**Intersecting cultures in Deaf mental health: An ethnographic study of NHS professionals diagnosing autism in D/deaf children**

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**Abstract**

Autism assessments for children who are deaf are particularly complex for a number of reasons, including overlapping cultural and clinical factors. We capture this in an ethnographic study of National Health Service child and adolescent mental health services in the United Kingdom, drawing on theoretical perspectives from transcultural psychiatry, which help to understand these services as a cultural system. Our objective was to analyse how mental health services interact with Deaf culture, as a source of cultural-linguistic identity. We ground the study in the practices and perceptions of 16 professionals, who have conducted autism assessments for deaf children aged 0-18. We adopt a framework of intersectionality to capture the multiple, mutually enforcing factors involved in this diagnostic process. We observed that professionals working in specialist Deaf Services, or with experience working with the Deaf community, had intersectional understandings of assessments: the ways in which cultural, linguistic, sensory, and social factors work together to produce diagnoses. Working with a diagnostic system that focuses heavily on ‘norms’ based on populations from a hearing culture was a key source of frustration for professionals. We conclude that recognising the intersectionality of mental health and Deaf culture helps professionals provide sensitive diagnoses that acknowledge the multiplicity of D/deaf experiences.

**Introduction**

Clinicians and health professionals face an assembly of challenges in autism assessments, particularly when there are intersecting issues to consider such as a child’s distinct cultural and linguistic experience. The autism assessment is therefore considerably more complex when the child is deaf. For children who use sign language, social, communicative, and cultural experiences will be different from their hearing peers. These experiences are relevant for a deaf person in any clinical encounter but are perhaps especially important in relation to the construct of autism, which is intimately linked to language and social communication. Structural factors also play a key role in the assessment process, as an early diagnosis of autism may be helpful to enable access to education and other services (Mansell and Morris 2004; Liptak, et al. 2008). These complicating factors are compounded by communication difficulties experienced between deaf people and hearing professionals, *and* by symptoms of autism that impair language development (du Feu and Fergusson 2003). Children with autism are also more likely to have a degree of deafness than their typically developing peers, with nearly 8% of those with autism being reported as having mild to moderate deafness (Rosenhall, et al. 1999). These structural, linguistic, and developmental issues all contribute to the disproportionate numbers of late or mis-diagnoses in deaf children (Roper, et al. 2003). This paper explores this complex diagnostic process, taking seriously both clinical understandings of deafness and mental health, and the deaf community’s experiences of inhabiting a distinct cultural identity. We look at how these elements intersect in a particular mental health context in the United Kingdom.

Despite the small, and growing, body of literature on deafness and autism, very little is really known about the overlap and interactions between these two conditions (Szymanski and Brice 2008; Szymanski, et al. 2012)*.* Research on both conditions is rooted in clinical data about the socio-cognitive abilities of deaf and autistic children. One well-recognised feature of autism is an inability to make accurate guesses about the thoughts and beliefs of another person (Baron-Cohen, et al. 1985). Cognitive psychologists have termed this a child’s ‘theory of mind’: a social cognitive ability, which guides much of our social communication and understanding of other people’s ‘inner worlds’. Because children with autism develop this social cognitive ability differently, they communicate differently to their typically developing peers, missing out or mistaking much of this talk about others’ thoughts, feelings and beliefs. Some deaf children experience delays in theory of mind development, particularly after a delayed diagnosis of deafness (Wright and Oakes, 2012). This is bound up with early language development: deaf children are more likely to experience a degree of linguistic deprivation, as a majority will be born into a non-signing family. This causes delaysin theory of mind for *some* deaf children, who do not have access to a rich linguistic environment (oral or signed). These theory of mind delays tend to disappear by adolescence, unlike a child with autism, who will have on-going difficulties for life (Peterson and Siegal, 1999). Despite this difference, some of the behaviours seen are very similar between deaf children and children with autism, meaning that socio emotional developmental delay can “masquerade” as autism (Wright and Oakes 2012).

The above described research has provided valuable clinical insights into how and why these diagnoses are so complex, but it does not offer a cultural perspective on the process of assessing deaf children in a mental health context. We take a different approach to the existing literature on this assessment process, focusing not on the population of deaf children as our analytical focus, but on the cultural systems that surround them. More specifically, we focus on the multidisciplinary professionals who come into contact with these children and their families, and who deal with these issues in their clinical practice. We carried out ethnographic research in England’s National Deaf Child and Adolescent Mental Health Service (National Deaf CAMHS, hereafter referred to as the Deaf Service) and the equivalent generic services operating parallel to this. All of this work took place within the National Health Service (NHS).

*The emergence of a cultural model of Deafness*

In the last few decades, the idea that deafness should be perceived from a cultural perspective has gained recognition, and support for deaf people’s struggle for social rights has made its appearance on the agendae of political parties (see for example, the websites of the European Union of the Deaf, and the World Federation of the Deaf). Deaf culture is difficult to define, but is a vital part of what it means to be part of the ‘Deaf community’: a group defined by Deaf activist-scholars as “those deaf and hard of hearing individuals who share a common language, common experiences and values, and a common way of interacting with each other, and with hearing people” (Baker and Padden 1978, cited by Ladd 2003: 41). The use of a capital ‘D’ for Deaf denotes a cultural linguistic model of being deaf, rather than a medical one (Napier, 2002). The Deaf community is international, speaks many sign languages, and intersects with (sub)cultures across the world. The emergence of the cultural model of Deafness has been a unique social and academic movement. The model challenges the medical approach to understanding deafness, ,favouring instead one defined by language and community (Padden 2005; Ladd, 2003), which exists within a larger discourse about social and medical models of disability (Snodden & Underwood, 2014)”.

