAs in the study had the responsibility of identifying, engaging and extending opportunities of learning. This emphasises the importance of the TA role as a practitioner who is able to watch closely and build a responsive relationship with children with disabilities that the classroom teacher will not necessarily have the time or resources to do.

Education should not be a race to an end product, but an active process that values learning as a social practice (Pinar *et al.*, 1995). Arguably, education is political, through dominant ideologies which may sit within a hidden curriculum which is tacit and dynamic (Pinar *et al.* 1995). In this way, education can become a social movement which is what is needed for inclusion to progress. Collective learning recognises that learning is shaped in different contexts and cultures, which means that there is no quick solution to problems. On the other hand, children who spend more time away from the class will miss opportunities to build and contribute to a social practice.

6.2.1. *Valuing slow knowledge*

Valuing slow knowledge has enabled me to consider learning as a shared social practice (Lave & Wenger, 2004; Rogoff, 2008). A part of slow knowledge is noticing patterns, making connections, making meaning and sharing this with a community that benefits everyone by solving real life problems. Participatory research in this study is an example of slow knowledge that actively includes participants and practitioners that the research is about (Orr, 1996). Slow knowledge works as fast as people can understand the knowledge, and how it can be used (Orr, 1996). Similarly, Freire (2005) suggests deeper knowledge encourages learners to develop critical reflection in questioning underlying assumptions. Losing the time needed to process deeper knowledge can result in decisions that are less considered, which may not connect deeper understandings or critical questions.

Elkind (1987) claims that the unhurried approach celebrates children's own learning priorities and pacing. He describes a space that enables children to learn through a safe, secure, supportive and non-pressured environment. By implementing Continuous Provision, Littlewood School ensured that all equipment and resources were accessible to children. Their principles align with the unhurried approach by inviting children to direct their own learning, take responsibility and, therefore, flourish (Bryce-Clegg, 2015). Similarly, the Montessori method (Montessori, 2004) and Reggio Emilia (Edwards, 1993) principles emphasise the importance of the child having autonomy of their own learning priorities and pace, with practitioners acting as facilitators and guides.

Child-centred pedagogies recognise children's individual differences, demonstrated by practitioners who prioritise children's own interests and enable them to pursue them at their own pace. Similarly, when working outside of the classroom, Ms Jacobs was able to listen to what the three children were talking about and take time to encourage important social communication skills. In contrast, the rest of Ryan's class were considerably quieter and concentrated on classroom tasks, more so than the other schools I visited. Children's actions hinted at a competitive performativity culture of learning as they celebrated knowing the right answers and quiet, on-task behaviour. This mirrored England's neo-liberalising agenda which focuses on improving education outcomes (Ball, 2016). Part of the education reforms aimed to close the achievement gap for disadvantaged pupils which in turn seemed to align social justice with economic growth (Wilkins, 2015).

Wilkins (2015) argues that the performative frameworks comprising data driven management of individual teachers and schools are particularly intensive in England. Of course, this is based on assumptions surrounding the norm and how a neurotypical child should perform (Vandenbussche & De Schauwer, 2017). As Hodkinson (2012, p.3) claims "performativity was pitched against presence, standards against segregation and ableism against absence" which is significantly troubling for social justice advocates. For example, Ryan left the classroom whilst the rest of the class practiced SATs questions, and many of the children with WS worked in areas outside of the classroom which arguably could be claimed as absent. Therefore, the standards agenda is in a direct struggle with social justice issues if schools are measured on academic performance rather than equitable provision for all children.

6.2.2. *Managing different paces*

Another challenge for celebrating children's own priorities and paces is managing the variations within one classroom. Although every child is unique, children with disabilities can have more distinctly different paces than other children at their chronological age, which can accentuate the gap. Moreover, the current education system in England does not lend itself to an unhurried approach for schools to manage different paces, and therefore this relies on staff recognising and understanding children's pace themselves.

All the children with WS in the study were working at different levels from their peers. Staff acknowledged that the children would go at a different pace, offering time outside of the classroom with the TA to work at the child's own pace.

Ms Pennywell stated:

> We'll be doing the stories next week, a new story, so I gave Ms Dot the book, so she then takes Wendy out to have a read of it after we've read it as a class and work through it like that at Wendy's pace (WT2, p.2).

Practitioners might consider it to be impractical within the classroom if everyone was working at their own pace, despite all children having different needs and priorities. This is because the majority of the children in the classroom are viewed as able to work at a similar pace to others, and therefore do not need time outside of the classroom to work at their own pace.

Research shows time spent away from the class teacher and peers may emphasise children's differences (Norwich, 2008), prevent quality input from a qualified teacher (Radford *et al.*, 2015) and result in fewer opportunities for children to interact with their peers (Carter & Hughes, 2005). However, my research highlights the high-quality input from teaching assistants that support children with WS. This challenges the view that a qualified teacher provides higher quality input. TAs learn to recognize and identify children's needs and build some knowledge of WS through their experiences. Therefore, by spending more time outside of the classroom, children with WS may have more focussed support which uses slow pedagogy, and child-centred support that recognises their own learning priorities. It can also be recognised that this can, to an extent, depend on the knowledge and skills of the TA as training between schools for this role can be varied. In contrast, teachers must be qualified for their position.

6.3. Knowing what to look for

Previous research has revealed specific social strengths for individuals with WS, and their eagerness to interact with others, whilst also suggesting significant social difficulties due to low cognitive ability (Järvinen, Ng & Bellugi, 2015). Staff may have been unaware of the meaning of a child's verbal communication, misinterpreting their intention. Conducting research that did not rely on verbal speech but engaged in an active listening approach offered opportunities to understand children's experiences of primary school.

I argue that to support children with Williams Syndrome, practitioners need understanding about the syndrome in order to be able to support children (Reilly, Murtagh & Senior, 2016). Currently, TAs working very closely with children learn the subtle nuances of children with WS experiencing anxiety, enjoying music or needing additional support. This is problematic when the TA is not available because they must work with a different child in a different part of the school or is absent due to sickness or for training. During the study, a TA's absence was noted when the other practitioners were unsure how to support Orla, what expectations to have and how her day was usually structured to best support her. For example:

> *Whilst the whole class warmed up, thought about working together to form a Rocket, a circle and worked on jumping, half turns and quarter turns, jumping with their knees bent, swinging their arms. Orla moved between different children, talking. Ms Hampson felt that Orla did not listen to her, and was unsure how high her expectations should be of Orla. Kris was opting out, and began to lie down with her head on her hands. Orla noticed at one point and also laid down in the same position* (O5, p1).

A familiar tension here is the notion that labelling is unhelpful because it can lead to stereotyping, and practitioners may risk over- or under-estimating children's abilities and difficulties (Arishi, Boyle & Lauchlan, 2017). Norwich (2009) debates the complex dilemmas of categorising students with an SEN or disability as this labels children as different. It may also cause stigma and reinforce traditional negative views of disability. Norwich's (2009) dilemmatic framework describes the different dimensions of identification which can contribute towards an inclusive and positive vision by identifying needs that are common to all children, specific to children with disabilities, and unique to individuals. Practitioners supporting children with WS are therefore working across the dimensions of a subgroup of disabilities and unique to individuals.

As my study shows, children with WS are at risk of being misunderstood because of the complexity of the syndrome. This suggests that practitioners must work closely with children with WS, alongside an increased knowledge of the syndrome from resources such as WISHES (Tynan,

2018) to develop their understanding of supporting children with WS.

6.3.1. *"He doesn't seem worried about anything"*

Although families seem to be aware of the risk of anxiety disorders due to the growing research base for WS and anxiety (Ng-Cordell *et al.*, 2018; Royston *et al.*, 2017), this did not always transfer to schools. Staff were not necessarily aware of what anxiety looked like, or what to look for, because children seemed to cope well with changes to their day. For example, during my visits children had to manage changes in timetable or the fire alarm sounding for a practice fire drill.

Ms Jacobs suggests that Ryan does not seem worried during the fire alarm:

> Sometimes, he does the robot dance, he dances to the alarm. Sometimes it goes off and he'll go home and that's all he'll talk about that it went off. In school he's like "oh this is fun." We don't know what he's saying at home that's made him anxious in the day because during the day he doesn't seem worried about anything (RTA, p.8).

According to Udwin, Yule and Howlin (2007)'s WS Guidelines for Teachers, repetitive questioning could stem from a child's obsessional interests and can be discouraged through answering once and then ignoring. The recently updated WS Guidelines for Educators locates repetition as a pragmatic difficulty in speech and language ability, and most importantly suggests that talking excessively about favourite topics may be "a symptom of anxiety. The child may revert to their topic of special interest if they are bored with the content being taught, if it is pitched too high and they are unable to participate in the discussion about the current topic or if they are self-calming" (Tynan, Kye & Van Herwegen, 2021, p.14). However, it is difficult to distinguish between genuine fascinations of interest, or a need to self-calm. This shows the difficulty within school for staff to identify and support children’s management of anxiety.

Being able to communicate verbally with staff did not always enable children to share their thoughts and worries. Sophie’s repeating “wake and shake in the hall” does not directly tell others that Sophie was worried that the drums would be in there. At the same time, staff’s focus on school tasks does not give them the opportunity for time and space to understand everything that the child is meaning when they say something. Ms Hughes was informing the whole class of the events of the day ahead, and so nodded to Sophie to signify she had heard the correct information that Wake and Shake would be in the hall. Similarly, Ms Watts who was teaching a small phonics group needed the children to demonstrate their understanding of words with the digraph ‘–ng’ and therefore it was not an appropriate time for Sophie to talk about the hall. This example illustrates the issues raised by Ball (2012) and Glazzard (2011) when teachers are held accountable for the performance of learners in a competitive education system. For example, staff will be more focussed on the measurable outcomes that they are accountable for, as opposed to tuning in to children’s subtle and complex communication.

Research on WS shows increased risk of anxiety disorders but does not look at how anxiety presents in different ways. It only explores whether the parents, carers or educators could recognise it (Klein-Tasman & Lee, 2017; Royston *et al.*, 2017). This is challenging in that it relies on practitioners understanding how children with WS show their anxiety, for example, by talking repeatedly about the fire alarm sounding at school or needing to see the hand dryer.

Other research on anxiety shows it is a highly complex and dynamic concept, which is problematic when measured in different ways. In a study of children, authors suggest anxiety is directly connected to worry (Verstraeten *et al.*, 2011). Wendy's worry about whether there is a hand dryer in the toilets of the school they were visiting helps practitioners to know that Wendy needs support to enter the toilets. However, Dykens (2003) categorises specific phobias as one of the most commonly reported anxiety disorders for children with WS. If Wendy is experiencing a specific phobia, then more support is needed to manage something that can significantly impact her daily life.

Furthermore, the relatively happy and caring nature of children with WS was identified as a potential problem by Ms Watts, who recognized that as Sophie was not causing any 'problems' in the classroom, she may be overlooked:

> Sophie is quiet and she follows instructions really well, so she can be missed (STA, p.3).

For example, she did not partake in the bucket game or groups for specific interventions such as Thrive. As well as being quiet, I question whether the complex nature of how children with WS experience anxiety can mean it is difficult for practitioners to know how and when to support them. However, TAs who work responsively with children with WS can learn how to manage the subtle and complex ways their anxiety present with the appropriate knowledge, training and time.

Wendy presented similar repetitive behaviours to parental reports from Royston *et al.* (2021) showing a worried look and an increase in talking to others about the hand dryer during my visit.

Exploring executive functioning and specific phobia, Ng-Cordell *et al.* (2018) points out that children who struggle to self-regulate or shift attention away from the perceived threat can lead to the development of irrational fears of specific objects. Wendy kept her eye on the hand dryer, and talked about it with others, asking if they also use it. This highlights her need for support with self-regulation.

Additionally, the increasing focus on objects that bring about anxiety can cause confusion for practitioners. Sophie's eagerness to have a drum for her birthday does not reflect the issue that "I just want to look at it… because it's so loud" (Audio S2). It is important therefore that practitioners know the higher risk of anxiety associated with individuals with WS, and how it may present.

Children with general intellectual disabilities also have a higher risk of an anxiety disorder (Whitney *et al.*, 2019). The increased risk of experiencing anxiety indicates a potential problem from a social model point of view that society is traditionally set up for a neuro-typical person. Anxiety can often be treated through identifying the cause and known triggers, which relies on complex verbal exchanges and rich, detailed contextual information. This could be particularly difficult for an individual who is masking anxiety and being misunderstood.

