AN APPROACH TO WORKING WITH CHILDREN WHO ARE DEAF AND AUTISTIC IN A SCOTTISH GROUP CARE SETTING

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ABSTRACT: This paper discusses the development of a training course for a staff group working in a residential school for deaf children. Through the course, the staff were assisted in facing the challenges of working with autistic children who were also deaf. There has been very little work done in this area, yet it is a problem that may present itself much more often in the future, given the reported rise in the incidence of autistic spectrum disorder. The staff group had been presented with challenging behaviours from young people who were deaf and autistic, and they were unsure about how to intervene. A two-day staff training programme was developed based on research in the field, the author's observations of the staff and children in the unit, and contributions from professionals in the fields of deafness, autism, and group care. Evaluation of the training course revealed positive outcomes for the staff and the children in their care. The issue of working with children with a dual diagnosis and the importance of raising awareness of autism are discussed.

Key words: autism, deafness, training, group care

INTRODUCTION

> Many autistic people affectionately, humorously refer to themselves as aliens. They feel displaced on a vast planet, which has a code of life and understanding they can't ever quite subscribe to. (O`Neill, 1999, p.125)

> What is it like on the road of life/To meet a stranger who opens his mouth-/And speaks out a line at a rapid pace; /And you can't understand the look on his face/Because it is new and you're lost in the race? /You have to be deaf to understand. (Madsen, 1971, on line)

The two quotes above illustrate the lived reality of people who may be deaf or people who are autistic. The communication challenges that the world presents to these people are clearly profound. Where a child is both deaf and autistic, and in a group care setting, the communication challenges are greatly increased. This paper outlines some of the areas that had to be explored when setting up a training initiative for staff working with children who are both deaf and autistic.

In Britain today, the incidence of autism appears to be rising. Reports on the incidence of autism tend to vary. In their epidemiological study in Camberwell, Wing and Gould (1979) reported an incidence of 21 children per 10,000 live births. Happe (1998), in her summary of epidemiological studies, reported an incidence of between 4-10 children per 10,000 live births. Recent figures from the National Autistic Society (2003) indicate that 60 per 10,000 children are affected by autism. Looking at figures for the past ten years, it is clear that the reported incidence of autism is rising. Although the explanations for this rise in incidence vary, Happe (1998) suggests that this is related, in part, to better assessment and diagnosis.

There is a range of professionals who work with autistic children. Some of these professionals encounter autism as a part of their work and learn about it as an adjunct to their everyday practice. In this paper, although the role of professionals who work primarily with deaf children will be described, the implications for other professionals will be discussed.

The Co-occurrence of Deafness and Autism

Figures from the British Deaf Association (2003) indicate that 10 in every 10,000 people will be born profoundly deaf and that 20 in every 10,000 people will have become profoundly deaf in the course of their life. They may use Sign Language and probably also lip-read. British Sign Language (BSL) is the first or preferred language of around 70,000 people in the UK. Given these incidence rates, it would be reasonable to assume that some young people who are deaf and autistic will be finding their way into services. It is important to establish the extent of dual diagnosis. In their study of 46 children with a hearing impairment, Jure, Rapin, and Tuchman (1991) found that 5.3% were also autistic. They indicate that, given the difficulty in testing children and young people who are autistic, the prevalence rates could be higher. They were also concerned about the negative impact that late diagnosis can have on the education of this group of children, as well as the lack of specialist facilities for children who are deaf and autistic. Rosenhall, Nordin, Sandstrom, Ahlsen, and Gillberg (1999), in their study of 199 autistic children, found that 3.5% of the group were profoundly deaf. Gordon (1991) suggested that the comorbidity rate could be higher than expected and concurred with the findings of Jure et al. (1991).

Deafness and Autism: Challenges in Communication

Higgins and Nash (1987) report that the vast majority of children who are deaf (just over 90%) are born to hearing parents. In this way, a peculiar familial situation emerges in that, from the outset, parents and children do not share a common language. This leads to the creation of a distance between the child and the parent which results in the development of different ways of relating to the child who is deaf in comparison to parent-child relationships in the hearing world. Due to an often deferred age of diagnosis of deafness, even in the world of contemporary medicine,

research has tended to focus on primary-aged children. The fact is that we do not know very much about the picture for children who are deaf before this age.

Montgomery (2003) notes that the onset of deafness is a key issue when examining the development of language. As indicated earlier, some people become deaf later in life, and only around 0.1% of the population are profoundly deaf. The advent of deafness after the acquisition of spoken language does not have the same influence on speech production as does the same degree of deafness before the acquisition of spoken language. In this way, pre-verbal children who are profoundly deaf face major challenges in terms of communication.

