

MY DEAF AUTISTIC SON AND ME

by

ANGELA P. MORRIS

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ABSTRACT

This self study is in the form of a series of vignettes and describes the challenges I experienced as the mother of a deaf autistic child trying to find an education system that could accommodate my son's needs. It describes my attempts to find support for him and for myself. The study describes the difficulty I had in obtaining an accurate diagnosis of my son's disabilities due to the fact that both deafness and autism present similar language difficulties. My son's deafness was diagnosed well before his autism, which resulted in his education beginning in a system specifically designed for deaf children, so that he received no early intervention for his autism. My study describes the stress entailed in moving our son from one school system to another in an attempt to find a teacher who had expertise in both deafness and autism. I found gifted and caring teachers of the deaf and teachers who had experience in teaching children with autism but, at that time, was not able to find anyone with expertise in both. In later years, we moved our son back to the School for the Deaf where a program for deaf/plus children had been developed. My data have been culled from documentation I gathered from the time my son was an infant and up until the age of 10 years. I have compared my experiences with the literature.

My study ends with several recommendations for teachers, namely: (a) recognition of parental stress, (b) culturally Deaf signers for deaf autistic children, (c) an autism workshop for teachers of the deaf, (d) inclusion of autism in training for teachers (particularly teachers of the deaf), and (e) research plan of action in deaf autism.

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TABLE OF CONTENTS

ABSTRACT	ii
ACKNOWLEDGMENTS	iii
TABLE OF CONTENTS.....	iv
CHAPTER 1: INTRODUCTION.....	1
Purpose of the Project.....	3
Definition of Key Terms.....	3
Deaf/Hard of Hearing	3
Autism.....	4
Deaf Autism	6
Overview of the Project	6
CHAPTER 2: LITERATURE REVIEW AND METHOD	7
Deafness.....	7
Early Diagnosis.....	7
Intervention.....	8
Autism.....	13
Early Diagnosis.....	13
Intervention.....	17
Deaf Autism.....	22
Early Diagnosis.....	22
Intervention.....	23
The Need for Trained Educators and Parent Support in Both Deafness and Autism...	29
Method	31

Data Sources	32
Ethical Issues	32
CHAPTER 3: A SERIES OF VIGNETTES	34
The Vignettes	35
1. Why was Alistair’s full diagnosis not made during his preschool years?	36
Questions.....	38
2. Why was Alistair obsessed with light bulbs?	39
Questions.....	41
3. Did the School for the Deaf recognize the signs of autism in Alistair?.....	42
Questions.....	44
4. How did the School for the Deaf help Alistair?.....	45
Questions.....	47
5. How did stress affect my actions?	48
Questions.....	50
6. Why did Alistair and I need a special ed. specialist?.....	51
Questions.....	53
7. How do schedules and calendars help Alistair?.....	54
Questions.....	56
8. Why is Alistair’s watch so important to him?	57
Questions.....	59
9. What did we have to do to ‘fill in the gaps’ to understand Alistair’s attempts at communication?.....	60
Questions.....	62

10. What did we learn over the years about Alistair with regard to his receiving sign language?	63
Questions.....	65
11. Is Alistair able to show empathy?.....	66
Questions.....	68
12. Why did I need the support of other parents?.....	69
Questions.....	71
Where are we now?.....	72
CHAPTER 4: DISCUSSION AND CONCLUSIONS.....	74
Recommendations to Help Teachers	74
Recommendation 1: Recognition of Parental Stress.....	74
Recommendation 2: Culturally Deaf Signers for Deaf Autistic Children	75
Recommendation 3: An Autism Workshop for Teachers of the Deaf.....	75
Recommendation 4: Inclusion of Autism in Training for Teachers of the Deaf	75
Recommendation 5: Research Plan of Action in Deaf Autism.....	76
What I Have Learned.....	76
REFERENCES	79

CHAPTER 1: INTRODUCTION

I knew when I was pregnant with our fourth child, Alistair, that there was a possibility that he would have a hearing loss. We already had two children with a hearing loss, one moderate and one severe, and there was a strong possibility that my husband and I were both carrying a recessive gene for deafness, especially as only one of our children was hearing. When Alistair reached 6 months we took him for a hearing check and we were given the news that he was deaf. As I had experienced this diagnosis before in the family I was able to recover from the news fairly quickly and decided to start documenting our son's progress in a series of articles which I wrote for a publication called "The Voice," published in Texas. I thought it would be interesting to document how Alistair learned to communicate and how I, as a mother, felt as he progressed. I called the set of articles "Talk to me Little One."

I didn't realize at the time that my "little one" would not be able to talk to me for a very long time and that I would never, in fact, actually hear his voice. It was going to be several years before anyone realized that Alistair was not only profoundly deaf but that he was also autistic and that language was going to be a huge challenge for him. His brother and sister had had to be given language but Alistair was going to need to be given the very concept of language!

Once Alistair began his schooling in a School for the Deaf in Canada, we began corresponding with the teachers through a system of "Home and School" books. The teacher would write us a few lines each day telling us about our son's progress, and we

would respond that night describing what had happened at home and any concerns we might have. These “Home and School” books turned out to be a great support for me.

Over the course of 3 years at the School for the Deaf it became very evident to everyone that Alistair was not progressing well. We took Alistair out of the School for the Deaf and placed him in a small special education school near our home with an experienced special ed. teacher who was able to explain to my husband and me why our son was behaving so strangely and how we could help him. She had experience with autism and had many techniques to help him understand his world. Again our interactions were documented in “Home and School” books. Now Alistair was getting the best education he could for an autistic child but I was worried he was not seeing fluent sign language. Our search for the system that could successfully accommodate both our son’s deafness and autism continued, and we moved Alistair to different schools to find the “perfect” school ... there wasn’t one!

In 1991, I wrote a play for the Queen’s experimental theatre and visually showed the audience the challenges and joys of having a deaf autistic son. We called the play “Turn on the Light” partly due to Alistair’s obsession with light bulbs and partly because I had heard a keynote speaker at a conference on autism comment “When will someone turn on the light for these children?” I have a very strong desire to “turn on the light” for deaf autistic children and to shine the spotlight on the needs of these children and their families.

Purpose of the Project

My self study that forms this project is presented in the form of a series of vignettes and describes the challenges I experienced as the mother of a deaf autistic child and my efforts to succeed with those challenges. My son's autism was diagnosed much later than his deafness and, during his childhood, there was no educational system that had the experience and skills necessary to effectively teach him. These vignettes describe my attempts to find support for him and for me.

Definition of Key Terms

For this study the reader needs to know the definitions of deaf/hard of hearing, autism, and deaf autism. Each of these terms is explained in the sections that follow.

Deaf/Hard of Hearing

Persons are considered to be medically/audiologically deaf when they have little or no functional hearing and therefore have to depend upon visual methods of communication, such as sign language, lip-reading, speech-reading, and reading and writing (Canadian Association of the Deaf, n.d.). This definition is consonant with that of Gallaudet University, a university that specializes in the education of deaf students.

The word "Deaf" refers to those deaf people who share a language (sign language) and a culture (National Association of the Deaf, n.d.). In contrast, the term "hard of hearing" refers to someone who has some hearing and who is able to use it to communicate. In audiological terms, these people may have a mild to moderate hearing loss (National Association of the Deaf). It can also refer to a deaf person who doesn't want any cultural connection with the Deaf community (Padden & Humphries, 1988).