6.3.2. *"What's that noise?"*

When the door in the corridor had a small beeping noise to signal an error, Orla spent a lot of time standing near to it, repeating "that noise" to others to ask if they knew where it was coming from (O2, p1). Semel and Rosner (2003) propose that individuals with WS can be very distracted by noise to the extent of leaving all activity to find the source of the sound.

Researchers have drawn comparisons with restricted and repetitive behaviours (RRB) often seen in individuals with ASD. It has been questioned whether RRB is used to reduce anxiety or could instead be a consequence of anxiety. However, in a cross-syndrome comparison of parent self-reports, research did not find a link between higher levels of RRB and anxiety for the WS group (Rodgers *et al.*, 2012). Similarly, Huston *et al.* (2021) found no link between the severity of individuals with WS's compulsions or stereotypies (repetitive thoughts and behaviours) although there was a link between higher anxiety and severity of obsessions. In a visit from the speech and language therapist, Orla compliments the lady's lipstick to avoid answering a question (see 4.3.1). Her restlessness then turns into lip picking until Orla has picked the skin off her lip. These behaviours signal an anxiety that may not be clear to practitioners without knowledge of WS.

Parent and teacher reports of children with WS age 6-17 years highlighted anxiety difficulties, attention problems and repetitive behaviours such as obsessions, compulsions, and picking nose or skin (Klein-Tasman *et al.*, 2015). However, the study used The Child Behaviour Checklist School Age Form which limits participants to pre-selected options, closed responses and does not offer examples of real lived experiences. Results showed attention deficit/hyperactivity were most common, particularly related to thought problems which suggest a difficulty or inhibition of impulses such as obsessions, compulsions and skin-picking (Klein-Tasman *et al.*, 2015).

Anxiety can manifest in different ways and relies on an awareness of WS to understand children's experiences. Children with WS may not mean exactly what they say, because their social disposition can hide the meaning behind their words. For practitioners, it can be difficult to distinguish intense fascination with a specific object and a specific phobia or bout of anxiety. Knowledge of the high risk of anxiety and phobia is important, as well as a reflective, responsive relationship with children to understand their perspectives.

6.3.3. *The leaf blower man*

Orla's anxiety of being near the leaf blower man was described in conversations with her TA and Orla herself who often would ask to identify the source of different sounds. Orla's experience gradually improved between Reception and Year 1 as Ms Turner recollects:

> If he's leaf blowing, she's actually okay with it now. She can hear it, whereas in Reception, she would run inside screaming and we'd have to shut the door or I'd have to take her somewhere where she couldn't hear that noise or put her ear defenders on. Yes, so really, really sensitive to that noise (OTA, p.8).

Hyperacusis has been defined by Glod, Riby and Rodger's (2020) systematic review as "four categories of abnormal reactions to sounds, including true hyperacusis— understood as lowered hearing thresholds, odynacusis— lowered uncomfortable loudness level, auditory allodynia— auditory aversions to or fear of certain sounds and auditory fascinations" (Glod, Riby & Rodgers, 2020, p.34).

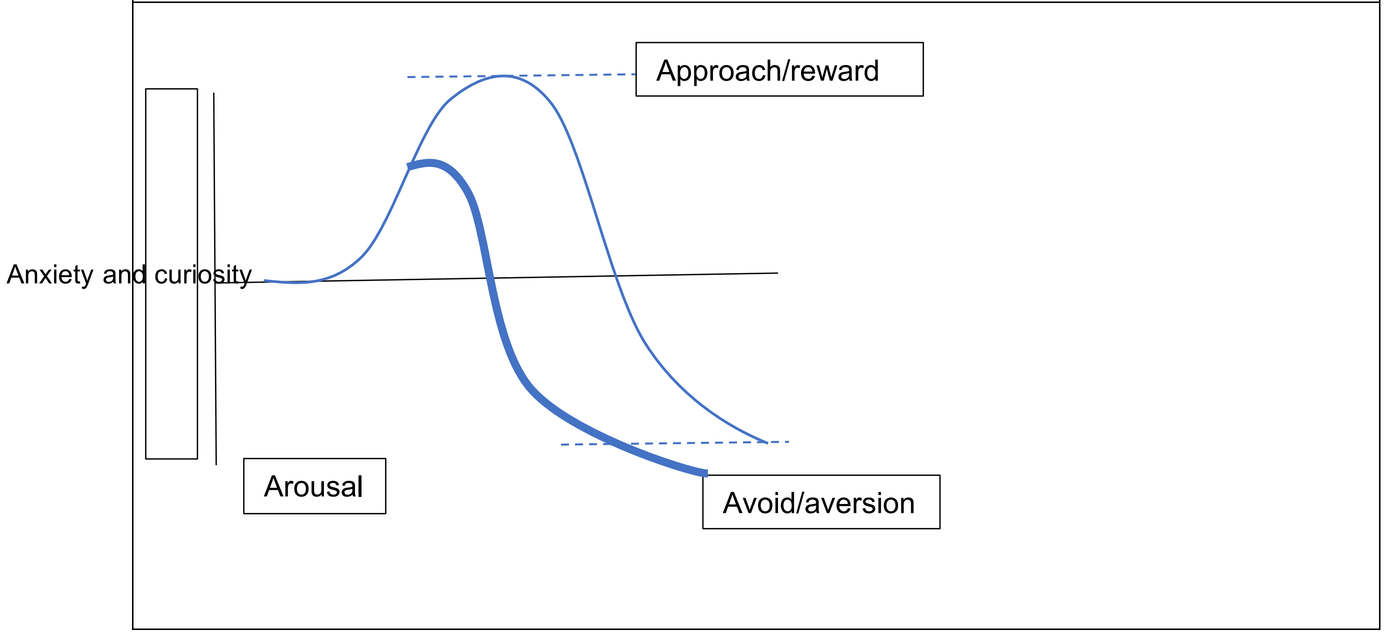
My task with Orla was interrupted when she needed to find the fan which was making a quiet humming noise. There is a challenge here that practitioners may not appreciate the extent to the anxiety caused by certain sounds. Furthermore, this problem increases when children actively seek out the source of the noise, which can seem like they are distracted by, or fascinated with the noise. Without background knowledge of WS, practitioners may not know to use strategies to help children manage their sound sensitivities or anxiety around sounds.

Ear defenders are often a tool offered to individuals with sensory difficulties, and most of the children in the study had access to a pair, although none were used during my short visits. Would the opportunity to wear ear defenders help Sophie to go into the hall more confidently? Would they support Ryan on the playground to interpret the roaring noise differently? For this to be effective, an in-depth knowledge of children's sensitivity to sound and the sometimes ambiguous or unknown consequences for their experience (such as avoiding the hall or roaring on the playground) is required.

For children with WS however, there is a specific risk of this oversensitivity to daily environmental sounds, and challenges to overcoming their difficulty through exposure to the sound (Gothelf *et al.*, 2006). Gothelf *et al.* (2006) propose that children's cochlear hearing loss was linked to repeated exposure to high level noise, suggesting using behavioural desensitization through repeated exposure would not work. Therefore, strategies to support children with WS must take a very considered, gentle and gradual exposure approach, combined with reassurance, clear explanation and opportunities for children to control the sounds (Tynan, Kye & Van Herwegen, 2021). A recent play therapy informed approach has been developed for children specifically experiencing reactions to loud noises such as 'loud noises, flushing toilets' where play and humour facilitates engagement with gradual exposure to the stimuli (Klein-Tasman *et al.*, 2022). Five of seven participants found parental ratings of anxiety and fear decreased over an 11-23 month follow up period. This illustrates the potential for developing an intervention which enables children with WS to manage their specific fears and phobias, whilst also emphasising the need for school staff to be trained in specific knowledge of WS.

Although Orla's school took the decision to turn off the hand dryer, Wendy must use the hand dryer because part of being a primary school pupil in her school means drying her hands in the girl's toilets using the hand dryer. Researchers of social anxiety highlight the approach avoidance framework to help make sense of the ways individuals navigate these situations (Kashdan, Elhai & Breen, 2008).

Figure 12 (for reference only; identical to Figure 1)



Wundt's (1874, cited in Berlyne, 1960) curve shows the relation between exposure and arousal potential, which Berlyne (1960) adapted to note reward and aversion systems. Spielberger and Starr (2012) suggest that the increase in stimulus intensity would increase both curiosity and anxiety. They support Berlyne’s assumption that the aversion system curve which brings negative reinforcement is greater than the positive reinforcement from the reward curve, hence the bolder line in Figure 12. Most importantly, curiosity and anxiety are recorded in combination (Spielberger & Starr, 2012).

Spielberger and Starr (2012, p.231) extend this further by stating that, “curiosity is conceptualised as an emotional-motivational system that stimulates exploratory behaviour” and that anxiety is conceptualised as motivating stimulus avoidance. They suggest that with increasing stimulus intensity, subjective experiences increase in arousal to the optimal level, then decrease in pleasantness as the strength of the unpleasant feelings (anxiety) increase, resulting in approach-avoidance conflict.

The perceived excitement for Wendy to see photos of the hand dryer indicates her complex relationship with sound. Practitioners may misunderstand children’s repetitive talking about a sound and curiosity to explore the source, particularly with their generally happy social dispositions. It is interesting to reflect on Ryan’s robot dance during the fire alarm as a signal of anxiety that may be masked by his desire to please others or manage unpleasant feelings. Whilst some individuals manage approach-avoidance in daily tasks, for example by waiting for a resolution to a fear, children with WS may not be developing or managing this type of self-regulation and sense of control. The introduction of self-regulation focus in the 2021 EYFS

Framework suggests that practitioners in Early Childhood Education can draw on their training and knowledge alongside their observation and noticing skills in understanding how to help children manage self-regulation (DfE, 2021). On the other hand, a focus on meeting behaviour expectations by learning to follow the rules prioritises conformity, and encourages children's desire to please, which could suppress children's own thoughts and feelings.

Another challenge to the complex sound dilemma for children with WS was the knowledge that many children with WS have an affinity to music, and can experience emotional reactions to music, but also may experience heightened sensitivity to sounds. School staff commented on Ryan's emotional reactions to music in assembly, and his admiration for the electric guitar played by his Dad. Individuals with WS may experience powerful and emotional reaction to music (Thakur *et al.*, 2018) as well as difficulty regulating their emotions (Tynan, 2018). This emphasises the importance of practitioners aiding children with WS in regulating and understanding their emotions and experiences.

6.3.4. *"Don't cry"*

Children's perceived empathy was often classed as a strength by practitioners who viewed the children with WS as caring and very aware of other people's feelings. This mirrors research describing empathy as a strength among individuals with WS (Klein-Tasman & Mervis, 2003; Tynan, Kye & Van Herwegen, 2021). Tone and Tully (2014) describe empathy as a 'risky strength' when describing the increased risk of internalising problems such as anxiety. This supports recent WS research linking the emotions of others with children's anxiety (Royston *et al.*, 2021). Goodall

(1986) asserts that if we know someone is suffering, this can become emotionally troubling. However, the social cognitive skills required for empathy have been recognised as challenges for individuals with WS (Serrano-Juárez *et al.*, 2021). This suggests that although individuals may experience intense emotional reactions to others, they are experiencing what Smith (2009 describes as 'emotional empathy' rather than cognitive empathy.

Rosner (2001) argues that empathy and sympathy derive from a personal discomfort or distress when reacting to another person. Children showed experiences of an emotional sensitivity to others that were often connected to illness or a change in emotions. For example,
Ryan's reaction in the play when his peers were showing a sad face, or Sophie's experience of going to see her peer who was upset. It is unclear whether children's experiences are based on connecting with their peer's feelings, understanding their mental states, or responding to their own distress at seeing someone upset.

Ms Hughes shared:

> I think I'll just be sat there, my angry teacher face and she'll come up to me and be like, "Are you sad?" (ST, p.11).