In the field of Deaf studies scholars explore deaf people’s social life from various social scientific perspectives. A cluster of features have been brought forward to define cultural Deafness, such as its language, social norms, historical roots, and international links across communities (Ladd 2003; Bauman 2008). The extent to which deaf people draw on such shared characteristics for their cultural identity, falls along a broad spectrum. As this ethnographic work and other researchers have found, it is therefore sometimes hard to categorise someone as Deaf, ‘with a capital D’ (Friedner 2010), with deaf identities taking different trajectories (Bat-Chava 2000). This is particularly true for deaf children, as the majority are born to hearing parents. Developing a Deaf identity takes place over a long period of time. During the early stage of a deaf person’s life, other cultural identities (likely to be defined by spoken languages, geography or nationality) may well also play a key role in this developmental process. Ahmad, Atkin and Jones (2002) have explored young people’s negotiation of “*being deaf and being other things*” in depth, finding little support for notions of singular or primary identities amongst the young South Asian men and women they spoke to in the United Kingdom. Although our findings do not delve further into such experiences of cultures-within-cultures, such research has informed our conceptual framing of the issue of cultural identity. In line with this thinking, we have found it useful to adopt Deaf activist and scholar, Paddy Ladd’s notion of “Deafhood” as an identity that deaf children and adults may discover to a greater or lesser degree, rather than a single category that they do or do not fall into (Ladd 2003). In this sense, identity becomes an evolving, developmental process shaped by the huge variability in human experiences.

*The Deaf community and mainstream mental healthcare*

In line with the notion of a **D**eaf cultural identity implied in such a perspective, bilingual, bicultural models of deafness have been discussed in fields such as education and health care. In the United Kingdom for example, specialised services for deaf patients like the Deaf Service, have, since 2004 when it was first piloted within the NHS, adopted a cultural-linguistic model of deafness (Ladd 2003; Wright, et al. 2012). The establishment of this service has been an important and progressive move within the NHS, as the relationship between the medical world and the Deaf community has historically been a difficult and contentious one (Padden and Humphries 2005; Alexander, et al. 2012). Attending to historical accounts of mainstream health systems failing to recognise Deaf culture and language, responds to calls within medical anthropology to consider the culture of medicine itself, as well as the culture of the ‘other’ in clinical contexts (Kirmayer 2005; Fox 2005; Lock and Nguyen 2011).

*(Deaf) cultural identity and diagnostic systems*

Awareness of the importance of a person’s cultural background is also part and parcel of professional practice (Kleinman 1988; Jenkins, et al. 2004; Carpenter-Song, et al. 2007; Canino and Alegría 2008). In any given diagnostic setting, deaf patients will almost always encounter hearing professionals, meaning the latter have to assess someone with a different language and cultural background. The growing number of studies in transcultural psychiatry demonstrates how much these situations challenge western psychiatry’s existing assumptions and practices (Lopez and Guarnaccia 2000; Kirmayer 2005). These contributions usually analyse situations where cultural difference is connected with the ethnicity of people encountering the biomedical system. However, cultural differences are also important for Deaf people, who may or may not have a Euro-American background, but in any case, do not identify with the oral culture dominant within biomedicine. Indeed, many researchers have understood deaf people in mental health settings to be a cultural group vulnerable to isolation, stigma and poor access to services (Cabral, et al 2013; Cohen 2004). Applied literature on deaf mental health care also highlights the need for more cultural sensitivity and better support communication services (Williams and Abeles 2004; Peters 2007; Chovaz 2013). Thus, the differences in cultural backgrounds between hearing professionals and the Deaf people they provide support for has become an important area of study.

Diagnostic systems should be treated with caution (Good 1996; Charman and Baird 2002; Baca-Garcia et al. 2007). It has been found that autism is diagnosed differently or is under-diagnosed in children from cultures outside of the Euro-American (and we would add, oral) milieu from which the category first emerged (Dyches, et al. 2004; Begeer, et al. 2009). Of particular significance to this study is the practice of using diagnostic tests that have been developed and validated to identify mental disorders in *hearing* populations, to assess *D/deaf* service-users. The problems that arise from this practice cannot be solved simply by translating tests into sign language (Moore, et al. 2013), as studies have found that there are often psychometric differences in the constructs of psychiatric disorders themselves between hearing and deaf populations (Crowe 2002; Rogers, . 2013). To make sense of this theoretically, it is useful to attend to Kirmayer’s (2005, 193) framework for “exploring the significance of culture for psychiatric nosology”, in which he builds on the work of Kleinman (1988) and others in the field of transcultural psychiatry. The core argument here is that constructs of psychopathology and the diagnosis of psychopathology are socially and culturally embedded. This framework has not thus far been applied to Deaf mental health, but its broad theoretical focus gives us insights into how to understand encounters between deaf children and mainstream mental health care. As such, the ways in which autism is generally defined and assessed is embedded in a hearing culture, which under-represents the Deaf cultural experience.