Autism

Autism or Autistic Disorder is a neurobiological condition resulting in social interaction and communication difficulties and restrictive and repetitive behaviours (Le Couteur, Haden, Hammal, & McConachie, 2008). It is one disorder under the larger classification of Autism Spectrum Disorders (ASD). There seems to be a difference in opinion with regard to the prevalence of ASD. The discrepancy appears to be because most of the research is focused on finding the prevalence of ASDs in particular populations, e.g., how many boys have the disorder compared to girls in a particular province. Also different studies have concentrated on a selected age group which differs from study to study. For example, a recent study using the National Epidemiologic Database for the study of autism in Canada, looked at children 1-14 years of age and found that the prevalence of Pervasive Developmental Disorders (PDD; another term for ASD) was 28.4 per 10,000 in Manitoba and 35.2 per 10,000 in PEI (Fombonne, 2008). In contrast, Chakrabarti and Fombonne (2001, 2005) found that the prevalence of ASD was at least 60 per 10,000 in their study of children 6 years and under in a town in the Midlands in England, which corresponds with studies in recent years undertaken in both the UK and Canada that have concluded that the prevalence of all autism spectrum disorders is at least 0.6% to 0.7% which would be approximately 1 child out of every 150 children in the population (Fombonne, 2008). However, the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition-Text Revision (DSM-IV-TR, American Psychiatric Association [APA], 2004) reports that prevalence rates vary from 2 to 20 in 10,000, depending on the study.

According to the DSM-IV-TR (APA, 2004), the following criteria are used to diagnose Autistic Disorder:

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
 1. qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - b. failure to develop peer relationships appropriate to developmental level
 - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. lack of social or emotional reciprocity
 2. qualitative impairments in communication as manifested by at least one of the following:
 - a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c. stereotyped and repetitive use of language or idiosyncratic language
 - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 3. restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
 - a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - d. persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

There are thus four main conditions that need to occur for a child to be diagnosed with autism. The child needs to show impairment in both social interaction and communication and have restricted repetitive and stereotyped patterns of behaviour, interests, and activities. Also, the child must demonstrate some impairment in at least one of the following before the age of 3 years - social interaction, language as used in social communication, or a delay in symbolic or imaginative play. If all four conditions are not met, the child cannot receive a diagnosis of autism.

Deaf Autism

A deaf autistic child is a child who demonstrates the criteria needed for a diagnosis of both autism and deafness. It is presently unknown whether the presence of both disabilities together is an additive effect or multiplicative. An additive effect means that the challenges of the two conditions are simply added, whereas a multiplicative effect means that the dual diagnosis results in much higher degrees of challenge.

Overview of the Project

This project consists of four chapters. Chapter 1 outlined the introduction, purpose of the project, and definition of key terms. Chapter 2 describes the literature review and method and ethical issues. Chapter 3 is a series of vignettes based on my experiences with my son, while Chapter 4 contains the discussion and conclusions, including recommendations for teachers.

CHAPTER 2: LITERATURE REVIEW AND METHOD

This chapter gives an overview of the literature based on early diagnosis and intervention for deafness, autism and deaf autism. There is also a section that overviews the literature based on the need for trained educators and parent support in both Deafness and Autism. The last section consists of the method and ethical issues.

Deafness

Early Diagnosis

In 1984 when my son was born, young children were not routinely tested for hearing loss. A child's hearing was only tested if there was a delay in language or the child was showing signs of not responding normally to sound, or, as in the case of my son, if there was a history of hearing loss in the family (Madell, 1984). At the present time, all infants can be tested either in the hospital soon after birth or shortly after that time in their own community. This program is known as the Infant Hearing Program (Ontario Early Years, 2002).

To test hearing in a baby, soft sounds are played through a small earphone placed in the baby's ear. The ear's response is measured and recorded during which time the baby generally sleeps comfortably. The parents are given the results immediately. Those babies who do not pass this hearing test will be referred to an audiologist for a hearing assessment. The babies who are referred to the audiologist may not actually have a hearing loss. A baby fidgeting during the testing or the baby having debris in the ear may also cause a false positive result. If the audiologist does find that the baby has a hearing

loss, he or she will then direct the parents to the appropriate services and supports (Ontario Early Years, 2002).

Intervention

According to the Joint Committee on Infant Hearing (2007), the role of early hearing detection and intervention (EHDI) is to ensure that deaf and hard of hearing children are able to develop maximum linguistic and literacy skills. This development is essential because, without a language, these children will fall behind in communication, cognition, reading, and social emotional development. For EHDI programs to be successful, parents and professionals need to work together as a well coordinated team. The team members should include: birth hospitals, families, paediatricians or primary health care professionals, audiologists, otolaryngologists, speech language pathologists, educators of deaf and hard of hearing children, and other early intervention professionals involved in intervention, such as ophthalmology, developmental paediatrics, service coordination, and counselling. There is a recommendation by the committee that intervention options should be made available both in the home and in a centre. Intervention services should begin as early as possible, and not later than 6 months.

Children need intervention in early infancy because it has been shown that babies who receive early intervention make more gains with their expressive language than those who do not (Pipp-Siegel, Sedey, VanLeeuwen, & Yoshinago-Itano, 2003). But, as noted by Marschark and Spencer (2003), no single method of communication is going to be appropriate for all deaf children. Parents need information about the various communication options available for their child and the information needs to be given to the parents in a nonbiased manner. The language learning environment is far more

important than the mode of communication used. Early intervention programs need to guide the parents to the appropriate professionals who have expertise in the particular communication and language method the parents have chosen (Joint Committee on Infant Hearing, 2007).

Technological advances have now made it possible for children with a hearing loss to access sound, and most children can now use hearing aids and/or cochlear implants to acquire much or all of their spoken language (Simser, 2004). Hearing aids and similar devices (such as FM systems) amplify the sound, whereas cochlear implants bypass the damaged part of the ear to directly stimulate the auditory nerve.

If the parents choose personal amplification for their child then hearing aids should be fitted within one month of the hearing loss being identified (Joint Committee on Infant Hearing, 2007). Yoshinaga-Itano et al. (1996) found that infants who were fitted with hearing aids before the age of 6 months, and were part of parent-infant programs, had near to normal speech and language scores by the time they were 3 years of age but those infants who had hearing aids after the age of 6 months did not progress as well. It is important, therefore, that parents have immediate access to such technology.

A cochlear implant is “an assistive listening device that conveys aspects of the speech signal, such as the number of syllables, intensity, intonation, and stress patterns. These features, when combined with lip reading, enhance the ability to communicate in social and work situations” (Cohen, Waltzman, & Fisher, 1993, p. 237). According to the US Food and Drug Administration guidelines, cochlear implant can be provided at 12 months of age for children with a bilateral profound hearing loss and at 24 months of age for children with a bilateral severe hearing loss (US Food and Drug Administration,

2008). In the 1990s cochlear implants were controversial in the Deaf community because members of the community felt there would be a negative effect on their Deaf community and culture. Today there tends to be a feeling in the Deaf community that it is a personal decision about whether or not to have a cochlear implant, but there is continuing concern that parents may not make informed decisions (National Association of the Deaf, n.d.).

Thoutenhoofd et al. (2005) point out that outcomes of the implant vary and the reason for this variation is not yet understood. According to the National Association of the Deaf (n. d.), those who benefit best appear to be those recipients who have intact eighth nerves, those who have the implant relatively shortly after the onset of their severe or profound hearing loss, and those who have become deaf after having had language (e.g., 4 or 5 years or older because they have had previous experience with sound and speech). Nikolopoulos, O'Donoghue, and Archbold (1999) concluded that the long-term benefit of having a cochlear implant is most pronounced when the child receives the device at an early age. Early identification is therefore of paramount importance.

Regardless of whether the child uses an amplification system, such as a hearing aid, has a cochlear implant, or has no assistive technology to support hearing, there are two basic approaches to education for deaf children: the auditory-verbal approach and sign language. Although the success of the approach depends to a certain extent on the amount of hearing the child possesses, either or both approaches can be used.

The auditory-verbal approach stresses the development of a verbal language by commonly having students listen to sound using amplification from hearing aids and/or using the hearing potential of a cochlear implant (Simser, 2004). An auditory-verbal therapist trains parents to teach their deaf child speech and language at home through

structured listening and ongoing language work incorporated into daily life. There are four levels of auditory skills – detecting the presence or absence of sound, discriminating between different sounds, identifying the meaning of the sound, and understanding the meaning of connected language (Auditory-Verbal Center, 2008).

Although, traditionally, the choice was for children to take either an auditory-verbal approach or to use sign language, Archibold, Sach, O’Neill, Lutman, and Gregory (2006) found that parents valued both in that they wanted their children to be part of the hearing world and also wanted them to sign. Furthermore, some children start with an auditory-verbal program but have to move to a sign language model if those strategies fail.