When Sophie checks to see whether her teacher is sad, she has noticed a difference in facial expression that has caused something to change. The teacher interpreted this as being "really sweet" and "that caring nature" but also an understanding that Sophie knows when something is not quite right. There is a concern here that children with WS experience emotions intensely and this can influence how they see others. When practitioners or peers present changes in their emotions, children with WS may experience anxiety or discomfort either through affective empathy or a difficulty in managing their internalising of emotion (Tone & Tully, 2014). Rosner (2001) proposes that this type of personal distress is an aversive reaction to another person's state.

We can start to link this to how anxiety may be presented in WS: being overly concerned about someone, or something unpredictable happening. This further demonstrates that what a child with WS is saying does not necessarily represent what they mean. Children with WS who are concerned for others when they can see a negative emotion are checking what is wrong from a place of concern. Therefore, responsive practitioners must learn to notice (Mason, 2002); they should listen to more than what children are saying, but interpret these subtle messages to understand how they are feeling in order to help support them.

Smith (2006) suggests that empathy comprises of a variation of the relationship between both 'cognitive empathy' and 'emotional empathy' and that it is the emotional empathy aspect that we see in WS. Smith's (2006) proposal of models of cognitive- and emotional- empathy could explain the heightened emotional reaction. However, his research heavily cites Semel and Rosner's (2003) research that individuals with WS can manipulate social situations and pass false belief tasks (a theory of mind study where children understand that another person does not have the same knowledge that they have). Indeed, children with WS have made evaluative comments, audience hooks and empathic markers in storytelling (Jones *et al.*, 2001). On the other hand, this could suggest that the children with WS in their study used their strengths in specific social skills rather than understanding the characters' mental states in the stories. Other research shows that groups of individuals with WS experience more difficulty with false belief tasks, understanding sarcasm, metaphors and non-literal language (Godbee & Porter, 2013; Weisman *et al.*, 2017) which would be indicative of skills for cognitive empathy. Ms Jacobs also noted that Ryan could benefit from more support in understanding what another person is thinking or feeling (R2, p.2). This supports research that shows children with WS experiencing difficulty with false belief tasks (Weisman *et al.*, 2017).

Smith (2006) suggests that the possibility of higher cognitive empathy is likely impacted by their intellectual disabilities. Overall, these emotional experiences can become problematic when children with WS focus more on the speaker's emotions than the content. This is challenging in schools when many instructions are verbal, and even more difficult for children who become distracted, preoccupied and ultimately distressed by other people's emotions.

Tynan (2014) indicates that individuals with WS experience some confusion over understanding negative emotions. Studies show children with WS perform better at emotion recognition than typically developing peers and peers with DS which they suggest might be due to their language abilities in practising labelling emotions (Ibernon, Touchet & Pochon, 2018). Tynan (2014) found children with WS could produce sentence stems relevant to happy and sad emotions, but that negative emotions were more difficult to express. This could be due to vocabulary of emotion, and highlights the importance of naming, labelling and exploring feelings. Similarly, Tynan's (2014) study indicated that children may be afraid of the intensity of sadness, and as a result, calls for a teaching of emotional vocabulary which is directly linked to children's own experiences.

In her small-scale study on learners with WS, Tynan (2014) noted negative feelings were frequently reported related to teacher or peer behaviour. Tynan's (2014) findings indicate that children with WS may have more self-regulation at school than at home, since parents reported more hyperacusis than teachers. Children are learning to manage and cope with their needs during education or alternatively, they are hiding their distractibility and challenges. Tynan's (2014) study also showed that teachers described more social strategies than parents, however her research found strong links to teacher behaviour which suggested that children were using their sociability to influence the teacher's mood. For example, Sophie repeating "I love you" to adults that are working close to her could be used to influence the adults' moods. This management of using compliments could be to avoid a difficult task, or to find out the adults' feelings and intentions. Similarly, it is suggested that children watch adult's faces to see if they can work out their feelings and respond (Tynan, 2018).

Orla's concern when a practitioner was poorly the week before shows when she interrupts to ask, "did you scream, did you cry?" (O3, p2). Royston *et al.* (2021) linked empathy with anxiety when parents' interviews related children's experiences of anxiety to the negative emotions of others. Her following statements "don't cry" and "don't feel sad" may be mirroring what practitioners or their families have said to her. However, this may be problematic. If children are being encouraged to stop feeling their emotions, it could negatively impact their understanding of their own wellbeing. There is a growing body of research that is encouraging children to talk about their emotions: to accept, validate and feel them (Cahill *et al.*, 2014). Personal social emotional development is a significant part of the EYFS to support children's development in understanding and managing feelings. The EYFS directs that young children must understand and talk about both their own feelings and others (DfE, 2021). This can be found in frameworks encouraging managing self and building resilience, however, is less visible in the primary curriculum apart from fewer timetabled sessions under Personal, Social, Health and Economic (PSHE).

My fieldnotes from Ridgeview School highlight Ms Watt's focus on talking about and accepting feelings. Sophie was observed being upset, with her mouth turned down. However, when she noticed Ms Watts looking, Sophie would put on a big smile. Therefore, Ms Watts had conversations with Sophie about her feelings, emphasising that it is okay to be sad (S3, p.1). Interestingly, when Ms Watts used a firmer voice to redirect the children's focus to the work, Sophie replied 'it is okay' in a comforting way. This could indicate Sophie's 'emotional empathy' or being able to verbalise that which she internalised from her learning about her feelings.

Similarly, when Ryan was working with the rest of the class in a play rehearsal, his peer showed him a sad face which represented the goodbye in the story they were acting. Ryan became upset, and Ms Jacobs helped him manage this by explaining that "it's pretend, it's not real, it's pretend". To stop him crying, Ms Jacobs arranged with his peer to show a happy face because it did not need to be a sad goodbye (R1, p.2). Although Ms Jacobs emphasised the pretence and reassured Ryan, she then asked his peer to show a happy face so that the problem does not occur again.

This illustrates the conflict between the time constraints of the rehearsal, to prevent the situation of Ryan becoming upset, rather than helping Ryan and his class to accept and manage his emotions. Children with WS would benefit from learning emotional vocabulary, as well as the tools to help regulate their emotions.

6.3.5. *Giving the right answer*

In a school context, children frequently want to give the right answer to a question, because there is often value put onto the correct answer by staff. Furthermore, the notion of power held by adults as people in authority can impact children's eagerness to give 'the right answer'. This relies on the traditional concept of childhood that adults are the dominant, more able and competent actor, rather than viewing children as independent, active and capable (James & Prout, 2015). Moreover, there may be a relational aspect, which expands earlier discussion of empathy as children wish to please adults in the form of sharing the right answer to comfort the adult and ensure their happiness.

Children with WS often have a good grasp of verbal expressive language, and their outgoing, endearing nature can be useful in avoiding difficult tasks or masking their difficulties (Klein-Tasman *et al.*, 2022). Some literature shows children with WS have difficulties with both expressive and receptive language (Laws & Bishop, 2004), particularly pragmatic understanding and comprehension indicated by Van Den Heuvel *et al.* (2016). Schools, without knowledge of WS, may struggle to anticipate their "poor structural language skills and, particularly, limitations in language comprehension [which] may lead to poor referential communication skills" (Van Den

Heuvel *et al.*, 2016, p.912).

Simplifying and restructuring instructions is particularly important and an aspect of the total communication approach for children with SEN/D (Jones, 2000) which can help to strengthen meaning behind words. Research shows the most common type of early intervention for children with SEN/D as 'Augmentative and Alternative Communication', which can involve the use of sign language, symbols and electronic aids (Millar, Light & Schlosser, 2006).

A total communication approach uses more than one method of communication such as verbal speech and signing, or the use of visual cues, as well as considering the child's preference of communication style (Mayer, Marschark & Spencer, 2016). Originally for deaf education, this philosophical approach stems from both Universal Design for Learning and social model view of disability that removes barriers to inclusion for every person (Rose & Meyer, 2002). None of the schools were using sign language, although often the TAs would use gestures by pointing and using facial expressions to emphasise their communication. In some of the schools, symbols and text were used to represent a visual timetable.

With various strengths and difficulties within language, it is unsurprising that children with WS can find difficulty in communicating their true meanings. There may be subtle differences between what children are saying when they use words, and the meaning interpreted by others. Austin (1975) proposed utterances have difference effects, for example to show meaning, or to bring consequences. Perlocutionary acts are a causal effect by saying something, and illocutionary acts declare an intent (Austin, 1975). It is this element of speech that the children with WS in the study found difficult to cause the right effect on the listener with their communications. This increases the risk of misunderstanding, not hearing the child's voice, and potentially not being able to give the right support. For example, Sophie telling Ms Hughes that Wake and Shake was in the hall, and Ms Hughes nodding because she has heard that Sophie has successfully listened to her instructions to the class.

Children were often offered verbal sentence starters for them to finish, which resulted in guesswork or needing further cues (4.3.4). Research studies propose difficulties of understanding social context and picking up cues (Fisher and Morin, 2017; Van Den Heuvel *et al.*, 2016). This could be linked to the high distractibility that many children with WS experience, which means that they were focussing on something else, or looking elsewhere. However, the issue is that children need more support to both understand meanings and communicate their messages within social communication. As a consequence, it is important that staff are trained in both understanding specific WS communication needs, and general support for children with disabilities who benefit from a UDL approach.

At times, children in my study replied to staff with an answer that linked to their particular interest, such as "princess" or a favourite song (S2, p.2; R4, p.2). This raises several points. Children may reply using their interest because they want to talk about their own interest. However, it is more likely that their reply is a result of not understanding the question, or not knowing how to answer. Sophie's staff used many prompts and reassurance to teach Sophie to say “I don’t know” rather than “princess” when she did not know the answer. Therefore, children with WS may need more instructional input in learning how to reply in different situations, particularly when they may be searching for a distraction or hiding their difficulties.

Research examines the ‘mismatch’ of the socio-cognitive profile of people with WS, including difficulties with relation/conceptual language, pragmatics and constructional abilities (Mervis & Klein-Tasman, 2000), false belief tasks, jokes, sarcasm and understanding social cues (Godbee & Porter, 2013; Weisman *et al.*, 2017). Fisher and Morin (2017) point out the difficulty for adults with WS initiating, maintaining and understanding conversations without understanding social context, picking up on social cues, and understanding another person’s perspective. Parents in a study by Fisher and Morin (2017) shared their children’s difficulties understanding situations; individuals with WS would interrupt a conversation to start their interaction, unaware of when it is appropriate to join, interrupt or start a conversation. Therefore, it is important for individuals with WS to be taught several specific social skills in order to enable them to participate in conversations.

Research into social skills education suggest that children with WS can develop social skills through role play, practising different scenarios (Fisher & Morin, 2017). On the other hand, not every scenario can be taught, and children with WS therefore need opportunities to practise real situations which can be unpredictable. In continuous provision, Ms Roberts highlighted the increased opportunities Orla had to develop social skills such as taking turns, sharing and talking to peers:

> I personally think the situation she’s in now is the best possible situation because she’s exposed to those situations where she is snatching, or she isn’t taking-turns or she isn’t sharing. Those real-life situations rather than having to engineer them (OT, p.6).

6.3.6. *Physical learning areas*

Another area noted among school staff and in my own observations was the various types of support that were in place to develop fine and gross motor skills, balance and coordination. I had observed Orla appearing unsteady in the classroom as she bumped into tables frequently. Likewise, Ms Roberts shared:

> She is, to me very wobbly, very unbalanced and obviously fine motor and gross motor is a real challenge (OT, p.3).

This supports research reporting challenges for individuals with WS with balance, tone and coordination (Barozzi *et al*., 2013; Morris & Mervis, 2021).

When the staff began to prepare for my visit, they had been given Tynan’s (2014) WISHES book which helped Ms Roberts identify an area they had previously not worked on. Ms Roberts then found an online leaflet by an occupational therapist which outlines a range of activities for children to use to develop gross motor skills. Orla was previously signed off by her own occupational therapist. This emphasises the importance of educational staff looking at physical learning areas. It also highlights the difficulty of supporting children with a rare developmental disability where professionals may benefit from specific syndrome knowledge which can be difficult for rare disabilities with limited literature (Dall'Alba *et al.*, 2014). Furthermore, school staff may not have previously considered Orla’s difficulty as a spatial awareness and proprioception difficulty, perhaps because she was wearing glasses to aid her visually, or because of her excited, energetic movements around the classroom. This meant that specific knowledge of WS was helpful for highlighting areas of balance and coordination difficulties.

