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"It's such a battle": A phenomenological account of raising a child on the autistic spectrum; a battle with bureaucracy and behaviour

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Abstract

A sharp rise in the prevalence of Autism Spectrum Disorder (ASD), has led to it becoming one of the most widely researched neurodevelopmental conditions. Although the predominant focus in autism research is child centred, research on parent outcomes has highlighted considerable impact, in terms of parent's mental health and wellbeing. Previous studies have shown that parents of children with autism suffer extremes of distress, in excess of that of parents of children with other disabilities. However, why this is so is less understood. Interpretative phenomenological analysis was used to analyse data, gathered from semi-structured interviews of seven parents raising children diagnosed with autism. Through qualitative investigation of parents' lived experience, four main themes emerged; bureaucracy, behaviour, socio-affective impact and a child-centred focus, with bureaucracy emerging as the superordinate theme. Analysis of the data revealed two key areas underpinning parental distress; a protracted diagnostic and statement-of-education process and an absence of professional support and information to manage challenging behaviour. Suggestions for improvement were discussed, in terms of streamlining bureaucratic processes, through better awareness of autism in frontline health professionals and the provision of parent training.

Introduction

Rationale

Parenthood can be inherently challenging. Nevertheless, general consensus amongst mothers and fathers, suggests the rewards far outweigh any difficulties (Sofronoff & Farbotko, 2002). For parents of children diagnosed with autism, the experience is not so balanced and can be overwhelming (Walsh, Mulder, & Tudor, 2013). Whilst the demands of caring for any disabled child can be stressful, the message that permeates current literature suggests that parents of autistic children, experience stress and anxiety levels far in excess of those experienced by parents of even the most profoundly sick or disabled children (Steiner, Koegel, Koegel, & Ence, 2012; Matthews, Booth, Taylor, & Martin, 2011; Pottie & Ingram, 2008). This phenomenon has been repeatedly found in studies over many years (Hartley, et al., 2010; Myers, Mackintosh, & Goin-Kochel, 2009; Pottie & Ingram, 2008), however 'why' this should be so, is less understood.

In an attempt to illuminate this question, this study will explore the lived experience of raising a child on the autistic spectrum, grounded in the real-life stories of seven mothers and fathers. Through analysis of these rich personal narratives and naturally emerging themes, I will aim to unpack the mechanisms that underpin such extreme affective and social consequences for so many parents.

Prevalence, incidence and aetiology

Since the early 1980's, according to current UK statistics, reported rates of autism have risen dramatically, from 5 in 10,000 to more than 1 in 100 (The National Autistic Society, 2013). U.S. figures are substantially higher at 1 in 68 (Centres for Disease Control and Prevention, 2015). Although the epidemiology of this is still being heavily debated, both a broader diagnostic criteria and better detection methods have been posited as responsible (Blumberg, et al., 2013). Currently, there are approximately three-quarters of a million people in the UK with autism, 100,000 of whom are children. This makes autism the single most common lifelong developmental disorder, touching the lives of over 2 million people every day. Despite its prevalence, little is known about autism's aetiology. Potential triggers from failed bonding or 'cold parenting' to genetics have been speculated, however thus far, scientists have been unable to pinpoint the cause. This ambiguity can be a source of stress for parents who look for answers, but find none.

Working definition and history

As a heterogeneous neurodevelopmental disorder, autism is characterised by deficits in social reciprocity and communication, often with restricted repetitive or unusual behaviours and interests (American Psychiatric Association, 2013). Being a spectrum condition, individual differences mean that no two individuals with autism will be affected or present in the same way (The National Autistic Society, 2015). Some may be highly functional and relatively unaffected by their condition, whilst others may have an accompanying intellectual deficit and require lifelong specialist support. Comorbidity with internalising disorders, particularly anxiety, is common (van Steensel, Bogels, & Bruin, 2013), as are splinter skills such as hyperlexia and albeit less frequently, savant abilities (Treffert, 2014). These often emerge early, masking other deficits. This can further complicate and delay diagnosis, as diagnosticians endeavour to avoid incorrect labelling (Fleischmann, 2004; Treffert, 2014).

Raising a child with autism

The primary concern for most expectant parents is that their child will be healthy. Suspecting a problem with a child's development, strikes fear into the heart of any parent. For mothers and fathers of autistic children, the realisation that 'something is wrong' often comes after a period of normalcy, met milestones and established familial expectations (Davis & Carter, 2008). As children are rarely diagnosed in infancy, diagnosis can be a catastrophic event, as it is usually made during or after toddlerhood, when symptoms start to become more evident (Woodgate, Ateah, & Secco, 2008). Although an adverse reaction could be expected and understood from any parent receiving a diagnosis of disability for their child, for parents of autistic children, the scale of impact in terms of disrupted functionality and affective consequences is unprecedented (Nealy, O'Hare, Powers, & Swick, 2012).

Described as 'a watershed event' or 'the moment lives were forever changed', the diagnosis commonly elicits feelings of shock and expressions of disbelief or denial, irrespective of whether or not the diagnosis was anticipated (Fleischmann, 2004; Ludlow, Skelly, & Rohleder, 2011). Feelings of loss and grief for the child they thought they had often follow, as parents frequently report a sense of bereavement, particularly in cases where the child seemed to develop typically before becoming symptomatic (Lutz, Patterson, & Klein, 2012).

Diagnosis signals much adjustment. Parents must come to terms with their child's condition, accommodate its implications and adjust their expectations (Ludlow, et al., 2011). Whether already present or emerging, parents must also confront and manage daily communication and behavioural difficulties, without prior preparation or training and often unsupported (Nealy, et al., 2012). Social isolation, depression and stigma are common side effects, often exacerbated by judgements and misconceptions of friends and strangers alike (Hock, Timm, & Ramisch, 2012). This makes the challenge of raising a child with autism a uniquely difficult one, requiring exceptional skills and care-giving ability from often ordinary people.

Autism parenting and functional disruption

The disruption of normal daily function is often cited as having the biggest impact on parents (Nealy, et al., 2012), with behaviour management the frequent catalyst for the disruption. Challenging behaviour is a major trigger area for parental distress as it impacts across so many domains (Myers, et al., 2009). Social communication and interaction outside the family can be a particular casualty, as this is often avoided by parents, in fear and anticipation of such behaviours occurring. Normal activities such as shopping or attending appointments can be impossible without the child becoming anxious and placing themselves in danger, leaving parents feeling tied to the house (Ludlow, et al., 2011). Parents that do attempt social engagement, often report regret in doing so, as manifest behaviours are frequently socially inappropriate and exigent.

The responses of others can be particularly painful for autism parents. Reaction to child disability is usually met with tolerance, accommodation and compassion as most disabilities have visible characteristics or cues. These cues such as a physical difference or the presence of a wheelchair facilitate understanding and attitudinal adjustment from others. Autism provides no such clue as autistic children have no particular defining features. They generally appear neurotypical until unusual speech patterns or behaviours present, or they become overwhelmed and dissolve into autistic 'meltdown'. These high states of arousal, often mistaken for naughtiness, are difficult to manage as well as to witness. They can be disturbing for those who do not

understand them and public reaction can be one of repulsion and distancing (Fleischmann, 2004). For example, a mother struggling to get a wheelchair aboard a bus is more likely to be helped than a mother trying to get an autistic child aboard who is experiencing an anxiety triggered 'meltdown'. These actions, inactions and reactions of others are significant triggers for parental distress and form the basis for marginalisation and isolation for those with autism and the parents who love and support them. Negative social experience generally results in parents' complete withdrawal, in order to protect their child from hostile reactions that emanate from the uninformed, but also to avoid public judgements of their parenting ability (Roa & Beidel, 2009).