Sign language is another communication option available to deaf and hard of hearing children. It is not a universal language, and each country has its own sign language. In North America, American Sign Language (ASL) is used by the deaf. According to the National Institute on Deafness and Other Communication Disorders (2000), “American Sign Language is a complete complex language that employs signs made with the hands and other movements, including facial expressions and postures of the body” (p. 1). As sign language does not have a written form, bilingual-bicultural programs have been developed where young deaf children learn to communicate in sign language and then learn to read and write English as a second language later (Evans, 2004).

The American Sign Language and Early Literacy program has been developed to help and improve parents’ ability to support their child’s language and literacy before the child receives formal instruction at school (Outreach ASL and Deaf Mentor Programs,

Sir James Whitney School for the Deaf, n.d.). The Provincial Schools for the Deaf provide ASL instruction and the home visiting professional, who can visit parents of young deaf children up to one half day a week in the home and guide parents to develop techniques to interact with their child, e.g. conversations, story telling and interactive activities. They can also link the families with members of the Deaf community. In some areas, local nursery programs may be available (Ontario Ministry of Education, 2008).

To learn sign language, deaf children need to see it. As Stewart (2006) remarks, “deaf children can and do acquire fluency in ASL at a young age if they receive adequate exposure to it” (p. 214). However, the majority of children who are deaf have hearing parents and receive far less early linguistic input than deaf children with deaf parents or hearing children of hearing parents (Marschark, 2001). To develop communication with a deaf child, it is essential to get the child’s attention first before the message is given. The child needs to pay attention to the hand shape, position and movement of the hands plus the signer’s face, while at the same time paying attention to the objects and events that are being discussed (Harris, 2000). In a study by Jamieson (1994), it was found that the deaf mothers of deaf children first got their child’s visual attention, then delivered the linguistic message, and then finally redirected the child to look at the object of discussion. Spencer, Bodner-Johnson, and Gutfreund (1992) found that deaf mothers were very good at moving their sign closer to the object being discussed so that the child could see the sign and the object at the same time. This process is referred to as “displacing” a sign as the sign is not in the correct location. Harris, Clibbens, Chasin, and Tibbitts (1989) noted that, in their study, the mothers were mainly using the sign in the correct position once the child was 20 months old. In addition, Spencer and Lederberg

(1997) found that deaf mothers would be more likely to use physical strategies, such as tapping their child or waving, to get the child's attention.

Autism

Early Diagnosis

A diagnosis of autism depends on a multidisciplinary assessment (Le Couteur, Haden, Hammal, & McConachie, 2008). This assessment needs to include a detailed developmental history of the child, a description of the child's current behaviours, a cognitive and language assessment of the child, and observations of how the child functions in a variety of settings (Le Couteur, Haden, Hammal, & McConachie, 2008; Ozonoff, Goodlin-Jones, & Solomon, 2005). A consensus of opinion is then combined with the information from the multiple sources to arrive at a diagnosis.

Two of the most widely used diagnostic instruments for autism are the Autism Diagnostic Interview-Revised (ADI-R), which is information gained usually from an interview with the parents/caregivers of the child (Le Couteur, Lord, & Rutter, 2003), and the Autism Diagnostic Observation Schedule (ADOS), which is information gained from observing the child. Intensive training of the administrator is needed for both (Lord et al. 2000).

The Autism Diagnostic Interview-Revised (ADI-R) is an investigator-based semi-structured diagnostic interview with the child's parents or main caregiver that gives the framework for a developmental history of the child (Le Couteur et al., 2008). This interview includes questions that ask the parents to recall details about their child's

behaviour over the last three months. There are 111 questions, and the interview usually takes about 2-3 hours.

The scoring for most of the items runs from zero – no impairment with respect to the behavioural definition for each item to three - severe impairment for the individual and her or his family. The interviewer needs to make judgments with regard to the child's behaviour from the recollections of parents/caregivers. The scoring algorithms developed from the information relate to social interaction, communication, and repetitive behaviours with a scoring cut-off for autism. The ADI-R thus focuses on three areas – language and communication, social interactions (reciprocal), and behaviours and interests that are restricted, repetitive, and stereotyped.

According to Harris and Handleman (2000), one of the best predictors of outcome for autistic children is the level of intellectual functioning of the child (IQ). The child's IQ is associated with how severe the autistic symptoms are and the child's ability to develop skills and how functionally adaptive the child is. As Ozonoff et al. (2005) point out, it is often difficult to test the IQ of a child with suspected ASD due to language challenges, tendency to get off-task, distractibility, and variable motivation. There need to be accommodations made to the testing process with these children such as frequent breaks or dividing the testing over several shorter sessions. Care must be taken in choosing the appropriate test, taking into account the child's chronological and mental age, and making sure that the test covers a full range of standard scores (in the lower direction). The Leiter International Performance Scales–Revised can be used for children with a mental age of 2 years or more as no expressive or receptive language skills are required. For very low functioning younger children, the original Leiter may be clinically

more successful (Tsatsanis et al., 2003). The Differential Abilities Scales can also assess both the child's intellectual and academic skills. This test can be given to children from 2 and a half to 17 years of age and can be repeated to track progress (Elliott, 1990).

Level of expressive language is the other best predictor of outcome and is therefore something that is important to measure. There are several instruments that can be used to test a child's language. The Peabody Picture Vocabulary Test (Dunn & Dunn, 1997), Expressive One-Word Picture Vocabulary Test (Brownell, 2000), Clinical Evaluation of Language Fundamentals (Semel, Wiig, & Secord, 2003), and Preschool Language Scales (Zimmerman, Steiner, & Pond, 2002) have been used to measure receptive and expressive language abilities for children with ASD. However, a speech-language pathologist can give a more comprehensive evaluation and provide language recommendations (Filipek et al., 1999).

Information regarding how the child functions in a variety of settings is most often obtained by directly observing the child using the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000). This schedule involves a standardized semi-structured observational play and activity assessment of the child, which usually lasts about 40 minutes. A particular module is chosen according to the developmental and language level of the child. Module 1 is appropriate for young children with no speech or single words and consists of 10 sets of materials and play activities. Module 2 is suitable for more fluent young children with phrase speech. This module involves 14 activities from which around 30 behaviours are coded on a 3- or 4-point scale. Selected items relating to social interaction and communication are then entered into an algorithm and the scores are then transformed. To be diagnosed with Autism or ASD, the individual's

scores must meet the separate cut-offs for both the communication and social areas and the cut-off for the summation of the two. Repetitive behaviours are not included in the ADOS summary algorithm but are recorded and coded (Le Couteur et al., 2008).

Although most previous information focuses on diagnosing autism when the child is at a developmental level when he or she should be capable of oral communication, work by Baron-Cohen and colleagues indicate the possibility of earlier diagnosis. Baron-Cohen et al. (1996) isolated three key behaviours that are normally present in children without autism at 14 months of age. The first key behaviour is pointing at an object to get another person to look at the object which is called “protodeclarative pointing” (as differentiated from pointing to obtain an object); protodeclarative pointing generally develops from between 9-14 months of age. It is absent or severely limited in autistic children even when they start school (Baron-Cohen, Allen, & Gillberg, 1992). The second key behaviour noticeably absent in autistic children is gaze monitoring, which is when the infant follows the gaze of the adult to see what the adult is looking at. Again, in a normally developing infant, this behaviour can be detected between 9-14 months of age. Both of these behaviours are considered to be “joint attention behaviours” (Baron-Cohen et al., 1996). The third key behaviour deficient in autistic children is pretend play, seen in normally developing children by about 14 months of age in a simple form. In pretend play, the child substitutes objects and/or attributes properties to objects or situations that are absent (Baron-Cohen et al., 1996). In contrast, an autistic child will only use a toy according to its conventional function (Baron-Cohen, 1987). Baron-Cohen et al. (1996) therefore concluded that, if these three key behaviours are present in normally developing young children by the age of 14 months and absent in school-aged

children with autism, then they might be an indication of the presence of autism in young children. Thus if the three key behaviours are absent at 18 months, there is a very high risk for autism. However, if there is a deficit in protodeclarative pointing and pretend play but not in gaze-monitoring, then the child would be at risk of developmental delay without autism. CHAT (Checklist for Autism in Toddlers) can be used to check for these behaviours (Baron-Cohen et al., 1992), but Baron-Cohen et al. (1996) stress that CHAT should be used only to alert the health professional to suggest a paediatric referral with a child psychiatrist and should not be used as a diagnostic instrument as of itself.