Similarly, Sophie's experience with an occupational therapist and the SENCo from Ridgeview School also focussed on her eyesight, and resources such as a writing stand, handwriting course or her positioning on the carpet. It was Ms Watts, the TA, who identified her difficulties with fine motor skills and coordination and she had created games and activities to help her practice these skills. However, Ms Watts was unsure how to teach specific pincer movements without strategies or input from others. These examples indicate the difficulty in establishing the responsibility of finding the right support from a range of professionals, including outside services such as the occupational therapist, and staff within the school such as SENCO, class teacher or teaching assistant. All roles will have varying levels of knowledge of WS and the specific child they are supporting.

Ms Hughes was also aware of Sophie's difficulty gripping a pencil for writing, and suggested using an iPad particularly in the next year to enable Sophie to continue to progress:

> My main concern is if she can't get her fine motor skills quicker, when it comes to Year 2, she's going to find it really difficult. So, if we can start fighting for it now going [asking] "Actually she needs to be using an iPad a bit more" and then can physically type the letters (ST, p.7).

In referring to a fight, Ms Hughes emphasises the length of time required to build an argument for the resource (see 5.1).

On the other hand, Ms Lock proposed that the foundation for writing was for Wendy to be able to manipulate objects in her hands, and that the fine motor skills were key to helping her to hold a pencil. Wendy removed counters stuck into playdough to practice the pincer movement (W1, p1-2; W4, p.2), whereas Ms Watts was given playdough by Sophie's parents, without knowing how to teach Sophie how to use specific movements. Although communication may be good between home and school, it is reliant on the appropriate knowledge and training to be available and resourced.

Edgewater Primary School were running a 'Fun Fit' session for a group of children from Year 1 who were identified by the lead of the Foundation Stage as benefitting from an intervention. Ms Dot explained that the Foundation Lead suggested having a small group of children to work on gross motor skill development, balance, coordination and spatial awareness. The children accessed a range of tasks and activities such as catching a ball and walking along an upside-down bench. When I asked Ms Jacobs about this area of learning for Ryan, she showed me the Stepping Stones scheme and asked Ryan to practice a few activities such as throwing and catching a ball. Wuang and Tsai (2017) suggest that difficulties with specific cognitive tasks such as visuospatial perception (understanding and processing the space) will result in challenges for individuals with WS in developing their fine and gross motor control. Therefore, it is an area of particular need for children with WS to practice and develop.

All of the schools had various outdoor play equipment which included an obstacle course. Ms Watts used a lot of encouragement to support Sophie to climb across the course. Wendy's peer held her hand and started her at the beginning of a climbing course but became distracted by other friends and so Wendy approached a teaching assistant and took her over by the hand to do the course (W2, p.2). Ryan much preferred playing on the bikes. Although there was an area for climbing, he did not use it during my visit. Orla's class had protected time to play on the obstacle course outside one afternoon.

Overall, children had various opportunities to practise and develop their physical learning needs, but there were some challenges in knowing how to identify their specific needs which required knowledge of WS. Although there were some general schemes of activities for children, these are often short-term schemes, or not used as often as other interventions. It is important for practitioners to understand different physical learning needs, particularly for children with WS. Sharing these insights with others can also provide good opportunities for schools to compare generalised support for all children with diverse learning needs.

6.4. Support from others

Children experienced support and guidance from both staff and peers in their classes. In all schools, there were children with various levels of support, including 1:1, additional time outside the class or different resources such as writing stands or separate desks. Staff developed an understanding of how to support children with WS by working very closely with them, whilst peers showed different ways of offering support.

Some children adopted a role model approach, offering encouragement to other children or physically helping to show children where to stand or sit. In Littlewood School, the class had been encouraged the previous year to support Orla with patience as she learnt how to share. This meant that the children in Orla's class could learn that children learn at different paces, although it also emphasised Orla's differences.

6.4.1. *The helpful peer*

Some children in schools appeared very helpful and supportive, for example, by showing Wendy where to stand in line or helping her in and out of her seat. On the other hand, there were times where Wendy became frustrated by being over handled, or overcrowded. Staff saying, "she's not a doll!" and "let Wendy do it herself" prompted children to become more aware of Wendy's own independence and autonomy. This reflects an experience in Parry's (2014) case study where staff intervened to prevent pre-school children from mothering a child with disabilities, resulting in a more balanced relationship.

Research into relationships between children with and without disabilities found that typically developing individuals enjoyed helping others and liked the recognition for helping others. Roles included being a carer, helper, protector, facilitator and communicator for their peers with a disability (Anderson *et al.*, 2011; Avramidis, 2013). However, Anderson *et al.*'s (2011) study interviewed children about their friendships with children with cerebral palsy who were using an augmentative and alternative communication device. Generally, this means that the children may have less of a cognitive disability and more of a physical disability, which can change how peers view them. For example, Laws and Kelly (2005) found differences in gender and the type of information about disability impacted children’s motivations towards friendships with a child with a physical or intellectual disability.

The image of the over-helpful peer who strives to be a good role model stirred a memory. I remember a group of adults over enthusiastically praising school children for playing with the group of children with disabilities from a special school. Although I can understand how positive the experience was for the children, the emphasis of praise to the children without disabilities irritated me considerably, because *playing with children with disabilities was not considered normal.* In my memory, the adults were surprised and thrilled that the children were playing well together, which meant that they did not expect them to. In an inclusive society, it should be expected that children play together, embracing their differences and learning from each other.

Placing higher importance on the non-disabled peer as a role model might help encourage others to practice more patience and care towards peers with disabilities, but it also highlights the difference in expectations surrounding friendships and peer interactions for children with disabilities. Additionally, staff need to be aware not to exploit relationships with peers, such as always selecting the same people to sit next to a child with disabilities, or asking children to support in a way that is more than a friendship but becomes viewed as a care giver or even teaching assistant role (Anderson, Balandin & Clendon, 2011). Ms Jacobs was particularly aware of this from pervious experiences supporting a child with SEN/D who was often paired with the same child in class, and she was keen for this not to happen.

In an earlier example, I felt a tension where the children were presenting themselves to me as a role model, which emphasised the differences in how they responded and valued children with diverse needs. Chris asked Orla to tell him what the letter sounds were, and then looked at me pointedly. Orla's class had been taught specifically during their Reception year that Orla needed more time, and to be patient because she was still learning to share. Meyer (2001) argues that this type of encouragement can label a child as someone that everyone helps but is not expected to help anyone else. This is problematic in that instead of normalising helping situations, staff may create a hierarchical social status among the class. Instead, children with and without disabilities need to have mutually beneficial interactions without being assigned to work with or support the other (Meyer, 2001). Furthermore, this reflects Nodding's ethics of care theory which suggests children who receive more nurturing help will develop a desire to want to help others (Noddings, 2002). For example, when a new girl in the class started, Sophie was eager to show her where the toilets were.

6.4.2. *The informed peer*

When there is a child with disabilities in the class, children learn to be patient, develop empathy (Anderson *et al.*, 2011), be more tolerant of differences, to celebrate differences, and most importantly, that all children are different, and therefore learn at different paces. Parents of typically developing children report that inclusive education helps their children to learn about and accept individual differences (De Boer, Pijl & Minnaert, 2010).

Literature on social interactions between children with and without SEN/D suggests that children with SEN/D have fewer opportunities to practice developing their social skills and building relationships with their peers (Carter & Hughes, 2005; Cutts & Sigafoos, 2001). Furthermore, Eriksson, Welander and Granlund (2007) suggest that children with disabilities are more engaged in school activities when they are included with their peers, but often participate less depending on the type of activity, such as maths, science or break times. Therefore, using different spaces for working areas may limit opportunities for children with and without disabilities to interact, and for children with disabilities to be more engaged in the lessons.

When the children attempted to help Wendy use a tissue for her nose, they noticed that she needed support but did not know how to provide that support. This can result in children doing things for other children, which prevents them from practising or learning problem solving skills. Similarly, Anderson *et al.* (2011) reported problems with children who were guessing or interpreting their friends' communication as failing to enable children using an augmentative and alternative communication device to express their own thoughts and opinions.

Expectations from staff might also impact how children behave towards their peers. It is therefore important that teaching staff consider the role of peers in whole class discussions or peer mediated games to encourage children to think about how to support each other (Sperry, Neitzel & Engelhardt-Wells, 2010). For example, Sophie was unsure how to play with her peers when they were playing superheroes. In their research study, Sperry, Neitzel and Engelhardt-Wells (2010) suggest using scripts and visual instructions during role play and dressing up for children with disabilities. Dyson (2005) suggests social interactions need to be promoted between children with and without disabilities, as well as specific interventions to raise awareness of less visible disabilities. Sperry *et al.* (2010) report that quality and quantity of social interactions can lead to positive outcomes.

There is a difference between facilitating and directing interactions between children and peers (Parry, 2014). For example, staff expressed knowing when to stand back and observe so that children developed contacts themselves. However, turn-taking and learning how to share were necessary moments for staff to intervene. This occurred in Littlewood School, particularly when Orla was interacting with other children with diverse learning needs or who also found it difficult to share and take turns. Ms Turner would use these moments to role model to children, talk them through their challenge and offer solutions to their problems. Other staff shared direct approaches such as asking Sophie to find a certain child on the playground or by encouraging Wendy to hold the hand of a peer in the queue. Looking towards other contexts, staff in preschools in Japan would not intervene at all, so children have to learn to sort out problems between themselves (Tobin, 1999). This is based on the view that children should experience handling disputes and social interactions themselves rather than being directly taught from an adult (Hayashi & Tobin, 2014).

Avramidis (2013) proposes that teachers implement activities for all pupils rather than identifying children with SEN/D, as his study highlighted social isolation as a risk for all children, although it was higher for children with disabilities. Suggestions include buddy schemes, mixed grouping and teacher-led games such as story building and turn-taking. Similarly, Sperry *et al.* (2010) suggest pairing children with partners during transition times, so they work together to tidy up. On the other hand, Anderson *et al.*'s (2011) study emphasises that friendships were often naturally occurring and without engineering from the teachers, young children were able to build social interactions between themselves. However, friendships are challenging to measure and define. Kalymon *et al.* (2010) suggest that establishing a relationship requires congruence, mutuality and regular contact between peers. Typically developing peers notice that their friendships with children with disabilities are different. They may have difficulties finding similar interests or similar social competence levels; they require a lot of patience, understanding and trust (Woodgate *et al*., 2020).

Ryan had less of an informed peer approach, as my fieldnotes show:

> *The class are becoming more aware of Ryan's differences. When sat on the carpet for show and tell, Ryan asks "where did you get that from?" to the girl showing her karate belt. "From my karate class" she replies, and Ryan reacts "wow… I think I love you". Most of the class visibly react, with some wide eyes, gasps and chuckles, but there is an overall awkwardness as the class seem to know that this was not a usual response and were unsure how to react to it. Ryan does not seem to recognise the awkward response, instead cheekily grinning at nearby children* (R1, p.1).

In this situation, I wonder if Ryan knew that the class were praising the girl for her achievements in karate and wanted to also show his appreciation. It is difficult to know whether Ryan needs support in using the right vocabulary or understanding what the karate belt meant to her and the rest of the class. Staff or other peers could have acted as 'interpreter' or indirectly facilitating (Parry, 2014) by interpreting what Ryan means when he said he loves her, such as he is impressed with her hard work. Alternatively, showing Ryan what the karate belt means by demonstrating a move, or watching a video could help aid his and the rest of the class's understanding of the context of her show and tell. This situation also highlights the difficulty for children in knowing how to respond to their peers.

This prompts the question: how do staff teach children about differences? This depends on staff knowing how to approach this within the constraints of the National Curriculum. A Personal, Social, Health and Economic (PSHE) lesson in Sophie's class lead to conversations about noticing differences in eye colour, hair type and glasses, which could have revealed opportunities to discuss more complex nuances of differences in learning. Freer's (2021) systematic review highlighted the need for school interventions to be evaluated rigorously to identify ways to address ableism.

