Parent and Teacher Understandings of the Needs of Autistic Children and the Processes of Communication between the Home and School Contexts

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ABSTRACT

Introduction: Autism is a spectrum condition with symptom presentation varying widely. Teachers and parents face challenges in supporting autistic children. There are similarities in how teachers and parents make sense of autism, but there may be differences in priorities and approach potentially leading to misunderstandings. Where parents are actively engaged in their child's school life the impact on outcomes is positive. SAFE with Schools is a new intervention in development designed to support parents and teachers of autistic children to build collaborative relationships. The study aims to explore understandings among parents and teachers, areas of difference and agreement and perceptions of communication between the two contexts.

Methods: Teacher–parent units (N=32) for 13 autistic children, were recruited. The parents and teachers completed reflective journals and carried out semi-structured interviews focusing on the aims of the study. A blended thematic interpretive approach drawing from IPA and Thematic Analysis methodological approaches was used to analyse the resulting data. The analysis proceeded by extracting themes for the parents and the teachers separately. Subsequently these were compared, to identify which themes appeared for both and how they were employed in similar or divergent ways.

Findings: The following 6 themes emerged from the data: *Each Child is Unique, Behavioral Differences between Home and School, Building Positive Relationships as Essential to Child's Wellbeing, Emotional Impacts of the Autism, Bureaucracy as a Barrier and Feelings of Control.* Although these themes were shared by teachers and parents there were differences in emphasis and expression in practice between the two contexts.

Discussion: The findings related to various bodies of both clinical and educational literature which highlight the need for interventions such as SAFE with Schools that take a systemic, attachment-based approach to facilitating strong relationships with and around the autistic child.

Keywords: Autism; School-Home; Systemic; Communication; Intervention

INTRODUCTION

Diagnostic criteria for autism centres on difficulties with socio-communicative interaction and restricted repetitive behaviour [1], however, autism is a spectrum condition with a wide range of presentations, vastly differing severity of symptoms and a variety of co-morbid conditions. For example, it is now widely recognised that symptoms may look very different in girls compared to boys with autism [2]. Children can also exhibit hypo or hyper sensitivity to a wide range of stimuli [3]. In addition, diagnostic criteria can be changeable and hard to interpret. For example, in 2013 Asperger Syndrome was removed from DSM-5 and a number of associated conditions combined under the umbrella term Autism Spectrum Disorder [4].

Clinicians also struggle with the overlap of symptoms between autism and other conditions, in particular attachment difficulties [5,6]. Consequently autism can be a confusing condition and generalisations about the autistic child are problematic.

Parents and teachers focus on the individual child in their care, but understandings, structure, priorities and norms at home and school may still differ and in some cases there can be a sense of helplessness, disagreement and confusion about how to respond to symptoms. In such situations home and school may be in conflict

and responses to problematic behaviour can be inconsistent, further exacerbating misunderstanding and contributing to very high numbers of formal and informal exclusions among autistic children [7,8]. Limited research does suggest some commonalities, however, in difficulties experienced by families and educational settings, particularly around secondary issues associated with autism, such as mental health problems and extreme emotional outbursts referred to as 'meltdowns' which may be particularly troublesome and concerning both at school and at home [8-11].

Social constructionist perspectives alert us to the fact that explanations and theories, including diagnoses of autism, are not simply objective entities but are given meaning in the ebb and flow of interactions and conversations at home and school [12-14]. Despite DSM-5 criteria, the meaning of 'autism' may vary in these different conversations and importantly in the interface between home and school. It might be suggested that parents and teachers need to be 'educated' in what autism is. This is hard to achieve given the debates between professionals, but also because what 'autism' means has to be translated specifically for each unique child, family and school. More radically, social constructionism suggests that how autism is understood, emerges from these interactions at home, in school and between home and school. The child, families and teachers are actively participating in constructing the autism discourse and what it means and implies. Conversely, there is opposition to these ideas, particularly within the autism community, where the discourse focuses on neurodiversity as a central feature of identity for autistic individuals. In such debates, care should be taken to avoid unfairly minimizing or negating the very real struggle experienced by families, teachers and autistic people themselves, who require a differentiated approach to their development and education

What autism means may also differ depending on context. School and home may have different beliefs, understandings and competing priorities which can potentially conflict and make the system around the child disjointed and unable to support the child in a cohesive way [15]. Parents and their children may argue that the 'difficulties' they experience at school are not necessarily generated by a personal deficit, but exist as a direct result of having to navigate the neuro-typical world, within a prescriptive framework that is not able to adjust to perceptual and experiential differences [8]. Research regarding autism is also continually evolving and parents and teachers may have different awareness of developments and of the political stances that are being adopted [16]. For example, whether the parents and teachers wish to refer to the child as 'having autism' or being an 'autistic child'. These terms have different implications for how the child is viewed, for their identity and for strategies to manage behavioural, emotional and educational issues.