Paradoxically, staying at home has been shown to be equally destabilising, with parents struggling to maintain an environmental equilibrium that doesn't reflect the natural variety of real-life (Myers, et al., 2009). Even here, escaping judgement from others is unlikely, as friend and family support is rarely given in silence. A lack of understanding of autism within personal social networks can result in conflict and dissolution of close relationships, further increasing isolation (Nealy, et al., 2012).

Marriage is a close relationship frequently reported as a casualty of autism. Parents report working for many years as a 'tag-team', relying on each other, with little or no external support (Hock et al., 2011; Gau, et al., 2012). Pressures become additive and wearing and the shift in focus diverts attention away from the relationship, inhibiting reparation. Additionally, parents, especially mothers, find maintaining employment difficult due to the lack of suitable child care. This can place financial pressure on relationships and create conflict over the division of labour (Benson, 2006).

Benson (2006) described this phenomenon where one stressor engenders others, across previously unrelated areas of function, as 'stress proliferation'. It acts like ripples on a pond, emanating outward across all life domains, often with devastating consequences on mental health and wellbeing. Depression is a common outcome for parents, particularly as the full implications become apparent; there is no cure for the autistic condition and caring for their child will be a lifelong undertaking (Fleischmann, 2004). This often leaves parents in the unusual position of facing their own mortality from an early age, with the fear of what will happen to their child once they are gone, constantly hanging over them. This is something not generally considered in neurotypical parenting, as parents are still young, have strong social networks and diminishing concerns as their children get older and move toward independence. For parents of autistic children the opposite is true, concerns increase with advancing parental age (Fleischmann, 2004).

This fear is compounded by parents who look to social systems for support. The needs, behaviours and deficits that characterise autism are unremitting and complex, but the provision of professional health, education and social systems are often found to be homogenous, confusing and inadequate. Despite the increased number of families affected by this condition, there has been little improvement in terms of services for children with autism or their parents (Ludlow, et al., 2011).

In contrast, a growing body of evidence suggests the extremes of negative experience are not insurmountable and may be mitigated by empowering parents through behavioural and developmental training (Koegel, Bimbela, & Schreibman, 1996). In 1996 Koegel, et al., reported that child intervention which improved

behaviour and functionality, ameliorated parental stress and improved parents' global interactions with their children. In a more recent study, parent's sense of self-efficacy was increased as a result of bespoke parent training and education (Steiner, et al., 2012). A small body of literature suggests some parents express a benefit from their experience in terms of spiritual growth (Phelps, Hodgeson, McCammon, & Lamson, 2009) with reports of improved family cohesiveness, a reduction in stress, increased patience and a renewed appreciation of life (Steiner, et al., 2012; Hock, et al., 2012). Spirituality has also been acknowledged to be protective against depression in some cases. Parents enlisting support and guidance from their spiritual leader and community reported a strengthening of their emotional health and wellbeing (Phelps, et al., 2009), although the durability of this type of support requires further research.

The behavioural and developmental complexities of autism are as diverse as these children are in number, yet primary responsibility for the behavioural management and development of these children, is being undertaken by parents who are often thrust into the role ignorant, ill equipped and unsupported. It is unsurprising then, that as personal resources become overstretched and tested, negative effects on parents surface quickly and are typically enduring.

Qualitative research - Interpretive Phenomenological Analysis (IPA)

The aim of this study was to gain a deeper understanding of the impact of raising a child on the autistic spectrum, through analysis of the lived experiences of each participant. Research in this area has historically been dominated by quantitative enquiry, a methodological approach perhaps too reductionist when exploring the human condition. Interpretive phenomenological analysis (IPA) aims to capture the individual's context and explore the essence and underlying meaning of a person's story, revealed in their own words. Therefore this person-centred interpretive approach was chosen for its particular suitability of understanding how people make sense of their life events. Each individual narrative provides a rich contextual account of life raising a child with autism. Through free discussion and the absence of any predetermined hypotheses, a personal truth, meaning and interpretation of experience is hoped to be revealed, reflecting a unique perspective of raising a unique child.

*"When you've met one person with autism, you've met one person with autism."
Dr Stephen Shore*

Method

The study aimed to explore the lived experience of parents raising a child on the autistic spectrum, to gain an understanding of the consequences and challenges experienced by parents, who raise a child from a very different perspective.

A statement of my reflexivity

It must be acknowledged that the disclosure of a lived experience is by definition an interpretation of that experience, as a person begins to explore and make meaning of it. Interpretation of that meaning through IPA, however impartial, is subject to double interpretation once analysed by another. This may interfere with hermeneutic consistency as it is almost impossible to negate all influence of the researcher's own background and experience within the analysis (Smith, Flowers, & Larkin, 2009). Therefore as the researcher and author of this project and for the purposes of

authenticity, I would like to present my reasons for selecting this topic and declare my interest in its findings.

I have approached this subject from a position of more than a decade of shared personal experience with my participants. I am the mother of a twelve year old son, who was finally diagnosed with autistic spectrum condition at the age of four. This came after three years of immersion in a world with my child that was alien to all other parents around me and was at odds with all my expectations of motherhood. From the moment of diagnosis, I began my autism journey side by side with my son, through his early intensive behavioural intervention supporting his learning and development, to where he is today, taking his first tentative transitional steps into adolescence and emerging independence. Through him I found my motivation to begin my self-directed education in all things autism. This has led naturally to the support and guidance of other parents, an area where more research and assistance is desperately needed and where I intend to direct my future work.

Participants

Seven participants were recruited, three males and four females. Each was a parent to a child diagnosed as having an autistic spectrum condition. Each participant was personally approached by myself and voluntarily agreed to take part without incentive. All participants were either previously known to me through existing personal relationships (i.e. participant 'G' is my husband) or connected to me via a mutual membership of various community support networks and forums for parents with autistic children. To preserve confidentiality, all transcriptions were made anonymous, with names, places and identifying features modified.

Participants ranged in age from 33 to 53 years. All participants were of a similar socioeconomic position and were employed or self-employed in professional roles. All participants were married. Participants A and B were both mothers of boys with autism, aged 6 and 12 respectively. Participant B was married to the father of her son, whilst participant A was divorced from her son's biological father but had latterly remarried. Two husband and wife dyads took part. Participants C and D were married as were E and F, although participants C and D were amicably separated, whilst still sharing the family home. Couple C and D have a 15 year old son and couple E and F have a 5 year old daughter. Participant G is my husband and father to our son age 12. Of the five children of the participants, four were male and one was female. This is consistent with the 4:1 males-to-females diagnosed sex ratio of cases of autism.

