CASE REPORT

A case study: the impact of the deaf milieu in treating autism like problems

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ABSTRACT

Deaf children are more vulnerable to mental health problems and this includes the presence of Autism. However autism like symptoms can also be found in deaf children without fulfilling a whole diagnostic Autistic Spectrum Disorder category. Deaf children can show delays in theory of mind development due to early communication problems and this can manifest into deficits in social skills, anger, frustration and a need for routine. In this case study the author describes a young girl presenting with autistic traits. A referral to CAMHS (Child and Adolescent Mental Health Services) is initiated by her GP (General Practitioner) as a consequence of concerns voiced by her parents, and an educational psychologist. After a lengthy assessment including gold standard diagnostic instruments and input from two deaf aware members of the team, the conclusion was that this young person did not fulfil the criteria for a diagnosis of Autism. A combined plan with National Deaf Services was agreed to arrange therapeutic support for this young person with recognition of emotional vocabulary, social skills training, and behavioural management to be delivered from her new deaf boarding school. Further assessment indicated that some of the behaviours and difficulties described previously were greatly improved after gaining access to a deaf milieu in her new school. This case illustrates the importance of helping young deaf individuals to access peers, and how access to the milieu can increase deaf children self-esteem and social skills.

KEYWORDS

Deaf milieu, autism

Introduction

The prevalence of mental health problems in deaf children is known to be higher than on the hearing population. Unfortunately different methodology used in this research means that there is great variability in the rates reported. Hindley\(^1\) reported a prevalence of approximately 40% in UK. A recent North American study found greater rates of attention deficit hyperactivity disorder, conduct, autism spectrum and bipolar disorders and deaf children spent three times longer in treatment than their hearing peers.\(^2\)
According to Symanski the prevalence of autism among children with hearing loss is 1 in 59, twice as common than in the hearing population (1 in 91). Significantly more children with profound hearing loss had a comorbid diagnosis of autism than those with milder forms of hearing loss. Children whose deafness is caused by factors that also cause pervasive brain damage, such as intrauterine viral infections, neonatal meningitis and severe prematurity are particularly more vulnerable to ADHD (attention deficit hyperactivity disorder) and autism spectrum disorders.

Conversely we must also consider alternative explanations for the manifestations of autism like symptoms: Heiling and Eideval report how problems with attention, hyperactivity and social interaction also have to be differentiated from the sequelae of lacking communication. Falkman’s research on mentalising ability has proven that a delay on the theory of mind development is not always connected to an autism spectrum disorder. These results also concur with Remmel’s research at Gallaudet university. Hindley describes how a study by the NCDS in 2003 reported that 70% of deaf seven years old were unable to understand that other people think and feel differently from them. It is important to be aware of this research when considering a possible diagnosis of autism in a deaf child.

Clinical case

Anna is a 9 year old girl referred to the author’s service by her general practitioner with longstanding concerns regarding her social communication and behaviour.

Her parents described the following concerns:

Anna finds change very distressing and becomes angry with others if they do not follow particular rules. She describes her as constantly disruptive and playing jokes inappropriately a lot of the time. She seems anxious about new situations and new places. Anna struggles to develop and maintain friendships. She often interrupts conversations, misreads situations and seems unaware of the feelings of others.

Family composition

Anna is the only deaf person in the family. She has one brother. There is no history of psychiatric problems in the family.

Developmental History

Anna’s mother developed preeclampsia during the pregnancy. She was delivered by ventouse at 39 weeks after being induced. She weighed 8 pounds. She did not require special care. Anna was diagnosed with bilateral deafness at the age of 10 months and received cochlea implants at the age of 3 years. She was breastfed. She started to eat solids at 4 months and had no particular feeding problems. As a baby she had difficulties with sleeping. She used to cry a lot and find it difficult to settle. She had some night terrors. She had a normal motor development and started crawling at 8 months and walking unaided at 13 months. She has no major problems with her fine and gross motor skills and her coordination is reasonably good other than some difficulties with running. She is left-handed. Anna has attended a mainstream school with a deaf unit from an early age. She spends time in the main stream and in the centre for the deaf with a teacher of the deaf and 3 teaching assistants in a group of 5 children. She is very demanding of adult’s attention. She struggles to get on with her peers and has great difficulties with her emotional vocabulary.

Investigations

3di Autistic Spectrum Disorder Developmental Interview

The 3di is a parental interview for pervasive developmental disorders (including autistic spectrum) that can be administered to unselected clinical and general population samples; it measures both symptom intensity and co-morbidity across the full range of the autistic spectrum. It is a computerised procedure, for administration by trained interviewers, which generates symptom and diagnostic profiles for both autism and non-autistic conditions. It follows the ADI R (Autism Diagnostic Interview Revised) same categories of social reciprocity, communication and patterns of behaviour. This interview takes place with the parent/parents.

Results: Anna scored within the lower end of the diagnostic threshold for social reciprocity and communication and score below threshold for repetitive behaviours.

To make a reliable diagnosis a 3DI interview needs to be accompanied by an observational interview of the young person. We chose the ADOS (Autism diagnostic Observation Schedule) as it is one of the most investigated and employed instruments worldwide for autism spectrum diagnosis.

ADOS
The ADOS\textsuperscript{11} is a semi-structured assessment that takes around 45 minutes to administer. It consists of various activities that allow the observation of social and communication behaviours related to the diagnosis of autism spectrum disorders. These activities provide interesting, standard contexts in which interactions can occur. During the administration of the ADOS, observations are recorded and later coded according to specific criteria. These codings are summed under various categories and cut off scores are provided to indicate when an individual appears to meet the criteria for the broader diagnosis of autistic spectrum disorder (also called Pervasive Developmental Disorder or PDD), as well as the traditional, narrower, conceptualisation of autism.

