Does Socio-emotional Developmental Delay Masquerade as Autism in Some Deaf Children?

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ABSTRACT

It is reported that autism is more common in deaf children. It is also now well established that theory of mind delays are common in deaf children particularly where there is linguistic and communicative poverty in infancy. This paper discusses the literature in these areas and proposes that socio-emotional developmental delay is distinct from autism in deaf children with different presentation, aetiology and prognosis. Careful assessment should distinguish between autism and socio-emotional developmental delay in deaf children, and lead to appropriate differential interventions.

KEYWORDS

autism spectrum disorders, assessment, development, deaf children

Introduction

In England, UK in the last two years a new National Child Mental Health Service (NDCAMHS) has been funded by the National Specialist Commissioning team. There are ten centres mapping onto the ten Strategic Health Authorities (see Wright et al, 2012 for further descriptions). These centres have taken the lead in autism spectrum assessments in deaf children because they have multidisciplinary teams with deaf and hearing staff (and well qualified interpreters), trained to carry out autism assessments. They have also spent some time honing the quality of assessments to be tailored to deaf children and their families. From these services a common clinical theme is emerging in the context of deaf children. Many children who have attended for assessment of autism are qualitatively quite different from those with autism. Examples of differences include a rich imagination, enjoying and engaging in social contact and more obviously, the healthy use of gesture and sign language.

These clinical observations have led the authors to question the basis of the commonly held assumption, often based on the work of Jure and colleagues¹, that there is a significantly higher prevalence of autism in deaf children and young people. This paper will consider the literature on prevalence in more detail and then review one of...
the central models of autism, theory of mind, in the context of the development of a deaf child. It will suggest that clinicians and researchers may themselves have neglected to develop an adequate theory of the mind of a deaf child and that this could be one contributory reason for any perceived increase in prevalence. This leads to the need for further research, taking the initial perspective of the deaf child, and the family of that child, with important implications for clinical assessment and early intervention.

**Autism in deaf children**

As has been noted, it is commonly reported that deaf children have much higher rates of autism than in the general population with figures quoted at 4%, citing work in the United States. However this is the only large study that has attempted to look at the diagnosis of autism in deaf children. Participants in the study were 1150 children drawn variously from a neurology clinic, a unit for providing audiological testing in those where behavioural testing was problematic, and a whole school population of healthy deaf children with severe to profound deafness. The authors themselves acknowledge that there are selection biases here, and comment that this is not a representative population of deaf children. Using this study to quote prevalence is therefore not appropriate.

The figure is likely to be lower than 4% although other work has suggested it may still be higher than in children who are not deaf. Large surveys of deaf children annually in the US report the figure perhaps more plausibly as 1.6% in 32,000 deaf children across US although information was not available in a further 5000 (13% of the total sample). Since the data collection is by report rather than a research based clinical assessment, inaccuracies are still likely to be present with some possible under or over-reporting. It is argued that the rates of autism spectrum disorders are approximately 7 per 1000 in the general population and the extent to which this is exceeded amongst deaf children remains untested. What is known about autism in deaf children is that complex assessment factors mean that autism is often being diagnosed later than in hearing children with autism. The question remains as to whether such assessments are clinically valid and based on robust evidence.

Before leaving the issue of prevalence, it is important to note that there are some specific groups amongst whom there are clear associations with deafness and increased autism. Causes of autism in deaf children may be through a common pathway such as congenital rubella where one study of 243 children in schools for deaf children found that 7% had autism through brain insult. Again this study may have selection biases. Intrauterine Cytomegalovirus, birth hypoxia, CHARGE syndrome and meningitis are other known common pathways of deafness and autism. These pathways are themselves rare in the countries where studies have reported ASD prevalence and would not serve to explain the apparent overall differences in prevalence of autism amongst deaf children.

**Theory of Mind and deaf children**

In considering current ideas about autism and the models that continue to receive attention, Theory of Mind is amongst the most widely accepted. Theory of Mind development relates to the growing ability of children to infer the thoughts, feelings, perceptions or attitudes of others. It is seen not as an all or nothing phenomenon – rather it is also best placed on a spectrum that develops over time. Previous research in deaf children have suggested that it is often delayed with suggestions that this is because deaf children are more likely to have autism spectrum disorders. What is the basis for such a suggestion?

Theory of Mind has indeed been shown to be significantly delayed in deaf children from hearing families in several studies. It is found to be usually delayed in native signers in healthy deaf families. Some suggest that Theory of Mind delays may be because tests rely on linguistic skills, since it is known that language ability correlates with theory of mind skills in both deaf and hearing children and developmental abilities of cognition, language.
and theory of mind interweave. As a result, studies have tried to control for this. Delivering the test in the child’s first language, British Sign Language or using a non-verbal task improves performance but deaf children are still found to be behind expected levels. Delays seem to exist even when linguistic abilities are controlled and tasks are deaf friendly. Deaf children in hearing families are an average of 3 years behind hearing children in these skills. For example, 40% of 13-16 year olds in one study passed a test that 80% of 3-5 year old hearing children pass. Eleven-twelve year old deaf children are less likely to correct a false belief in a negotiation scenario. Theory of Mind has also been shown to be delayed in children with cochlear implants.