Materials

All participants were supplied with a document pack. This consisted of a Plymouth University standardised form for informed consent, a research brief outlining the purpose of the study and a three part quantitative self-report inventory. Part 1 of the self-report inventory was the 60 statement NEO-FFI personality scale, to gain a broad measure of personality factors such as neuroticism, extroversion and conscientiousness. Statements such as *'I am not a worrier'* and *'I really enjoy talking to people'* were responded to on a five-point Likert scale ranging from 'strongly disagree to strongly agree'. Part 2 of the self-report inventory was the 60 statement COPE scale to indicate dispositional coping style when faced with everyday stressful situations. Statements such as *'I discuss my feelings with someone'* and *'I make a plan of action'* were responded to on a four-point scale of; 1: I usually don't do this at all; 2: I usually do this a little bit; 3: I usually do this a medium amount; 4: I usually do

this a lot. Part 3 of the self-report inventory was the 36 statement Parenting Stress Index (PSI) short form, to measure reactions to parent-child specific, situational stress. Statements such as *'I feel trapped by my responsibilities as a parent'* and *'My child rarely does things that make me feel good'* were responded to on a five-point Likert scale ranging from 'strongly agree to strongly disagree'. Statements 22 and 32 were 'choice' statements and 33 was 'quantity' selection. None of the self-report inventory statements were reverse coded.

The semi-structured interviews were conducted using a flexible interview schedule as a tool to guide discussion, Questions were informed by past literature and from personal experience. Questions that explored areas of psychological and functional impact such as *'How did you feel when you received the diagnosis for your child?'* and *'What coping strategies do you employ to manage day to day behavioural difficulties?'* were asked, but generally the schedule took on its own unique a direction reflective of the individual's experience. All interviews were recorded using a digital voice recorder and a back-up iPod recorder and uploaded to a PC for transcription. A debrief containing outline research aims, researcher and supervisor contact details was given to all participants at the end of the interview.

Procedure

Following participant recruitment, a suitable day and time was arranged for the semi-structured interview to be carried out at each of the interviewee's homes. Each participant was sent the research document pack, which they were asked to read and complete, in advance of the interview day. Consent forms were checked for signature on the day of the interview and collected with the self-report inventories, which were collated for later analysis. Married participant couples 'C and D' and couple 'E and F' were asked to complete their questionnaires separately and were interviewed on different days. The quantitative data was gathered to provide support for qualitative points but did not form a large part of the research data or analysis.

The interviews were unrestricted in length to give the interviewees opportunity to relax and engage with the process. This was to facilitate deeper exploration of their lived experience, allowing them freedom for the expression of emotional recollections without discomfiture. Although questions were designed to broadly examine the personal impact on parents of raising a child with autism, they were intended to vary according to the interviewee-led direction of the conversation, to enable themes pivotal to the individual's own experience, to emerge naturally. The interviews ranged from 30-60 minutes in length and were audio-recorded to ensure accurate transcription and analysis.

The sensitivity of this research was acknowledged, due to both the potential for participants to relive difficult experiences and the extreme vulnerability of their children. Therefore interviewees were reassured both verbally and in the research brief that they did not have to answer any questions they did not want to. Participants were assured of their anonymity and that of their data and offered post-interview support with a trained bereavement and support counsellor should they require it. Participants were also fully advised about their right to withdraw at any time and have their data permanently and safely destroyed.

Procedural analysis

The initial stage of the analysis entailed repeated engagement with the recordings and word for word transcription of all seven interviews, in accordance with interpretative phenomenological analysis (IPA) transcription template guidelines. Manually penning the interviews verbatim, enabled familiarisation with the participant's story and engagement with the data, simultaneously detailing important or revealing aspects of the dialogue in the left hand margin. The subsequent stage of the analysis involved reanalysis of significant disclosures during interview that were interpretable and exposed specific and/or recurring themes, particularly those that were psychologically revealing. These emergent themes were clustered and set out in a master table.

Quantitative results

Prior to transcription, the quantitative data scores on self report inventories were gathered and total scores produced for each parent to provide a broad measure of personality traits (Table 1), dispositional coping style (Table 2) and situational stress levels (Table 3). These raw scores were used to support qualitative points.

Table 1

| NEO-FFI (Short) | | | | | | |
|-----------------|-----------|-------------|-----------|---------|-----------|-------------|
| Participant | | N | E | O | A | C |
| A | Raw Score | 33 | 36 | 29 | 43 | 40 |
| | T Score | 66 | 63 | 53 | 69 | 59 |
| | Range | Very High | High | Average | Very High | High |
| B | Raw Score | 3 | 31 | 28 | 33 | 38 |
| | T Score | 64 | 55 | 52 | 48 | 55 |
| | Range | High | Average | Average | Average | Average |
| C | Raw Score | 35 | 19 | 24 | 30 | 37 |
| | T Score | 69 | 34 | 45 | 42 | 53 |
| | Range | Very High | Very Low | Average | Low | Average |
| D | Raw Score | 4 | 40 | 26 | 28 | 48 |
| | T Score | 32 | 72 | 48 | 42 | 73 |
| | Range | Very Low | Very High | Average | Low | Very High |
| E | Score | 19 | 26 | 33 | 24 | 37 |
| | T Score | 48 | 46 | 60 | 29 | 53 |
| | Range | Average | Average | High | Very Low | Average |
| F | Raw Score | 40 | 20 | 36 | 27 | 14 |
| | T Score | >75 | 38 | 65 | 40 | <20 |
| | Range | Above Scale | Low | High | Low | Below Scale |
| G | Score | 23 | 29 | 36 | 33 | 38 |
| | T Score | 57 | 53 | 65 | 52 | 57 |
| | Range | High | Average | High | Average | High |

Table 2

| COPE Scale - General Coping Disposition | | | | | | | | | | | | | | | |
|---|--------------|--------------|--------------|-------------|-------------|-------------|--------------|-------------|--------------|-------------|-------------|-------------|-------------|-------------|-----------|
| Ppt | AC | P | SISS | SESS | SCA | TR | PRG | RC | A | VE | D | MD | BD | ADU | H |
| A | 16.00 | 15.00 | 15.00 | 8.00 | 13.00 | 16.00 | 16.00 | 13.00 | 12.00 | 10.00 | 4.00 | 10.00 | 4.00 | 1.00 | 12.00 |
| B | 13.00 | 12.00 | 8.00 | 5.00 | 9.00 | 4.00 | 10.00 | 8.00 | 7.00 | 4.00 | 8.00 | 9.00 | 6.00 | 1.00 | 5.00 |
| C | 11.00 | 13.00 | 14.00 | 14.00 | 10.00 | 4.00 | 12.00 | 8.00 | 12.00 | 15.00 | 4.00 | 11.00 | 5.00 | 1.00 | 9.00 |
| D | 13.00 | 16.00 | 10.00 | 13.00 | 7.00 | 16.00 | 16.00 | 7.00 | 13.00 | 4.00 | 4.00 | 15.00 | 4.00 | 4.00 | 16.00 |
| E | 14.00 | 16.00 | 9.00 | 9.00 | 9.00 | 4.00 | 14.00 | 10.00 | 12.00 | 7.00 | 4.00 | 8.00 | 4.00 | 2.00 | 5.00 |
| F | 9.00 | 9.00 | 8.00 | 9.00 | 9.00 | 4.00 | 10.00 | 9.00 | 12.00 | 15.00 | 10.00 | 8.00 | 10.00 | 2.00 | 7.00 |
| G | 13.00 | 15.00 | 11.00 | 10.00 | 12.00 | 7.00 | 13.00 | 11.00 | 12.00 | 8.00 | 7.00 | 8.00 | 4.00 | 1.00 | 10.00 |
| Mean | 12.71 | 13.71 | 10.71 | 9.71 | 9.86 | 7.86 | 13.00 | 9.43 | 11.43 | 9.00 | 5.86 | 9.86 | 5.29 | 1.71 | ND |
| Pop-Mean | 11.89 | 12.58 | 11.50 | 11.01 | 9.92 | 8.82 | 12.40 | 10.28 | 11.84 | 10.17 | 6.07 | 9.66 | 6.11 | 1.38 | ND |
| SD | 2.26 | 2.66 | 2.88 | 3.46 | 2.42 | 4.10 | 2.42 | 2.53 | 2.56 | 3.00 | 2.37 | 2.46 | 2.07 | 0.75 | ND |