Ozonoff et al. (2005) point out that there are limitations to all measures. One of those limitations is that observation of the child involves a reliance on current behaviour. Signs of autism (such as deviances and delays) are most apparent in early childhood and occasionally these may not be recognized when the child is older (Boelte & Poustka, 2000). Furthermore, in their study, Le Couteur et al. (2008) found that the findings of both the ADI-R and the ADOS had a complementary effect in helping diagnosis when the results were taken together. However, when used individually as a single assessment instrument, either could over- or under-score some behaviours. This finding emphasizes the need of multiple measures to diagnose autism.

Intervention

There are several reasons why parents need an accurate early diagnosis of their child's autism. The first is that early diagnosis leads to early intervention¹ for the child, which may include a behavioural program based on the needs of that child (Roper,

¹ “Intervention refers to a plan of services and supports designed to help the child overcome some or all of their neurobiological challenges” (Scott & Baldwin, 2005, p. 174).

Arnold, & Monteiro, 2003). The importance of early intervention for autistic children is further reinforced by Horner, Carr, Strain, Todd, and Reed (2002) who provide a summary of the research on behavioural interventions for autistic children. Specifically, the researchers note there is a significant risk of young autistic children developing problem behaviours that will continue or become worse if intervention is not given. Intervention should therefore include strategies for both preventing and intervening with those problem behaviours.

Intervention that starts early in the autistic child's life and is both intensive and highly structured with strong parent involvement can make a very big difference (Scott & Baldwin, 2005). In a study by Samms-Vaughan and Franklyn-Banton (2008), the researchers found that early identification and intensive intervention led to the best outcomes for children with autism. The study surveyed 117 children diagnosed with autism in Jamaica over a 5-year period. The study found significant delays in the diagnosis of autism with the mean age of diagnosis at approximately 4 years of age (95 percent of all children were diagnosed prior to age 8). The researchers concluded that the first early contacts with health care professionals are a great opportunity for intervention to reduce diagnostic delays.

Once the diagnosis has been made, intervention can help young autistic children in a variety of ways – one of which is improvements in joint attention skills. Jones and Carr (2004) describe joint attention as a social communicative skill, which develops early, in which two people (usually a young child and an adult) share attention by using gaze and gestures to share attention to an object or event. Jones, Carr, and Feeley (2006) claim that joint attention plays a central role in the development of language and social

skills and that training joint attention should be an essential component of home- and school-based interventions with very young children with autism. The authors maintain that determining age appropriate target behaviours is critical. Similarly, Schertz and Odom (2007) explain that joint attention is a milestone that fails to develop naturally in autism. These researchers describe an intervention that was carried out in the homes of three toddlers who had been identified with autism. The participants were all mothers with their children, and the intervention consisted of four phases: focusing on faces, turn-taking, responding to joint attention, and initiating joint attention. All of the toddlers improved after the intervention – two engaged in joint attention repeatedly. The third improved in focusing on faces and turn-taking (possibly precursors of joint attention).

According to Wiseman (2008), the many treatment options for children with autism can be divided into three categories: developmental, organizational, and behavioural. Developmental treatments focus on filling in the child's gaps in development, whereas organizational methods focus on establishing a physical environment and routines that help the child to function and learn to the greatest extent possible. Behavioural treatments are very structured and focus on teaching the child specific skills and behaviours using repetition and rewards.

Wiseman (2008) describes two treatments that help young autistic children fill in gaps in their development with parents acting as the therapists in both. The DIR/Floortime (developmental, individual-difference, relationship-based) is a therapy where parents sit with their child on the floor for 20 – 30 minutes several times a day engaging their child in back and forth communication and meaningful play, starting at the level of the child and developing into longer and richer interactions. With RDI

(Relationship Development Intervention) therapy, the parents direct the child to tune into the actions and emotions of people by engaging the child in highly structured games. They then move on to exercises in back and forth communication, shared experiences and play, and then on to less structured interactions that build social awareness and competence. Parents need to attend training sessions and need supervision by a therapist trained in the method. Aldred, Green, and Adams (2004) found that an intervention that focuses on the to and fro of communication between an adult and the autistic child can improve reciprocal communication and expressive language for the child and can start a positive cycle of more effective communication and greater enjoyment for both parents and children.

There are also therapy approaches that focus on creating an environment and routine that will help the child to learn and function (Wiseman, 2008). The most common organizational approach is the Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH). Some parents use some of the suggested techniques of TEACCH at home, but it is most often used in the classroom to help children to work independently and develop life, communication, and social skills. The child learns in a structured environment with predictable routines and use is made of picture schedules. Personalized schedules are also mentioned by Mesibov, Browder, and Kirkland (2002) who maintain that predictor strategies, which would include personalized schedules, are an important form of support for positive behaviour. O'Reilly, Sigafos, Lancioni, Edrisinha, and Andrews (2005) examined the effect of individualized schedules on levels of engagement and self injury for a 12-year-old boy

with severe autism. There was significantly less self injury and significantly increased engagement during the Schedule condition.

The most common treatment for autism is a behavioural one, Applied Behavioural Analysis (ABA). It uses behaviour modification aimed at increasing appropriate behaviours and decreasing inappropriate ones (Wiseman, 2008). A highly structured method is used to teach specific skills and behaviours to the child using constant rewards and repetition. The goal is to reinforce all kinds of learning and appropriate social interaction while reducing those behaviours that block learning and communication. ABA programs can start at home, at school, or both, and the therapy often takes from 25 hours to 40 hours a week (Scott & Baldwin, 2005). The program may become less structured as the child progresses and may be included in the child's daily activities and routine. Most home therapy is given by college students who are supervised by experienced behavioural specialists though parents may be trained as therapists. A study by Reed, Osborne, and Corness (2007) found that, although ABA did not result in recovery from the symptoms of autism, it did help the child significantly with intellectual and educational functioning.

Although ABA is the most popular treatment for autism, it is not without its difficulties. As Scott and Baldwin (2005) point out, ABA programs are intensive and can take from 25 hours to 40 hours a week, which is a great deal of time for a child to be presented with repetitive training. I worry for the psychological health of these children as they are faced with therapists constantly trying to change them and not really accepting them for who they are. Do these children really understand why the therapists want them

to act in a certain way or are these children simply following instructions but not gaining any real understanding?

Sherer and Schreibman (2005) point out that not all children respond in exactly the same manner to intervention programs, and therefore these authors feel that a single treatment approach for all children with autism is inadequate. They point out the need for practitioners to determine which treatment is appropriate for each individual child.

Easterbrooks and Handley (2005) also conclude that one intervention may not be appropriate for all students.

Deaf Autism

Early Diagnosis

To be diagnosed as deaf autistic, a child must meet the criteria for both disabilities. However, it is difficult to diagnose autism when the child is profoundly deaf because there are communication-related issues connected with both disabilities (Roper, Arnold, & Monteiro, 2003). Either the deafness or autism can be missed or diagnosed late (Garreau et al., 1984; Jure, Rapin, & Tuchman, 1991). For deaf autistic children the autism often goes undiagnosed until much later than the deafness even though problems in development may have been identified at an early age (Roper et al., 2003). In fact, it may be the earlier diagnosis of developmental disorder and/or deafness which masks the existence of the autism. Indeed, in a study comparing three groups of participants—deaf autistic, deaf learning disabled, and hearing autistic children—Roper et al. (2003) found a later diagnosis of autism for the deaf autistic compared with the hearing autistic group,

even though the prevalence of autism among children with hearing loss at 5.3% is much higher than the prevalence among hearing children (Jure et al., 1991).