Research comparing how parents and teachers make sense of autism is limited. Stone and Rosenbaum [17] explored parents' and teachers understandings of autism and found that both teachers and parents in contrast to a panel of experts tended to 'view autistic individuals as less cognitively impaired than research findings' indicate, but this was most marked for parents. They also found that in contrast to teachers, parents of children without intellectual disability tended to view autism as a more transient condition and that most children will 'outgrow' the autism. They go on to argue that this more optimistic outlook might 'serve a useful purpose in facilitating their ability to cope with the disorder' [17]. They also argue that parents and teachers both focused more on emotional factors than a panel of experts. This study highlights that such differences in understandings between teachers and parents may lead to conflicting expectations about academic achievements and the need for social and emotionally oriented assistance.

The attitudes of parents about school and teacher efficacy to support autistic children are frequently negative, and school and teacher attitudes about parental efficacy can be equally contentious, often with parents and teachers positioning each other as part of the problem instead of the solution [18,19]. The relationship and communication style between teachers and parents can range from; supportive of each other but disempowered or lacking in confidence to make adequate change to the child's behaviour and progress; to combative and blame focused, where each will blame the other for the child's behaviour and poor outcomes. Conflict between parent and teacher may share similar negative impacts to those reported widely in research into triangulation of family dynamics [20,21]. However, where a child has a diagnosis of autism, the potential for misunderstanding and disagreement is arguably greater in terms of understanding what the condition is, how best to manage the condition and to nurture the emotional and educational development of the child [17]. Where families are positively involved in their autistic child's school life, however, child behaviour, parental self-efficacy, sense of safety and effective support for the child are shown to improve [22-24].

This study stems from the development of a new intervention called SAFE with Schools which brings teachers and parents together to build stronger relationships around the child to enable the child to flourish and help parents and teachers to work consultatively together. Conflict and misunderstanding between parents and teachers involves viewing one another negatively, rather than as an essential source of support [25]. Positive interactions between systems of care, in this case, collaboration between parents and teachers, are known to be developmentally beneficial for typically developing children and children with disabilities alike [26,8,23], as well as being mutually supportive for parents and teachers [27]. SAFE with Schools is a systemic attachment-based intervention which acknowledges the importance not only of parents and teachers as attachment figures for autistic children but also as providing a cohesive supportive network around the child to facilitate transitions between home and school, enhance a sense of safety and comfort and develop mutual understandings. This study contributes to the development of this intervention by exploring parents' and teacher's understandings of autism and of the processes of communication regarding autism. Specifically, the study addressed the following questions:

- What are parents' understandings of the needs of ASC children in the home and the school setting?

- What are teachers' understandings of the needs of ASC children in the home and within the school setting?

- What are the areas of agreement and disagreement between parents' and teachers in their understandings of the two contexts?

- How do parents and teachers perceive their communication, especially areas of conflict and areas of co-operation?

This study is Stage 1 – The Exploration Phase of a larger programme of research focusing on the development of the Safe with Schools intervention for assisting teacher–parent relationships, communication and problem-solving. The findings will contribute to enhancing the effectiveness of the SAFE with Schools programme.

METHODOLOGY

Participants and recruitment

Teacher–parent units (N=32) for 13 autistic children, were recruited to the study via brochure and presentation to a West of England SENCO network, local autism family support groups and personal self-referrals from the regional autism network.

They consisted of 13 teachers and 1 teaching assistant and 13 mothers and 5 fathers (all participating fathers attended with their child's mother, 8 mothers attended alone) from 9 schools in the South West of the UK. All but one child of the parent participants had a formal diagnosis of autism, with one child on the autism pathway, confirmed by educational psychologist at a pre-diagnostic stage. Of these 13 children, 8 were male and 5 were female.

The current ethnic diversity of the West Country is inherently extremely low, which resulted in limited diversity within the sample hence all of the participants were white, with a split of 84.5% being White British and 12.5% White Eastern European with English as a second language and 3% white other. The socio-economic demographic was mixed, with 67% of parents employed either on a full or part-time basis (by default 100% of teachers were employed either full or part-time), 100% of the fathers were employed as were 54% of the mothers.

Design

Data collected for the study consisted of two parts

Reflective Journals: Parents and teachers were provided with and asked to keep a diary of notable interactions occurring between themselves and their child, at home and at school. They were asked to focus on:

- Successful interactions: Reflecting on what happened, what went well and how they felt about it;

- An interaction where a difficult or challenging behaviour was averted - reflecting on the event;

- Episodes of interactions that resulted in a negative escalation, challenging behaviour or an autistic meltdown/shutdown.

Interviews: Individual semi-structured interviews were conducted with parents and teachers to explore their understandings of autism and their experiences of the impact of autism in relation to:

- Relationships: The effect of autism on family and home, or classroom and school life;

- Participants' experience of challenging behaviour and meltdowns/shutdowns: the effect on family and home, or school and professional life;

- Parents and teachers perceptions of the each other's contexts.

The interviews also drew on questions from the Parent Development Interview, for example, in focusing on their reflections about an episode between them that went well or was problematic and their mentalisation about the child [28]. Interviews were conducted either at the participating school, in the parents' or teachers' homes, or at the university, whichever the participants chose as a more convenient and comfortable location for them.