Efforts are being undertaken to solve these issues within the NHS: in parallel to this study, a large-scale clinical validation trial of autism assessment instruments adapted for deaf children is taking place (see ‘acknowledgements’ below). Deaf team members who are clinically trained can also help make standardised assessments more accessible and culturally sensitive, and furthermore, trained sign language interpreters can broker more meaningful co-working between hearing and deaf clinicians, and between hearing clinicians and deaf clients when deaf professionals are not available (Napier 2002; Dean and Pollard 2011). However, there remains a gap in the literature about sign language interpreting within the field of transcultural mental health (Tribe and Raval 2003), and in clinical practice with deaf children and young people.

*Intersectionality as an analytical tool*

We have used intersectionality (Crenshaw 1989) as an analytical tool that allows us to take into consideration the multiple complicating factors in diagnostic processes. This allows us to understand how multiple categories of identity and difference “depend on one another and are jointly associated with outcomes” (Cole 2009:170). As such, identifying with more than one minority group means more than just an accumulation, or ‘stacking up’, of the different issues associated with those groups: it means that these issues will *interact with one another* to create distinct outcomes. For example, those considering disability have used this framework to explore beyond individual pathology to allow in-depth consideration of how race and social class interact with disability to create particular forms of exclusion in schools (Liasidou 2013). We see several ways in which this tool can be used to understand the way specialised professionals negotiate the intersecting issues of D/deafness and autism: 1) by recognising multiplicity *within* groups as well as between groups (Carastathis 2013); 2) by recognising certain similarities or shared experiences *across* minority groups; 3) by acknowledging not only the layering of different conditions or identities but the ways in which they *interact*; 4) by thinking about (bio)social categories in the context of institutions and cultures, as well as just individual characteristics (Cole 2008; Friedner 2010; Liasidou 2013) and 5) by looking beyond a framework of norms (e.g. cultural, medical or biosocial) to define identity.

**Study context and research methodology**

The fieldwork for this study was carried out using as a base one of the ten specialised centres, which make up the Deaf Service in the United Kingdom. Over a period of three months, the primary researcher was based at this clinic and research centre, working alongside the highly specialised team of clinicians, sign language interpreters, and deaf outreach workers. A fuller description of the study site and broader research context can be found elsewhere (Brenman 2014). The clinical and research teams based at the site included a number of Deaf professionals, which provided valuable insights into Deaf culture. As well as this, data was collected about the broader Deaf community through interviews with a range of NHS professionals interacting with deaf children, deaf parents and the Deaf community. The ten centres formed part of an integrated national service with one service specification, which enabled the researchers to access professionals across the country.

All of these professionals existed alongside and within a predominately hearing culture: the NHS in the United Kingdom. The bilingual, bicultural approach that the Deaf Service adopts responds to the serious and enduring gap between services tailored for the Deaf community, and generic (mental) health services. Despite this service’s continual work to bridge these gaps, a major challenge for them is that most parts of the United Kingdom have no dedicated education units for deaf children with autism. Placing a deaf child in an autism unit with mainly hearing children means they do not have access to deaf-friendly resources or staff. Equally, if a child is placed in a hearing impairment unit within a mainstream school or a school for the deaf, the staff will not have been adequately trained to provide support for a child with autism. A key role of this specialised Deaf Service is to advocate on behalf of a deaf child with autism and their family, helping to negotiate where it might lead them in terms of their future educational placements and opportunities. The difficult decision-making processes surrounding this issue were a key focus for our research.

As well as our in-depth ethnographic work at the primary clinic and research centre, the researchers visited other National Deaf Service centres, NHS clinicians, and generic child and adolescent mental health professionals from a range of teams for observation and interviews. This is therefore an ethnography of multi-disciplinary professionals within the Deaf Service, extending into the wider NHS (e.g. community paediatricians) and generic child and adolescent mental health services. We examine how these cultures interact and overlap with those of the Deaf community: how mental health professionals encounter Deaf culture, and how clinical features of deafness and autism become entangled with the cultural experience of being deaf.

*Informants*

Sixteen multidisciplinary mental health professionals took part in the study, including specialist Deaf Service staff and professionals from generic services: psychologists, psychiatrists, specialist deaf outreach workers, Deaf Service consultants, clinical sign language interpreters, (speech and) language therapists, family support workers, paediatricians, and teachers of the deaf. There was therefore considerable heterogeneity in terms of discipline, some being medically trained, and others having clinical, educational or social work backgrounds. Within the health system, the Deaf Service is part of the top ‘tier’ of mental health services, which is described as ‘highly specialised’. Generic services, on the tier below this, are more broadly specialised, usually have much less experience working with deaf children and their families, but often have considerable experience working with children with autism.

All informants had been involved with at least one autism assessment for a deaf child and for professionals within the specialist Deaf Service, usually many more. Experiences ranged from just two or three such assessments (mainly in generic services) to over 50 (in the Deaf Service). The majority of the informants were hearing, with three informants from the Deaf Service being Deaf. We have not identified Deaf informants as such, in order to maintain their anonymity but have identified informants as coming from the specialist Deaf Service or from generic services. All members of the Deaf Service were able to sign, were familiar with Deaf cultural norms and how the experience of being deaf interacts with the presentation of mental health issues, whereas this was not the case with generic professionals.