In terms of the normal pattern of speech and language development, Fry (in Hayes & Orrell, 1993, p.172) outlined the main sequence of acquisition. One of the early stages identified by Fry was babbling. Both hearing and deaf babies go through this phase at around the age of six months. Many parents assume that this is a sign that their child can hear, but this may not be the case. It is only after this stage that the hearing child starts to differentiate speech sounds, whereas the child who is deaf does not. This is one of the factors that can contribute to a late diagnosis of deafness for the child.

When examining these facts, there are many similarities between children who are deaf and children who are autistic. Often, the diagnosis of autism is delayed until around the age of three to four years, or beyond. In terms of language production, children and young people on the autistic spectrum may range from being completely non-verbal to having quite complex language skills. As is the case for deafness, highlighted by Naremore and Hopper (1990), the production of language is not the key criterion for judging what type of assistance these children need.

As Happe (1998) indicates, the primary diagnostic indicators for autism used in the DSM-IV cannot be used reliably before the age of three to four years as behaviours associated with communication, socialisation, and imagination are not yet well developed. Schopler (1995) also indicates that parents are not well prepared to support their child who is autistic, and this is similar to the experience of parents of children who are deaf. Both sets of children face major challenges in terms of communication.

Cognitive Development and Communication: Parallels Between Deafness and Autism

Children who are deaf and children who are autistic face particular challenges in terms of delay or deficit in cognitive development. The child who is deaf is not exposed to sophisticated models of language in the way that a child who can hear is, and this factor contributes to what Higgins and Nash (1987) call *linguistic developmental delay.* The work of researchers such as Piaget (1958) would suggest cognitive development may be delayed because of the delay in language development, as the child is not being provided with the tools to make sense of his or her world. Piaget

looked at differences between abstract and concrete thinking among children at different developmental stages. Younger children tend to think concretely, taking things literally and having little understanding of the consequences of their actions. Older children tend to be more analytical in their interactions, with greater ability to reason. If cognitive experience is still mainly at a concrete level, this has implications for practice, as children who are deaf are more comfortable communicating in a concrete way.

The issue of cognitive development in children who are autistic has some parallels. Baron-Cohen, Leslie, and Frith (1985) have suggested that children with autism have a deficit in "Theory of Mind". This would suggest that children with autism may be functioning at what Piaget would define as a pre-operational level, or at a very early stage in their concrete thinking.

In the case of children who are both autistic and deaf, it is especially important for staff to realize that communication must be pitched at the correct level of the child's cognitive development. If this does not happen, then the type of communication system used is of little consequence, for the child will struggle to understand. Roper, Arnold, and Monteiro (2003) showed that diagnosis for deaf autistic children tends to be much later than that for hearing autistic children. Hence, the problems that arise for this group of children places them in a position of severe disadvantage.

Considerations for Staff Working with a Dual Diagnosis

Given the rising incidence rates of autism outlined earlier, it is suggested that children who are on the autistic spectrum will be finding their way into specialist services for deaf children. Indeed, this was the case at one specialist resource in Scotland. Donaldson's College is the main national residential school for children who are deaf. All of the children who attend this resource are what Higgins and Nash (1987) would refer to as *prelingually deaf,* and use Sign Language as their primary mode of communication. The residential staff within this resource found that they had a small number of children who were on the autistic spectrum. The comorbidity rate for the resource was around 9%, which concurs with Jure et al. (1991) and Gordon (1991) who felt that the incidence of comorbidity in general would be higher than that discovered in their own studies.

At the Scottish Institute for Residential Child Care (SIRCC) we received a letter from one of the senior residential child care officers at the resource asking if we could provide some training to help staff to deal with children who were both deaf and on the autistic spectrum, and who presented challenging behaviour to the staff who worked with them. SIRCC is funded by the Scottish Executive to provide training, education, and consultancy to residential child care workers all over Scotland.

SIRCC's initial search indicated that there was abundant information on working with young people who are deaf and on working with young people who are on the autistic spectrum, but that there was no information about how to work with young people in group care who are both deaf and autistic.

A working group was set up to develop a training programme for the residential staff at Donaldson's College. The group consisted of the author, a speech and language therapist who specialized in working with autistic children, the senior residential worker who contacted us and who was skilled in working with deaf children in a group care setting, and a training officer from SENSE, which is one of the main voluntary agencies working with people who have a sensory impairment. After the initial "thought shower" session, the group generated a range of ideas. The author and the senior residential worker then worked together to develop a two-day training course for the residential staff.

