

Accessing good communication Deaf children in a mental health assessment

By Prof Barry Wright

In order for a good assessment to take place there has to be good communication between the two people in the interaction. Clinicians often have to make fine judgements about communication. For example, a good mental health clinician will be able to spot the difference between a child presenting with the delusional assertions made in a psychosis versus someone with very strong beliefs from a subcultural group, or a language impairment and an Autism Spectrum Condition (ASC). In deaf and hearing worlds there may be cultural differences in the way that things are expressed for example in the way that eye contact is used. There may be big differences in the way that prosody changes meaning. For example, the tone of the voice can convey sarcasm or humour in a hearing person and the change of facial expressions, hand shapes and the use of the signing space can do the same for a deaf person. Vast difference in meaning can be conveyed by small changes in these things. In this way understanding the language of another person is not as simple as a literal translation. Given that nuance and meaning is often embedded in more than simple words/signs and phrases used, being able to assess someone in their first language becomes important to make an accurate assessment that will then guide treatments.



If we focus on assessments for deaf people whose first language is sign language then we can see just how important this may become. In the UK BSL became a recognised language in 2003, and one might assume from this that attaining an assessment in one of the land's recognised languages would be an acceptable thing to expect. However, most deaf people attending primary care for an appointment described poor communication usually without the benefit of a qualified sign language interpreter or similar (Emond et al, 2015).

There is surprisingly little written about this issue until recently. Working alongside deaf clinical colleagues Vicci Ackroyd, who runs the interpreting services in the Northern arm of the National Deaf Child and Adolescent Mental Health Service (NDCAMHS), laid out a set of straightforward principles for good practice (Ackroyd et al 2018) - see box 1. These are now usual practice in the 10 centre NHS England funded NDCAMHS service across the country. For people arriving in GP practices or emergency services these are not always readily available and can be dependent on local decisions and funding available. The good news is that there are a growing number of helpful services that can be accessed online. These include services where a deaf person can sign into a computer camera to someone on the end of the videoconference and that person will then speak back to the assessing clinician and then translate into sign language when that clinician responds. BSLHealthAccess is a collaboration between charity SignHealth and InterpreterNow, a social enterprise, who is the provider for some NHS 111 access (see https://www.bslhealthaccess.co.uk/). Other examples include SignLive and Sign Video.

Assessment for ASD as an exemplar

From conception through to childhood our brain and nervous systems are developing. Neuro-developmentally we are changing all the time and these changes are not just responsive to our genetic coding, but also highly responsive to our experiences, interactions, our lifestyle (e.g. sleep, nutrition) and a range of other things that are interacting. Neurodevelopmental difference is therefore complex. As a separate domain from medical diagnosis it presents a number of challenges when we are assessing a child at one specific point of time for the presence or absence of neurodevelopmental differences such as autism spectrum conditions. The assessment conditions also make a difference.

One of the things that we often assess for as part of the assessment process in Autism Spectrum Conditions (ASC) is 'theory of mind'. This is our ability to make guesses about how someone else is thinking or feeling and is one of the markers for ASC. However, even in ASC this set of skills changes as we grow and develop and is influenced by our experiences.

Several pieces of important research have shown that theory of mind and empathy skill delays can occur in a range of conditions other than ASC including children with language impairment (Peterson, 2016; Andrés-Roqueta et al, 2013) and children who are neglected in early life (Luke & Banerjee, 2013). Early life trauma also disrupts the way we pay attention to or respond to the thoughts or feelings of others (Fonagy et al, 2017). We simply don't have enough research yet to fully understand whether the developmental trajectories of these different pathways are different, or whether different interventions may be more or less effective for each group.

Another group where there is a wealth of international research showing theory of mind delays is a group of deaf children with language deprivation in early life (Peterson, 2016). Signing deaf children in signing families usually do not have these delays (Schick et al, 2007). This can lead to the misdiagnosis of some deaf children as having autism. Some believe that this is almost indistinguishable from autism whilst others believe that the two sets of circumstances are different. with different developmental trajectories and different responses to intervention (Wright & Oakes, 2012). Further research needs to be done into this important area, because many of these deaf children with social and emotional developmental delay are placed in education autism units. Given that they already have communication difficulties as a result of being deaf, then placing such children in an autism unit may restrict their potential for the rich experiences needed for social development.