*Data collection and analysis*

Ethnographic methods were employed to collect the empirical data for this study: observation, in-depth qualitative interviews, and focus group discussions paid close attention to the “talk and work” of medical professionals in their local context (Atkinson 1995). Observational data was collected throughout the fieldwork period, through attending both formal meetings and clinical discussions and the day-to-day ‘backstage’ practice of professionals at the Deaf Service where the primary researcher was based for three months. The most consistent source of observational data was the weekly team meetings of the Deaf Service, as well as observing equivalent meetings in generic (non-specialist) services for comparative work. Here, the diagnostic decision-making processes that took place within these multi-disciplinary teams were a key focus. School visits, video data of autism assessments and consultation meetings provided further data for clinical practices, whilst organisational meetings provided the system-level context.

The focus groups and in-depth qualitative interviews took place in the informants’ own professional settings: clinics, paediatric wards, schools, and Deaf Service units. All interviews were tape-recorded and transcribed. Interviews and focus groups with deaf informants were carried out with a professional British Sign Language interpreter. The spoken English of the interpreter was recorded and transcribed as with other interviews. This data, along with field notes and ethnographic memos were analysed inductively. NVivo 10 software was used for the coding and analysis of the data.

*Ethics*

Ethical clearance for the study was granted by both the University of Amsterdam, and the NHS ethics committee and Research and Development department via IRAS ethics procedures. The principal investigator was granted full access to the study sites and given an NHS honorary contract to work with the Deaf Service at the primary site.

Informed consent was obtained from all individual participants included in the study: the background, procedure and aims of the study were communicated in written English and reiterated orally with a sign language interpreter where necessary. All participants were assured that their information would be kept confidential and that no payment would be given for participating. Informants were not identified by name in any transcript, report or publication to maintain anonymity. Particular diligence was paid to protecting the anonymity of Deaf participants, who may have been easier to identify by other members of the Deaf community or colleagues in their field than their hearing counterparts. Specific details of job roles and personal histories have therefore not been described. All informants gave their informed consent in writing, prior to participation.

**Findings**

The findings are presented thematically, outlining crosscutting issues that arose from the ethnographic data.

***Deaf child development: what does it mean to be ‘normal’ and Deaf?***

You need to know what ‘normal Deaf’ looks like really before you can start to assist with ‘something odd Deaf’

Team member, Deaf Service

Professionals within the Deaf Service showed a strong preference for the cultural-linguistic model of deafness. There was a firm belief (particularly amongst Deaf staff and interpreters) that being D/deaf means being part of a minority group. With it, came a belief that there are features of the deaf experience that should be understood as a unique set of norms, distinct from those of a hearing population, but nevertheless healthy. Informants who were part of, or had close contact with the Deaf community believed that this was essential for professionals to understand before attempting to assess deaf children for signs of atypical neurological development (i.e. autism). They were concerned that hearing clinicians would be more likely to misinterpret a deaf child’s behaviour if they were unfamiliar with these norms. According to these informants, hearing clinicians may still *misinterpret* ‘healthy’ deaf communication as an indicator of autism, because of the Deaf cultural norms that they are not familiar with. Professionals at the Deaf Service (both hearing and Deaf) had a deep and tacit understanding of these norms, which they were able to describe as a certain “directness” which is connected to both the pragmatics of visual or tactile communication (for example tapping someone for attention). This directness was also said to be a core element of the humour and social norms recognisable within the Deaf community. This can be mistaken for social insensitivity, which is particularly salient in an autism assessment:

Well deaf people tend to ‘call a spade a spade’ and be very direct. And it might even be regarded as rude sometimes. Well, if you’re assessing autism and the child came up to you and said ‘how did you get that scar on your face?’ you might think that was inappropriate because it was an insensitive thing to ask and you might think, “has this child got a theory of mind problem?”

Child Psychiatrist, Deaf Service

This “directness” is one of the characteristics that informants at the Deaf Service attributed to being deaf rather than insensitive, or even autistic.

Professionals in the Deaf Service had on-going concerns that clinicians in mainstream settings would have insufficient opportunities to become familiar with the characteristics of deaf children. In particular, they were concerned that this might result in a failure to diagnose a child with autism. According to one specialist, an inexperienced hearing clinician in a mainstream setting would consider unusual behaviour as “just the way deaf people are” (Clinical Interpreter, Deaf Service). In doing so, they might fail to notice difficulties that a child has with sign language, that are *not* associated with their experience of being deaf. One professional, who was very experienced with deaf children’s language development, highlighted how communication difficulties can often be pinpointed as “*something else”* other than deafness (Teacher of the Deaf, Generic Service). This “something else” could well be autism.

Alternatively, unfamiliarity with deaf children may result in professionals erroneously attributing unusual behaviour to autism, because they do not recognise that behaviour as something typical or common amongst deaf children. For instance, a clinician may pick up on the characteristic of being inflexible, and attached to routine, as a sign of autism but be unaware of how common it is amongst typically developing deaf children. This characteristic is common in deaf children because, in the words of one deaf specialist: “the hearing world for a deaf child is unpredictable”(Clinical Psychologist, Deaf Service). Equally, a child who has grown up in a Deaf family may behave in ways that are less common in hearing culture, for example, using particular exaggerated facial expressions in linguistic communication. The point here is that what a hearing person might see as “*abnormal”*, a deaf clinician might see as *“perfectly within usual limits”* (Specialist Deaf Outreach Worker, Deaf Service).