The age of children played a significant part in their role as peers to children with WS. As children move through the year groups, the gap between peers will widen as children with WS move at more noticeably different paces. All the children in the study aged between 5-6 years were in classes with children the same chronological age. In her Canadian study, Dyson (2005, p.96) argues "the preschool years are also the time when children begin to display negative reactions toward individuals who are different". However, a study interviewing American middle school boys who even though they had explained to them the different levels of disabilities at the beginning of the study, the pupils still focused on peers with physical or severe intellectual disabilities, which tended to be more visible (Kalymon, Gettinger & Hanley-Maxwell, 2010). This suggests children are more aware of physical differences rather than cognitive, social or emotional differences. Therefore, staff need to implement activities to promote acceptance, diversity and understanding about different levels of disabilities and how they can present themselves. Similarly, Woodgate *et al.*'s (2020) systematic review of 45 social inclusion studies found peers were more accepting of visible disabilities and less accepting of more severe disabilities that impacted problem solving or emotional regulation. Barriers included the presence of a teaching assistant or lack of social competence; both relevant areas for children with WS.

Children who are in a class with a child with WS experience a range of roles as a peer and receive different levels of support in order to facilitate, direct and interact with children with disabilities. Research suggests that children with and without disabilities need to have opportunities to interact with one another, to help develop positive attitudes towards disability and to challenge preconceptions (Freer, 2021; Woodgate *et al.*, 2020; Sperry *et al.*, 2010). However, children with disabilities continue to experience fewer opportunities to participate in daily school activities due to their individual interests, needs and how they are supported. For example, Sophie did not join her class for assembly through her own choice, and Ms Watts felt that she could work better with Sophie on her own by practicing a task to develop specific skills such as fine motor development, and speech and language interventions.

Research shows children with SEN/D report feeling lonely and excluded (Woodgate *et al.*, 2020) and loneliness becomes more apparent for adults with WS (Fisher, Josol & Shivers, 2020) despite their eagerness to socialise. It is therefore important that children with WS are supported to interact with peers in the various ways of facilitating, prompting and interpreting that TAs often use. Furthermore, children in primary schools need support to challenge preconceptions and develop their understanding of differences to help position children with SEN/D as competent and capable at their own pace.

7. Conclusion

The final chapter will build upon the previous chapters to look ahead at future agendas. My own experiences with Tom have shaped my responses to the children in the study who I know will become older children and adults with WS. This study highlights the complexity of children with WS's experiences in primary schools, and the different ways of providing support.

One of the original aims for the study was to return to the four schools to share collective considerations of how to support a child with WS in a mainstream education setting. Although I was unable to return to the schools due to the global pandemic, the creation of the photobooks (see Appendix) and my subsequent involvement with WSF as regional coordinator and presenter has enabled me to share some of my own understanding and reflections. A bi-annual blog in the WSF magazine has provided families with summaries of the key findings and reflective points, as well as providing contact details for participants to contact me for further information about the study. It is useful for families to learn about different provision and the types of support that can be available for children with WS in education.

Orla, Wendy, Sophie and Ryan shared their experiences of being a primary school pupil which included listening to instructions from adults and learning to take responsibility for their belongings. They each shaped the research with their unique personalities, strong interests and the spaces they used, or did not use, in their school. For example, avoiding the assembly hall was a significant part of Sophie's experience of managing Williams Syndrome and the unpredictability of drums in the hall being played by others. Likewise, using the girl's toilets was a significant part of Wendy’s experience of coping with her sensitivity to a daily environmental sound which was an expected task as part of her daily school experience. These experiences in primary school offer glimpses into the opportunities and difficulties that will lie ahead for them.

7.1. Questioning inclusion

The increasingly difficult and undefinable inclusion agenda has resulted in children with disabilities attending primary schools with varying levels of successful inclusion. Practitioners continue to conflate inclusion with integration, by focussing on the placement of children being inside the classroom or outside the classroom. Hodkinson (2012) refers to the ‘symbiotically intertwined’ absence and presence of inclusion where teachers decided when and who could be included. Teachers have this power without necessarily having training, knowledge or understanding of SEN/D or inclusion (Hodkinson, 2009). Furthermore, teachers have pressures from the marketization of education and pressures of accountability which continues to value conformity against individuality (Biesta, 2012) rather than a democratic education (Dewey, 1916).

Each child had different experiences of being inside or outside of the classroom. Inside the classroom, Sophie and Wendy experienced moments of being overcrowded or overwhelmed by the activity from the rest of the children whereas Ryan and Orla often found themselves distracted by other children, environmental sounds and their own interests. Both issues impacted on children’s’ ability to listen and understand instructions. On the other hand, outside of the classroom children were able to have very focussed, 1:1 interactions with their TAs who helped them to listen, follow instructions and complete work set which built on their previous knowledge and experiences. Staff were less confident with these children being able to complete this 1:1 work within the classroom due to the amount of conversation and discussion needed, or the flexibility to meet children at their own pace including opportunities to use the toilets, have a snack or break which would distract others.

Literature suggests children are at risk of isolation because of close TA contact (Vincett, Cremin & Thomas, 2005), and the different work set (Norwich, 2009). However, this depended on how the class teacher and the school managed and organised the learning. Littlewood School's Year 1 class did not have clear ability groupings, and the emphasis on children's independent self-directed learning meant that the different work set for Orla did not ostracise her from the rest of the children. On the other hand, Sophie was able to complete tasks within the classroom as the teacher had grouped children based on ability. This meant that the work was a similar task for the children in the group, but it also meant that Ms Watts had a complex challenge of supporting children with a range of very high needs. Furthermore, ability groupings can still emphasise the differences between children's learning needs with the rest of the class, and can position children as less able.

Literature argues that children working with a 1:1 supporter are at risk of having less opportunities to practice social interactions with their peers, and this may lead to social isolation (Carter & Hughes, 2005). However, teaching assistants in this study prioritised children's learning holistically, recognising the specific areas children needed support with, which included Sophie's fine motor skill development or Ryan’s social communication and spatial recognition. TAs reflected on how to best support children to increase their independence and confidence, for example by using encouragement and praise to accomplish a difficult task, or by increasing children’s responsibility for their own belongings.

7.2. Inclusive support

TAs in the study had the responsibility of identifying, engaging and extending opportunities of learning. This emphasises the importance of the TA role as a practitioner that is able to watch closely and build a responsive relationship with children with disabilities that the classroom teacher will not necessarily have the time or resources to do. Findings indicate the high-quality input from TAs that support children with WS which challenges the view that a qualified teacher provides higher quality input. Teaching assistants often had the specific art of noticing, using more than what children seemed to be saying. The relationally responsive type of understanding that Shotter (2006) named “withness” enabled staff to understand the children’s needs and wishes, despite the subtle nuances in their ways of asking.

On the other hand, TAs have contrasting work conditions to classroom teachers including lower pay and status which can impact how they are viewed and valued in the school (Mackenzie, 2011). TA’s limited time is spent directly supporting children with WS which enables them to understand and respond to children. However, without the time or funding to access training, TAs work additional hours to engage with materials from families to learn about WS. Furthermore, their restricted time can limit their opportunities to join meetings, discussions or pedagogical conversations with the class teacher which would help them to share knowledge and responsibility for supporting children with WS with others. It does not seem possible for all staff to build a trusting, responsive relationship which recognises children with WS at the unique pace and experience. Therefore, TAs must be recognised as pivotal to the successful inclusion and support for children with WS, and this should be reflected in their status, pay and training. Shifting roles, temporary contracts and low wage is a part of a wider picture of working conditions in public services which requires change (Ravalier, Walsh & Hoult, 2021).

Mainstream education in England needs a shift in recognising different paces and valuing slow knowledge against performativity culture in order to implement inclusive education. Otherwise, a divide between children who can perform at the 'expected' levels and children whose diverse learning needs require support at their own pace will continue to replicate the traditional educational system of special or mainstream education. Hence the debates from researchers considering whether a special pedagogy or an inclusive pedagogy is needed (Mintz & Wyse, 2015; Ridgway, 2019).

Practitioners bring varied backgrounds, perceptions and understanding of SEN/D to their roles. A UDL approach which is underpinned by the social model view is helpful in recognising diversity which benefits all people in creating an inclusive society. However, like my family, teachers must also learn how to navigate disability in order to maximise the support for children which might mean using a psychological view of disability (Ridgway, 2019). Therefore, CPD could be an effective opportunity to build on staff's knowledge and reflect on how to manage inclusive support for each individual child.

Challenges in schools occurred for staff working on different schedules who needed to find opportunities to share their knowledge and understanding. TAs developed knowledge from responsive, observant experiences with children, but this often stayed with the TA due to limited time to share lesson planning, resourcing and communication. Staff recognised the benefits of collaborating and contributed towards a community of practice, but TAs are often excluded from conversations with external advisors and professionals. There were some opportunities for pedagogical conversations which would help staff develop their confidence and knowledge, yet this was spontaneous rather than protected time.

The children in the study often talked about their friends as the children in their class, or those they spent the most of their time with, including the teaching assistant. Research shows children with SEN/D report feeling lonely and excluded (Woodgate *et al.*, 2020) and loneliness becomes more apparent for adults with WS (Fisher, Josol & Shivers, 2020) despite their eagerness to socialise. TAs facilitate, prompt, encourage and interpret so that children with WS can practice and develop skills needed to interact with their peers and build friendships. However, labelling all peers as 'friends' may lead to challenges in understanding the concept of friendship. Furthermore, children in primary schools need support to challenge preconceptions and develop their understanding of differences to help position children with SEN/D as competent and capable at their own pace. More research is needed to understand how increasing opportunities for children with WS to socialise with peers could lead to more friendships. Using the experiences shared in this study, it is interesting to consider the role of peers and the differences in their expectations of children with SEN/D, and the various ways they look to support or position them.

7.3. Williams Syndrome

Working closely with children with WS, alongside an increased knowledge of the syndrome from resources such as WISHES (Tynan, 2018) enables practitioners to develop their understanding of how to support children with WS. However, my study shows staff need specific knowledge of WS in order to understand the subtle and complex ways children with WS manage risks to anxiety, specific phobias, sound sensitivities and physical learning areas. This psychological positioning of disability as categories suggests that staff need knowledge of WS to be able to implement inclusive pedagogy that meets children's individual needs. On the other hand, my study also highlights the relational view of disability that suggests staff learn the subtle and complex ways children with WS ask for support by their close encounters of experiential, tacit learning.

Children with WS have several challenges including spatial awareness, visual perception, balance and coordination (Wuang & Tsai, 2017). On the one hand, there is a risk of diagnosis overshadowing which might prevent schools from meeting children's needs, and every child with WS can experience WS differently. On the other hand, a diagnosis can enable children with WS to access funding and TA support, as well as syndrome specific knowledge and awareness.

Children with WS generally display a happy, social disposition which can mask their anxiety. It is unclear whether children with WS manage to reduce their anxiety, or display anxiety in different ways. For example, restricted and repetitive behaviours could be a way of reducing anxiety, or a consequence of anxiety which may need addressing. It is interesting to reflect on Ryan's Robot dance during the fire alarm as a signal of anxiety that may be masked by his desire to please others or manage unpleasant feelings. How anxiety is viewed can impact on staff's ability to recognise and understand children's experiences, particularly when they are unable to communicate when they are worried.

Further challenges arise when practitioners misunderstand children's repetitive talking about a sound and curiosity to explore the source, particularly with their generally happy social dispositions. It then becomes difficult to distinguish between genuine fascinations of interest, or a need to self-calm as part of an approach avoidance conflict (Spielberger & Starr, 2012). The perceived excitement for Wendy to see photos of the hand dryer indicates her complex relationship with sound and the difficulty in school for staff to identify and support children's management of anxiety.

Without specific knowledge about WS, there is a risk that staff may over-simplify or reduce children's experiences of non-social anxiety, phobias or general anxiety. A type of specific phobia and anxiety management that uses play therapy and humour (Klein-Tasman *et al.*, 2022) shows the potential for developing an intervention which enables children with WS to manage their specific fears and phobias. This also emphasises the need for specific knowledge of WS as part of CPD for all school staff.

Research suggests children with WS have strong empathy, due to their connection with other people's emotions (Rosner, 2001). Staff commented on how caring children with WS are to others, and children with WS became very concerned when another person was upset, cross or unwell. However, having empathy can increase the risk of internalising problems such as anxiety (Tone & Tully, 2014), and it is not known whether children with WS are experiencing empathy or strong emotions based on what they see. These emotional experiences can become problematic when children with WS focus more on the speaker's emotions than the content of the message. This is challenging in schools when many instructions are verbal, and even more challenging for children who become distracted, preoccupied and ultimately distressed by other people's emotions. Internalising feelings from emotional empathy requires support to manage their feelings, concerns and worries which might link to increased anxiety. Understanding another person's feelings and thoughts requires teaching about recognising and identifying feelings.