A questionnaire was given to the staff to ascertain their skills at the beginning of the process. It quickly became apparent that the staff group had a high level of skills in working with deaf children. They also had an excellent understanding of the role of clear communication in relationships with children. However, the staff had little knowledge of autism and had not been given an opportunity to examine their definitions of challenging behaviour as they had not been faced with this before to any great extent. Philosophically, the staff worked from a social model of disability. Middleton (1996) characterized this philosophical stance succinctly when she said:

> Disability is a social construct and it is never value free. The term often provokes negative reactions in people. As a society, we do not really want disabled children. Attitudes and structures in society tend to exclude disabled children and deny their gender, their sexuality, their race and even their rights as human beings. (p. iii)

The participants in the course had few formal qualifications. This had to be accounted for in the design of the training program. It was decided to use adult learning principles to inform the design of the training. When adults learn, Knowles (1994) tells us, they enter educational activities with a life-centred, task-centred or problem-centred orientation. These principles were at the forefront of the curriculum design for the training course.

A Curriculum for Staff Working with Children Who Are Deaf and Autistic

The main aim of the course, which was highly experiential in nature, was to encourage staff to enter into the world of the child who is both deaf and autistic. It was important that the staff see the child as an individual and not just as a diagnosis. It was also felt that it was important that the staff realize that they already had a key skill in working with children who are deaf and autistic--their primary focus and excellent understanding of clear communication. The objectives of the course were as follows.

- To provide participants with a basic knowledge about autistic spectrum disorder

- To encourage participants to view challenging behaviour in its widest sense
- To examine strategies to create an autism-friendly environment for deaf children

During the first day, the staff were encouraged to examine and clarify their definitions of challenging behaviour. They were then asked to reframe this definition so that the behaviour could be viewed as a form of communication. They were given some input on autistic spectrum disorders, on the implications of the "Triad of Impairments", and on the Theory of Mind. During the final part of the first day, staff were asked to identify and to become aware of the skills they already had in working with deaf children, and to look at how these were transferable to working with children who were both deaf and on the autistic spectrum.

On the second day, staff were introduced to the idea of functional analysis as a means of helping them identify the communication content of behaviour. Some didactic input was given on cognitive and language development, and the staff were subsequently asked to reflect on their personal experiences of development. The speech and language therapist, who had worked on the ideas for the course, gave a short talk on tools and strategies that could be used to help aid communication with children who were both deaf and autistic. This introduction included looking at the rationale behind systems such as the Picture Exchange Communication System (PECS), and how to adapt techniques such as Social Stories, developed by Gray (2000). A substantial part of the second day was spent on looking at the needs of the children who were actually living at the school, and developing action plans to create a more autism-friendly environment for them. Another important feature of the course was the use of quotes and writings from people who were deaf or people with autistic spectrum disorder. These writings served to highlight the lived realities of people such as O`Neill and Madsen, whose quotes were used at the beginning of this paper. They also served as lively points of discussion for the group. The programme for the two days, and some typical examples of the materials and activities used, is reproduced in the appendix.

EVALUATION

The immediate post-course evaluation was extremely positive, with staff reporting that they felt much better able to cope with the challenges facing them. They also reported that they felt a much greater empathy toward the deaf, autistic children with whom they worked. As described in the training program notes (see appendix), a substantial part of the second day was spent on the development of an action plan on how to make the residences of the young people more autism-friendly. A follow up evaluation showed that staff had implemented most of the ideas that had been generated in the training. For example, they had organized the lounge into different coloured sections to help structure, in a visual way,

activities that took place in this large open-plan area. This means that the quality of the group care experience that the resource offers this particular group of young people has been enhanced in a life-affirming way. The training experience was positive for all concerned and appeared to have real benefits for the children.

DISCUSSION

This paper illustrates several points. One is that children with autistic spectrum disorders may be present in a variety of services that do not have a specialist focus on autism. Another is that staff, when presented with behaviour which they do not understand, may label these children as difficult or as having challenging behaviour. These labels can follow young people into other services and have potentially harmful results for their life outcomes. Becker (1963) explained that "Labelling Theory" focuses on the reaction of other people and the subsequent effects of those reactions which create a view of that person as deviant. When a person is labelled, she or he is then segregated from society. Becker noted that this process of segregation creates "outsiders" who are outcast from society. When more and more people begin to think of these individuals as "deviants", they respond to them as such. A label of being "aggressive" and "violent" or having "challenging behaviour", therefore, can have severe consequences.

The paper also illustrates how a simple training programme can help staff who have no specialized education in autism work with young people whose diagnosis includes autistic spectrum disorders. This group of staff, who already work with children and young people with communication issues, seemed to be particularly receptive to the ideas presented during the training period. However, if this type of training were to be carried out with groups of staff who were not already in tune with some of the relevant issues, adaptations would have to be made based on a training-needs analysis of the particular staff group.