Note: Active Coping (AC); Planning (P); Seeking Interactive Social Support (SISS); Seeking Emotional Social Support (SESS); Suppression of Competing Activities (SCA); Turning to Religion (TR); Positive Reinterpretation and Growth (PRG); Restraint Coping (RC); Acceptance (A); Venting Emotions (VE); Denial (D); Mental Disengagement (MD); Behavioural Disengagement (BD); Alcohol and Drug Use (ADU); Humour (H)

Table 3

Parental Stress Index - Situational Coping

| Participant | | DR | PD | P-CDI | DC | Total Stress |
|-------------|-----------|----|--------|--------|--------|--------------|
| A | Raw Score | 24 | 45 | 26 | 49 | 120 |
| | %ile Rank | | 97 | 85 | 99 | >99 |
| | Range | | Upper | Upper | Upper | Beyond |
| B | Raw Score | 22 | 43 | 37 | 48 | 128 |
| | %ile Rank | | 96 | >99 | 98 | >99 |
| | Range | | Upper | Beyond | Upper | Beyond |
| C | Raw Score | 24 | 38 | 46 | 50 | 134 |
| | %ile Rank | | 94 | >99 | >99 | >99 |
| | Range | | Upper | Beyond | Beyond | Beyond |
| D | Raw Score | 24 | 31 | 49 | 33 | 113 |
| | %ile Rank | | 80 | >99 | 85 | >99 |
| | Range | | Normal | Beyond | Upper | Beyond |
| E | Raw Score | 22 | 38 | 17 | 33 | 88 |
| | %ile Rank | | 94 | 40 | 85 | 89 |
| | Range | | Upper | Normal | Upper | Upper |
| F | Raw Score | 29 | 43 | 20 | 46 | 109 |
| | %ile Rank | | 96 | 55 | 97 | 97 |
| | Range | | Upper | Normal | Upper | Upper |
| G | Raw Score | 16 | 27 | 19 | 34 | 80 |
| | %ile Rank | | 60 | 50 | 87 | 76 |
| | Range | | Normal | Normal | Upper | Normal |

Note. Defensive responding (DR) (sig if <10); Parental Distress (PD); Parent-Child Dysfunctional Interaction (P-CDI); Difficult Child (DC).

Analysis and discussion

The purpose of this qualitative study was to explore the lived experience of parents raising children with autism, a responsibility often portrayed as negative and extremely challenging. Previous research has demonstrated that parents of children with autism, experience higher levels of distress and have poorer mental health outcomes than parents of children with other disabilities (Steiner, et al., 2012). However, there is a dearth of research to suggest 'why' this is so.

Interview analysis revealed four main themes in terms of recurring frequency; bureaucracy, behaviour and the socio-affective consequences, all profoundly interrelated and contingent on one another, with an underlying child-centred focus implicit throughout. This interrelation has been preserved within the discussion, to avoid imposing artificial distinctions on a complex and heavily interconnected data set. However, it is the theme of bureaucracy that saturates these narratives and deeper analysis has revealed it to be both the root and potential remedy of much of the early distress, experienced by parents of children with autism. As the superordinate theme, bureaucracy will be the main focus of this discussion. I will attempt to explain how bureaucratic function is both enmeshed in and responsible for, much of the behavioural and socio-affective impact and with a dichotomous participant comparison revealed in the data, illustrate how manipulation of this one variable could drastically change the experience and outcome for these parents.

Bureaucracy and behaviour in the pre-diagnostic context

From the moment a parent notices something is amiss with their child and professionals are engaged, the child and the parents become part of process that is alien to them and can be expensive in terms of personal resource, at an emotionally vulnerable time. In this study, parents' reports of the bureaucratic process and professional engagement, can be broadly categorised as either positive or negative and time-framed in terms of watershed events, such as life pre and post diagnosis.

For some parents in this study, the pre-diagnostic phase and assessment period was particularly negative. They reported feeling alone in their initial concerns for their child, unheard and unsupported by health professionals and assumed to be 'over-anxious' parents. Early suspicions about their child's development, gave way to desperation as behavioural symptoms emerged. Parents tried desperately to understand what was happening to their child and make sense of their family life, which was developing contrary to their expectations, at odds with child raising experience and was noticeably different from other families in their social circle.

Ppt C L77-79 "...I was at the end of my tether to be honest, I didn't know what on earth to do"

Ppt D L35-42 "... he didn't interact, the way he, he was just completely different from everybody else's child, it was all the bad behaviour, the shouting the screaming, the 'no no no', the smearing when he wasn't in a nappy and all that, which had a devastating effect at that time ..."

Already anxious about their child's aberrant behaviours, parents describe discussions with front line health professionals as doing little to alleviate their concerns, even leaving parents with doubts about professional competency.

Ppt B L126-128 "... the doctor's going 'no you don't need a referral there's nothing wrong'..."

Ppt C L221-227 "... the doctor then turned around and said well that's ok so we can't, won't, he's not autistic, can't be, you know, so obviously he's not autistic [laughs] you know so you know we we, just, they weren't sure, they didn't have a clue then."

Managing challenging behaviour is a theme that winds through parents' narratives. A lack of skills for effective behaviour management of an autistic child, coupled with the response behaviours of others, underpins much of the socio-affective negativity that parents experience.

Ppt C L521-527 "... it's very isolating it's very lonely um you know, even so much as going to the pre-school groups and play groups you know, your child is the child that every mother grabs their child away from."

A disparate bureaucratic process plays a significant role in exacerbating this negativity. This is reflected in parents' frustrations when engaging with professionals, heard in their frequent appeals for edification, to know '*what to do*', but getting no response.

For most parents of this study, their child's behaviour was the first indicator that something was not as it should be.

Ppt C L18-25 "knew something was wrong with John from 9 months old when I couldn't console him, couldn't um appease him when he was crying um when he was laying in the street screaming 'cause I couldn't move him when I was trying to take him down the shops"

Parents describe struggling to navigate their child's behaviour, which was frequently 'odd', even aggressive on occasion, but often simply dangerous to the child themselves. Parents interpret interactions with their child as being 'on duty' or 'high alert', a response that does not foster deep engagement and affection with the child, removing much, if not all of the joy of parent/child relations.

