

EMPIRICAL MANUSCRIPT

Parental Conceptualizations of Autism and Deafness in British Deaf Children

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Abstract

The co-occurrence of childhood deafness and autism raises complex challenges for diagnosis and family support. In this article, we explore with hearing and Deaf parents their observations of the interaction between deafness and autism and identify how the intersections of deafness and autism are conceptualized in everyday life. Eight parents participated (two of whom were Deaf BSL users) in semi-structured interviews in either BSL or spoken English. Data analysis was underpinned by a phenomenological approach in the hermeneutic tradition. Findings are discussed in terms of parents' perceptions of the relevance of deafness to their understanding of autism for their particular child, the effects of autism on sign and spoken language development and the relationship between deafness and autism in terms of their own and others' attributions of their children's characteristics. The significance of the findings for parental contributions' to diagnostic assessment and the tailoring of family support are considered.

Deafness and autism in children are both inextricably linked with language and social development (Brenman, Hiddinga, & Wright, 2017; Hansen & Scott, 2018) with many developmental features associated with deafness also associated with autism; for example language delays, problems with specific language functions, pragmatic language difficulties and delayed theory of mind (for review see: Szarkowski, Mood, Shield, Wiley, & Yoshinaga-Itano, 2014b). For the vast majority of parents of deaf children with autism, both the developmental challenges of deafness and those of autism come as new experiences and new knowledge (Wiley, Gustafson, & Rozniak, 2014; Zaidman-Zait & Curle, 2018).

Fewer than 5% of children who are born with some degree of deafness are born into families where one or more parent is d/Deaf (Mitchell & Karchmer, 2004). The far more usual occurrence is that deaf children have hearing parents with no prior experience of deafness or of raising a deaf child (Marschark, 2017). Parents of deaf children typically face the challenges of new

knowledge acquisition, adaptations in interaction and communication, and personal and familial processes of adjustment at a very early stage in their infant's life (Young, 2010; Young & Russell, 2015). A diagnosis of autism, including the process of its investigation and assessment prior to diagnosis, also typically involves considerable emotional, psychological, and practical challenges for parents and the wider family (Karst & Van Hecke, 2012). These encompass, be it for different reasons, many of the domains of new knowledge and concern faced in parenting a deaf child, for example, investigation of implications for development, education, and future prospects together with adaptations in communication style and use of language (NICE, 2013, 2017; Oono, Honey, & McConachie, 2013).

What might constitute a typically developing deaf child is itself unknown or uncertain for most hearing parents (Marschark, 2017; Young, 2002) let alone what might be indicative of an autism spectrum disorder (ASD). For the minority of parents who are d/Deaf themselves and who have a deaf child with autism, the

picture is potentially different in that deafness and its challenges are familiar, even if only from personal experience. Comparisons between expected and varying developmental norms begin from an alternative personal perspective, understanding, and experience than that available to hearing parents with no prior experience of deaf children. However, the small body of previous work that has examined the lived experience of parents who have a deaf child with autism have not reported on d/Deaf parents' perspectives on autism (Beals, 2004; Myck-Wayne, Robinson, & Henson, 2011; Wiley et al., 2014; Zaidman-Zait & Curle, 2018). Studies involving d/Deaf parents have been confined to those which examine sign language development in deaf children with autism (e.g., Denmark, Atkinson, Campbell, & Sweetenham, 2014; Shield & Meier, 2012; Shield, Meier, & Tager-Flugsberg, 2015).

The prevalence of autism in deaf children remains unclear (Hansen & Scott, 2018; Szarkowski et al., 2014b). It has been estimated that 9% of deaf children in special education in the United States also have an autism spectrum disorder (Szymanski, Brice, Lam, & Hotto, 2012). An international systematic review has demonstrated that as many as 3.5% of children with autism are also deaf or hard of hearing (Beers, McBoyle, Kakande, Dar Santos, & Kozak, 2014) and a Swedish single hospital site study that the prevalence of autism is higher in deaf children than in the general population (Rosenhall, Nordin, Sandstrom, Ahlsen, & Gillberg, 1999).