Part of the difficulty with the early diagnosis of deaf autism is that professionals may not want to “label” a child and, as such, may be reluctant to give the diagnosis of autism. Beals (2004) describes the challenges of finding help for her deaf autistic son, and how professionals were far less direct about her son’s additional problems than they had been about his deafness. The psychiatrist told her that he didn’t like labels. However, such a reluctance may have negative consequences. When deaf autistic children have a late diagnosis of autism, there are clear implications for their assessment and intervention, such as whether or not they are educated primarily as deaf or deaf autistic (Roper et al., 2003). It is thus vital to get an early diagnosis of the autism for these children because their programming needs to be tailor made to ensure that educational strategies are adapted to their patterns of skills and disabilities (Jordan & Powell, 1995).

Intervention

Until recently, although intervention methods were available to help autistic children and children with a hearing loss, there was no research available on any therapy that could be used for a child with both (Malandraki & Okalidou, 2007). As a result, researchers interested in the dual diagnosis of autism and deafness had to rely on information provided about deafness and multiple disabilities. At the forefront of this research are Ewing, Jones, and Jones (e.g., Ewing & Jones, 2003; Jones, Jones, & Ewing, 2006).

Ewing and Jones (2003) point out that, over the years, deaf students with multiple disabilities have not had the same educational opportunities as their deaf peers.

Professionals need to look at students with multiple disabilities as individuals and build on their strengths rather than dwelling on their deficits (Ewing & Jones, 2003). The researchers list four things to consider when planning for deaf students with multiple disabilities – teachers need to truly believe that every child is capable of learning; linguistic skills and social skills are the two most important things for these children to develop, and both of these are best learned from peers; the efforts of the family are essential for the success of any program; and service providers should share information and skills across disciplines (the transdisciplinary model; Ewing & Jones, 2003).

The education of deaf children is significantly complicated when there are additional disabilities present (Ewing & Jones, 2003). One suggestion is that deaf autistic children be placed in a specialized program in a school for the hard of hearing (Jure et al., 1991). In contrast, Ewing and Jones (2003) point out that special education research shows that children with special needs are at an advantage when they are educated with peers without disabilities in an inclusive setting; in these settings, they demonstrate an increase in language skills and pronounced academic gains. This example, they feel, can be used as a parallel to the situation of deaf children with multiple disabilities using the general curriculum. Ewing and Jones feel that the best way to get linguistic interactions is to place these children in settings with other deaf children who do not have other disabilities.

Jones et al. (2006) maintain that not only do students with multiple disabilities have the right to access the general education curriculum but that they have the right to have that curriculum adapted to maximise their learning potential. To plan for the child, there needs to be an assessment of the student so that the teacher can have a clear

understanding of the needs of that individual child (Jones et al., 2006). To adapt the curriculum for the child, teachers can use materials, such as textbooks and other materials, that are at the child's level of understanding. They can also use materials that are based on experience such as journals, magazines, literature, and art.

Attention needs to be a particular emphasis in these adapted curricula, in that maintaining attention is a critical challenge for children with a variety of disabilities including autism (Jones et al., 2006). Deaf autistic children may need more time than other deaf children for interactions so that there is time to attract and maintain their attention. Also some may need extra time to process information that is given them. Comprehension may be helped by introducing pictures or words as a reinforcement. These pictures and words can focus attention.

In addition to the work of Ewing and colleagues, three studies have been published on interventions with deaf autistic children involving a single participant. Each of these studies indicates how a specialized curriculum might benefit a particular deaf autistic child.

Malandraki and Okalidou (2007) used a Picture Exchange Communication System (PECS) to help a 10-year-old child, C. Z. , who had no functional communication, to interact with others using pictures. C. Z. had been found to have a profound hearing loss at the age of 2 years and 6 years but his autism had not been diagnosed until the age of 10 years. Teachers and caregivers of the boy said that he rarely communicated interactively. For the study, five of C. Z.'s caregivers at the residence for the school and his teacher at school were trained to use the PECS method of

communication. PECS enables the person to approach someone and exchange with the other person a picture of something the first person wants (Bondy & Frost, 1994).

After 4 months of intervention using the PECS system, C. Z. spontaneously used a PECS communication book. The success of the intervention was therefore considered adequate. There was also an unexpected outcome to the intervention. During the phase that involved building sentence structure and responding to “what do you want?” C. Z. started to vocalize at exactly the time he was choosing the cards to put on the sentence strip. This vocalization appeared to be an attempt at reading the words aloud. No one had ever observed him making vocalizations before.

The PECS system also had an effect on C. Z. from a social point of view. The other children, who had always acted positively towards him, became even more positive and began to play with him more and were seen to copy the trainers by using the cards to communicate with him, and C. Z. was no longer obsessed with sitting alone on a chair. There was also a change in C. Z. with regard to his connection to his mother. In the past, C. Z. had acted almost indifferently when his mother had come to the school to collect him but during the intervention he started to look forward to her arriving and quickly grabbed his bags and ran to her with a smile.

The second study was developed by Easterbrooks and Handley (2005) who had the hypothesis that applied behaviour analysis (ABA) would prove to be effective for individuals with ASD/PDD. The subject was a 6-year-old boy (Andy) diagnosed with both deafness and pervasive developmental disorder not otherwise specified (PDD-NOS). In first grade, Andy’s behaviour was becoming a problem. He was demonstrating behaviours that obstructed his learning and socialization, e.g., self-stimulating

behaviours, tending to obsess over objects being in line, and ritually repeating himself. The study focussed on the self-stimulating behaviour, which consisted of his crossing his arms and squeezing. At first, the teacher would reach out and touch Andy's arm and request he put his arms down. After 7 days, the instruction was reduced to a meaningful look from the teacher. The teacher would wink and nod to show approval of Andy's efforts. The child responded very well to this intervention, and only one recurrence was seen over a 13-day period. Andy was included more in peer groups after this intervention. Easterbrooks and Handley noted that they had not expected Andy to respond so quickly to the intervention. They concluded that teachers of the Deaf need to use ABA as a means of intervention for students with deafness and ASD/PDD.

The third study described one family's experiences with early intervention for their son, Jason, whose deafness was diagnosed before his autism (Beals, 2004). This is the account of a mother's intense frustration at trying to get help for her child. The professionals who worked with the deaf were divided on which intervention method to use. This family found themselves in the middle, judged badly by everyone because they wanted to mix their intervention methods. The author felt that when professionals disagree on the best method of intervention for a child, the disagreement prevents them from working together collaboratively and affects the choice of the parents.

The other reason for the author's intense frustration is the fact that it was much easier to get adequate intervention for her child's deafness but very difficult to get adequate intervention for her child's autism. Although divided, the professionals in the area of deafness had tried and true methods for teaching a deaf child. In contrast, the author found that autism is less straightforward with experts not agreeing on the key

problem “which leads to wildly different, mutually contradictory, intervention strategies” (Beals, 2004, p. 285). The parents couldn’t find specific intervention materials even though they had been told that these materials existed.

The observation made by Roper et al. (2003) that, for deaf autistic children, the autism often goes undiagnosed until much later than the deafness appears to be verified by these studies. The participants in all three studies had their deafness diagnosed before the autism. These studies therefore demonstrate that regular access to a language such as verbal speech or sign language is not enough to enable a deaf autistic child to develop functional communication.

Ewing and Jones (2003) point to linguistic skills and social skills as being the two most important things for children with hearing loss and multiple disabilities to develop. The Malandraki and Okalidou (2007) study and the Easterbrooks and Handley (2005) study show that there is a link between the two. Their results indicate how communication skills not only have an effect on the child’s behaviour but also have a beneficial effect on the child’s social interaction with peers.

These studies have some limitations. All three studies had a single participant as the base for their study. It is not therefore clear if the results of these studies actually reflect the experiences of other deaf autistic children or not. These studies will have to be considered “best practice” until such time as there are more studies developed involving more participants. Not only does this area of research need far more studies to show if intervention methods (such as PECS and ABA) can help these children but there is a need to know the long-term effects of the intervention methods. We need to know how successful the PECS method would be at moving children on from using the pictures to,

ultimately, using verbal or sign language. A further limitation on the Beals' (2004) study is reliance on the author's recall without supporting documentation. Thus while this research is hopeful, it is only a drop in the ocean of what needs to be done.