PROCEDURE

Participation in the study required at least one parent plus the child's main teacher to take part and up to two parents and two teachers,

one of which must be the child's main primary school teacher. Future study would accommodate multiple parents to account for blended family contribution and multiple teachers to accommodate specialist and job-share teachers. Neither was required for this particular study, with parent-teacher units containing two, three or four members. Agreement from the school was also obtained. Interested parties (school, teacher or parent) who contacted the researcher, were given information about the study and asked to discuss it with the respective others, to ascertain a shared interest in taking part. An initial visit was made to the school, meeting with a member of the School Leadership Team (Head, Deputy Head and/ or SENCO with mandated authority) to gain the school's consent, and to meet potential parent and teacher participants. This initial visit served to provide prospective participants with an overview of the study and enable any questions to be asked. Interested parents and teachers were then visited separately to discuss the research in more detail, to ensure the participants' wellbeing and fitness to take part, to take informed consent and issue the interaction reflective journal that all participants were required to complete for a minimum of four weeks. The interview was then arranged and conducted and the reflective journal collected which concluded this phase of the research. The study was approved by the University of Plymouth ethics committee.

ANALYSIS

A blended thematic interpretive approach drawing from IPA and Thematic Analysis methodologies was used to analyse the accounts from the interviews and open-ended comments in the reflective journals. The analysis proceeded by extracting themes for the parents and the teachers separately. Subsequently these were compared, to identify which themes appeared for both and how they were employed in similar or divergent ways. This is an important aspect underpinning this research, as it provides the rationale for the intervention. By understanding how parents and teachers understand autism and the areas of agreement and disagreement between them, areas of difficulty and challenge can be identified and problem-solving behaviour supported through the intervention.

FINDINGS

The findings are presented in terms of the most prominent themes that were shared between teachers and parents. Although themes are presented as shared, within them there were differences in emphasis and differences in how the themes were evident in daily interactions at home and school. The child referred to in quotations is indicated by the insertion of CWA (Child with Autism) (Table 1).

Each Child is Unique

This contained the underlying theme that each child is unique and that despite the generic nature of the diagnosis they remain unique, including how they learn, interact with other children, show their feelings etc. Comments such as '*I always thought G was just being G*' or '*that's typical K, that is who she is*' permeated the parental narratives in interviews, meetings and journals. Although all parents accepted their child's diagnosis (*which some parents had expected and others did not, but all had undergone a battle over*), with many engaging strongly in the clinical autism discourse, most described their child as '*not fitting the typical profile*' of the condition. Instead, they highlighted their unique characteristics, of how autism affects them differently, often pointing out their child's strengths, talents and typicality,

Table 1: Themes shared between teachers and parents.

SL.N0	Theme	Subthemes
1	Each Child is Unique	• Autism is variable and influences each child differently • Understanding autism and how it relates to each child • Importance of not losing recognition of the child's uniqueness as a person • Impact of the label on approach to, and expectations of, the child • Diagnosis not very helpful in offering guidance for dealing with challenges • Acknowledge aspects of the child applicable to any child (being 'normal') • Build on competencies of the autism • Parents wanting child to be understood
2	Behavioral Differences between home and School	• Autism is related to anxiety • Child shows more emotions, anxieties at home • Attachment (transitions, comfort and manifest anxiety) • Holding it in - disguising feelings, anxieties at school and meltdowns at home
3	Building Positive Relationships as essential to child's wellbeing	• Relationships at school and at home - Impact of attachment • Varied relationships home/school - Sometimes felt other was doing a good job sometimes other (P or T) was not doing a good job - blame • Autism as requiring more supportive relationships • Need for reassurance through structure • Communication with home/school is important but not always easy • Practical constraints • Misunderstandings due to lack of opportunities for communication
4	Emotional Impact of autism	• Coping as a challenging, draining, stressful and exhausting • Autism as rewarding and creative • Impact on other family members • Relationship impact (husband/wife, friends, family) • Sense of urgency and a need to 'tell their individual story' to someone who would listen • Parents feeling alone and resigned to situation • Parents fear about future
5	Bureaucracy as a barrier	• Funding a barrier for support for P,T and CWA • Red tape and inflexibility of the system to adapt to the child's needs - adjustments limited • Battle perception for any help - crisis response only not proactivity • System not working for the teacher/family. Underlying pressure for results and to comply with all the rules without variation • Lack of services and being *"fobbed off"*.
6	Feelings of control	• Importance of maintaining control • Challenge to 'who I am' (adequacies/inadequacies of parenting/teaching a CWA at odds with expectations and/or prior experience) • Feelings of being out of control or loss of control

particularly when able to contradict expected autism deficits by showing, for example, empathy, humour or creativity:

"Has been an eye opener to have an autistic child, but she is so unique and special in her own way that you couldn't not love her...we'll get pictures or we'll get like, I love you sort of like, letters or things like that, and when I get pictures on my cover, I can walk from my bedroom that she's stuck pictures up and are like, "I love you mummy" (Parent).