From a clinical perspective, the co-existence of autism and deafness in children raises the fundamental question of whether the condition might be expressed differently in children who are deaf *and/or* whether typical features, such as behavioral characteristics are actually fundamentally the same but just harder to recognize (Brenman et al., 2017; Hansen & Scott, 2018; Kellogg, Thrasher, & Yoshinaga-Itano, 2014; Szarkowski et al., 2014b; Szarkowski, Flynn, & Clark, 2014a; Szymanski et al., 2012). The lack of appropriate screening and diagnostic assessments that have been adapted for use with deaf children and tested for reliability and validity make it difficult for clinicians to evaluate adequately children who are both deaf and may have autism (Brenman et al., 2017; Szarkowski et al., 2014a). Diagnostic overshadowing is also a concern (Wright & Oakes, 2012) “be that autism masking hearing loss or intellectual disability, hearing loss masking autism or intellectual disability, or the presence of intellectual disability masking both.” (Szymanski et al., 2012, p. 2034).

Parents/carers are acknowledged as essential contributors to the diagnostic process for children with autism. Their accounts of the early developmental history and observations of their child, reflections on what might be typical for their child and contextual adaptations made to meet their child's needs are integral to diagnostic screening and assessment tools such as the Autism Diagnostic Interview (ADI-R) (Lord, Rutter, & Le Couteur, 1994) as well as important for evaluation of the effectiveness of ongoing care and support. However, if parents have little or no prior experience of what might be typical or atypical for a deaf child, recognizing and reporting what might be of concern in relation to possible autistic characteristics becomes much more complex, as it does for clinicians too (Brenman et al., 2017; Szarkowski et al., 2014b; Szymanski & Brice, 2008).

In previous studies, specifically concerning parental accounts of their experience of raising a deaf child with autism key themes identified include: the complexity and frustration faced by parents in confirming a diagnosis of autism because of the lack of overlap of professional expertise in both deaf child development and autism (Beals, 2004; Myck-Wayne et al., 2011), the inappropriateness of some diagnostic assessments (Wiley et al., 2014; Zaidman-Zait & Curle, 2018), the challenges of

identifying appropriate support from services usually set up to support either families with a child with autism or families with a deaf child but usually not both (Beals, 2004; Wiley et al., 2014), and the parenting challenges faced in developing their children's language (Zaidman-Zait & Curle, 2018). The largest study focused solely on parents of deaf children with autism who had a cochlear implant (Zaidman-Zait & Curle, 2018).

In this study, we are less concerned to describe parental experiences of raising a deaf child with autism but rather seek to use their accounts of the diagnostic process and everyday life as the means by which to examine *how parents conceptualize* the interaction of what it is to be deaf and to have autism. In other words, we are seeking to identify the potential differences and similarities in how parents understand what is to be deaf with autism and what the consequences might be for services and families in how this interaction is perceived.

Methods

Research Aims

- To explore with hearing and deaf parents their observations of the interaction between deafness and autism.
- To identify how the intersections of deafness and autism are conceptualized in everyday life.

Design

A phenomenological approach within the interpretative/hermeneutic tradition underpinned the research design (Moustakas, 1994). This tradition is interested in how people interpret and make sense of their experiences (Giorgi, 2006). It treats the experiences of individuals and the meaning they make of them as valid in their own right regardless of recourse to any objective reality(ies) (Kvale, 1983). Interest lies in how features of context and previous life experience, sometimes referred to as fore-knowledge, shape the meanings people derive from new experiences and how they describe these ('lived experience') (van Manen, 1990). It was appropriate to this study's interest in exploring and understanding parents' diverse, contextually based knowledge about their children including the inferences they draw from specific behaviors and communications as well as how they interpret the significance and consequences of these.

Sample Definition

“Parent” in the context of this study was defined as the adult with the most consistent and longstanding parenting relationship to the child, whether biologically a “parent” or not; it included step parents, adoptive parents, and grandparents if they were the principal caregivers fulfilling the parenting role. The term “deaf” refers to children with a measurable hearing loss who may be British Sign Language (BSL) users (Sutton-Spence & Woll, 1999) or spoken language users (or both). Deaf with a capital D refers exclusively to adults who are culturally Deaf, it does not encompass hearing people who may regard themselves as culturally Deaf, or deaf adults who do not sign, nor is it used to refer to children whose cultural identity may yet to be determined. “Hearing” refers to parents who are audiologically hearing whose primary or only language is a spoken one. Some hearing parents may use some BSL but they are not “deaf.” Deaf children 16 years old and younger were included in the sample regardless of degree of hearing loss.