The Need for Trained Educators and Parent Support in Both Deafness and Autism

Given the complexities surrounding deaf autism, teachers need further assistance in working with these children. For example, as Easterbrooks and Handley (2005) indicate, teachers of the deaf are not able to get guidance from the literature on how to teach deaf children with a dual diagnosis. This sentiment has been reiterated in a number of studies where researchers gained information from parents about their interactions with the school system concerning their children with a variety of exceptionalities.

Parents need to know that the school system understands their child's disability and is able to address the challenges faced by the child. For example, Lake (2000) interviewed parents of children with disabilities who had requested remediation. The parents felt that the school had limited understanding of their child's individual needs and that it tended to focus on the child's weaknesses when they really needed the schools to provide them with hope. It was a shock to find that, sometimes, the schools were not the experts! Similarly, Pruitt, Wandry, and Hollums (1998) interviewed parents/caregivers of children with disabilities. They found that parents wanted teachers to have more knowledge about individual disabilities. Parents also indicated that there was a need for special educators to develop concrete strategies to improve communication with the families and that they wanted special educators to listen to them (Pruitt et al., 1998). In another interview study, parents indicated they needed diagnostic certainty to help them

emotionally, to give them some possibilities for helping their child, and to help them cope with an uncertain future (Graungaard & Skov, 2006). In addition, teachers needed to develop a philosophy for initiating positive contacts with parents right at the beginning of the year and maintain this contact through the year. If parents only hear from the school when there is something negative to address, parents will often avoid contact with the teachers so as to avoid the “bad news” (Darch et al., 2004).

Some studies have specifically included parents of children with autism. The participants in the Starr, Foy, Cramer, and Singh (2006) study were parents of children with ASD, Down Syndrome, and learning disabilities. The data were obtained by a survey in which the most commonly cited need of the parents was for school personnel to be better trained in how to teach their children effectively. In much the same fashion, parents of the autistic children in Siklos and Kerns’ study (2006) reported greater need for consistent therapies for their child and professionals who were knowledgeable about autism. This desire might be traced to the belief that focusing more on the child’s needs may lead to significant recovery or even a possible cure in children with autism

Baird, McConachie, and Scrutton (2002) recommend that parents be introduced to another parent of a child with similar challenges (ideally a parent who has had some training in befriending). They comment that parents of young children with a disability would appreciate knowing how other parents felt when they first heard the diagnosis. However, if parents don’t get a full early diagnosis, they lose this opportunity for support. In their study, a mother commented that she found talking to another mother was a great help. Professionals can also learn a great deal from the experiences of parents living with children with disabilities (Webb, 2005).

My project covers many of the concerns expressed by parents of children with disabilities. Parents need an early accurate diagnosis of their child's challenges, and my series of vignettes demonstrates to professionals that it is important to remember that a child may have more than one disability and that they need to be aware that, sometimes, one disability may mask another – as in the case of deaf autistic children. Once an accurate diagnosis has been made, parents need to find teachers who have knowledge and expertise in their child's disability/disabilities. My story clearly shows the stress experienced by me, a parent of a child with multi-handicaps, when I found myself without an available educational system that could fully address all of my child's needs. Parents have stressed the need for regular communication with their child's teacher, and I have included in my series of vignettes information that demonstrates my appreciation for the home and school communication system. In my project, I show techniques that helped my child, and the vignettes also demonstrate my need to have the support of other parents who understood my particular challenges. My hope is that my story will start a dialogue with teachers of the deaf and show them that deaf autistic children can flourish in the deaf community, but only if they are guided by teachers who understand their particular challenges.

Method

To write the vignettes that follow, I looked into the documentation that I had gathered over many years to find a list of issues that were important to me during my deaf autistic son's childhood (up to the age of 10 years). These issues, along with my reading of the relevant literature, inform the themes that are highlighted in my vignettes.

Data Sources

I first decided to document my experiences with our son when I began writing articles for a magazine called “The Voice” during our son’s early childhood. I felt strongly that my experiences would encourage other mothers. From the time my son was 4 years of age, my documentation was in the form of entries in “Home and School” books. This was a daily communication system between special needs’ teachers and the parents. These entries, which continued all through Alistair’s elementary years, have been a key source of information for my project. In 1991 I developed a play with the Queen’s University drama department depicting the challenges our family had encountered living with a young deaf autistic child and how we coped with those challenges. This has been another source of information for my project. To a lesser extent I have used information depicted in home video clips, photographs, and cassette tapes.

Ethical Issues

Obtaining ethical clearance to go ahead with the writing of my vignettes was given by Queen’s University, but the process was more difficult than I had expected. There have been three major ethical issues for this study. First, I am not able to guarantee the anonymity of any family members mentioned in this study. I informed them that they were free to make their own decisions on whether to participate or not without any consequences. They have all agreed to this participation after reading the Letter of Information. I am not able to guarantee my deaf autistic son’s anonymity and have obtained consent on his behalf from his father (my husband) to include information about him in my project. I needed the consent of other persons’ information as the educational settings were easily identified. I have obtained consent from the two main school systems

attended by my son during the period of time covered by my project (a public school board and the Provincial Schools for the Deaf) and personnel connected with these two school systems. Nobody has been interviewed further for these vignettes.

CHAPTER 3: A SERIES OF VIGNETTES

This portion of my project consists of 12 vignettes that describe my life with my deaf autistic son through his childhood up to the age of 10 years. These vignettes describe the challenges I experienced trying to find an education system that could accommodate a child with both profound deafness and autism at that time. The vignettes also give the reader some insight into the challenging and often humorous situations that our family experienced over the years, living with a child like Alistair and what we learned from those situations.

The purpose of this set of vignettes is to help educators understand the challenges and needs of parents of children with both deafness and autism. I am also hoping that information we have gained about Alistair over the years will help educators in their programming for these children.

I sincerely hope that parents of deaf autistic children will also be helped by reading these vignettes. Some of our experiences may be similar to the experiences of other parents, and we need to learn from each other. Although Alistair's behaviour was very challenging and difficult to understand as a young child, it is important for parents to know that he has grown up to be a young man of whom I am immensely proud. We have learned to rejoice in his successes and not dwell on his difficulties.

Each vignette is followed by a set of five questions designed to encourage discussion. These vignettes could be used as a workbook for both educators and parents and may encourage more research in this under-researched area.

The Vignettes

1. Why was Alistair's full diagnosis not made during his preschool years?
2. Why was Alistair obsessed with light bulbs?
3. Did the School for the Deaf recognize the signs of autism in Alistair?
4. How did the School for the Deaf help Alistair?
5. How did stress affect my actions?
6. Why did Alistair and I need a special ed. specialist?
7. How do schedules and calendars help Alistair?
8. Why is Alistair's watch so important to him?
9. What did we have to do to 'fill in the gaps' to understand Alistair's attempts at communication?
10. What did we learn over the years about Alistair with regard to his receiving sign language?
11. Is Alistair able to show empathy?
12. Why did I need the support of other parents?

1. Why was Alistair's full diagnosis not made during his preschool years?

Alistair was born in 1984, which was well before infants were screened routinely for hearing loss in North America. However, due to the fact that we already had two children with identified hearing loss, we were advised to have him tested as a baby. Alistair's hearing loss was thus identified by an audiologist at 4 months, and he was officially tested and found to be deaf at 6 months. At this time, electrodes were attached to Alistair's head while he was asleep and his brain waves were monitored. The brain waves had very little response to sound. I had known there was a chance that he would have a hearing loss, but I didn't expect for him to be profoundly deaf.