Such disparities in notions of ‘normal’ was a key theme within clinical decision-making meetings, where members of the Deaf Service demarcated their impressions of what is normal and healthy from the impressions of adults and professionals who work solely in hearing and oral environments. Deaf Service professionals tended to adapt their perception of ‘the normal’ according to their experiences working with deaf children.

***Understandings of the deaf experience***

The complexity of diagnosing a deaf child with autism lies not only in separating out behaviours as ‘deaf’ or ‘autistic’*.* As a psychiatrist in the Deaf Service explained, deaf children may be isolated for a range of communication or anxiety-based reasons. He commented that a deaf child in a hearing mainstream school may find it difficult to make friends and this might be noted in an autism assessment. Children with autism may also be isolated because they have limited empathy and little desire for social contact.

“My point here is that the clinician needs to understand deafness.  The clinician also needs to understand autism.  But the third and important element is that the clinician needs to understand how deafness and autism may interact.”

Child Psychiatrist, Deaf Service

What this psychiatrist is observing is how the isolation that comes with having different language and communication style to others, might interact with behaviours that are associated with neurodevelopmental conditions. The language and cultural barriers can extenuate the behaviours that indicate autism, and make them more difficult for the child (and people in the hearing environment) to manage. This highly specialised psychiatrist thus points to the importance of understanding *both* conditions, and the ways in which they interact, as an essential ingredient for negotiating these complex cases.

The linguistic and cultural gap between hearing professionals and deaf children can make autism assessments particularly challenging in a generic service where deafness is rarely encountered. As well as the overlapping features of deafness and autism described above, there were many biases and misunderstandings amongst hearing clinicians. This relates to anuncertainty surrounding the way that hearing professionals assess deaf children, stemming from the fact that hearing clinicians, will “never be able to experience the way they [deaf children] experience the world” (Clinical Psychologist, Deaf Service). The phrase often used by Deaf Service team members, that “they don’t know what they don’t know” was accompanied by suggestions that training would helpfully raise awareness about deaf mental health in generic services. The close collaboration of deaf and hearing staff therefore becomes an important part of a well-functioning service for deaf people.

The perceived gap between hearing professionals and deaf service users was most pronounced when the child was a sign language user. This was reported to be particularly challenging when the family is signing and culturally Deaf.

If you don’t speak the same cultural language or if you don’t speak the same language [at all] then you’ve got barriers there. So I think that’s a major issue.

Clinical Psychologist, Deaf Service

The ‘”cultural language” this clinical psychologist refers to is the broader framework of Deaf culture, which is intrinsically connected to sign language. This includes the values, norms and features of non-verbal communication within the Deaf community, all of which are relevant to an autism assessment. Firstly, because they frame what is considered as typical social communication for deaf individuals (vital contextual information for a clinical assessment), and secondly because cultural sensitivity is paramount when working with Deaf families in a predominantly (hearing and oral) health system.

Understanding these intersecting patterns of deafness and autism came from informants with a high level of oversight and experience. Most medical practitioners, particularly within generic services, were focused on disentangling or separating the diagnoses rather than looking at how they might overlap, confound, or influence each other.

**“They don’t know what they don’t know”: *bridging gaps between hearing professionals with D/deaf service users***

Working with interpreters emerged as a complex but essential means for hearing clinicians and signing children and their families to work together. Interpreters negotiate the culture gap as well as the language gap during assessments. This is in line with models of sign language interpreting that have moved away from interpreters as conduits or literal translators to a practice professional model, which is more interactive and flexible and meeting the cultural and linguistic needs of the clients. Interestingly, those professionals with more sign language skills and experience with the Deaf community relied more heavily on the role of interpreters than those with less experience with the Deaf culture and language. In the Deaf Service, interpreters (alongside Deaf staff) held a highly respected position within the team. Many generic professionals, by contrast, would often not offer interpreting services at all during assessments, believing that they could “communicate through a variety of means”. Several members of the Deaf Service had encountered cases where professionals relied on the lip-reading skills of the child, or on a family member as a translator. This was something that Deaf Service professionals were highly critical of, believing it created a range of potential biases, and could potentially be unsafe in terms of information exchange and potential errors. It was also strongly believed that asking children or young people to translate for family members was unacceptable, given the burden of responsibility it brings.

Generic service professionals tended to be satisfied with their (relatively rare) experiences with sign language interpreters and considered them to be comparable with spoken language translators: “It’s not particularly different from working with any other kind of interpreter”(Child Psychiatrist, Generic Service). Deaf Service professionals, however, saw the role of interpreters as more complex and considered their job to be about *interpreting* language and acting as ‘cultural brokers’ between the hearing and Deaf communities rather than simply translating word for word. This was particularly true for the specialist interpreters, who all had strong personal ties with the Deaf community.