Principal exclusion criteria were the following: (a) parents who were not bringing up their children in a home where BSL and/or English (spoken or sign supported) was the primary language of the home (i.e., parents who might be using a spoken language other than English or a signed language other than BSL were excluded however spoken English included signed supported English as a visual representation of English, rather than another language); (b) parents who were raising their children with more than one spoken language (i.e., spoken language bilinguals/ multilinguals); (c) parents who were raising their children with more than one signed language e.g., sign language bilinguals/multilinguals who may use ISL and BSL, or BSL and ASL; (d) children who are deafblind as these may be regarded as a different group of children with sensory impairments than either deaf or blind children; (e) children whose physical disabilities arise from neurological impairments and/or have a recognized medical /genetic condition which may impact on the clinical characteristics and autism presentation; (f) parents who lacked capacity to give individual informed consent.

Ethical Approval

The study received National Research Ethics Service approval on January 28, 2014 under their proportionate review scheme (approval number IRAS 124197) and accepted onto the CLRN (Clinical Local Research Network) portfolio on 28/03/14 [CSP124187].

Recruitment

Two recruitment routes were used. Route one involved advertising through parent-representative organizations in the UK such as the National Deaf Children's Society (NDCS) and the National Autistic Society, through parent to parent support groups and through Deaf (BSL community) online networks and media. If parents responded to an advert and supplied their contact details they were sent further information with the option to self-select for interview. Additionally, we emailed study details to 25 special needs schools although the number of recruitment packs distributed by the schools is unknown. Route two involved clinical services. We used the National Deaf Child and Adolescent Mental Health Service (NDCAMHS) data base for England to identify those families with children who have a formal diagnosis of autism, in current or previous receipt of clinical services, and who fell within the study inclusion/exclusion criteria. NDCAMHS is an England-wide specialist mental health service for deaf children and their families within the National Health Service and children may be referred directly to it from their local physician (Wright et al. 2012). The keyworker clinician for each eligible child on the data base was sent an information pack about the study to distribute to parents. Within it, there was a reply slip to the research study team indicating consent to be contacted for inclusion in the study. Additionally, we designed a poster for display in the NDCAMHS clinics to raise awareness of the study and potential for participation. If potential participants were interested in taking part in the study, they contacted the study team who were separately located from and not directly involved in the local clinical service. No personal or clinical data were passed from their medical home/clinical service to the study team for purposes of recruitment. A total of 90 recruitment packs were distributed via route two. Participant information sheets and consent forms were supplied directly to those parents who contacted the study team via either route and these were available in both BSL and plain

English. On return of a consent form the named researcher (Author b) arranged a time and location for an interview.

Data Collection Procedure

Data were collected by means of semi-structured interviews. The interview schedule was designed in such a way as to enable the parents to focus on their personal journeys of coming to understand what autism and deafness meant for them and their families; it was not constructed chronologically to take parents through the diagnostic pathway or to document the support and intervention services that they had received. It began with parents being asked to talk about their child's individual characteristics, strengths, and challenges and asked them narratively to recount typical stories that encompassed their experience of parenting their deaf child with autism. We deliberately sought to encourage contextualized parental accounts within the family, rather than parental accounts of a clinical and support pathway.

Parents were interviewed separately or together depending on preference. Each parent was interviewed only once for between 1 and 2 hours. Interviews were conducted in either BSL or spoken English depending on the parents' preference. In the case of BSL interviews these were conducted without interpreters by a Deaf native signer who was a post-doctorally qualified, experienced qualitative researcher. The same researcher who was bilingual in spoken English in addition to BSL carried out the spoken language interviews as well with an interpreter available if required. The interviews were audio and/or video recorded depending on the language(s) used.

Analysis

The interview data were transcribed and/or translated into English and uploaded to QSR NVIVO 9. Where data in BSL existed, this also was uploaded in order to view the original in source language alongside the translation. The data were read and viewed independently by the primary researcher who had carried out the interviews (Author Ferguson-Coleman) and the principal investigator (Author Young). Using an open coding approach first, each identified a series of initial areas of interest (initial codes) in the data. For the sake of transparency, we make no claims that prior considerations in the study did not influence the coding process nor do the authors adopt any claims to bracketing off pre-existing influences on the topic area as is common in some form of grounded theory. Some of the initial open codes were directly derived from the aims of the study and flowed from the sections in the topic guide for the interviews (e.g., "stages in the process of diagnosis"). Others, however, arose inductively from the data (e.g., "professionals' claims to expert knowledge").