The first indication that Alistair might have other challenges, in addition to his deafness, was during his first year. Alistair cried a great deal and appeared to be in distress. Our doctor commented that a baby crying that much was like a red flag to a paediatrician. Also, at a time when other babies were developing the beginnings of communication, Alistair was showing little interest in sign language, the communication system we had chosen for him. Even though we had a deaf daughter and a hard of hearing son who had some sign language, and my husband and I had learned some sign language, Alistair didn't seem to respond to our attempts at communicating with him. There were noticeable differences in Alistair's play too. He just didn't play with toys in the same way as other children did. For example, at a time when other children his age would be playing with toy cars and dolls, Alistair was arranging objects in a line. I remember the family having a game of soccer in the yard. Alistair ran over and grabbed the ball but instead of making an attempt at kicking the ball, he picked it up and put it in a flower pot!

I believe that Alistair's autism wasn't recognized in his early years for a few reasons. First of all, during Alistair's preschool years, his difficulty with communication was presumed to be due to his profound deafness. One of the early signs of autism is difficulty with language but communication is also a challenge to deaf children unless they are in a family with Deaf parents and are surrounded by fluent sign language from birth. The teacher of the deaf who used to visit us blamed Alistair's lack of progress with sign language on me. She felt that I wasn't signing to him enough. I remember feeling upset at the time and told her how difficult it is to keep signing to someone who isn't signing back. It didn't occur to either of us that Alistair might have a communication disorder in addition to his deafness.

A second factor that I think resulted in a late diagnosis was that Alistair had only had a few months at a preschool program for the deaf in the U.S. when my husband's company suddenly transferred him to Canada. Because of the move, we lost the teacher from the program who was just beginning to get to know Alistair and who might have guided us to a diagnosis earlier had we stayed. In addition, the move was stressful both for Alistair and for me. I tried to rush him into another preschool program when we arrived in Canada, but it was too much stress for Alistair, after such a big move, and we were advised by our doctor to keep him home and wait for him to start pre-kindergarten at the age of 4 years at the School for the Deaf. Finally, I believe that an accurate early diagnosis of autism wasn't made for Alistair because his doctors were genuinely concerned about labelling him. As a result of all these delays, it wasn't until Alistair was 5 years 8 months that a psychiatrist diagnosed him with autistic features.

Questions

1. Can you think of any other circumstances that might have delayed a child's diagnosis of autism?
2. Why do you think the doctors might have been afraid about labelling Alistair?
3. In what ways do you think it would help a mother to know her child's full diagnosis as early as possible?
4. Babies nowadays are checked for hearing loss within a few days of birth. What are the positives and negatives to knowing your child is deaf so soon after birth?
5. By not knowing my child had autism when he was very little, I was not guided to meet other parents of children with autism. What would be the benefit of knowing other parents of children with similar disabilities to your own child's?

2. Why was Alistair obsessed with light bulbs?

One of the most challenging things about Alistair as he was growing up was his tendency to have obsessions. At times he was totally fascinated by light bulbs. At other times his attention was taken by Japanese items and religious statues. It didn't really matter what the object was; the problem was that his mind kept going back to the object and he couldn't stop thinking about it and wanting it. It was this constant dwelling on something that was so hard for me to understand and so very difficult for me to live with. The first really noticeable obsession, and very probably the strangest, was that of light bulbs. This obsession began when Alistair was a really young child, somewhere between three and four years of age.

Alistair began to really notice the shape and colour of light bulbs and the type of element inside every light bulb he looked at. He loved detail, which is why I think he loved them so much. He had an uncanny ability to notice when there was something different about a light in a room. It was almost like he was drawn to it like a magnet. One time we were sitting in a restaurant and Alistair jumped up to examine a lighting fixture on the ceiling. Within moments people at the tables around us wanted to know what he was looking at. When we explained that our son always noticed unusual bulbs they immediately followed his gaze and stared up at the ceiling too and commented that, indeed, it was an interesting light bulb. All I could think was "He's got the whole restaurant doing it now."

Alistair not only wanted to admire the shape and type of light bulbs; he wanted to examine them and do something with them. He would sometimes take the bulbs from the lamps while we were sitting watching television and plunge us into darkness because he

had plugged in a small light and he wanted to see the effect. We were having a good night if all the light bulbs stayed in their rightful place. One day I found Alistair removing a tiny light bulb from the back lamp of one of our bicycles in the garage. I remember wondering why on earth he was doing that. My instant reaction was to insist he put it back immediately but something made me stop to see what he would do next. Alistair held on to the little bulb while he climbed up to reach a lantern that was on a shelf nearby. He then proceeded to carefully replace the lantern's broken bulb with the one from the bicycle, which was a perfect match.

It became a real problem when Alistair started to want to walk around with a small light bulb in his hand. He would even want to take one to school with him – either that or some electrical wire. We had to take a stand and make a deliberate effort to show him that light bulbs were not play things. We knew there were all sorts of dangers entailed with holding on to a light bulb, but Alistair still tried to do so without us seeing. One very memorable time we were standing in a queue waiting to be seated at a restaurant. Unknown to me, Alistair had a small projector light bulb in his hand and proceeded to drop it. I find it hard to explain why such a small bulb should have made such an explosive sound, but it sounded like a small bomb had been detonated. It broke into thousands of tiny pieces. The shock was indescribable.

For Alistair, I think the biggest problem was that tunnelling his attention on one object was to the exclusion of other things of interest. Over the years, we have tried to give him a wider variety of experiences and I've noticed that his obsessions have become less extreme. He still "googles" light bulbs on the computer and we still have to stop at the lighting section in stores, but he has allowed other interests into his life now too.

Questions

1. Lots of people collect things so why do you think we found Alistair's fascination with light bulbs so odd?
2. Can you think of any ways in which Alistair's teacher could have used his love of light bulbs in the curriculum?
3. Can you imagine some of the skills we taught Alistair at home as he grew older that had some connection with light bulbs?
4. Alistair loved the detail of light bulb elements and was visually very aware when there was an unusual light bulb in a room. What careers might be an option to someone like Alistair?
5. Do you think we should have used Alistair's love of light bulbs to help him in some way or do you think we should have guided him away from this obsession?

3. Did the School for the Deaf recognize the signs of autism in Alistair?

Alistair started the School for the Deaf in September, 1988 when he was 4 years 3 months and was placed in a Junior Kindergarten class. When he arrived at the school he had already been diagnosed with a profound hearing loss but his autism had not yet been identified. Alistair's teacher was very observant and clearly pinpointed several of the traits in him that would later be identified as those of an autistic child. The word autism is not used in any of the reports in Alistair's pre-kindergarten year but the teacher unofficially spoke with me towards the end of that year and told me that Alistair was reminding her of an autistic boy she had known.

His teacher described Alistair as a real challenge – very stubborn one minute and very co-operative the next. She kept track of his progress in regular monthly reports. One of the first areas she noticed there was a problem was in social interaction. She noted that Alistair was having difficulty with eye contact and that his ability to make eye contact was inconsistent. There were also times when he seemed to be in a world of his own. During the year the teacher noted that she had seen glimmers of Alistair opening up and letting her get close to him. She also commented that Alistair was connecting with one little girl in the class (one day apparently she had put her foot on Alistair's chair. He had reacted by gently taking her face in his hands and smiling at her before he took her foot off his chair). But by the end of the year, the teacher wrote that there had been very slow and limited improvement in Alistair's response to people over the year. Her gut feelings were that Alistair was intellectually capable of learning but that, for whatever reason, he had shut out the world around him and narrowed in on selected bits (that

mostly didn't include people) such as switches, knobs, pieces of machines, etc. She also noted that he liked little things that could be taken apart or fitted together.

During his pre-kindergarten year, Alistair's teacher described him as a child who didn't have a strong *desire* to communicate. By the end of his first year his teacher wrote "most children want to connect with other people and even deaf children will try hard to make you understand them. Alistair does not have this strong urge to communicate and is content in his own world most of the time." She added that they were trying every day to force a need in Alistair to communicate. As the year progressed we were told that he was receiving more sign language than he could express. In the area of play, his teacher observed that he had a tendency to play by himself. Alistair was showing indications of being able to engage in make-believe play, for example, pretending with characters in the doll house and signing "dad sleep." He also could manipulate each character in the doll house to do a different thing. By the end of his pre-kindergarten year, Alistair's play skills had improved somewhat in that he would now watch other children playing and would allow himself to be a prop in other's play, such as a baby, a customer in the restaurant, or a patient. He would even play with a little girl in the class with the two dressing up in play clothes from the toy box.