**Socioemotional delay in deaf children**

This research is central to our understanding of the development of theory of mind in deaf children, but the presence of Theory of Mind delay is not synonymous with a diagnosis of autism. Research with cochlear-implanted children suggests that early work discussing thoughts and feelings of others with children can facilitate a healthy Theory of Mind development. Furthermore, studies show that deaf adolescents appear to have good Theory of Mind when they are tested in false belief tasks or narrative tasks suggesting that they catch up with time. Some have suggested that early communicative poverty may be the culprit in earlier theory of mind delay. There may also be subtle differences perhaps related to the deaf child’s experiences of growing up. Fund of knowledge is undoubtedly an issue when children are left out of significant percentages of communicative and social learning experiences in the home, on television and in school. Incidental learning of emotions and social interaction from ‘overhearing’ in hearing children is often not available as a learning experience for deaf children. In an informal user group, a number of deaf children reported missing “at least 50%” of what was being said around them, and that parents frequently told them ‘it doesn’t matter’ or ‘it wasn’t to do with you’ when they requested clarification of family interactions. These differences may leave deaf children accessing less communication generally and less social and emotional communication specifically. It is not surprising therefore that 6-10 year old deaf children tend to view the world more from a self perspective, and refer to their own desires more often than hearing children. However, they refer to the beliefs of others as much as hearing children. Compared to children with autism there are subtle differences in the sequence of development of Theory of Mind amongst deaf children, but it does progress.

Are there other examples of young people whose social and emotional development is altered by early experiences in a way that might be confused with autism? Theory of Mind skills are reported to be delayed in a range of other groups in the research literature. These include institutionalised children, maltreated children in foster care and in language delayed children. It has also been shown that early life neglect can cause autistic like symptomatology with a better prognosis. It is possible to see that a number of circumstances can lead to uneven and perhaps delayed development of communication and emotional literacy. Such communicative and emotional challenges might in turn result in atypical development of Theory of Mind, and social and emotional delay that can masquerade as autism.

**Early intervention: a positive option**

The notion of a different development of Theory of Mind, coupled with the idea that deaf children may experience a subtly different early environment, leading to behaviour suggestive of autism, are supported by more positive literature. In respect of early communication, children with good communication in healthy communicative families are less likely to show these delays. In respect of the development of emotional understanding, it has been found that children of parents with flexible and resourceful problem solving skills do better in this aspect of their development. Studies show that specific learning programmes addressing emotional understanding appear to be helpful.

This positive picture is also seen in the possibilities of early intervention in deaf children.
Early intervention for deaf children in intervention programmes is both highly feasible given large numbers of motivated parents, and also achieves good language and communication and developmental outcomes\(^\text{38}\). Indeed, early intervention has been shown to be helpful for deaf children for some time\(^\text{39}\), especially for communication and language development and for global development. This varies from simple advice to programmes of support and/or education. Deaf awareness training for parents\(^\text{40}\), school pupils\(^\text{41}\) and school staff\(^\text{42}\) are important. The importance of making language visually available to children from an early age\(^\text{43}\) can be of great help. Similarly the level of early support can help hearing mothers adjust to having a deaf baby\(^\text{44}\). In preschool children the use of deaf role models working into families, with a focus on communication, has been shown to improve language development\(^\text{45}\).

Early intervention programmes benefit parents and their deaf children\(^\text{46}\). The Colorado Home Intervention Program (CHIP) in the United States promotes development using a family centred approach with home visiting. Language and communication is placed at the centre of this. The programme shows improvements in language development\(^\text{47}\) and communicative and socio-emotional outcomes\(^\text{48}\) when deafness is identified early (before 6 months of age) and the early intervention programme starts early. There are similar findings from the Nebraska Diagnostic Early Intervention Program\(^\text{49}\) and the UK Hearing Outcomes Project (Wessex and Whipps Cross early intervention programme)\(^\text{50}\). They also showed that family participation was particularly important in those picked up late with severe to profound permanent loss. Early identification and support in the Western Washington State Early Childhood Home Instruction Program (CHIP) also shows significant improvements for both receptive and expressive language skills at three\(^\text{36}\). The SKI HI curriculum in Utah is a family centred programme targeted at infants and young children\(^\text{51}\). The programme has a curriculum, resources for parent advisors and involves support to the family as they adjust. This includes advice about technology and amplification, the development of deaf children and the acquisition of parenting skills to promote healthy development. Language development outcomes have been shown to be good in large numbers of children\(^\text{52}\).

In respect of emotional understanding there are also some positive opportunities. Interventions to improve emotional understanding appear to be helpful\(^\text{53,37}\) and programmes developing socio-emotional competencies in children, such as the promoting alternative thinking strategies (PATHs) programme for children aged six and above, show good socio-emotional outcomes in children\(^\text{54}\) generally and in deaf children specifically\(^\text{53}\). Work to support the understanding of emotions in self and others and social problem-solving skills training are helpful ways of enhancing development.

**Conclusions:**

**Understanding deaf children - implications for practice and research**

There are clear implications here for both clinical practice and research. In clinical practice, assessment will need to take serious account of possible alternative explanations for autistic like presentations. Part of this might be to undertake child centred assessments that give the current developmental profile of a child rather than a diagnosis of autism. Of central importance here is the suggestion that communication, emotional understanding and hence Theory of Mind can be delayed as a result of communicative poverty in early life where the other symptoms of autism are not present. We suggest that the description **socio-emotional developmental delay** might be more helpful in many children with delayed Theory of Mind secondary to communicative poverty in early life where the other symptoms of autism are not present. It suggests a unique profile, a situation that can change over time and is suitable for early intervention work. The additional advantage of such an approach is that for deaf children, where the autism spectrum is indeed the most
appropriate way to understand them, it will be possible to assess and plan support more accurately for appropriate and tailored early intervention.

In the research literature it is clear that the arguments set forward here are essentially untested. What is needed is a typical profile of development of Theory of Mind in deaf children and young people alongside a much clearer understanding of differences in presentation for deaf children with autism. This can then form a legitimate rationale for research into the prevalence and manifestation of autism in this group, and more importantly interventions to improve outcomes. We suggest that the label socioemotional development delay might inform better interventions with more hopeful and realistic prognosis attributions, and might be more appropriate than a diagnosis of autism in many instances.

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References