Ppt D L389-397 "how do I deal with this behaviour, how do I stop my son from hitting me in the face? ... How do I stop him hitting my wife in the face? Um, these, Steven was just about born then, ... there was a lot of hitting and punching to do with a very young child"

Ppt F L683-687 "so anywhere, anywhere outdoors, you know all the escape routes have to be noted ... all the areas where she can hurt herself"

Maintaining this type of vigilance was exhausting for parents and spilled over into multiple areas of daily life. Parents often described fearing the judgment of others when outdoors, finding their child's behaviour 'embarrassing' or 'shameful', resulting in self imposed isolation impacting psycho-social functioning.

Ppt A L219-222 "I was embarrassed by his behaviour, I didn't know how to handle it, I didn't like being the mum on the playground that everyone hated..."

Without knowledge of behaviour management and with no professional support in this area, some parents felt unable to attend social events. The result of this was to allow external relationships to wane as the cost of personal resource to maintain them, was often too expensive. Parents made frequent cost/benefit decisions as to whether the social engagement was important enough to warrant their effort, often opting to stay at home. This retreat behaviour is not unusual with autism parents, a collateral effect of being unskilled in behaviour management (Roa & Beidel, 2009).

Ppt A L991-998 "I no longer practice the art of engaging with people in a social situation ... no, I've forgotten how to do it. Don't have the confidence to do it anymore"

The cumulative socio-affective impact of these decisions was crippling for some parents, creating a spiral of withdrawal which was impossible to come back from,

particularly as parents prioritised personal resources for their child, such as time and energy, leaving little but the bare minimum for themselves.

Conflicting opinions within the professional community as to the developmental difficulties of these children, further exacerbated some parents' frustration and anxiety. Parents felt torn, under pressure to take action from education professionals on one side, who like the parents had noticed a problem, only to be summarily dismissed by health visitors and GP's on the other. Parents describe front line health professionals as having a chronic medical model bias, with a reluctance to even consider mental health issues in children, preferring instead to level responsibility at parents for being unskilled or over anxious.

Ppt C L28-41 "...even to the point when he was running down the hall and bit the walls, you know it's 'bad parenting' "nothing wrong with the child". Even the primary, no the pre-school they were having problems with ... but we had no support from any professionals at all..."

Ppt B L120-121 "... it made us feel a bit like piggy in the middle ..."

As front line health professionals were also the gatekeepers to specialist help, parents felt stymied, undermined and tangential in the progress of their child. They expressed feelings of helplessness and living in 'a nightmare' as they 'watched' their children continue to develop atypically. Parents remained on the outside, looking in, unable to reach or connect with their child, whilst their concerns continued to be met with indifference. This approach by health workers often led parents to internalise negative events, blame themselves and doubt their own parental competency.

Ppt D L52-59 "...it was our fault we couldn't do anything with him, we weren't able to deal with it, we didn't have any skills, all that was then, it was a very very low point. The second the GP said that there was something wrong, we actually then felt better"

Ppt F L223-228 "...the diagnosis, yeah, it kind of, it was a bit of a relief in that, oh-er I wasn't just getting it wrong as a parent and there was a reason for it."

This escalated anxiety in the parents as they felt powerless to do anything to help. Delays and recurring review periods increased frustration and helplessness. The depletion of personal resources was common, as parents continued to manage their high demand child on a daily basis, alone, uneducated and ill equipped.

Ppt C L259-268 "... I was talking to her [diagnosing psychologist] on the phone, and I was like, we can't get anything, you know we need some help with him, and she was like 'oh I don't really like to label him' ... I fought so hard with her on the phone, I just stopped in a little alleyway, was crying me eyes out, John was just rolling around ..."

Ppt B L168-1275 "... battles really, um yeah we got the referral to the paediatrician and I remember her just going 'we'll r-review it in 6 months time' in six months again 'we'll review him again in six months time again' I'm like 'just tell me!' ..."

Parents viewed the reticence to diagnose autism as being particularly harmful. The bureaucratic process was so convoluted, obstructive and in many parts broken, even some clinicians resorted to extreme measures, in an attempt to help parents access professional help. One parent described the conflict and shame she felt after surrendering to pressure from her GP to 'lie', in order to speed up the process.

Ppt A L471-481 "... 'I [GP] don't know how to help you, all I can do, with your permission, is write to CAMHS and tell them that if they don't get a move on, you will take your life and that of your son'. And that was the only way I could get anything speeded up for Hugh, and I agreed to it, not that I would, I wouldn't do that and I felt ashamed in having to say I would ..."

The protracted nature of the bureaucratic process often saw parents left living in crisis for long periods, barely coping from one day to the next. As autistic behaviours escalated during this time and without the requisite skills to manage such behaviours, parents' social networks became a particular casualty. Friends and family began to distance themselves from what were uncomfortable interactions. This placed substantial restrictions on social communication and further increased parents' isolation. This clearly highlights the interrelatedness and power of the bureaucratic process to impact behavioural and socio-affective outcomes.

Ppt C L250-254 "... we didn't know what the hell we were doing with his behaviour we were just sort of living day to day really and um we just didn't know what on earth to do ..."

Ppt D L593-601 "We lost a lot of friends when John was young, when he used to be invited to birthday parties at people's houses ... because he kicked off or he smashed something or he hit somebody, he never went back, then the parents stopped talking to us..."

Detachment and dissociation were recurrent within the narratives, often as protective coping strategies, as some parents reported years of 'battling' to get a diagnosis, leaving them exhausted and both emotionally and cognitively spent.

Ppt B L304-311 "... it was expected, we knew it was coming because I mean, yeah he got diagnosed last year so at the age of five, so it had taken a good four years to get to there, but I remember feeling really numb like I wasn't in the room."

For parents, the assessment and diagnosis process took precious personal resources away from their child. Their naturally inclined 'child-focus' was repeatedly diverted, as they '*did battle*' with a system that was designed to help them.

For some, the eventual diagnosis brought with it mixed emotions of relief, shock and despair.

Ppt C L86-95 "... the GP, um and he just put his pen down, leaned back in his chair and said "I think we've got problems here" and I burst into tears and cried to him and I said "thank Christ for that". I said I have known there's been problems for such a long time, but all the professionals have said it's bad parenting"

Ppt E L181-187 "... *that*' diagnosis came pretty much as a shock because we'd kind of geared ourselves up to the ADHD thing, which I'd done a bit of research about and I felt it wasn't really a big deal, but the autism diagnosis for me felt huge..."

Ppt A L266-268 "... I said to her, I can cope with the ADHD but if he's got Aspergers, I think I might kill myself"

Some parents were particularly distressed as they had expected, or were living in hope of, an ADHD diagnosis instead of autism. This was a frequent misdirection of expectancy set up in parents by professionals. Hoping for one disability over another for your child, suggests that the level of stigma, fear and misunderstanding attached to autism is so great, parents feel ADHD is somehow more acceptable. Even clinicians display a tendency to default to the expectation of an ADHD diagnosis, over the consideration of autism, which could go some way to explaining the diagnostic delays. Although ADHD is also classed as a neurodevelopmental disorder (American Psychiatric Association, 2013), it is often managed under a medical model which many clinicians are naturally inclined towards. Additionally, because ADHD is so often pharmacologically controlled, it is likely that parents were hopeful of an ADHD diagnosis to give them a 'magic pill' option and a potential end to, or at least management of, the communication and behavioural symptoms they were living with and so exhausted by. As studies show that without intensive early intervention

autism symptoms tend to remain stable over time (Howlin, Savage, Moss, Tempier, & Rutter, 2014), the reality of an autism diagnosis over ADHD, meant no remediation and a potential life sentence for both the child and their parents.