The paper also highlights the need for professionals from all disciplines to work together to ensure that children with a dual diagnosis get the best possible service. Using professionals from different fields to develop this particular training course showed the contributions that each discipline can make to the overall content and presentation of training. It also highlighted the need for a more acute awareness of autism on the part of professionals who work in a variety of related fields. If all professionals (e.g., teachers, nursery staff, health visitors, residential child care workers, and social workers) who worked with children and young people had a basic awareness of autism, they might be able to set in motion effective intervention at an earlier stage.

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APPENDIX

Training Program

Day One

9.15-9.45 Introductions, aims, and objectives

9.45-10.15 Challenging behaviour: A personal perspective
Staff were encouraged to reflect on situations they find challenging, and why. For example, they may feel angry if someone jumps their place in a queue. This is because this behaviour is against social conventions. Other examples from the group were explored.

10.15-10.45 Challenging behaviour: A workplace perspective
Staff were asked to list what behaviours they found challenging at work. Examples given included spitting, hitting, and biting. Comparisons were made with the earlier discussions.

10.45 – 11.00	Break
11.00 – 11.30	Social contexts Staff were asked to examine the contexts of the behaviours they had identified and when these would be acceptable. For example, hitting would be acceptable in a boxing ring. They were then asked to analyze the behaviour in terms of what message it might be conveying.
11.30 – 12.00	What is autism? Staff were given a short lecture on autism, emphasising the triad of impairments.
12.00 – 12.30	The lived reality of an autistic child Poetry and quotes from autistic people were read and discussed. Exercises were done in which staff were prohibited from using their preferred language.
12.30 – 1.30	Lunch
1.30 –2.30	Theory of mind Staff were given a short lecture on the Theory of Mind and then given exercises to simulate mind-blindness.
2.30 – 2.45	Break
2.45 –3.30	Behavioural theory and functional analysis Staff were given a short lecture on this topic and then a worked example. The purpose was to give them a tool to work out the communication content of the challenging behaviour of an autistic child.
3.30 – 4.00	The implications of the triad of impairments Staff were asked to thought-shower the implications of the triad of impairments for young people. This was built upon the following day.
4.00 – 4.30	Plenary
Day Two	
9.30 – 9.45	Introduction to the day

9.45 – 10.30	Cognitive development and communication The speech and language therapist gave a short lecture on this topic and followed through with working examples. She then encouraged staff to draw examples from their own practice and reframe some of the behaviours they had seen in terms of its communicative value.
10.30 – 10.45	Break
10.45 – 12.30	Creating an autism-friendly environment for deaf children Staff used what they had learned to develop action plans for the deaf-autistic children they were currently working with. They had to work in the context of the children's environments and draw up ideas taking into account the triad of impairments and deficits in Theory of Mind.)
12.30 – 1.30	Lunch
1.30 – 2.30	Creating an autism-friendly environment for deaf children (cont.)
2.30 – 2.45	Break
2.45 – 4.30	Feedback, useful resources, plenary, and evaluation

SAMPLE EXERCISE 1 (DONE ON DAY ONE)

Instructions to Participants

The exercise on routines will be divided into two parts. The first part will be a pairs exercise. Each person in the pair will get to act as interviewer and interviewee. Each interviewer should be allowed five minutes to draw up a routine for their interviewee in the space below. Hence, this part of the exercise will take ten minutes.

The second part of the exercise will be a pairs exercise. Participants will now be matched with another person from a different pair. They will take with them the routine from the pair they previously worked in, as noted below. It will be their job to tell their new partner that this will be their new partner's new daily routine. The added complication is that their partner will not be able to communicate verbally about what they think of their new routine! This part of the exercise should take about ten minutes (five minutes for each person).

Your Partner's Routine

(The partner's routine would be written out here).

When the exercise is complete, we'll discuss this as a group, focussing on the feelings generated by the second part of the exercise.

> (The aim of this exercise was to illustrate how valuable our routines are to us [as they are for any child] and the feelings of anger and frustration that can occur when our routines are taken away from us and we are placed in a position of not being able to communicate what we think! Wouldn't you be angry and upset--maybe you'd hit out or scream if you couldn't do anything else!)

SAMPLE EXERCISE 2

Participants were asked to read the following poem and discuss it.

Home

A child encapsulated
Her inner world of music,
sensations luscious honey,
spicy-rich-warm cinnamon,
a sanctuary of soft movements.

Rocking body,
fingers floating before deep eyes,
feet wandering soothing circles, Serene in autistic quiet,
Serene eyes,
Serene hands,
Happy
Living in her simple coloured box,
Her blown-glass world,
Home
Self-enclosed dream child,T
oe-steps her own exotic rhythm,
She shields the egg of her universe
with wide wings.

J. L. O'Neill