The open codes by the two authors were compared for duplicates and any which could be collapsed into a single code and then applied to the data transcripts. The material across all of the interviews that was allocated to each initial code was then read in depth individually by each researcher carrying out the analysis. At this point, it was confirmed that all identified codes could be encompassed by the two overarching themes, THEME 1: Interactions of deafness and autism leading up to diagnosis; THEME 2: Intersections of being deaf and being autistic in everyday life. A third overarching theme was not required. Scrutiny of the coding structure led to the identification of a series of sub-themes reflecting the wide diversity of the experiences of parents in this study i.e., not all participants in the study had experiences

that would be encompassed by all sub-themes but all sub-themes illustrated the breadth and diversity of the overarching theme (Table 1). The data transcripts were re-coded to explore the sub-themes further and to check their validity in terms of their presence in the data as well as to highlight when and for whom some sub-themes did not match their experience.

Findings

Participants

Eight parents of seven deaf children with a confirmed diagnosis of autism were interviewed. In the case of the child from a Deaf family, both parents chose to participate in the interview. In a very small Deaf community such as exists in the UK, how the participant characteristics are presented presents a real risk of identification be that unintentionally (Young & Temple, 2014). This consideration has influenced how we have chosen to present child and parent participant characteristics in separate tables (Tables 2 and 3).

The variation in age of identification of deafness is reflective of the age of the children in terms of the stepped roll out of newborn hearing screening in England at the time (Uus and Bamford, 2006). It is of note that children whose deafness was identified before the age of 6 months were diagnosed with autism at a younger age than those whose deafness was identified after the age of 6 months old. In the case of parents of Children B, D, F, and G the definitive diagnosis of autism was a very recent event in terms of the age of their child and their participation in the interview.

THEME 1: Interactions of Deafness and Autism Leading Up to Diagnosis

None of the parents interviewed reported that the formal diagnosis of autism was unexpected when eventually it came. For some, it felt like a natural conclusion to a process, for some it represented a relief to have a “label” that could be useful in securing appropriate support and services. All, in different ways, described examples of their own observations and concerns leading them to question initially that something might be wrong or different. This was true regardless of whether their child had received an autism diagnosis under the age of five years or later. What was remarkable, however, were the different connections parents reported making between their sense that something needed looking into and knowing their child was deaf. There were three different kinds of interactions

between “deafness” and “autism” that parents remarked on in the period leading up to a diagnosis of autism.

False and uncertain attributions

Parents reported false attributions being made by others between the child’s behaviors/ communication and what was assumed to be “normal” for a deaf child. For example, one hearing professional advised one of the Deaf parents that difficulties in making eye contact was “not unusual for a deaf child.” This remark was made in the context of a deaf child growing up in a Deaf family who were using sign language as the home language and where a child’s ability to use direct eye contact is a pre-requisite for communication in a visual language:

“The health visitor said it’s because he’s deaf [that he does not make eye contact] and it’s common for a two year old. I felt annoyed as I knew it wasn’t common for two year olds as I had other friends with two year olds and I could see that he was different.”

Another parent, who described a 10-year process from her first suspicions that her child may have additional needs on top of their deafness to a final diagnosis of autism, remarked that a key problem along the way were assumptions made by others that the behaviors they saw in her child were “typical for a deaf child,” such as not wanting to mix socially with others, spending long periods of time in her own company, never being invited to parties or other events by peers.

“I do think her deafness may have masked some of the things. They’d say, “it’s because she’s deaf” but I didn’t agree because I don’t think just because you’re hearing impaired you would behave like that.”

This parent’s perspective is particularly noteworthy as she had more than one deaf child and therefore had ongoing experience to inform her observations.

For some parents, the difficulty was not so much false attributions made by others, but rather their own uncertainty about what might be normal for a deaf child; for example, whether difficulties in learning could be reasonably assumed to be consequences of being deaf, or something to be concerned about.

“We don’t know whether their slowness in learning, inability to pick stuff up from their surroundings is because of their autism; or because they are not hearing things, but disappearing into their own world inside their head.”