The different strengths and challenges for children with WS in language and communication can cause confusion for practitioners. Children seemed excited to talk about topics, repeatedly asked questions or answered questions with their favourite topics of interest. However, children also needed support in learning how to reply in different situations, particularly when they were distracted by their emotional and sound sensitivities. The UDL approach can benefit children with SEN/D if practitioners use multiple methods of communication to strengthen their meaning. However, it is useful for staff to be trained in understanding specific WS communication needs. Children with WS need support to understand meanings, and to communicate the message they mean to send.

Another recorded challenge for individuals with WS is difficulty understanding how to react to strangers (Fisher, 2014) combined with an eagerness to interact with others. This problem did not occur within the scope of my study, but I was classed as a safe adult to approach due to the extensive background checks when visiting or working with a school. It is difficult to suggest how schools support children with WS to interact or not interact with strangers. However, it is useful for staff to know that this is a challenge for children with WS, to help prepare them to develop skills in the future for keeping safe.

7.4. Researching with children with WS

Predominantly, research about children and young people with Williams Syndrome has focussed on cognitive and behavioural phenotypes, characteristics and issues of a highly complex socio-cognitive disability (Martens, Wilson & Reutens, 2008). However, this research has traditionally ignored the real lived experiences of children living with a disability, as it does not include the voices of children themselves. Studies using questionnaires, surveys and scales use pre-selected answers and may be interpreted differently between parents, carers, staff or professionals considering social, cultural and economic differences. Furthermore, surveys and scales do not offer insights as to why or how challenges are experienced.

This study uses an adaptation of the Mosaic approach, videos and interviews with key school staff which adds rigor, richness and depth to the inquiry (Denzin, 2017; Flick, 2018). The methods chosen included children's own experiences of education which could be used as insights to reflect on wider instances of inclusion for children with other disabilities and differences. The basis of the Mosaic approach was to help very young children evaluate their space. By using a research method framework that enables children to share their perceptions of the space they use, children with WS could highlight their experiences of the areas and objects in their school; particularly their experiences of non-social anxiety.

Creating photobooks for each of the children helped to explain the process of research, in an accessible format with children's own pictures of their school. Seeing the pictures that they had taken would help to reiterate the research process of taking photos, looking at the same photos, and sharing the photos with others. Furthermore, the books provided another opportunity to consider the consent process. By sharing this book with their class and family, the children were positioned as authors, researchers and teachers. A limitation of this study was the omission of the follow-up visits to schools. It would have been useful to revisit the schools as intended, so that I could join in the experience of sharing my own reflections with staff and pupils.

This study in itself was a route to self-advocacy by providing time, space and materials for children to share their perceptions. Part of the findings showed that children with WS had many more opportunities than their peers to share their thoughts with staff because of increased contact time with a TA. This could be helpful for children with SEN/D to develop skills for sharing their own perceptions in order to contribute to decisions made about them, which is an important part of the SEND Code of Practice (DfE, 2015). Therefore, it is important that schools enable children to learn when to self-advocate, and recognise the opportunities to develop skills for self-advocacy.

Although the research aims and purpose was my own decision, and my presence influenced the participants, children were still able to confidently direct the research in their own way, either by glueing, cutting, or following the noise (Audio S3; Video O3). It is our responsibility as reflective and responsive researchers to carefully listen to children, and not override the opportunities or remove spaces that encourage agency and voice.

7.5. Reflections from the study

The process of completing a PhD of this length meant that the children who participated in this research may not benefit directly from the findings and implications of this study. However, it is hoped that their participation using the Mosaic approach enabled them to consider their experiences of school in relation to others, and as preparation for self-advocacy. Staff were able to share their concerns or questions, and TAs were given time to discuss children's strengths and needs, which was a rare gift in a time-limited role.

I was keen to minimise disruption from the children's educational experiences for several reasons. Firstly, part of the study was learning about children's experiences of education, and what they wanted to show about their school. Secondly, a research study focussing solely on one child in a class could emphasise their difference to other children. Thirdly, I wanted to respect the teacher's timetabling and priorities. Therefore, I was unable to spend as much time as I wanted directly with Orla, Wendy, Ryan or Sophie and their TAs. A further challenge was the ethical considerations of photographs and videos which meant that I could not film across the classroom or playground and only captured short segments of working in another area with a TA.

My presence emphasised the diagnosis of WS, and therefore influenced how much staff thought about it the week I visited. Although this could be argued to be a limitation, it was useful for both myself and staff to think about the implications for supporting a child with WS. Ms Jacobs considered whether she should be more lenient with Ryan because he found it difficult to sit still on the carpet. Ms Turner and Ms Dot were concerned with the little they knew about WS, and the lack of a practitioner network to share experiences.

Findings from this study highlight a moment in time, but schools continue to work, learn and develop their management of inclusion for children with disabilities. This thesis acknowledges the wider reality of the social, cultural and political landscape that affects teacher education, continuous professional development and the implementation of inclusive pedagogies. This study intends to pose critical questions at different levels of experiences, from children with a disability attending a primary school, to the wider perspective of different primary schools in the UK managing inclusion.

This study did not include parent or carer voice, although they played a significant part in contacting me, providing consent and a willingness to share their experiences as a family. Parents and carers should be included in decisions made about their child (DfE, 2015), and a future direction of this study might be to explore the relationships between school and home for children with disabilities. Education, Health and Care Plans were mentioned briefly by staff, but not as much as I had expected. EHCPs are an area which is useful to explore, particularly in understanding how the child and family are positioned as experts in knowing their child and knowing WS.

7.6. Returning to the question

This study featured case studies from four children with WS who attended four different primary schools in the UK. The main research question intended to investigate "What are children with Williams Syndrome's experiences of mainstream primary schools?" which included:

- What do children with Williams Syndrome show as important to them in their school?
- What do children with Williams Syndrome want to contribute to research about them?
- How do children with Williams Syndrome interact with peers and staff?
- What do participants understand about supporting a child with WS in school?
- How do schools facilitate inclusion of children with WS?

Orla, Wendy, Ryan and Sophie each shared their experiences of school through a range of photographs, videos, audio recordings and being with me through their week at school. They contributed to research by guiding, colouring, capturing and sharing their experiences of having WS and attending a mainstream primary school. Using a strength-based view of children, I adapted the Mosaic approach with the children to help understand their experiences of being a primary school pupil.

The findings highlight the differences in levels of support, understanding and knowledge from peers and staff. This included how different participants positioned a child with WS, or children with SEN/D, and depended on access to resources, training and experiences of disability and inclusion. In order to meet their needs for a fair, equitable education, children with WS need to be treated differently and apart from their peers, which challenges some of the principles of inclusion. We have yet to see the radical move from the medical model to the social model of disability in the Education system, but perhaps now is the opportunity to consider how to work with both these models of disability, as my family have learnt to navigate for Tom.

I would argue that if all children go to the same school, then they might learn to be aware of differences, and build some knowledge of disability. However, there needs to be more specific support for children to celebrate those differences, and not continue to see children with disabilities from a medical model view as less able, less competent and therefore less valued.

The inclusion debate continues as an argument with no solution (Allan, 2013), but a need for everyone to commit to advocate for listening to individual children and their voices; and noticing what they really mean. The expert in disability remains the child themselves, their family, and those working closely whose relationally responsive skills build knowledge of disability-from-experience. Hodkinson (2012) argued that inclusion is more of a spectacle because children with

SEN/D are included in the system but often absent from the classroom. There is agreement from both researchers and practitioners that all children should be welcomed and accepted as a part of the school community. However, there are limits to inclusion (Hansen, 2012) and perhaps it is not so important that everyone belongs to the same space, but that everyone has a space in which they belong.

8. References

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9. Appendices

Appendix 1

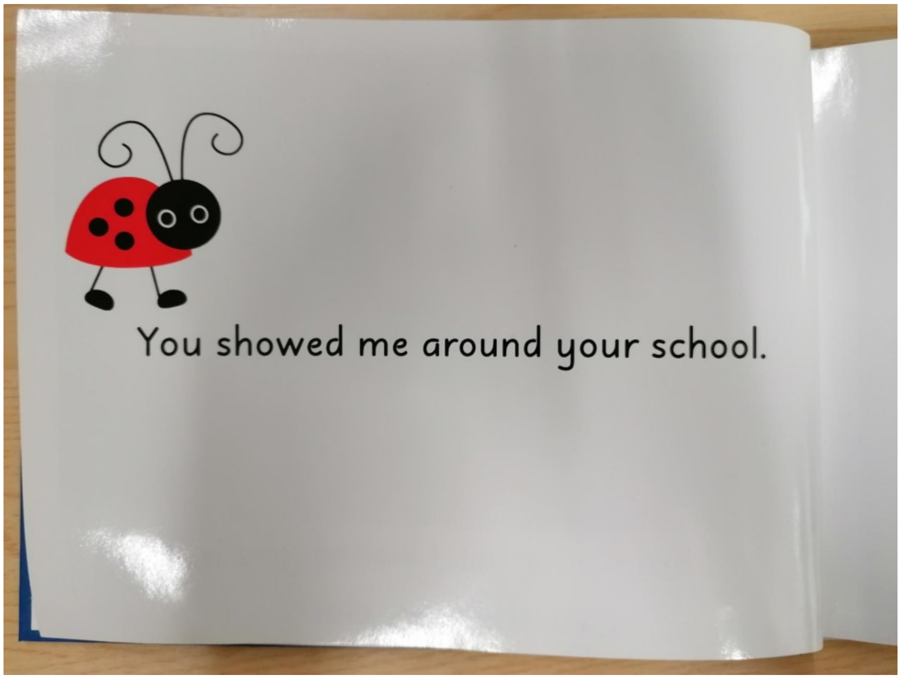
Photobook

A copy of Wendy's photobook was made with informed consent from her parents. I included a letter asking her whether I could have a copy of her photobook to share with other children, families and staff as well as the people at my University.

Figure 13 – Cover page

I am Katherine. I visited you in Grasshoppers class.

Figure 14 – page 1



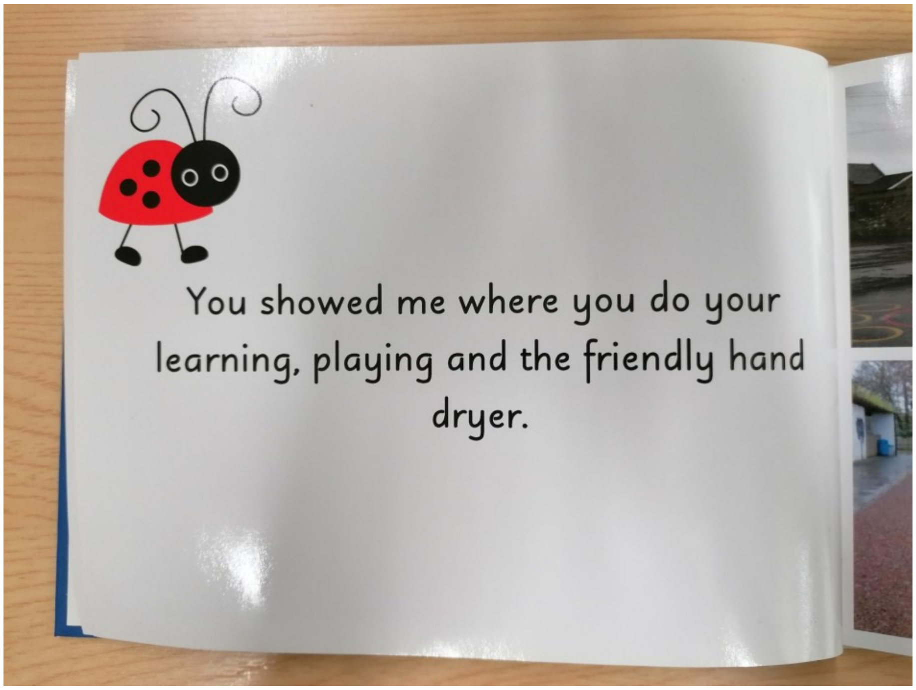
You showed me around your school.