Some of the fear and anxiety surrounding the diagnosis, possibly arose from initial global ignorance of autism, as none of the parents had much knowledge of the condition, beyond pop culture and stereotypes, until it entered their lives.

Ppt D L25-28 "...like a lot of conditions you never know that much about it until it personally affects you."

For one parent, a single trial experience of the condition during her youth, was so negative, it left her with a traumatic memory, forming a conditioned response to autism that was particularly aversive.

Ppt A L142-152 "... my parent's friends had had a teenager, I knew him as a teenager, who was autistic, he couldn't talk, he couldn't communicate in anything other than grunts and he killed himself ... threw himself out of the window of the Holiday Inn..."

This parent found it difficult to separate the memories of autism related suicide from a possible outcome for her own child, an internal ideation that was both frightening and hard to let go of. Indeed, her own reaction to the diagnosis was so painful, the need to escape it, initially triggered thoughts of taking her own life.

This reaction reinforces the need for good parental support from mental health professionals. However in this study, at diagnosis, a lack of professional engagement and follow-up left many parents floundering, not knowing what to do next. Parents reported delivery of the diagnosis as being 'cold' and 'uncaring', reinforcing feelings of abandonment, isolation and of being unsupported.

Ppt A L354-367 "Absolutely nothing, no they didn't even check that I was with someone or that I was, [pause] I treat patients myself and if I'm gonna deliver information that they might not like or if they're gonna be scared, I check how they've got here, how they're getting home and if anyone is with them, and that's on a much more minor scale than this, nobody did that for me, nobody gave a toss whether I got home safely or whether I drove my car off the Severn bridge, nobody did, no."

Ppt B L704- 709 "No, in fact we've probably had less contact since the diagnosis with people ... Yeah it's just, 'there's the diagnosis'..."

Frameworks such as the 'Right from the Start' template (SCOPE, 2015), exist to provide professionals with guidelines for delivering news of child disability and supporting parents to ensure the best outcomes. However despite these guidelines, none of the study parents received support or help with adjustment to their child's diagnosis. The disparity between medical model of services and mental health services could explain why autism parents suffer such extremes of distress compared to parents of children with other disabilities. Services are simply geared to a medical model, connecting hospital and community services to the parent.

Ppt A L765-792 "On the same day Hugh was diagnosed with autism, my friend's son was diagnosed with muscular dystrophy ... his mother was absolutely inundated with information help, people coming round, sympathy from friends ... we had a coffee and she was saying "*oh, are you sick of them ringing you, giving you this, giving you that?*" and I said 'uh, no [laughs] I have none of that' and she could not believe that because Hugh's disability is different to Larry's disability, I get nothing"

Feelings of shock and fear converged on parents before and after diagnosis. Many parents describe being either immensely distracted whilst navigating the bureaucratic

process, or felt cut adrift and left without adequate guidance. Much of this distress could have been alleviated simply by minimising delay and ambiguity during the diagnostic process, a catalyst for stress and anxiety. The provision of basic support and continuity of care, would have further protected parental outcomes.

This is exemplified by analysis of the experiences of parents E, F and G as not all parents experienced a delay in diagnosis or indifference from professionals. For parents E and F, a mother and father dyad, the experience of an efficient London process model for diagnosis, was quite positive.

Ppt E L140-153 " ... it wasn't a diagnosis that we'd battled for and I've heard lots of stories where people are like, I think my child's autistic and they're battling for a diagnosis, for me certainly it's kind of the other way round, it was kind of handed to her ... I think the school system in London is very very good..."

Similarly the international process model experienced by parent G left little time to feel helpless, as support, education and intervention came promptly following the diagnosis. This is more commonplace outside the UK and the positive effects are well supported in research, particularly as child and parent outcomes are so inextricably linked (Ingersoll & Wainer, 2011; Keen, Couzens, Muspratt, & Rodger, 2010; Strauss, Vicari, Valeri, Elia, Arima, & Fava, 2012). G's access to parent training and an evidence based plan of intervention to help his son, allowed him to retain his child-focus, gave him direction of what to do next, increased his sense of efficacy and decreased stress, the benefits of which remained with him over time. 'G' experienced little disruption to family functioning and felt equipped to integrate the needs of his son into normal daily living. This perhaps demonstrates how many of the challenges parents face, that shrink social engagement and disrupt daily functioning, can be attenuated by small changes such as adherence to a simple protective framework for delivering disability news and some basic training in behaviour management.

Ppt G L144-166 "... we were kind of fortunate really being in a different country I suspect because um one of the things that the paediatrician did do for us and that that these um the speech pathologist and the um and the sort of diagnosing uh psychologist helped us with, was contact with with people who were able to offer some sort of help in terms of education and things that we could do. So literally within weeks um we we we had engaged um we had engaged a company ... the lady came around and spent time with Henry and um seemed to know pretty much what was going on with him and then quite clearly started to lay out exactly what was happening and um what what we might do to help him..."

Much of the uncertainty was eliminated for these parents who had accessed efficient processes, where professionals communicated across disciplines and worked as a team around the family to deliver a prompt diagnosis, tailored support and interventions. Being among experts who were effective communicators, was reassuring and empowering for these parents. This helped reduce stress proliferation (Benson, 2006; Benson & Karlof, 2009) across other domains of their lives, a contributing factor of high distress for parents.

Ppt E L81-91 "... they [the pre-school] did all the hard work, they filled in all the forms they got her referred to speech and language um psychologist all that kind of stuff, she had several um several sessions where she was monitored at the pre-school, obviously all the reports came back to me and I did read them all, I'm not an absent parent, but I wasn't overly concerned ..."

Ppt G L183-200 "... parent training which um personally I found um in-in-incredibly useful, um not just because it gave us an insight into in this particular case behavioural management but also um some basic advice on how to cope with what was going on around us which I think was probably one one of the most useful things that they did for us. Um the the basic the basic theme being that we should take care to look after ourselves as well as our son, because if we

didn't look after ourselves then we were doing him no service whatsoever by perhaps burning out in the process of trying to help him. So it it led to a more balanced approach ..."

Analysis of the quantitative data, reinforces the power of the bureaucratic process on parents' experience. 'Dispositional' coping, which was unrelated to the narrative experience of autism, was unilluminating, demonstrating general coping scores were within expected limits for all parents (Table 2). However, the impact of positive professional engagement can be seen in parents' overall 'situational' stress scores (Table 3). It showed a distinction in outcome between parents E, F and G, all of whom entered a pro-active cohesive mental health system with their child and parents A, B, C and D, who did not. Parents who had positive engagement with professionals, had overall stress levels similar to those expected in parents with neurotypical children, whereas, situational stress levels for parents whose experience was the opposite, were so extreme, they scored beyond the scope of the measure. These scores were irrespective of neuroticism levels, taken from the personality index (Table 1), where for example parent F had a situational stress score within limits, despite a neuroticism score that was beyond the scale's maximum. A result worthy of further investigation however, is the openness score. Parents E, F and G all had high levels of openness, as opposed to average levels of the other parents. It is possible this personality trait, coupled with a positive experience at the outset, has been protective against some of the extremes of distress.