For another parent whose child was identified as deaf three years after having passed the newborn hearing screen, the main puzzle was how much the years of undiagnosed deafness were a good explanation for her son’s behavior differences in

Table 1 Data analysis themes and sub-themes

Overarching theme	Sub-theme
Interactions of deafness and autism leading up to diagnosis	False attributions being made between their child’s behaviors/communication and what was assumed to be “normal” for a deaf child Comparisons between the child’s behaviors/communication and typical trajectories of development for a deaf child Deafness was not relevant
Intersections of being deaf and being autistic in everyday life	Autism is a bigger part of the child than deafness Autism affects signed communication and sign language development Sound stimulation is important in supporting communication and interaction Sensory stimulation is vital; deafness might interfere Working out what might be deafness and what might be autism can be a puzzle Deafness is not considered

Table 2 Participant children characteristics (n = 7)

Child	Sex	Age	Age of identification of deafness	Age of diagnosis of autism	Deaf siblings (Y/N)	First-born (Y/N)	Special school or mainstream (S/M)
A	M	7	Birth	2 years			
B	M	4	Birth	3 years, 10 months			
C	M	7	Birth	3 years			
D	F	8	2.5 years	8 years			
E	M	4	4 months	3 years			
F	F	14	2 years	14 years			
G	M	9	3 years	9 years			

Table 3 Participant parent characteristics (n = 8)

Mother/father	Age	Parent ethnicity	Parent's main language	Additional communication used with deaf child with autism	Highest educational qualification	Employment status
Mother	35–44	White British	Spoken English	None	Higher degree	Homemaker/student
Mother	25–34	White English	BSL	SSE	A levels	Full time homemaker
Father	35–44	White English	BSL	Spoken English SSE	No answer	Employed part time
Mother	35–44	White English	Spoken English	PECS ^a	Degree	Employed part time
Mother	35–44	White English	Spoken English	None	Higher degree	Employed part time
Mother	45–54	White English	Spoken English	None	Degree	Employed full time
Mother	35–44	White other	Spoken English	None	Higher degree	Employed part time
Mother	35–44	White English	Spoken English	Total communication/PECS	Degree	Full time homemaker

^aPECS = Picture Exchange Communication System (Bondy & Frost, undated).

comparison with her other hearing children, or whether they were associated with his autism. She kept an open mind:

“My argument was that we’ve only just found he was deaf. Can we find out [whether] it’s just [his] deafness before we look at autism?”

Comparisons with typical trajectories of development for a deaf child

This category of assumptions was not the same as false attributions which usually took the form “because the child is deaf.” Rather the conclusions drawn were from making detailed comparisons of the identified child with typical child development for a deaf child. For example, where there had been close monitoring of a deaf child’s linguistic development, this had been helpful in detecting that expected milestones were not being met.

“It was the speech and language therapist. She noticed because deaf children have a progress monitoring book; before [my child] had been making great progress and she [the therapist] was able to tick all the boxes but then she was going through the list and realizing that [my child] could not do all those things. That was when he was two and a half. He finally got referred.”

However, the situation was not quite so clear cut for parents whose children were deaf but also had identified additional needs/ a recognized medical or genetic condition (prior to the diagnosis of autism) that were associated with the etiology of their child’s deafness. Delays in learning and child development in comparison with expected trajectories for deaf children were in these cases attributed to the child being a deaf child with additional needs resulting from for example the co-occurring/ co-morbid diagnosis such as a Cytomegalovirus infection in utero or auditory neuropathy spectrum disorder.

Deafness was not considered relevant

During the interviews, two parents (of different children) made no reference at all to their child’s deafness when discussing what first alerted them to the possibility that there was something different about their child’s development in comparison with other children. In neither case was the child growing up in a family with a deaf parent where deafness might be normalized so potentially not mentioned. A late diagnosis of deafness was also not a potential explanation for the absence of reference to the influence of their child’s deafness on parental concerns. In neither case did the child have complex needs where the extent of multiple sources of disability might mean that deafness was the least of considerations. Rather it was as if the child’s deafness did not exist as a reference point or a potential confounding influence in parents’ initial concerns about their child prior to a diagnosis of autism.

THEME 2: Intersections of Being Deaf and Being Autistic in Everyday Life

We were keen to explore with parents how they viewed the relative influences of autism and deafness on everyday family life. For every family, the experience of deafness with autism (or autism with deafness) was very different. We choose to present the following accounts family by family to reflect some of this diversity and its contextualization.

Autism is a bigger part of the child than deafness

One of the families had more than one deaf child and the child with autism was not the parents’ first deaf child. This meant that this parent’s summary about the relationship between

autism and deafness is likely to include information gained from previous experience of deaf children. It is notable for its emphasis on the individuality and personality of her particular child with autism.