This reflects Stone and Rosenbaum's [17] findings of more positive views of autistic children's abilities by parents, than those of experts, which may be due to parents' knowledge of their children being deep, nuanced and underpinned by an optimism and desire for a secure future for them:

"I just think...it's nothing wrong. He's just unique. Yeah, he's just unique, maybe in some areas better than others, in some areas maybe a bit behind but he's a lovely guy" (Parent).

Teachers on the other hand were mixed. Some approached their pupils from a unique perspective, by getting to know the child first, to understand them and their individual characteristics:

"It was just that period of transition of getting to know each other and actually that we- mum, dad, I and [CWA] met, we did like a mindfulness colouring activity and I said to her- '[name],' I was like, "...what's your

favourite picture to colour?" and she said, "Horse," like horse pictures so I found lots of different pictures of horses and we sat and we just coloured for 20 minutes and talked about how we could make her experience at school better" (Teacher).

Other teachers were initially more label focused, with a more classic view, adopting a clinical perspective of autism in preparation of teaching the child. In some cases, however, there was a realisation that the child did not fit their preconceptions:

"It's also made me realise that not all children with autism are what they show on the TV if that makes sense, so you will get this picture of children with autism to be very much you know, won't look at you, won't talk to you or flap, whereas this child is if you saw him in the street, you would not know that there was anything wrong if that make sense, until he had a meltdown... And that's made me realise that actually you- I can't treat all the children in here exactly the same" (Teacher).

This split strongly reflected teacher's prior experience of autism and how long they had been teaching, particularly if the number of years teaching predated the more recent educational reforms for inclusion of children with SEN within mainstream schools. Those with more years of experience seemed to maintain more homogenous or fixed ideas about the condition, the classic limitations of autistic children and the expectation of certain behaviours:

"*I have had experience of working with children with autism and I always find– personally, I kind of understand how to read them*" (Teacher).

In some cases the label became totalizing for teachers, explaining all that the child was:

Interviewer: "*And when you see [CWA] as a whole child, as a whole person, how much of that person is autism?*"

Teacher: "*I would say most of it*"

In contrast parents noticed that at times their child was the same as any other child:

"*Sometimes uh it can be like that [CWA] will uh will behave normal that nobody will notice that he's got uh maybe autism*" (Parent).

For these parents their flexible view of autism influenced their expectations for the future:

"*We keep saying he will be having a normal life and he's kind of person who he will do uh...he won't let harm...others harm himself because he knows what he wants to do and he's quite confident*" (Parent).

To less experienced teachers, the autism diagnosis was less influential; they tended to focus on the child, to understand what 'makes them tick' and enjoy their qualities:

"*She, she's very... Yeah, she just loves to follow the instructions properly which is amazing... So clever. And she like draws these beautiful pictures and she can verbalize beautiful stories as well*" (Teacher).

Teachers who were label focused with an expectation of what the child would be like, were in most cases contradicted by the reality of teaching them, recounting their surprise at how different teaching their student was compared to what they had anticipated and previously experienced, finding 'usual strategies' commonly applied to autistic children did not work and making comparisons to more 'classically autistic' children they had previously worked with. Comments such as "*He is surprisingly bright*" and "*He's really funny!*" highlights the power of the label to limit the expectations of others about the child's ability. This finding was linked to the parental desire for their child to be understood and frustration when who they are as a person was not recognised:

"*His teacher doesn't get it and never will*" (Parent).

To less experienced teachers, the label was less meaningful and the ability and potential of their child was not so surprising. This may be accounted for by a combination of factors; the increased public awareness of autism within the general populous, the fact that young teachers may have had autistic peers when they were at school (which for some was not long ago - norming for them what older teachers would not have experienced) and the improvement in inclusive practice within teacher training in recent years.

Behavioural differences between home and school

This theme was almost universally common to all parents and teachers, and almost entirely focused on challenging behavioural presentation. However despite this, no pattern of unification emerged. All parents and teachers experienced difficulties, but parents and teachers responses toward each other about it varied. What was consistent, was the level of parent or teacher stress, frustration or concern, related to the perceived degree of difficulty they had from their child and the level of disruption, destruction, distress or aggression they experienced at home or school, which also influenced their opinion of the corresponding parent or teacher:

"*I remember this time last year I was crying all the time ...I don't think really I've cried about work like my teaching and the children's learning, I think it's a bit more behaviour that I've cried about*" (Teacher).

"*We're just at our wits end particularly with all the school stuff, I was really worried was just going to end up in hospital at some point... we're getting to a point where we kind of feel like we're a family in crisis*" (Parent).