Figure 15 – page 2

You used a camera to take photos. You liked pushing the button.

Figure 16 – page 4

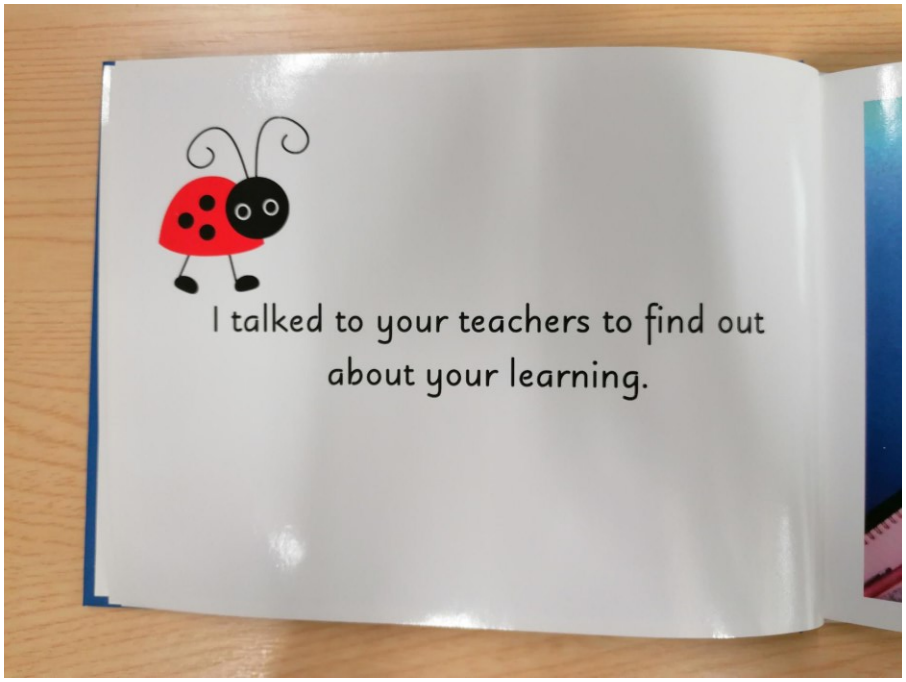
Figure 17 – page 5



You showed me where you do your learning, playing and the friendly hand dryer.

Figure 18 – page 6

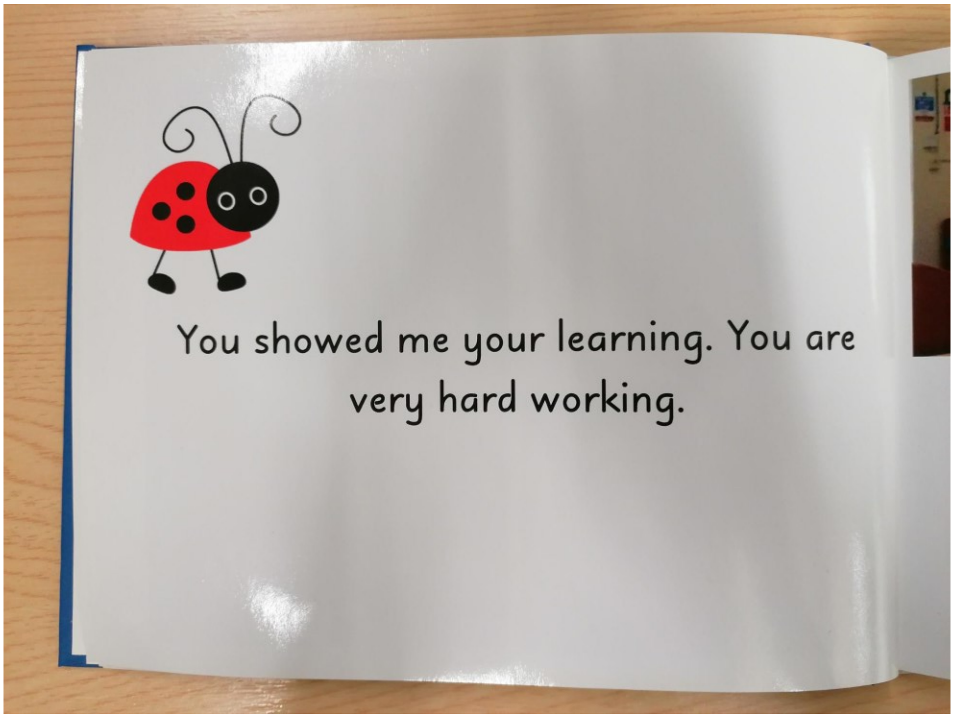
Figure 19 – page 7



I talked to your teachers to find out about your learning.

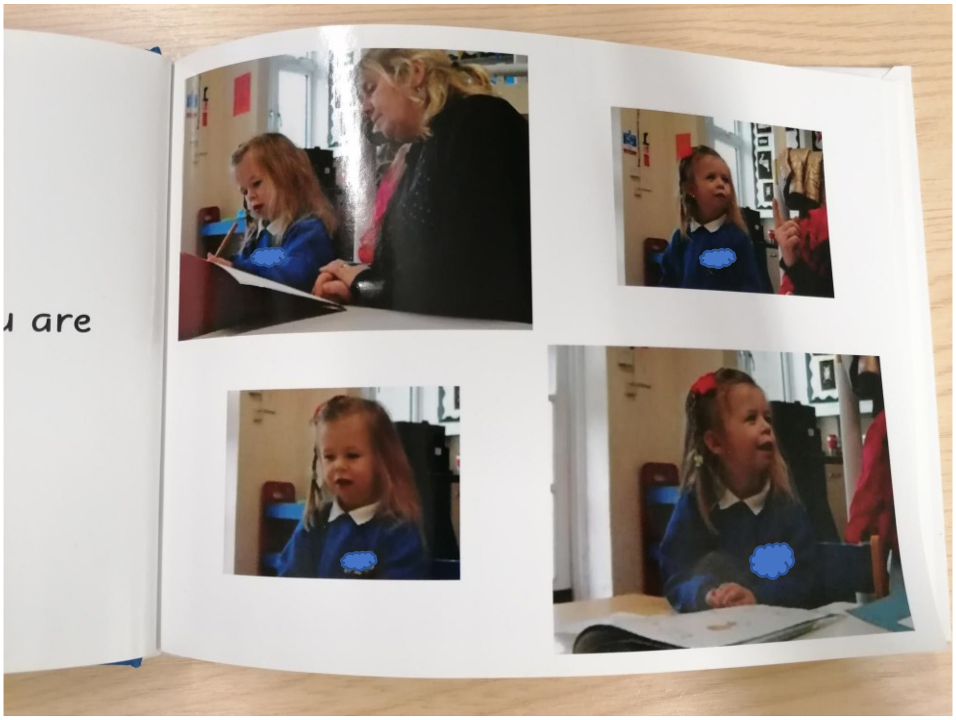
Figure 20 – page 8

Figure 21 – page 9



You showed me your learning. You are very hard working.

Figure 22 – page 10



u are

Figure 23 – page 11

We talked on the voice recorder.

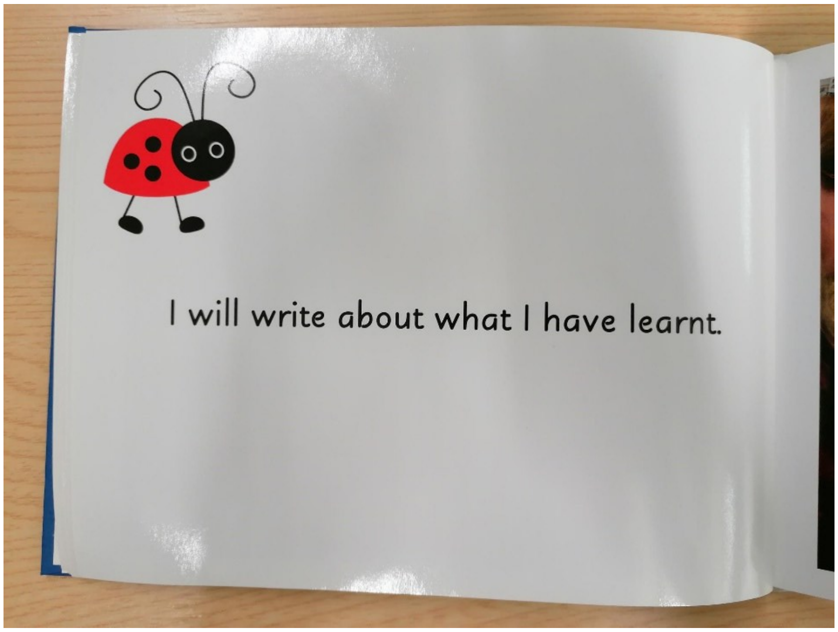
Figure 24 – page 12

Figure 25 – page 13

We talked about the photos of your school.

Figure 26 – page 14

Figure 27 – page 15



I will write about what I have learnt.

Figure 28 – page 16

Figure 29 – page 17

Thank you for showing me your school. I can help others with their learning.

Figure 30 – page 18

Appendix 2

Children's letter

Children's Information Sheet

Hello. My name is Katherine Gulliver.

I work at Plymouth University, doing **research**.

Research is finding out things, writing about it and telling others what you have found out.

I would like to visit you at your **school**, to do some research with you.

I would like to **record our conversations** on a recorder so that I can listen to them after.

I would like you to

- take me on a **tour** of your school. You can choose a friend from your class to join.
- take **photos** of your school
- look at the photos of your school with me and **talk about why you took them**
- have a **video** of you talking to your teacher, or doing an activity

Remember:

- You do not have to answer my questions.
- You can **say no at any time**. 🚫
- You can show me a Red card to stop, and a Green card to carry on doing research.

If you want to do some research with me, then I will organise a visit with your school.

Do you have any questions?

Katherine Gulliver

katherine.gulliver@plymouth.ac.uk

Plymouth University

Parent/Guardian Request for participation in Research Project

Dear Parent / Guardian,

The aim of this research is to understand how children with WS interact with peers and adults in schools, with a view to demonstrating inclusive research which ensures children with disabilities can actively participate. It is therefore important that I involve children within my research, giving them opportunities to show or tell me about their school. The research will be overseen by supervisor Dr Jan Georgeson janet.georgeson@plymouth.ac.uk.

I am writing to ask for your support in this research. If you are in agreement, there are four aspects.

- I would like to visit your child in their school. Through a child-led guided tour of the school, and an activity where your child takes photos, I aim to understand how they perceive their school, what they like to do and who they spend time with.
- Take a video of your child interacting with a teacher or assistant in a small task, conversation or activity.
- Talk to your child's classroom teachers and/or assistants about their perceptions on WS, education and social skill development.
- A follow up visit to your child's class where all children and staff can share, explore and develop how to interact with each other

Participation in this study is completely voluntary and all participants are free to withdraw and have their data securely destroyed at any time prior to the data being anonymised. My contact details are below, please let me know your preferred form of contact. I look forward to hearing from you.

Yours sincerely,

Katherine Gulliver
PhD Student, Plymouth University
katherine.gulliver@plymouth.ac.uk
Tel: XXXXXXXXXX

Headteacher Request for participation in Research Project

Dear XXXXXXX,

I am currently a PhD student at Plymouth University conducting a research study investigating how children with Williams Syndrome (WS) interact with others in mainstream primary schools. As you may be aware, I have been in contact with XXXXXXX, whose XXXX XXXXXX attends your school. My personal background is I have grown up with a brother with WS, who is now 29years old. Furthermore, I have worked in various educational and care provision for children and young people with a range of special educational needs and or disabilities.

The aim of this research is to understand how children with WS interact with peers and adults in mainstream schools, with a view to demonstrating inclusive research, which ensures children with disabilities can actively participate. It is therefore important that I involve children within my research, giving them opportunities to show or tell me about their school. The research will be overseen by supervisor Dr Jan Georgeson janet.georgeson@plymouth.ac.uk.

I am writing to ask for your support in this research. If you agree, there are three aspects.