"We have always felt that [name of the child] is more autistic than hearing impaired, if that makes any sense. His autism is more of him than his hearing impairment." (emphasis added by the research team)

She did not regard deafness as irrelevant to her child but that being deaf was incidental to his autism:

"...his autism seems to rule him and I honestly think that if he were hearing, I'm not entirely sure there would be an awful lot of difference. I think he's so insular with his autism that the hearing impairment just allows him to be more insular."

Autism affects signed communication and sign language development

This family used BSL at home and both parents, interviewed together, were culturally Deaf. Their discussions about their child reveal the particular difficulties they have experienced when using BSL (a visual spatial language) with their child with autism. They relate these difficulties strongly to the impact of some of the traits of autism that make visual language and use of space and touch problematic. For this family, their child's reluctance to make eye contact was an early indicator something was wrong and a major obstacle to interaction subsequently. Without routines of eye contact including sustaining eye contact with someone who is signing, communication in a visual language is blocked; look away and you do not see what is being said. This created everyday difficulties such as warning about danger as well as everyday frustrations associated with being unable to sustain a conversation.

From the parents' account, this child started signing single words (signs) from six months old such as CAT and DOG and although his parents noticed that he really enjoyed repeating the signs again and again, they were not unduly concerned. He also had started forming some two sign (two word) utterances such as MILK PLEASE. However, a key turning point came when the child reached the 150 words (signs) stage. His parents observed that he stopped using his signs both in terms of their frequency, but also in terms of their correct handshape and location (akin to correct pronunciation) and also that he dropped his signs, replacing lexical items with pointing or gesture.

"He stopped communicating with us. Before he used to repeatedly sign CAT then he stopped. He couldn't do it. He went quiet...Then we noticed when he signed ORANGE which he used to sign clearly, he had the wrong hand shape and positioning... Like with milk, he stopped signing MILK and just pointed and I didn't know what he wanted. He kept pointing."

The family has persisted, however, in encouraging their child to sign and develop his communication seeing it as a major priority. Whilst accepting his communication is limited they are, through sign language, seeking to extend it in everyday routines and encouraging mutual exchanges:

"If [child's name] wants crisps or a biscuit or a banana, we give it to him, like a reward for signing it. He can sign it. If he doesn't then we encourage him to do the sign, if he really can't then that's fine. We encourage him to sign TOAST; I'm happy for him to have it but if he asks again, I tell him that "he's already had some" [NO, YOU FINISH] And if he asks again then I sign NO, YOU, FINISH and he'll glare at me and sign WANT AGAIN but I will repeat NO YOU FINISH. I think that's better."

Sound stimulation is important in supporting communication and interaction

Another one of the participating families had chosen for their child to have bilateral cochlear implants. At the time of implantation the extent of her autism was unknown, although there were some indicators of potential learning difficulties. The parents' choice of cochlear implantation for their child was strongly influenced by their view that the provision of better access to the auditory channel would provide another means of stimulating their child's learning if something else, such as autism, might be impairing it. They felt they had made the right decision because they could see she was listening, particularly to music and rhythm which gave her pleasure. They felt that the implants also afforded her some degree of vocalization to express wants and needs:

"She loves to listen... she puts her implants straight back on and then she'll come over to me and she'll go "aaaahhhh" and vocalise which means I want "two little dicky birds sitting on a wall"; So then I sing it. I don't do the actions, so I know she's listening and then she'll do the action at the appropriate time of the song."

This parent also found the child's use of cochlear implants helpful for focusing her communication into clearer words and simpler phrases.

"It's constant learning. I try to keep my language really simple. But that goes for probably cochlear implant users and autistic children, you would do the same. So you know, we just give her key words like "bath," "shoes," "coat on."

Sensory stimulation is vital; deafness might interfere

For one family, their child's deafness was significant in relation to autism because of how it might impede a drive to increase and respond to their child's love of sensory stimulation. Whether sound, vision or touch, sensory stimulation was enjoyable for their child, calmed him, and brought him happiness. There were some exceptions to this picture such as disliking lumpy food and itchy hearing aids but overall sensory pleasure was important. Hearing aids fitted in because wearing them enabled him to enjoy music, and enjoy the sounds of everyday life around him. Deafness, therefore, was only an issue in so far as it might be barrier to sensory stimulation.