For some parents and teachers, their child's behaviours were consistent across both settings, being equally challenging to manage. Meltdowns or shutdowns were commonplace, oftenoccurring without parents and teachers understanding what triggered the distress or withdrawal. However, this area of shared experience between parents and teachers did not always serve to unify them in their approach or communication with one another. In some cases it did bolster the parent-teacher relationship, each empathising with the other's role, increasing the level of positive communication between home and school settings. However, in others it fuelled a more critical approach, that the other was somehow responsible for the child's behaviour, which had a knock-on effect into the other's context. Parents were critical that school did not offer the flexibility needed to support their child or their child was 'blamed' for something out of their control, or the school did not understand them:

"*It's so important that the school system get it right now. And because they've not only not got it right but they've actually got it in so incredibly wrong, it's been damaging and detrimental, um you know some of the behaviour we've had from [CWA] at home is again, it's so clearly a correlation with his experience at school*" (Parent).

Teachers were equally critical of the emotional state in which children were sometimes brought to school. Comments such as '*thanks mum*' from teachers, reflected their anticipation of a 'bad day' with the child, being of parental cause:

"*I've also found that [CWA] parents are quite anxious and I feel that sometimes her anxiety sort of stemmed from their anxiety and sometimes I'd- we've had meetings and I wonder sometimes whose anxieties I'm allaying most*" (Teacher).

Difficulty also arose when those differences were divergent across settings. Very often parents would experience meltdowns at home but school would see no sign of distress or challenging behaviour from the child, only compliance and sometimes withdrawal. In these cases parents were seen by teachers as too permissive, lacking in discipline or beinginadequate, lacking the resources to battle with the child. Whereas parents felt that children disguised anxiety which built up at school and they had to cope with when the child came home:

"*Mrs. V she said she's coping very well in school but as soon as she gets home it's a different matter...I think she holds it in at school*" (Parent).

In some cases teachers confirmed that they had difficulties identifying anxiety in the child but did not approach parents to help them unpick the difficulties:

"*[CWA] was having worries and anxieties that I couldn't pick up on because she wasn't communicating with me but then I totally understand that as part of her autism*" (Teacher).

Other teachers were able to communicate with the parents in a supportive way and understand what was happening in both contexts:

"*I've built up a really good relationship with the parent who, you know, the child was fine at school and they masked it really well, didn't they, in*

school, and then she was just completely having meltdowns at home. So I was able to try and support mum through that as well" (Teacher).

Parents and teachers agreed that autism will present itself differently at different times and in different situations at school and home. It also included the idea of 'triggers' and need to identify these:

"I feel like she's actually learning and engaging and enjoying it which makes me feel like I'm doing something right, whether I'm doing anything I don't know. But, yeah, it makes me feel... And I feel like I can handle the meltdowns a bit better now because I've started to find those little triggers" (Teacher).

Building Positive Relationships as essential to child's well being

This theme emphasised the view that the children were extremely responsive to the nature of the relationship and that if anything the children, because of their high levels of anxiety, needed extra reassurance of positive relationships. In school this could be indicated by anxieties for a child if a trusted teacher was unavailable:

"Mrs. R was off last month sick and [CWA] had a massive meltdown when she'd come home and then the next morning she was going, "Mum, my belly hurts. I feel really sick." I was like, "Okay," and we started walking to school and she wouldn't let go of my hand. When I walked her in Mrs. W was there. I was like, "Look, she'sthere," and she went straight over and let Mrs. R comfort her and she was all right then, and then she went off a few days later sick as well and the same thing happened" (Parent).

Both parents and teachers identified the importance of positive relationships and teachers were often recognised as attachment figures for the children as well as the family:

"Um, I mean me and [CWA] have a good relationship. I think I taught her when she was in Year 1 for a term, um, and then when I was off poorly, um, you could see that she—we get on really well and we had a good rela-... because she wasn't quite right—when I wasn't at school, she was really anxious because I wasn't there, and change of routine and things. So I think me and [CWA] have a really good relationship and so, she feels comfortable I think" (Teacher).

"We have such a lovely teacher in year four and we did get to know her and she got to know [CWA], I think in that sense, I was a little bit more, "Huh, okay, she's got someone that she knows, she likes, she gets on with, and she can go to" (Parent).

Both parents and teachers highlighted that maintaining good relationships between home and school could be difficult especially due to lack of opportunities for communication and the potential for misunderstanding. Both recognized, however, the importance of good relationships between teachers and parents for the child's wellbeing:

"I think she sees me and mum talk and I don't know if that helps facilitate because she could see that we're getting on really well" (Teacher).

"I always worked closely with the parents, that's really important" (Teacher).

Linking with the previous theme, in some cases differences in behaviour at home and school and perceived misunderstandings led to the relationship being conflictual:

"What we have found is whilst we've had those successful interactions, um, the- what I thought necessarily was successful within school when she went home [CWA] was still experiencing quite a high level of worry and anxiety" (Teacher).

"There's no such thing as coincidence with [CWA]. Time in school equals meltdowns at home without time in school, you don't get them at home" (Parent).

Emotional impacts of the autism

Both parents and teachers found coping challenging and many experienced stress and exhaustion:

"It's been really, really tough. It's been the most challenging and hair raising start to any year that I've experienced in my life this year... And um, there's times I've just felt really crushed by it all" (Parent).