***Resisting reliance on (inappropriate) diagnostic tools***

Another challenge that hearing professionals faced in their attempts to provide appropriate assessments for deaf children lay in the standardised autism assessment tools available to them. Tools such as the Autism Diagnostic Observation Schedule (ADOS) (Lord, et al. 2008), Autism Diagnostic Interview (ADI-R) (Rutter, et al. 2005), the DISCO (Wing, et al. 2002) and the 3Di (Skuse, et al. 2004) are designed for hearing populations and All Deaf Service staff were in unanimous agreement that they are not fit for purpose to use with deaf children.

Given the many uncertainties associated with the autism assessment process, informants often spoke of backing-up or challenging their professional intuition with more ‘objective’ methods such as standardised assessment tools. Ironically, however, the assessment tools (which aim to standardise and reduce error) were one of the biggest causes of concern and confusion during assessments:

It’s obvious you have to come up with a strategy to deal with the fact that it [the ADOS] ain’t Deaf friendly and ain’t visual language friendly.

Clinical Interpreter, Deaf Service

The sense of frustration in the words of this practitioner came from the fact that many of the items in the tool were not appropriate for use in an assessment with a deaf child. For example, the item that requires the child to use a traditional toy telephone: something that may seem unfamiliar or irrelevant to a child from a Deaf family who may not own a household phone. A mobile phone may be more appropriate as many deaf people use mobile phones for texting or video messaging. This is something that requires a great deal of sensitivity to what each item is looking for and how a deaf child or parent’s experience of it might affect the tool’s validity. It was not only the content of the tools themselves that were a cause for concern. Culturally appropriate ways of communicating also need to be built into the assessment. For example, calling a child’s name from behind them (a test in the ADOS) would not be culturally appropriate or ethical for a deaf child.

Professionals with more experience of carrying out assessments with deaf children highlighted several aspects of the tools that they adapted to make them more “*Deaf-friendly”.* Most staff using the ADOS with deaf children described making careful changes to account for issues such as these, which would by definition invalidate what is a validated tool. For those clinicians without access to the support of Deaf staff (i.e. clinicians from generic services), it can be very difficult to deliver tools such as the ADOS in a meaningful way:

She [a deaf child] didn’t really get what was going on. So she scored positively on the ADOS but that wasn’t anything to do with it… if only we’d had a different person to do it, like her support worker…

Child Psychiatrist, Generic Service

These limitations elicited a deep sense of frustration amongst almost all clinicians using the tests. They also created scepticism about the trustworthiness of the diagnostic tools amongst those who were not qualified to deliver them, but were nevertheless part of the assessment process. This mistrust in the tools led to reduced confidence in accuracy of the diagnostic process and an enduring sense of uncertainty, which is discussed below.

***Accuracy versus flexibility: managing diagnostic uncertainty within the health system***

The fact is we don’t know. We don’t know. They might have autism, but because some features can be seen in deaf children without autism, it’s very difficult in one assessment, in a single point of time. It’s very difficult to know.

Psychologist, Deaf Service

Practitioners in both the Deaf Service and generic services were open about the inherent uncertainty in such challenging cases. However, the uncertainty expressed was rarely expressed as individual self-doubt. Their experiences were understood in relation to the multiple actors involved in an assessment and intrinsically linked to the broader health system in which they worked. The way in which almost all professionals dealt with the challenges of using standardised diagnostic tools with deaf children is a case in point. Clinicians who recognised the cultural and linguistic problems with existing tools with deaf children were adamant that a certain amount of flexibility is essential:

Well the tools didn’t work, so it was all about being flexible

Child Psychiatrist, Generic Service

There was an open mindedness (particularly within the Deaf Service) to adapting tools to suit the child. However, this flexibility should not be construed as a lack of investment in coming to robust diagnoses. Even the most experienced professionals did not treat the assessment tools lightly, and regarded them as a framework for ensuring as many diagnoses as possible are correct and standardised. Those who were qualified to formally provide a diagnosis expressed wanting to use the autism diagnosis to set the child on the right pathway to the correct support and services. In this sense, the accuracy of a diagnosis was regarded as a clinical step on a pathway to obtaining appropriate services for children and young people. Professionals collectively managed the risk of misdiagnosis by relying on the input of the multidisciplinary team:

I think your main tool is your team! And your team’s experience. Not a developed standardised tool

Clinical Psychologist, Deaf Service

The multidisciplinary approach to diagnosis was foregrounded far more than any other aspect of the assessment process, particularly when discussing the fallibility of diagnoses and the need for different professional perspectives when dealing with both deafness and autism. Deaf team members clearly valued the perspectives of all multidisciplinary team members in comparison to some generic teams, which were more hierarchical.

***Healthy language and communication: A singular norm?***

“People have a fixed idea about what language and communication should look like”

Consultant, Deaf Service (communicating challenges in an NHS commissioners’ meeting)

Whether co-occurring or independently occurring, both deafness and autism result in ‘different’ communication, in the sense that it will not be straightforward, spoken English. According to some informants, clinicians must therefore establish a new norm against which to measure language and communication (see the very first quote, that you need to “know what ‘normal deaf’ looks like”). However, this was difficult for two reasons: first, because spoken language has a dominance and normative value in most mainstream contexts; and second, because informants relayed that there is no single communication style that represents ‘normal’ deaf communication in the United Kingdom. The first difficulty was largely implicit in the data, given the political nature of this issue: the belief that Deaf community is being marginalised by oral culture, (sometimes referred to as ‘oralism’) is often considered contentious, particularly in families who have chosen to raise their children within an oral culture. Whilst some individuals in the Deaf Service were critical of the dominance of spoken/oral culture over visual language, the service as a whole provided services to children and families of all backgrounds and communication choices.