"From the autistic children I have seen on television, in life and particularly at his school, they do seem to have sensitivity problems and throw tantrums, go into melt down when something isn't right. [child's name] loves sensation, loves stimulus, so really is not upset by anything that surrounds him and is just a very happy child. He's a happy autistic (laughs)."

Working out what might be deafness and what might be autism can be a puzzle

Three families had given a great deal of thought to the origins of some of their children's behaviors and preferences. They did this in part to consider what they might be able to do to support or improve particular problematic behaviors. If the origin of the difficulties seemed to lie with deafness that might suggest some different actions than if it lay with autism.

"Just because you're deaf you wouldn't have ten blankets on your bed, knowing exactly what order they're in. You know that's not a deaf [trait]."

"Whereas communication with people, I would, I did think that could be something to do with her deafness 'cos she doesn't really like to talk to

people 'cos she doesn't always understand what they're saying, doesn't quite get what they're on about, again you know she'd rather not talk, she'd rather... sit and let someone else do the talking and her try and keep up or, you know understand rather than one who is [talking] and I'd say that was her deafness...."

For one family, coping with their child's increasingly angry and difficult behavior at home, thinking about the impact of their child's deafness was a helpful way to try to understand why he might react the way he did sometimes:

"...it was his deafness first. That seemed to us the bigger picture of why he was so frustrated and angry, 'cos he was missing so much."

Coping with some of the interventions and strategies that resulted from deafness was also an important part of making sense of child behaviors that some families felt might be too easily attributed to autistic traits alone:

"For me, he was just trying to cope with learning to use a hearing aid and the new sounds. A three year old with a hearing aid [for the first time]! Yeah good luck! (laughs)"

Deafness is not considered

For one parent who was hearing, considerations associated with their child's deafness did not feature in relation to how they thought about their child's everyday life. They were very sensitive, child centered, and detailed about their child's behaviors and what they identified as autistic traits and how they managed these but considerations of their child's deafness did not feature in any discussions about everyday life, communication, adaptations or what their child enjoyed doing. This was not a child whose additional needs were so complex that deafness could be seen as only one, or the least significant of those. The absence of discussion or consideration of the interaction between being deaf and having autism was a true reflection of how this parent chose to approach everyday life with their child.

Discussion

This study adds to the small amount of previous qualitative literature on the lived experience of parents bringing up a deaf child with autism. Although the sample is small, this is in line with previous published studies' sample sizes and it is the first to include the lived experiences of Deaf parents who are sign language users and who are raising a deaf child with autism. Unlike previous studies that have focused on parents' experience of the diagnostic process and the lack of fit of deafness- or autism-related support services (Beals, 2004; Myck-Wayne et al., 2011; Wiley et al., 2014; Zaidman-Zait & Curle, 2018), the concern of the study at the outset was to examine in detail how the intersection of deafness and autism is conceptualized by parents. This is important for two reasons: (a) more effective recognition and diagnosis; (b) better understanding of the diversity of family experiences in everyday life.

Effective assessment and diagnosis of children with autism includes a detailed parental report of their child's development, together with observations conveyed to clinicians and direct assessment (NICE, 2017). Although parents will in one sense always be the ultimate experts on their own children, in another sense the vast majority of hearing parents will have no prior understanding of what might be within the normal range and usual diversity for deaf children. They will also not necessarily have reliable expectations of a typically developing deaf child. Therefore, examining how parents consider the interplay between deafness and autism in their particular children makes

an important contribution to the validity of parent report and parent contributions to diagnostic screening and ongoing clinical assessment (Wiley et al., 2014).

Our data also open a window onto what might be learned from Deaf parents with deaf children with autism who are likely to have reasonable expectations of deaf children's potential and so reflect the diversity of what is typical for deaf children. The visually attenuated descriptions by the two Deaf parents in our sample of how their child's signing changed, points to the potential for the development of a parent-centered child sign observation schedule in cases where there may be concerns about autism in a child growing up in a sign language using household. No such parent-led observational tool currently exists as a counterpoint to the small but growing studies of the characteristics of signed languages in children and adults with autism (Denmark, Atkinson, Campbell, & Swettenham, 2018; Denmark et al., 2014).