"I'm going through the motions. Um- but just before [CWAs] birthday ... I had a period where I just felt, it was like a couple of days where I just felt really, I just feltsuicidal actually. I went for a run and felt like I could throw myself off a bridge" (Parent).

For some teachers the child was seen to question their self-identity as a competent teacher:

"I felt like I was somebody who was excellent at forming relationships with children with autism. Then, [CWA] came along and he was very different from all of that.You know his behaviour and his profile were so, so different" (Teacher).

Nevertheless the relationship with the autistic child was also experienced by many of the parents and teachers as rewarding:

"It's the little things she comes out that made me laugh. So I could be teaching and she'll say, 'No Miss, it's supposed to be this,' she'll correct me and it just makes me laugh because I'm like, 'Actually, [CWA], you're right. I have said that, wrong.' (Laughter)" (Teacher).

Although other people within the family were sometimes supportive, parents also highlighted the impact on the child and other family members:

"We're in it together but it's still crisis, and then more family piles in with a, 'let's do something about it together then" (Parent).

"You know, the focusing on [CWA] as being sort of an identified person with a problem and not realising the dynamic for the whole family, the sort of the domino effect of that... and how that affected [sibling]" (Parent).

Parents also articulated the detrimental effect of issues such as poor sleeping patterns in their child and their own relationship as a couple:

"We don't have that time away to have adult discussions, and so that's why typically when they happen, we are stressed because it will be first thing in the morning when we're trying to get ready for work and school or you know, or just be like, when those things pop in your head and then we're tired so the communications is not clear either so we're like, reacting to each other again" (Parent).

Many parents communicated fear about the future, both for themselves and for their child:

"We're talking about basic life skills, survival as adult. I'm not going to be around forever, with my own health scare stuff that goes on, although I'm not at threat, I am you know scientifically considered more vulnerable in terms of my mortality, so Ithink well it's even more important that [CWA] is in a situation that helps him to be able to cope with the world because we're not going to be there for him forever, and if that happens sooner rather than later, he's going to- anyway, it doesn't bear thinking about for him" (Parent).

Parents also felt isolated and that others did not understand their child and they were not supported in taking care of them and coping with the difficulties this might entail:

"*I feel there is nobody else to look after them, and that's what's quite hard... And also like, I'll be too anxious to leave them with somebody else because people don't understand them*" (Parent).

In conducting the interviews the researcher noted a sense of urgency and a need to tell their story from parents and some teachers including talking about the past and their own emotional journey with autism:

"*It [diagnosis] was a terrible shock for me, [I: mm-hmm] I couldn't believe and I... oh when we have got uh meetings with teachers and uh with doctors I always cried at that time. It was, it was really very hard for me to speak about [CWA]*" (Parent).

"*It was really hard because I would take it all personally, but then that was because it was continually wearing, once he starts, he does not stop you know*" (Teacher).

Bureaucracy as a barrier

Both parents and teachers shared the view that funding and support was inadequate in both contexts. Funding was an issue for both teachers and parents so much so that at times people had to spend their own money to get the resources they needed:

Teacher: "*Being a massive reader myself, we've got these clouds and if they read three times a week that they're supposed to they get a sticker and after six stickers, theycan win a–I give them a book, so I buy them books. It's costing me an arm and leg but it's really worth it because...*"

Interviewer: "*Do you buy that with your own money?*"

Teacher: "*Yes, I do. Yeah, because there's no money*".

Despite difficulties providing what was perceived to be appropriate support not all parents blamed the schools and there was some appreciation that both contexts were struggling to do their best to support the child in difficult and confusing circumstances:

"*Whilst I am quite angry and critical about the way the school has behaved over the years, um I'm level headed enough to realise that it's not just them and it's not the individual people. There is a systemic failure going on at the moment and we've walked right into the middle of it. We walked into the deepest trough of the failings in the system*" (Parent).

Both parents and teachers expressed being let down by services that didn't materialise or that the child's needs were passed from one service to another:

"*We've had speech and language come in. They've worked with her for four weeks andthey're dropping her. They're giving her something to work on, prepositions basically uh and that's it. So she's doing under and on. She's been doing that for four weeks. They've moved her on to I don't know two more prepositions and then they've dropped her. And I can't believe that. Their view is that actually her needs are her autism. Her speech and language difficulties are a part of her autism therefore, it's not their place to support her*" (Teacher).

Parents reported a long journey of being passed around and support not being available from the school and other services:

"*It has been an uphill battle for us the entire way and even at the point of receiving diagnosis and acknowledgement there's something to be done it isn't done anyway. It'sstill not done, and there's a bunch of excuses, and it all came to a head before Christmas and meeting with the school*" (Parent).

"*We've been so incredibly let down by them and the system in general*" (Parent).

Linking to the previous theme on the impacts of autism, lack of support from the system was seen to exacerbate stress and anxiety and sense of physical and psychological wellbeing:

"*But it was all those things, well it was very stressful and I kept all my reports and everything...it finally did go to panel and then there was a delay because there were so many people going to panel, it took months, but at the end of the day we did finally get there, it just seemed to take such a long time, and when you're carrying a big child into school every day and you know, honestly I've had prolapse and everything*" (Parent).