The ADOS has 4 different modules which are chosen according to the developmental abilities of the interviewee. In Anna’s case module number 3 was chosen. The instrument is administered by one member of the team and observed by another who will take extensive notes. When the interview is finished both clinicians will score the algorithm together. In Anna’s case the clinician administering the interview was deaf aware. A BSL interpreter was present to facilitate communication.

\textit{Administration:} Anna engaged very well with the examiner and the BSL interpreter, she was able to interact well and reciprocate a conversation. She was good at communicating her areas of interest. Her comprehension of spoken language and signing was satisfactory. Throughout the course of the ADOS administration there was no evidence of immediate echolalia and she did not present with any language abnormalities expected in children with autism such as stereotyped or idiosyncratic use of words or phrases. Her conversation included some spontaneous elaboration of her own responses for the examiners benefit.

She used modulated eye contact well to initiate, terminate or regulate social interaction. The facial expression noted during the administration were limited and related to feeling happy on occasions. Anna went through the ADOS tasks without any persuasion and always appeared comfortable.

She was able to respond to cliff hangers (comments made by the examiner during the interview with the expectation that the interviewee will spontaneously request more information). For instance: the interviewee mentions: I have a dog, the interviewer will mention a cliffhanger: “I have a dog too”. The expectation will be that the interviewee will make a comment “oh really?” and/or enquiry for further information such us “what type of dog?” “What’s his name? etc.). She was inquisitive throughout. However, Anna demonstrated more difficulty with respect to recognising and understanding emotions. Whilst she was able to identify some basic emotions, she often struggled with more complex emotions and was unable to describe her emotions of feeling happy, sad, scared or angry.

Throughout the various tasks within ADOS, Anna demonstrated imagination and creativity.

\textit{Results}

Whilst her performance during the ADOS administration did demonstrate some strong deficits with emotional recognition and understanding, her overall performance did not meet the threshold for a diagnosis of autism.

\textit{CARS2-HF}

A school observation with two different members of the team (one deaf aware) took place to gain evidence for ratings of the Childhood Autism Rating Scale (CARS).\textsuperscript{12} This is a 15 item scale which provides brief, quantitatively specific, reliable and also comprehensive summary information to assist in determining diagnoses. Observation took place in the dining hall, in the playground and in the classroom (mainstream class). Observational information from her school teacher was also gained for the assessment and incorporated into the results.

The outcome of the observational assessment indicated that Anna is presenting with social communication difficulties but her presentation in this assessment was not significant to meet the criteria for a diagnosis of Autistic Spectrum Disorder. It was felt that much of her difficulties in relating to others and her emotional responses could be best accounted for by her struggles with accepting her identity as a young person with a hearing impairment. Anna appears to try to control her environment in order to defend against feeling anxious about being different and not accepted. She over relies on adults for reassurance and containment. Further support for her emotional and relational issues is necessary for her on going development in secondary school.

\textit{Outcome}

As Anna was due to start a boarding deaf school, arrangements were made with national Deaf Services to provide therapy to address Anna’s difficulties with emotional vocabulary, social skills, and behavioural
issues. Due to geographical issues a therapist was to be made available from the national deaf services to meet Anna regularly in her boarding school.

However after 8 weeks further assessment indicated that most of these issues have been already addressed through access to a deaf milieu. Anna was feeling more confident, accepted and part of the deaf community in the school. Teachers reported no particular problems with her social skills. She did not have the need to control her environment as she no longer felt different but accepted by her peer group.

Conclusion

This case illustrates the difficulties in assessing deaf children with autism disorders and the need for using specific tools for autism but adapted for their use in deaf children.

We are aware that deaf children appear to be at greater risk of developing autism. However we must also consider alternative explanations for the manifestations of autism like symptoms. For instance we can consider causality models secondary to impairments in communication. Landsberger2 describes how language forms the foundation upon which many developmental tasks are learned. Language skills impact and are impacted by multiple systems in a child’s environment, including parent child interaction and socialisation. Hearing parents with limited ability to communicate with their children lack the tools to socialise their deaf children and inconsistent language exposure produces a lack of language proficiency and an increase of frustration in the deaf child.

As mentioned before a delay on Theory of mind can be considered another causality factor for the inability to understand other peoples perspectives and points of view and therefore lacking the ability to read certain social situations.

Back in the 1970s the development of a milieu intervention program for treatment of emotionally disturbed deaf children started taking place. Following Erickson’s ideas that children need to experience and achieve the fundamental tasks of early development before proceeding to a more mature level of integration, Edelstein14 in US describes a therapeutic milieu setting which aims to help deaf children expand the child’s range of coping strategies. This is achieved by establishing consistency and predictability in the environment and providing an opportunity to expand and reinforce behaviour in the situation in which it occurs.

This model started to expand in Europe during the 1990s and reached the UK in 2000, when the first psychiatric deaf children’s inpatient unit opened. Hindley2 describes how access to an inpatient unit that uses a modified therapeutic milieu approach aimed at promoting the social and emotional functioning of deaf children using educational and therapeutic approaches is highly successful with 80% of children showing significant improvements in functioning and very high satisfaction ratings from parent and teachers.

This highly specialized services are run by very skilled deaf and hearing mental health professionals and are available for very severe complex cases. However less severe cases could benefit from a similar environment where deaf children will feel an integral part of the community and they have an opportunity to maximize their communication skills and obtain peer support. An example of this environment can be found in specialist schools for the deaf, and in Anna’s case, this was proved to be the treatment needed to support and facilitate her social skills and improve her interpersonal skills.

References


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