The reported high incidence of autism amongst children who are also deaf has led to questioning about clinical overshadowing and calls for better education of clinicians as well as better diagnostic tools (Szarkowski et al., 2012, 2014a). These data point to the potential for parental diagnostic overshadowing whether with respect to deafness and/or autism as this study has shown the striking diversity in how the intersection of deafness and autism is understood and seen by parents. Indeed, the differences were so vast that we chose to individualize them by family under the everyday experience theme as each one seemed to typify a potential facet of what this intersectional experience was potentially like. Not all parents were represented in all sub-themes but all sub-themes spoke to the overarching main theme. Some parents clearly had an integrated view of the relative contributions of deafness and autism to who their child was and how s/he communicated and behaved. This was true both for parents who gave greater emphasis to sound and speech for their children and for those who used BSL. For some parents, the relationship between autism and deafness was a puzzle to solve. Whilst some were searching for its resolution, others found it a helpful ongoing puzzle with which to engage because it enabled them to consider different ways of understanding their specific child's needs. For a minority it was possible to bracket off deafness as if of little relevance in the face of autism, whilst for others having autism was an additional impairment hampering access to visual language by its difficulties with eye contact and engagement. Sensitivity to such different approaches by parents in response to their children is important for *individualized approaches to family support*, the call for which is evident in much of the current literature but with little evidence to support these implications (Hansen and Scott, 2018; Szarkowski et al., 2014b).

Some of the complexities seen in hearing children with autism are apparent in our sample also. For example, 40% of hearing children with autism will have regression in infancy with loss of either language or social skills (Hansen et al. 2008). To our knowledge, the Deaf parents' description in our study of the regression they observed in their deaf child is the first time this has been reported in the literature with respect to a signed language and a child growing up in a signing home. One family explores the effects of their child receiving a cochlear implant commenting that this enabled their child to access pleasurable environmental sounds and give them as a parent more cues for them to understand and interact in their world, according with other studies of deaf children with autism and cochlear implants (Donaldson, Heavner, & Zwolan, 2004; Zaidman-Zait & Curle, 2018).

Conclusion

The social theory of intersectionality argues that multiple attributes do not form our identity in an additive manner but in an interactional one (Castiello Jones, Misra, & Mc Curley, 2010). Parents of children with deafness and autism are also faced with making sense of a form of intersectionality in how they relate to their children and also in how services relate to their needs. The evidence base concerning deaf children with autism, their diagnosis, management and family support needs is small but growing. This study makes an important contribution to that evidence base from the lived experience of parents which is under-represented currently.

There are a number of implications for professional practitioners from this study's findings. These include the following:

1. The assessing clinician or intervention specialist needs to have a solid understanding of typical deaf child development and how this may be the same and/or different for children growing up with a spoken language and/or a signed language. Without this foundation, false attributions are easily made that may delay diagnosis or cause unhelpful confusion or distress to a parent.
2. Sensory differences between how hearing and deaf children engage with the world is an important consideration whether in terms of a diagnostic/support pathways or in terms of everyday life for parents raising a deaf child with autism.
3. There needs to be purposeful consideration of being deaf in any clinical assessment but also in any guidance offered to parents. This means not bracketing off deafness from autism but rather seeing them in dynamic interaction which may have different implications for each child and family.
4. The implications of autism on signed communication are an important consideration not just in terms of assessment and diagnosis. Rather there are implications for support and guidance for Deaf families who will be signing with their child and a need to understand what kinds of strategies will work well within that linguistic environment. In this respect, there is much that is still to be learned from the lived experience of Deaf parents raising a deaf child with autism.
5. In working alongside parents of deaf children with autism, identifying how a parent not just experiences but conceptualizes the interaction of autism and deafness in their child is an important basis for individually tailored support and jointly developed goals and support strategies.

The study's main limitations concern its small sample size but this is still larger than all but one previous qualitative study that has focused on the lived experience of bringing up a deaf child with autism. The sample was self-selecting and it is not possible to claim that saturation was achieved in the data analysis. The sample was relatively homogeneous in that it was biased toward well-educated parents. Nonetheless, the diversity of experience evident lends the study validity based on saliency and breadth of examples. After Denzin (2012), we would argue that the number of participant interviews is of less relevance than number of "instances" of the phenomenon of interest contained within the interview. In a field with little data and where the parameters of the phenomenon of interest are yet to be discovered, the limitations on sample size should be appreciated in this light.

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Conflict of interest

Author C has a clinical role in the institution used in recruitment route 1 used to identify potential participants. No other author has a conflict of interest to declare.

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