The second difficulty faced by hearing professionals seemed to be getting a grip on the multitude of communication styles adopted by deaf children, which deviate from the general norm but are *not* indicators of autism: combining oral and visual techniques, managing other sensory or cognitive impairments, or adjusting to people around them who may lack awareness of the deaf experience and are unlikely to sign. Each child’s journey communicatively was different in terms of family communication experiences, a range of educational and social experiences and so on. A community paediatrician expressed uncertainty about how much she should take this into account for an autism assessment:

I was surprised [about the diagnosis]. But there was perhaps… well I guess when you’re dealing with a deaf child, you give them more latitude in terms of the way they engage socially, etcetera. I tend to anyway. I don’t know whether that’s right or wrong.

Community Paediatrician, Generic Service.

This “broad latitude” of social communication seems then to be understood as range of unusual or idiosyncratic behaviours, which you might expect from a healthy deaf child. Attributions about whether behaviours are ‘normal’ in a statistical sense, or ‘normal’ through a cultural lens, or in terms of what you might expect from that individual child in their particular context, may vary. Within this particular interview, the community paediatrician drew alternately from her knowledge of the medical literature, and her experiences working in clinical and community settings with deaf children, the latter often contradicting the former. She described children who don’t look up when she spoke to them, or had a tendency to answer a slightly different question to the one she thought she asked: both deviations from ‘normal’ communication experiences in this setting, but in these deaf children, exactly what she would expect, and by no means a sign of atypical neurological development.

Throughout the interviews, there were similar instances where it became apparent that the concept of norms (even deaf norms) was at best contentious, and at worst misleading in an assessment. The importance of establishing ‘normal and deaf’ tended to become more nuanced and complex over the course of the interviews. This was particularly true of those who specialised in autism or child mental health as well as deafness, where several individuals ended up rejecting the concept of norms, in favour of a more holistic conception of what would be adaptive, given other additional needs, both within the child and environmentally:

So ‘norms’ isn’t quite the right word. It’s—if you have a child in front of you—what sort of skills would you expect them to have, given their overall profile and history?

Speech and Language Therapist, Deaf Service.

This “overall profile and history” referred to by this therapist included the multitude of variables that shape a deaf child’s experience of the world: degree of hearing loss; levels of integration in the Deaf community or identification with Deaf culture; educational, social and family experiences; and other issues that intersect with the possibility that the child has autism.

**Discussion**

Through our analysis of the perceptions and practices of multidisciplinary professionals in child and adolescent mental health services, we have distilled the complexities of assessing deaf children for autism, along with some of the strategies used to negotiate these complexities. The main findings can be understood through the lens of intersectionality, as outlined in the introduction. One use of this lens was to acknowledge not only the layering of different conditions or identities, but also the ways in which they *interact*. The primary issue for many assessors was teasing apart which features or behaviours they should attribute to autism, and which to deafness. Professionals who were particularly experienced in working with deaf children with mental health problems took into consideration how features overlap, mask each other, or interact with one another. Key themes emerged about how this played out amongst professionals in specialised and generic services: sign language interpreters’ essential, but highly variable, role within different teams’ assessment practices; the frustration felt across all informants at the inadequacies of the mainstream mental health system in supporting the assessment and care of deaf children; and the way in which multidisciplinary teams *can* provide the expertise and flexibility for sensitive assessments, even within a challenging system. For these themes relating to diagnostic teams, sites and systems, we return to our argument that (bio)social categories must be considered in the context of institutions and cultures, as well as just individual characteristics (Cole 2008; Friedner 2010; Liasidou 2013). Finally, we made visible the complex story of how professionals work with, rework or reject the framework of norms, which is so central to diagnostic practice, but can be remoulded by the cultural and linguistic issues associated with being deaf. This final theme echoes other key elements of intersectionality we highlighted: that it enables one to recognise multiplicity within categories, to recognise certain similarities or shared experiences *across* minority groups, and to look beyond a framework of norms (e.g. cultural, medical or biosocial) to define identity.

This study provides a rich, ethnographic context in which to place the existing (but thin) clinical literature on the problems and challenges of assessing deaf children for autism (e.g. Jure, et al. 1991; Szymanski and Brice 2008; Wright and Oakes, 2012). Our findings also speak to several areas of social science literature, such as: the topic of contestation in psychiatric diagnosis, both in medical sociology (Manning 2000; Crossley 2006; Rosenberg 2006), and anthropology (Good 1996; Charman and Baird 2002; Baca-Garcia, et al. 2007); Deaf studies (Alexander, et al. 2012); and transcultural psychiatry (Kleinman 1988; Kirmayer 2005). However, no single body of literature captured the complexity of what informants encountered, given that it included multiple issues around being D/deaf (cultural and clinical), the professional field of autism, *and* a specific focus on children and adolescents. We therefore employed intersectionality (Cole 2008; Liasidou 2013) as an analytical tool, which helped capture how the professionals most successfully made sense of these issues, and particularly how these issues interact with one another in these complex assessments.