Feelings of control

Parents and teachers described that a sense of 'control' or having ability to influence their child was important. This related to their understandings and uncertainties about the nature of autism and specifically how it presented itself for their child. For parents they were shaped by a sense of how things had been in their own families and what to expect about their children and how to parent them. For teachers, likewise it related to historical factors such as their prior experience with children with the diagnosis and what training in autism they had received.For both of them there was a sense of a challenge to their identities in terms of what kind of a parent or teacher I am if I struggle to be able to control my child or to maintain order in the classroom. The sense of loss of control was experienced by some of them as quite a severe problem resulting in feeling depressed, tired and exhausted.

The sense of a loss of control was indicated in a sense of not knowing, not understanding or being able to predict what a child would do and how they would respond to their actions:

"*There's always that conflict between how we think parenting should be and then when you have a child who doesn't respond to those things, it's kind of really allowing you know, really letting go and I have to say you know, now I do question everything that we ever taught about parenting, but it's so engrained that it's hard to completely let go of it you know, so this is where the weekend thing would come in, I felt that I was somehow not being a good parent if I will just- if we just did nothing completely, you know*" (Parent).

At times this loss of control was also seen in adversarial terms such that the child started to be seen as 'attacking' the teacher below:

"*So, when I was brought in and it was like, "Okay, get this class working," ... And, getting them to just not talk over each other... it was insane, yeah. And so, I had that to do and then with [CWA] sitting there. So, I'm trying to raise these standards and instill habits and routines and just literally just ordinary school behaviour where they can line up and walk somewhere and it doesn't take them 10 minutes and he was immensely unhelpful because he would always directly attack my efforts*" (Teacher).

This sense of losing the ability to understand and influence also related to the help and support that parent sought. For example, below the mother describes how problems came to a head and seeking support from CAMHS was the only alternative. However, seeking such professional support also carried with it an implication of failure in not having been able to manage things themselves:

"*I suppose we had a bit of a shock a couple of years ago because things were so bad, it really came to a big- you know, she was very, very distressed, and then she was diagnosed with the autism, she went through CAMHS and then after that I kind of lost my confidence a bit as a mother, I guess, so I just took a step back*" (Parent).

Similarly a teacher described the development of difficulties with a child which led to a questioning of their abilities to influence the child, but also of feeling no alternative but to bring in outside sources of support as a consequent sense of futility and failure:

"*There were times when actually his behaviour became so disruptive that really I would have wanted him to just be carefully managed out of the*

classroom and there was just nobody to do that here. It doesn't happen. And so, I exit the class. And, that really irked me because I thought, 'You can't really hand him the amount of power to make everyone go away.' And, I didn't like that" (Teacher).

Resorting to bringing in others to assist was indicated in these quotes to have a consequence for further fuelling the sense of a loss of control and failure.

This theme also related to what was experienced as imperatives of how they 'should' be acting with their children. For example, parents described a sense of a cultural norm that they 'should' be doing things with their child at certain times like weekends:

"But I still have this thing, and I don't know whether it's a cultural thing you know, what it is, that I need to be doing stuff with my children you know, and I think like I was saying to you before, weekends always been a bit of a problem because I feel like we should be doing something" (Parent).

This notion of what is normal and to be expected was also evident in a mothers' quote below of a sense of drifting from being a 'perfect' family to a dysfunctional one. Her sense of a collapse of being able to assert control and influence can be seen in her reference to becoming 'depressed':

"It went from us being this like, almost that perfect family that everyone, 'Oh, you know, you're such a lovely family', and everybody will always say that, to suddenly feeling like we were this dysfunctional family...but we were I mean, I was depressed and we were all like bouncing... and I can remember I dropped them off at school and I just think- my heart will just be going and I'll just be thinking, 'Are we ever going to be carefree again you know, are ever going to be...' I just thought, "What's happened?' it's like just everything had just crashed, we're like this dysfunctional family" (Parent).

In a similar vein the teacher below describes how he experiences his attempts to have some control over the class, to make himself heard as being thwarted by a child and he likewise experienced a sense of helpless and hopelessness such that he wanted to 'cry all the time:

"He would discern that I was trying to get some order and routine... he would just do anything he could to stop that being able to happen and that's where he would talk over me, make silly jokes, try to make the other kids laugh and then escalate and then just be so noisy that they couldn't even hear me and I couldn't even hear them. So yeah, amazing, hard. I would feel tired and like I wanted to cry all the time. And, I would get up and dread coming in" (Teacher).

DISCUSSION

The analysis revealed the following shared themes between teachers and parent, Each Child is Unique, Behavioural Differences between Home and School, Building Positive relationships as Essential to Child's Wellbeing, Emotional Impacts of the Autism, Bureaucracy as a Barrier and Feelings of Control.