Recent research shows that families seeking an autism assessment for their deaf child often run into a range of problems accessing a good assessment and may experience long delays (Young et al, 2019). Clinicians feel under-skilled and unprepared to carry out such assessments (Brenman et al, 2014). For these reasons the Medical Research Council has funded a long piece of research to improve the autism assessment instruments for deaf children to include a screening instrument, a parent semi-structured interview and a play/interaction based assessment. This research will be reporting these important results to its 5 year study in 2020/21. Hopefully, this will lead to the important further research that is necessary to better understand the needs of deaf children with autism. This will also help to characterise children more clearly in order to be able to generate better interventions and better educational placements for them.

Experiences of parenting deaf children more generally shows just why specialised services are needed (Beresford et al, 2008). Deaf children requiring services should of course have access to generic services as usual, but they need access to deaf clinicians for playbased assessments and access to qualified interpreters if their first language is BSL.

Box 1: Advice to generic CAMHS clinicians carrying out an assessment with a deaf child or parent whose first language is British Sign Language

Reproduced by kind permission of Vicci Ackroyd from Figure 2 in Ackroyd, V. & Wright, B. (2018), Working with British Sign Language (BSL) interpreters: lessons from child and adolescent mental health services in the U.K. J. Commun. Healthc. 11: 195-204. doi: 10.1080/17538068.2018.1492218.

- Check that the interpreter is qualified, has three years post qualification experience that there is no conflict of interest and they are not currently working with the family in another setting.
- 2. Ask if the interpreter has experience of working in a CAMHS setting. They may need additional training.
- 3. Ask if the interpreter has experience of interpreting for deaf children using various communication modalities. Do they have knowledge of deaf children's language development? Do you need this information? Do you need the services of a deaf interpreter?
- 4. Check the interpreter has supervision arrangements in place, if not is this something that you/your service can provide?
- 5. Arrange a meeting with the interpreter, before a course of therapeutic sessions, to discuss how you will work together, and the particular therapy to be used.
- 6. Remember to schedule additional time for the appointment; include pre and post briefing with the interpreter.
- 7. Consider how you will contact families, for example are letters written in plain English or translated into BSL on DVD's, can you send text messages? Can you source someone to help with this you may need to discuss filming the interpreter translating/interpreting after a session (do you need to check your services information governance in regards to these?)

References

Ackroyd, V., Wright, B. (2018). Working with British Sign Language (BSL) interpreters: lessons from child and adolescent mental health services in the UK. Journal of Communication in Healthcare, 11(3), 195-204.

Andrés-Roqueta, C., Adrian, J. E., Clemente, R. A., & Katsos, N. (2013). Which are the best predictors of theory of mind delay in children with specific language impairment? *International Journal of Language & Communication Disorders*, 48(6), 726-737.

Beresford, B., Greco, V., Clarke, S., & Sutherland, H. (2008). An evaluation of specialist mental health services for deaf children and young people. York: Social Policy Research Unit, University of York.

Brenman, N. F., Hiddinga, A., Wright, B. (2017). Intersecting cultures in deaf mental health: An ethnographic study of NHS professionals diagnosing autism in D/deaf children. Culture, Medicine, and Psychiatry, 41(3), 431-452.

Emond, A., Ridd, M., Sutherland, H., Allsop, L., Alexander, A., & Kyle, J. (2015). Access to primary care affects the health of Deaf people. *Br J Gen Pract*, *65*(631), 95-96.

Fonagy, P., Campbell, C., & Luyten, P. (2017). Mentalizing. In S.N. Gold (Ed) APA Handbooks in Psychology. APA Handbook of Trauma Psychology: Foundation of knowledge (p373 – 383). American Psychological Association.

Luke, N., & Banerjee, R. (2013). Differentiated associations between childhood maltreatment experiences and social understanding: A meta-analysis and systematic review. *Developmental Review*, 33(1), 1-28.

Peterson, C. C. (2016). Empathy and theory of mind in deaf and hearing children. *Journal of deaf studies and deaf education*, 21(2), 141-147.

Schick, B., De Villiers, P., De Villiers, J., & Hoffmeister, R. (2007). Language and theory of mind: A study of deaf children. Child Development, 78(2), 376-396.

Wright, B., & Oakes, P. (2012). Does Socio-emotional Developmental Delay Masquerade as Autism in Some Deaf Children?. International Journal on Mental Health and Deafness, 2(1).

Wright, B., Walker, R., Holwell, A., Gentili, N., Barker, M., Rhys-Jones, S., ... & Moore, K. (2012). A new dedicated mental health service for deaf children and adolescents. Advances in Mental Health, 11(1), 95-105.

Young, A., Ferguson-Coleman, E., Wright, B., Le Couteur, A. (2019). Parental Conceptualizations of Autism and Deafness in British Deaf Children. The Journal of Deaf Studies and Deaf Education, 24(3), 280-288.