Findings relating to the cultural inappropriateness of diagnostic tests, and the low awareness of Deaf culture in generic services, are highly relevant to other work investigating transcultural issues in mental health. However, there are elements to our findings that make them incomparable to work focussed on assessing adults from other cultural or minority ethnic groups. For example, the majority of deaf children entering any mental health service use limited or no sign language, either because they have been brought up in a spoken English environment (more than 95% of deaf children are born to hearing parents) or because their autism or another cognitive impairment prevents (sign) language development. Because Deaf culture is very much defined by its visual language, this means a mental health problem such as autism (affecting language ability) can determine whether they can be considered to be, or can identify as, culturally Deaf. It would therefore be difficult for those children with severe autism to adopt dual identities, as did the young people in the aforementioned Ahmad, Atkin and Jones study (2002). As well as this, decision-making and choices relating to culture are not usually made by children but by the adults caring for them. Professionals with experience of working with deaf children *and* developmental disorders therefore knew that they had to consider not just how a child’s culture affects the experience or presentation of mental disorders, but how their identity is shaped by that experience, and how the (potential) presence of a mental disorder may actually disrupt the development of that child’s cultural identity. For example, the diagnosis may make it more difficult for a young person to access sign language or the Deaf community. These issues point to the limitations of working with Deaf culture as a singular or fixed cultural category. However, our analysis indicates that these professionals saw cultural identity not as fixed, but shaped by intersecting features of language, cultural background, experience, cognitive abilities and development.

There are some methodological limitations to our research, which need to be considered. Our commitment to maintaining anonymity of informants meant that deaf staff have not been identified as such. As a result, differences between hearing and deaf staff have not been made explicit, unlike differences between Deaf Service and generic professionals, which were clearly defined. Comparisons therefore only made visible the differences between the *cultures of the services* we studied, and not between hearing and D/deaf individuals. We have focussed on the sophisticated, intersectional approach to assessments, which many (but not all) professionals demonstrated in our study. One reason for this focus is perhaps a methodological bias. Whilst we tried to avoid selection biases by carrying out geographical, professional, cultural and linguistic purposive sampling, we obtained interviews with professionals from several of the ten highly specialised Deaf Services in the United Kingdom. This gave us a high degree of exposure to professionals with a dual understanding of deafness *and* developmental disorders. Moreover, generic service informants were (by responding to our invitation) ultimately self-selected, meaning most had some expertise or interest in this subject and were confident to discuss this in an interview. A more extensive and critical investigation of the challenges faced by less qualified clinicians could have been conducted from within a generic service, where there is less access to information, experts and interpreters. However, given our finding that often these professionals “don’t know what they don’t know”, we find it more fruitful, and potentially informative, to assemble the understandings of this group, who have more in-depth experience of deafness and the Deaf community than a more ‘representative’ sample would. This is arguably what moved the professionals’ discussion away from simply identifying norms and abnormalities, to a more fluid understanding of what ‘normal’ might be; an idea explored in depth within Deaf Studies (Davis 1995).

An implication of combining data from generic and highly specialised services is that it exposed the wide range of roles, and attitudes towards the roles of sign language interpreters in mental health services: from hearing practitioners not seeking to work with (or not having access to) interpreters when necessary; to the belief in word-for-word translation with no clinical influence; to the Deaf Service model, in which interpreters are expected not to provide translation furnished with “the relevant cultural and contextual variables”, (Kaufert and Koolage 1984; Drennan and Swartz 2002:175; Messent 2003; Tribe and Morrissey 2004). As the above references indicate, the latter approach has attracted much attention in the literature on interpreting in mental health work, however not necessarily in the context of sign language interpreting. In the Deaf Service, the sign language interpreters therefore occupied a distinct space alongside Deaf staff, at theintersection of mainstream mental healthcare and Deaf language and culture. Our findings suggest that, whilst the Deaf Service has adopted the notion of interpreters as “cultural brokers” (Singh, et al. 1999; Napier, 2002; Dean and Pollard, 2011) between Deaf and hearing communities, this practice professional model is not popular in mainstream mental health services. These gaps and disparities call for further research in the light of our suggestion that the most experienced professionals look to intersecting clinical, cultural and linguistic factors to make a diagnosis.

**Conclusion**

In our analysis of this particularly challenging clinical practice, we have shed light on core issues that arise when diagnoses are inexorably bound up with other cultural, linguistic, sensory and social factors. There are elements of Deaf language and culture that can profoundly disrupt what a (hearing) professional perceives to be the ‘norms’ of social communication. This multiplicity encountered by professionals made it extremely challenging to work within a system of knowledge, diagnostic instruments and pathways to care, which is based almost exclusively on the norms of a hearing population. This was a source of frustration across all informants, regardless of their own level of expertise or whether they routinely worked with deaf children or not. What worked well in this system, however, was the model of multi-disciplinary teams, particularly amongst highly specialised Deaf Services, where this included combinations of D/deaf, hearing, and a range of clinical, perspectives, respectfully and successfully working together. This enabled recognition of the many dimensions of a child’s experience and ability. We employed the concept of intersectionality to capture this way of thinking and describe its context: at the juncture between medical and cultural systems, and between Deaf and hearing worlds. We propose that this framework offers a critical and informed approach, which would be useful for understanding all complex diagnostic practices involving multiple cultural and biopsychosocial dimensions.

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