- I would like to visit your school to spend time within W's classroom. Through a child-led guided tour of the school whilst W takes photos, discussions and observations I aim to understand how she perceives school, what she likes to do and who she spends time with.
- Video of an interaction between W and a teacher or assistant, during a small activity, task or conversation.
- An audio-recorded discussion with W's classroom teachers and/or assistants about their experience working directly with children with the specific disabilities.
- A follow up visit to W's class where all children and staff can share, explore and develop how to interact with each other

Participation in this study is voluntary, all participants are free to withdraw, and have their data securely destroyed at any time prior to the data being anonymised. Please find attached consent and information forms. I am happy to organise a phone call, email or skype meeting at a time of your convenience to discuss further details.

Yours sincerely,

Katherine Gulliver

PhD Student, Plymouth University

katherine.gulliver@plymouth.ac.uk

Tel: XXXXXXXXX

Interview guide

Interview Guide for School staff

Welcome and thank interviewees for agreeing to meet and share their thoughts and opinions.
Explain the purpose of interview and the how the data is collected and that it will be recorded and analysed.

Get signed and verbal permission to use the data provided and for the interview to be recorded.

Start recorder and begin the interview with background questions.

Time in job
Job roles and responsibilities

Experience of SEN - Have you taught pupils with other SEN, genetic conditions? Have you experience of teaching in special settings? Professional development?

Reaction to having a child with WS - What did you know about WS? Where did you get information/support? - Experiences early in the year?

The child with WS - Tell me about … (personality, strengths, interests, challenges).

Who does (child) spend time with, why?

Discuss how you support (child) in different aspects of school life

Tell me about (child)'s behaviours and social development. What approaches do you use to support (specific behaviour)

Check interviewees are comfortable and continue with open-ended questions on social skill support.

What support do you think (child) needs to develop their social skills? How is this implemented? How effective is it?

How do you encourage social inclusion and development in the classroom? How does the school encourage this throughout? Describe the school ethos and principles

What does the school do to support you in delivering social skill interventions? E.g. training, meetings, ethos, headteacher, SENCO

What would you do differently to help (child) social skills if you could? What would you change? Why?

Those are the questions I have written down here, is there anything else you'd like to tell me?
Thank interviewees for their time and let them know they can always contact me if they have any questions.

Appendix 3

Data analysis sample

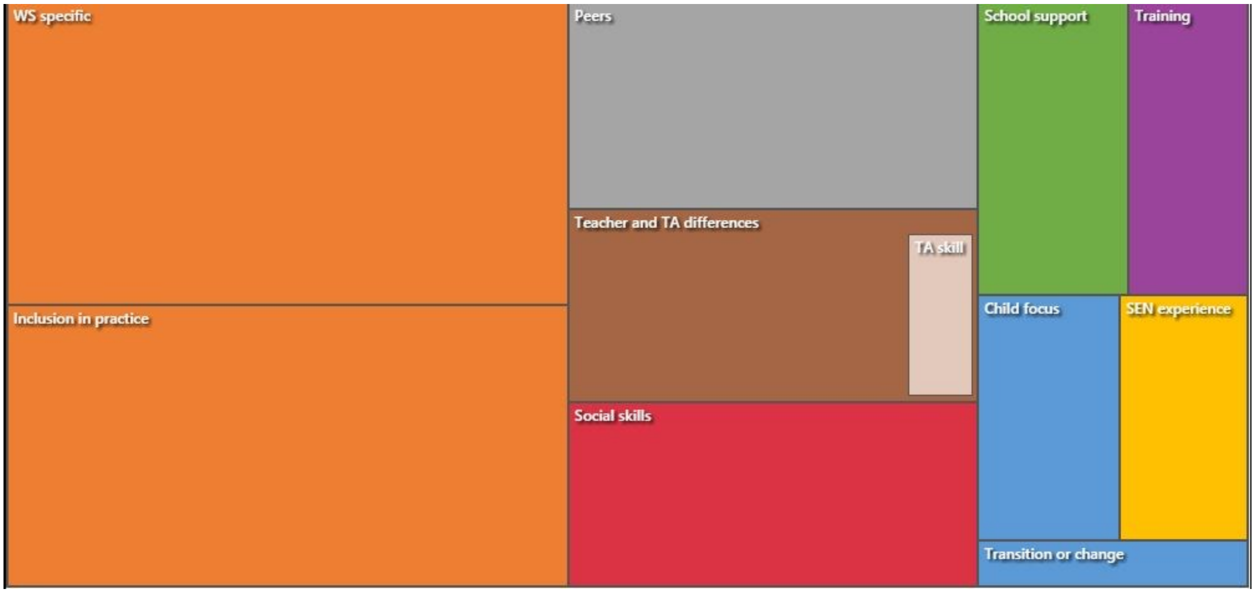


Figure 31: Staff interview data analysis

Transitions

<Files\\Teacher Interview> - § 2 references coded [6.33% Coverage]

Reference 1 - 3.95% Coverage

I think the beginning of the year I found it quite tricky to integrate her into the class because I think she… obviously in her head she was like, “It’s going to be like (Reception) class,” and actually obviously it wasn’t. I think to her, for the first couple of weeks she was very much like, “I just feel really lost. I don’t know what’s happening.” If I could re-do the year, I would want to take that away and be like, “It’s okay. You know what you’re doing.” So towards the end of last year I spent a lot of time with the class during golden play or just randomly, just randomly walking into A’s class because it was me and my partner teacher at the time. So I’d let her teach and I’d go off and hang out with them so then they recognised my face and knew that I was familiar. I should have done that with Saskia as well, rather than just looking at me and knowing me, because she was very comfortable with me at the beginning but it was just the classroom.

She was like, “I just don’t know. It’s a big classroom. There’s big chairs. I’m not familiar with the whole place.” I should have taken her around and gone, “This is your classroom. This is where you’re going to sit. Do you want to decorate it, put things up,” so then when it came to September she knew. So she was like, “Okay, I’m aware,” because she knew… so Abi and I every Friday we open up our fire exit doors so then we have free flow play so the receptions can come into Year 1 or Year 1 can go back into reception and play together. She’d always look at my door but never come in. So she was aware that that's the door she had to go into. She was like, "Cherry class," but she'd never go into it. I think if I were to have another child like that, I'd probably change it and go, "Let's have a conversation about this. You're coming into my class." I know a transition book was sent home for mum so then she could show her during the half term, go, "This is your class." There was a picture of me and the coat racks and the outside bit but not the inside.

So she was aware of everything else but just not the inside. Then I then noticed her going, "I'm not sure," and just having a bit of a worried face. She was still smiling. I'm like, "You can say you're scared. It's okay."

Reference 2 - 2.38% Coverage

I'm living with a couple of primary school teachers for this week and they said it's still transition term, isn't it, and actually then they thought, "It is weird. You've always been apple class and now suddenly you're cherry class." But you're the same class of children…

R: It's all of you just moving up, that's it. It's a lot to take on. Even when… bearing in mind it's the first week back of term two, when we're in assembly and we're like, "Cherry class," half of them are still sat down. I'm like, "No, that's you. Come on. Let's go all of you." They're like, "No, we're…" I'm like, "No, you're not apples. You're cherries. Come on, off we go." I think little things like that, I think if I'm still in Year 1 next year possibly just giving them a book going, "Now you're in cherry," with their face on it or something so then even if they take it home and they forget about it, at least it's a physical thing of, "This is what I am now. I'm not an apple. I've moved up." But yes, transition is what I think I'd take into more account. I think it was so much. I was like, "I want to get to know the kids," and then forgot actually they have no idea about my classroom and they don't know what's going on. I think with Mrs Rogers as well it really hit me because I've never taught reception. I'm aware of what they do but I've never taught it myself.

<Files\\ TA interview> - § 2 references coded [2.81% Coverage]

Reference 1 - 1.84% Coverage

Any change of routine, I don't know, like we have whole school days where we stop lessons but we do activities in our house groups and she's not that keen on those, especially in Reception, I had to just literally pull her out because she wasn't coping. It might be that there were four different activities throughout the day, two in the morning, two in the afternoon and then we had to follow our house round and do these activities.

In Reception, that was too much and K just said, don't do it, she doesn't need to do it, she doesn't need to be doing that, you can just sit quietly in the classroom, play, do some intervention work. If she wants to go back and try another activity, she can try it but there's no point, if she's not happy with it. It wasn't just her; we have several children that can't cope with that change of routine for various reasons, but she's got so much better at that now.

Reference 2 - 0.97% Coverage

So, she will sit and focus but once she's had enough, that's it, she's off and she just says, right I'm off now, actually she was done anyway but that was 10-15 minutes, that was her max really. So, that's the part that will be the test really, as in when we go to Year 2, where they don't necessarily follow … well they did follow continuous provision but the teacher felt that it wasn't working, so they've gone back to that classroom environment, that will be a challenge for her.

TA skills

<Files\\TA Interview > - § 1 reference coded [1.05% Coverage]

Reference 1 - 1.05% Coverage

She needs a lot of encouragement, telling me, keep asking her questions, what are they doing… If you don't, she will point and say two words, even though I do understand what she's saying but you've got to ask her to verbalise the sentence.

<Files\\ TA interview> - § 2 references coded [6.20% Coverage]

Reference 1 - 1.71% Coverage

Sometimes if I know that she's come in and it's not going to be a great day, we tend not to do too much because actually that can last a whole day and it will las the whole day. When she's really not with it, she does this thing where we just have to … because sometimes, like yesterday afternoon, when things get a little bit chaotic, she'll generally stand with you and if you say, right O we need to go and line up at the door now, she'll be fine.

But yesterday afternoon, she gets a little bit where if you're trying to say something to her, she won't make eye contact, she'll try and run away. So, you have to just literally hold her by her shoulders and stop her, slow her down. I kneel down on the floor and look at her and say, right O look at me, listen to the instruction. Then you need her to calm before you then carry on.

Reference 2 - 4.49% Coverage

I saw some of the work that the other schools had done. They tried as much as they could to stick to the timetable of school, E's TA, she showed me her book one day and E had been writing about the Tudors and I'm thinking, what she just literally copying words and I said, I don't want that for L, I want his words to have meaning, I want him to be able to write a really short sentence about something that he's passionate about.

So that he can actually then, two days later, read it to somebody, two or three words in a sentence and we chose the topic really, they're a really lovely big close family, he's got aunts and uncles in the village, he's got cousins that come to this school, his sister is still here at the school. So, C used to print off photographs, so any time that he used to do taekwondo, passionate about his taekwondo. She would print off about the latest belt that he got or if they'd been on holiday in half term, things that he did on holiday, his pets, his family.

He would happily sit, I'd show him a photograph and I'd say, look L and he'd be like, oh yes. I said, well what are going to write about that today then and it might just be that he'd been somewhere at the weekend and they got an ice-cream, just two or three words in a sentence but it meant something to him. I didn't want to go down that road of you're just going to copy this because this is about the Tudors, rubbish. It's not something that he's going to even comprehend, and mum was onboard with that, she was like, just go for it, this is amazing.

At the end of Year 6, I mean I kept all of his workbooks and she had them, she just said, this is the most fantastic thing, this memory of you and these books, this is just amazing because all through, I used to send home, we were really creative with his work. I haven't got to that stage with O yet because she hasn't got that sitting down and doing, he would just sit and we would cut and stick and make and sew, that's what I need to get her doing, some sewing, even if it's like, I've got one in her box actually, like the threading for her physical, I'll get that out, it's just every now and again, you think, I haven't done that for ages.

<Files\\TA interview> - § 1 reference coded [4.98% Coverage]

Reference 1 - 4.98% Coverage

I don't know how, at the moment, to get there, but what I'd like to see for her is that social bit more than anything. At the moment, it's probably obvious to anyone looking in, she feels… I don't know if she does feel different that's not what I mean actually… but she's separate from the others some of the time, as in, not going initiating play, I guess I'd like to see that, I don't know whether there's something else. In this job, it's ongoing thinking all the time about what can I do to get that right, what can I do to get that right?

What I mean is, by that, it was only last night that I started thinking: "She's not queuing up correctly, we've been doing this for a year now." So, I thought: "What can I do?" I thought if I get a photo, I might put it on the wall next to where we queue and one on the other doors, both doors, and just point to it every time we queue up and see how that goes. I used to have things on here but that didn't go so well, so I might just try it with them on the wall and point to it. It's like a process all the time, you're constantly thinking: "How can I get round that?" I probably could be putting my mind to how I can get her to interact better and see if there's something I could be doing to support her a bit more.