Bureaucracy in the post-diagnostic context

For most of the parents in this study, after a period of adjustment, a sense of hope was eventually attached to the diagnosis of their child. There was an assumption that official recognition of their child's autism would activate allied services, particularly in terms of education, the battling would stop and things would fall into place. Narratives revealed some attitudinal adjustment, as parents allowed themselves to begin to feel optimistic that their child would start to make progress, particularly in terms of communication, as a result of the anticipated support the diagnosis would bring. This temporarily relieved parents of some of the stress, anxiety and uncertainty they were experiencing. For parent G, who experienced an international process model, this was particularly evident.

Ppt G L212-227 "... being given a clear path of something you can do even even if there's no guarantee of of success, at least doing something is better than doing nothing. As it happened doing something turned out to be the right thing to do in in this particular case because we could see from the data that it was having a positive effect ... he was able to integrate with his peers he was able to go to to school with little or no aide and I'm I'm pretty sure that without that um he would have needed an aide in the class"

For parents E and F, a move away from the London process model, toward family support, meant a difficult compromise, having to relinquish access to professional support with no guarantee of future access in their new location.

Ppt E L304-314 "... we're [MDT] gonna write the full report, she said, if you were staying, we'd write the full report and we'd be booking all these things for you, you know, we'd be booking all these interventions and 'getting it [autism] sorted', but because you're going all we can do is write up this report and send all our recommendations down to where you're going to be ..."

They describe a loss of continuity and having to restart the process again, due to a lack of inter-authority connection. This typifies the disconnectedness within the process, often a source of consternation for parents. Moreover it highlights the disparateness of the process, where service and support are often a postcode lottery.

Ppt E L553-561 "... the school are doing a very good job, but we are, we're back at the stage now where we're talking to the school and the GP and she's got appointment with psychologists and we've got meetings with the school and we decided that we do need to push a little bit ..."

Receiving the diagnosis, in many cases, did not herald the end of parents' lonely struggle with endemic red-tape, nor did it signal the start of a more optimistic supported phase. Instead, for some, it only intensified the battle as parents entered the education system. This increased parents' frustration, as ironically in process terms, education is a discrete system and having a diagnosis of autism did not automatically suggest a need or qualify the child, for educational or social support.

Ppt B L320-324 "actually I probably had to fight harder afterwards, because although we had the diagnosis, we didn't have the help in school, so we still had to get the statement of need"

Ppt C L369-371 " you don't realise how hard you have to fight for everything."

Parents recall the statementing process and post-diagnosis battle for support as a just another iteration of their pre-diagnostic experience, where support and progress is obstructed and delayed at every juncture.

Ppt C L346-347 " It took six months ... to get the statement."

One parent recalls the statementing process as "debilitating", having to explicitly detail the most dysfunctional features of their child's behaviours and open their parent/child relationship up to scrutiny, in order to move along the process and access educational help for him.

Ppt C L384-387 "... when you write reports on your child, it is soul destroying, because it feels like you're just betraying them ..."

Having navigated the diagnostic process, it is not surprising that parents felt tested and punished at having to 'jump through more bureaucratic hoops', to justify their child's need for specialist help. When 'awarded' support then failed to materialise, parents felt this as an additive stressor.

Ppt D L204-214 "The forms you had to fill out, the meetings you had to go to, and the people you had to chase up because they hadn't done it and, oh, left hand wasn't talking to right hand and often left hand thinks there never was a right hand, trying to coordinate it, he was supposed to get speech and language ... and that's never happened in the whole of his time."

Every change brought a new raft of paperwork, meetings and explanations of their child, to a new professional who was unfamiliar with the family, in order to maintain what little support they had, or fight to active new support. This lack of continuity was and continues to be, an enormous stressor for parents, particularly as children grow and move between child and adult services.

Ppt D L939-952 "We saw a, I think he was a clinical consultant psych, he was a consultant psychologist anyway who said that autism in his mind was a mental illness therefore he should come under CAMHS. CAMHS in Exeter say its not a mental illness and we don't wanna know him, and he'll be sixteen next year, so he'll no longer come under education and he won't come under adult for two years, we've got nobody who will have him ... for professional support, he doesn't sit anywhere."

Parents' fear and uncertainty is exacerbated as they anticipate their children falling into bureaucratic black holes in terms of service provision. As each department passes responsibility to the next, parents feel sentenced to a lifetime of bureaucracy as well as a life sentence of autism.

Beyond bureaucracy into a child-centred future

Embedded within the narratives, the interviews revealed an underlying sense of fearful urgency to create a secure future for their child. For some parents, engagement with professional services had provided little reassurance that their child would be looked after once they were gone and the glacial pace of process was overwhelmingly frustrating and anxiety inducing, as parents felt time and opportunity to do something, slipping away.

Ppt D L888-893 "my worry for John has never ever been 'whilst I'm alive' my worry for John is always 'when I'm dead' cause there's nobody there that's gonna pick up the pieces for him"

Ppt C L1028-1031 "I will fight till my last breath to get him in independent living because at the end of the day, we're not going to be around forever ..."

Parents' motivation for perseverance when others may have given up, is revealed in their intense 'child-centred' focus, which is implicit throughout. Although the participants have the same unconditional love and commitment felt by any parent, their stories have enmeshed within them a desperation to find out 'how' to help their child. Their child is highlighted as a 'life's work', as parents frequently set aside their own needs, reframe their aspirations and even compromise their identity.

Ppt A L522-524 "I am Hugh's mum, that is my purpose, nothing else can matter."

Having the child at the centre of the family is not unusual, however, it is from this position children usually grow and develop to become an integral part of family life, rather than the unique focus of it, before then embarking on their own future. Parents in this study, experienced a complete disruption to this process. Autism has altered their future expectations and kept their child firmly at the forefront of everything they do, guiding their actions, thoughts and feelings. Most parents have actively acquired information and knowledge over time and sought out their own support, often through a shared experience with other autism parents. They have also expressed a range of emotions, some are optimistic, whilst others are less so, but all have an 'eye on the future'. There is a deep sense of responsibility toward their child woven throughout the narratives, creating an absolute child-centred focus that is unremitting.

Ppt C L740-742 "it takes over your life and it's the primary thing in your whole life"

For some parents with more than one child, this has caused excruciating internal conflict and much guilt. Placing them in a '*Sophie's choice*' situation, parents feel the demands of autism, has forced them to chose one child over another. Parents have allocated personal resource based on need and have sacrificed relationships with other children, in order to maintain focus on their autistic child.

Ppt A L504-512 "The bond between my eldest son and I, and we lived alone most of our lives, just me and him, everyone couldn't believe the close bond we had, it was brilliant, [pause] I hardly hear from him, I hardly see him, that's gone, um because he doesn't understand how much attention I have to give to Hugh..."

Ppt C L488-496 "John was dangerous and it was just, it was just horrible, I couldn't even enjoy Steven as much because of the difficulties with John and that he couldn't be left in a room alone with him, he you know, you had to keep watching him all the time for the fear of what he might do to Steven."

Ppt C L981-984 "John takes all our energy, ninety-five percent of our energies and Steven's been so good and not had so much..."