Less experienced teachers and parents tended to acknowledge the unique characteristics of the child and in some ways question the usefulness of the label in understanding and supporting the child. The abilities of the child were at times seen as surprising and the child was perceived to have areas of competence that could be built on. More experienced teachers appeared to have a more rigid, arguably pathologising perception of the child, based on beliefs about autism and what strategies had worked previously.

Ho [29] highlights the danger that over-emphasis on the diagnosis, rather than the unique qualities of the child, can lead to approaching all children in the same way regardless of their individual potential, strengths and interests. In such cases, the child as a unique person can be lost or become totalised by the label [30]. Whilst some can experience the label as liberating, in other cases the child becomes a list of deficiencies and is disempowered from constructing their own identity [31]. In our study this was also articulated by parents who felt their child was not understood. The more flexible approach of teachers relatively new to the profession may reflect an increasing move to embrace neurodiversity and question medical models of disability in favour of the concept of 'difference' [32]. Related to this, in our own sample understanding autism was important for teachers and parents, but this alone was not enough. Parents and some teachers felt it was also necessary to understand how autism influenced each individual child differently.

Within the theme Behavioural Differences between Home and School considerable emphasis was placed on anxiety as a feature of autism and resulting meltdowns as being problematic. Previous literature highlights the potential repetitive negative cycles of anxiety, meltdowns, exhaustion and helplessness experienced by families of autistic children [33]. In the current study, anxiety and distress were seen to be related to separation from important attachment figures and transitions between contexts. In addition, comfort and averting problems was characterised by warm relationships between families and teachers where the importance of key figures in each context was recognised. These findings echo discussions in the literature regarding the common co-occurrence of autism, anxiety and attachment difficulties and the need for attachment based interventions targeted at the system around the child [34,6].

In more problematic situations children were perceived to disguise or 'hold in' feelings at school resulting in emotional outbursts at home which could lead to mutual blaming and misunderstandings between home and school. These findings underline the heterogeneity of autism, the difficulties in identifying expression of anxiety from other behaviours and the need for teachers to be supported in understanding autism-related anxiety [35]. Existing research also confirms parent's perceptions of school as a potentially anxiety provoking context for autistic children linked to lack of understanding, sensory issues, academic expectations and social demands [36].

Both parents and teachers agreed that services were lacking and that more support was needed for those who care for and educate autistic children. Related to this, the school system was seen as inflexible and results-driven, not allowing teachers opportunities to adapt to individual needs or time to develop understanding of the autistic child. Both parents and teachers felt a pressure to maintain control and also at times a sense of not knowing how to support the child or manage difficult situations. Research mirrors these findings in identifying a lack of support for autistic children, their families and for schools, emphasising the need for collaboration, improved communication and mutual support between family, schools and available services [37,8].

Perhaps the most widely articulated concerns among parents and teachers were the emotional impact of autism and the pressing need for positive relationships around the child to promote wellbeing. There was a feeling that both teachers and parents had many demands on them and opportunities to talk and explore what happened in the other context would be welcome, but were currently very limited. The children were seen as very sensitive to and dependent on positive relationships with key people around them to maintain wellbeing and engagement.

Implicit in this was that everyone would be able to function more effectively if they felt connected and supported. The effect of perceived threat, anxiety and distress on all levels of cognitive function, including planning, memory, learning, attention and decision making, is well documented [38]. Many of the parents and some of the teachers in our study were experiencing stress and exhaustion. In addition, some parents reported fear concerning the future and a sense of isolation and resignation. They also reported distress and anxiety among other family members and the autistic child.

The importance of parents and schools working in partnership is well documented [39], with benefits reported for schools, parents, children and the local community [40, 27]. Indeed, some have argued that home-school collaboration is instrumental in a child's educational success [41]. From a systemic attachment-based perspective, positive relationships of key figures, both with the child and around the child, have long been known to foster a sense of security, confidence and wellbeing [42]. Systemic ideas have developed in parallel in clinical and educational contexts and current conceptualisations of the benefits of encouraging positive home-school systems around the child draw from both of these disciplines [43]. The findings reported here suggest that positive relationships between home and school were seen as very important not only for the child, but also for teacher and parent wellbeing, but this relationship was also seen as being difficult to maintain and foster. Issues such as lack of opportunities for communication and misunderstandings resulting from irregular contact were perceived to exacerbate difficulties. Where parents and teachers were able to maintain positive relationships, there was a sense that each understood the position of the other, not only in addressing challenges, but also that the teacher or parent was doing 'a good job' albeit sometimes in difficult circumstances.

IMPLICATIONS FOR PRACTICE

The findings of the current study add to the evidence for the benefits of positive home-school partnerships. Our findings add to a body of research which suggests that where positive home-school relationships exist, contextual understanding, sense of wellbeing and success is enhanced. The development of SAFE with Schools, as a systemic attachment-based intervention which supports teachers and parents to work collaboratively is a pressing need. Interventions which facilitate secure relationships with and around the autistic child, alongside shared understandings of autism and collaborative problem-solving, will benefit not only the child, but also those teachers and families who are experiencing distress, isolation, blame and sense of failure.

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