However, underlying this focus is an additional motivator to redress the balance. Parents feel pressure to create an independent future for their autistic child to protect siblings from feeling the responsibility of care, once they as parents, are gone.

Ppt D L919-932 "I can't put that backpack on his brother and say 'you will do that' I can't do that I'd never do that, he's got his own person- his own life ... I'm not saying he never would but I wouldn't make it his responsibility in life to do that, never, it's not fair, it's not fair on him he's had a hard enough life already with him, without, without giving it to him for the rest of his life, and that is, that is a big worry for the future."

For some parents the need to carve a new future, was not restricted to their child, it was also necessary for themselves, as wound into the undercurrent of 'child-focus' that flowed through parents' narratives, was evidence of personal change. Whilst this was not a main theme, it is worthy of a final note and perhaps some future research, as some parents believed that life raising a child with autism, had fundamentally altered who they were. Autism had set them in a different direction and therefore changed their future. They now walked an alternative path from the one they had expected, one that was now firmly side by side with their child, a position that over time they had come to fully embrace.

Ppt G L403-418 "...in the end we became a different sort of family to the one I, I guess we might have been ... I know what this family is, I know where it's going, and um, I've got a pretty good idea of how we're gonna get there."

Ppt F L1062-1063 "...I feel improved as a person, more tolerant."

Ppt A L1024-1036 "I am a much stronger, I wouldn't say fiercer person ... I now find myself taking up the struggles of others ... that was something I didn't know was in me..."

Undergoing personal change was an important outcome for some parents and should not be minimised. Whilst this was not universal across all the participants, those who did undergo change were profoundly altered by the experience.

Conclusion

This study aimed to explore the experiences of parents with children on the autistic spectrum and understand why they experience such extreme levels of distress. Analysis of the narratives exemplifies how raising a child with autism can interrupt and destabilise normal human functioning on multiple levels, whilst simultaneously eliciting extraordinary acts of inner strength, courage and patience. These accounts depict daily battles and struggles undertaken by parents, who despite often being ill equipped and unsupported, find the resource to continue undeterred, take pleasure in the small triumphs and place a high value on normalcy.

Parents revealed two clear influences that were pivotal in the amount of distress they experienced. The first was a protracted diagnostic/education process and the second was an absence of professional support and information to help manage challenging behaviour. All parents experienced both the diagnostic process and aberrant behaviours from their child; however there was some variation in behaviour type. Although psychological theory emphasizes that objective severity bears no relation to perceived subjective impact, some behavioural challenges may have been particularly difficult to manage. The fact that behavioural symptoms were not accounted for could be considered a limitation of this study, as parental wellbeing varied according to a parent's ability to successfully navigate them. Future research should delineate behaviour extremes, to help decide the level of support needed.

This study revealed parents were broadly split in terms of early distress experienced. Parents A, B, C and D reported a negative experience and high stress, parents E, F and G engaged with a positive diagnostic process and had lower stress.

A clear finding of this study is that much of the socio-affective negativity experienced by the unsupported parents can be attributed to an absence of positive professional engagement from the very outset. Poor recognition by health professionals in the early years set the foundation for self doubt, stress and anxiety. A protracted diagnostic process affected how parents received and adjusted to the eventual news that their child had autism. Subsequent engagement with an often counterintuitive bureaucratic education system resulted in these parents having to divert their already depleted resources to fight a process that was designed to help them. This was highly stressful and resulted in periods of depression and maladaptive coping. These stress levels were reflected in the quantitative data, where the situational stress scores of unsupported parents, all exceed the scope of the measure. These parents also revealed within their narratives, debilitating emotional states, including loss of control, anxiety and on occasion, suicidal ideation. Conversely, parents E, F and G, who engaged with an effective system, avoided much of the bureaucratic stress. This was reflected in their pragmatic and accepting approach to their child's condition and lower overall situational stress scores.

Chronic delays throughout the diagnostic and statementing processes were agonising for parents, adding a new layer of distress at every juncture. This issue is not easily remedied, as it is endemic within an established system and any drastic change to bureaucratic process, often requires a political undertaking. That said, initiatives to target frontline health professionals such as GP's and health visitors, to raise their understanding and awareness of autism, would be a good place to start.

Beyond this, the most effective way to support parents is to empower them through parent training. According to Koegal et al., (2006) and Steiner et al., (2012), parent training in behavioural management and positive engagement with intervention, can drastically improve psychosocial outcomes for parents by enhancing parent/child interactions and reducing behavioural disruption. A review of the transcripts identifies poor parent/child communication and parental efficacy for managing challenging behaviour, as the root of much of the overwhelming socio-affective impact parents experienced. Therefore, providing parents with the requisite tools to communicate effectively with their child and manage their behaviour, makes practical sense. In this study, parent G benefitted from an international model of parent training and intervention. This was demonstrably protective in terms of his mental health and wellbeing. By improving parent G's efficacy, he was able to use the adaptive coping strategies he gained through parent training and minimise his stress and anxiety. This outcome is reflective of previous research findings for parent training (Ingersoll & Wainer, 2011; Sofronoff & Farbotko, 2002; Strauss, et al., 2012).

This type of intervention has also been found to have far reaching effects on emotional adjustment, as training provides parents with specific skills needed to interact with their child effectively. Through increased parent responsiveness, child reciprocity, an area of particular distress for parents, is improved. High parental responsiveness has been shown to be beneficial for autistic children, as they generally achieve superior communication skills, compared to autistic children whose parents are lower in responsiveness (Keen, et al., 2010). Therefore training parents in effective communication for autism, is longitudinally reinforcing and highlights the

importance of providing the right information and training to parents from the very outset. Parent information and training has also been shown to proliferate positive effects across other domains of function (Banach, Iudice, Conway, & Couse, 2010). Therefore in terms of clinical implications, there is some justification for parent training to be made more widely available to parents.

Over time, parents in this study did eventually acquire knowledge of autism, by seeking help and support in the form of shared experience with other parents of autistic children. However this did not happen without first enduring much distress. For parents, the more information and knowledge they acquired, the easier life became. A better understanding of autism meant parents became less embarrassed by their child's behaviour and were better equipped to explain it if challenged.

The response from unsupported parents in this study was overwhelmingly an appeal for edification, preferably at the point of first contact with professionals. This clearly signals a need, particularly when assessed against the function and outcomes of the parents who were well supported. We can see from prior research (Koegel, et al., 1996; Tzoy, Connolly, & Novak, 2006) that information and parent training in autism can have a lasting positive effect.

To conclude, the two main emerging themes of bureaucracy and behaviour may be contributory to the phenomenon of excessive distress found in parents of children with autism. This is actually encouraging as both have the potential to be ameliorated using existing knowledge, without reliance on a medical breakthrough. As a first step, streamlining the bureaucratic process is critical. Identifying symptoms and delivering a prompt diagnosis with information and support, could reduce much uncertainty, distress and parental self-blame from the outset. Following up with behaviour management training could offer genuine relief from much of the overt distress and anxiety experienced by parents, particularly in social situations. Training parents, empowers them and will likely deliver enduring benefits, critical for improved psychosocial outcomes. From the small but purposive sample in this study, it is evident that interventions such as these are needed. With this in mind, further research to develop an appropriate support package of information and training for parents, should be considered, to support and improve their wellbeing and mental health outcomes.

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