By the beginning of the second year, Alistair's teacher described him as "very resistant to change." She stressed that they needed to investigate and find out what was wrong and what they could do about it before the school year progressed much further. The school's social worker recommended a specialist be brought in to assess Alistair and give recommendations with regard to how to help him.

Questions

1. Apart from the fact that both deafness and autism can affect a child's language development, can you think of any other ways the two disabilities might mirror each other?
2. Who do you think might have helped Alistair's teacher during that first year when she was first seeing signs of Alistair having such difficulty with his development?
3. In what ways do you think parents are affected by the fact that their child is very different from the other children in the school?
4. In what ways did the teacher try to stay positive and give me some hope that things would improve?
5. How did the teacher's monthly reports ultimately help Alistair?

4. How did the School for the Deaf help Alistair?

My husband and I chose to enrol Alistair in the School for the Deaf, because it was a signing environment and the teachers had expertise in teaching deaf children. However, we didn't realize at the time that Alistair was autistic as well as deaf and that any language system was going to be a huge challenge for him. I had thought that surrounding Alistair with sign language would open the door to communication for him, not realizing that Alistair had problems with the very concept of language.

When the school became aware that Alistair had little desire to communicate with people, they put into place a language intervention program that included individual tutoring from the school's speech pathologist. First, they decided to work on Alistair's eye contact at school and asked us to count how many seconds we could keep eye contact with Alistair at home. Second, Alistair's teachers and the speech pathologist deliberately gave Alistair a *need* for communication. They put him into situations where he needed to sign to get what he wanted. This strategy was a way of "forcing" Alistair to use sign language to communicate. For example, the speech pathologist described taking Alistair to play on the swings. She knew that this was an activity that he loved. After a while, she would stop the swing and not start it again until Alistair had signed "more push please." Another technique was the use of props to develop a picture from which sentences could be developed. These techniques had some success but, without a diagnosis, the school didn't realize at first that autism was affecting Alistair's ability to make consistent progress and that it would greatly affect the possibility of his becoming fluent in sign.

The school understood the challenges of Alistair's deafness, but it was his autism that was so difficult. Because he had arrived at the school without a full diagnosis, the

school was not aware at first that Alistair was, in fact, autistic. The teacher therefore spent valuable time in the first year being puzzled about Alistair's challenges. After observing him during his pre-kindergarten year, his teacher recognized that Alistair might have autism. She guided me to information on autism and insisted that Alistair be assessed and a diagnosis made. The speech pathologist travelled with me to see specialists at a centre for Autism to have them meet Alistair and to give us advice. The school's social worker recommended that a specialist be brought in to assess Alistair and develop a prescriptive teaching plan for the school and home. This assessment was going to cost \$2,200 but unfortunately we were not able to get funding for the testing through our insurance. Alistair was therefore assessed by a psychiatrist who found him to have a generalized learning disorder. He reported that Alistair appeared to be in the moderately retarded range at that time and that he did demonstrate some autistic features together with a severe hearing impairment. The psychiatrist recommended a coordinated behaviour management programme involving both home and school, which in fact was already in place. Otherwise, we could look into school opportunities in our district that would focus on improving Alistair's social attention. In the report, there was no mention of a prescriptive teaching plan to help the school. There was also no research base at the time to guide the school to develop programming. As far as I know, the school didn't bring in a special education specialist for advice on programming; such a specialist might have helped the school in that Alistair was the first student there to demonstrate deafness and autism. Now there is a specialist with experience in both autism and deafness in Alistair's school, and there is also a program specifically for deaf autistic children in another School for the Deaf in the province.

Questions

1. Alistair was born in 1984 and had a deaf sister and hard-of-hearing brother. Why do you think we might have chosen not to give him a cochlear implant?
2. How do you think it felt for me (Alistair's mother) to realize that the teachers of the deaf were puzzled by Alistair's challenges at first?
3. Alistair had a major problem with the very concept of language. If you were a teacher of the deaf and designing a language program for him, what would you include?
4. A program specifically designed to help deaf autistic children has been developed in another School for the Deaf here in Canada. How do you think this program will ultimately help other deaf autistic children in other parts of the world?
5. Do you think it is enough to bring specialists in deafness and specialists in autism together to help a deaf autistic child or do you think this is an area where there is a need for a specialist in both disabilities together?

5. How did stress affect my actions?

When Alistair started school at the age of 4 years, my husband and I both realized that our son had major challenges; we just were not at all sure what those challenges were. I have to admit that I, personally, had the very unrealistic notion that the School for the Deaf would be able to “fix” Alistair. It was to be many more years in fact before I was able to change my dream from somebody “fixing” Alistair into a desire for Alistair to be guided to reach his potential. It was going to take a great deal of trial and error to find what worked for Alistair and a large team of professionals, family, and friends to support us along the way.

By Alistair’s third year at the School for the Deaf, I was really feeling the stress of living with a child with autism. I think I could have coped with the deafness because we already had a hard of hearing son and a deaf daughter. It was the autism that was so very difficult. Over the years I had had to deal with Alistair’s extreme hyperactivity, which made any outing impossibly complicated. Living with Alistair’s obsessions had become difficult. He was totally obsessed with light bulbs and would fixate on them wherever we went. What was even more challenging was that Alistair would often appear to be in pain and I would dash him from specialist to specialist trying to find out what was wrong. He would sometimes scream with pain and he often had broken nights. He had his tonsils and adenoids taken out and also had tubes put in his ears because of fluid. However, we just couldn’t seem to find a solution to Alistair’s stomach problems. No amount of testing ever found out what exactly was going on. We tried taking different foods out of his diet, which sometimes seemed to help, but we were really grasping at straws and I was really worried that his food choices were getting more and more limited

and he was not getting a balanced diet. My husband was supportive but he sometimes had to travel with his work and was not always at home to help. Life was becoming more and more focused on Alistair, and it wasn't fair to our other children.

It was a real joy for me to receive positive notes from his teacher. A little bit of good news would make my day and give me hope. By the spring of Alistair's third year we were getting particularly hopeful notes. In March his teacher wrote that he had had a fantastic week and had been "right on the ball." The teacher was obviously thrilled to see Alistair's progress. But then, inexplicably, things changed. Alistair was getting sick again and started to miss more school. By May the school was noticing that Alistair was signing less and he appeared to be avoiding eye contact a lot. I think the teachers were as disappointed as I was. Alistair was reverting back into his own world and none of us could explain why and I felt deeply saddened to see it happen. Alistair really needed a program that had all the benefits of skilled teachers of the deaf AND the skills and experience of special ed. specialists. But as he was the first child in his school with autism, a program that could provide both was not yet available. (There is a special ed. specialist with experience of both deafness and autism based in the school now.)

Everything came to a head for me when I turned up at the school's Sports' Day. I was told that Alistair's teacher had taken him and two other children to play in the swimming pool. (I didn't realize at the time that Alistair's group had had their own games in the morning involving lots of water play and had really enjoyed themselves.) All I could see was that my child had been left out of something and all the heartbreak deep inside me exploded. I am sad and embarrassed to admit that, in a totally irrational move, I went over to meet them, picked up Alistair, and angrily left the school.

Questions

1. Why do you think it was particularly upsetting for me to see that Alistair was losing eye contact?
2. Why do you think notes from the teacher in the “Home and School” book are so very important to a parent of a child like Alistair?
3. Why do you think it is so difficult to investigate a health problem in a child like Alistair?
4. Why do you think Alistair’s hyperactivity made outings so difficult and how was this difficulty exasperated by his deafness?
5. How do you think that Alistair could have been included in the school Sports’ Day?

6. Why did Alistair and I need a special ed. specialist?

I realized that the only way I could learn to cope with the challenges of having a child with autism was to know that there was someone in his school who understood autism and who knew how to plan for Alistair. As Alistair's autism was really impacting his life, I decided to go and talk with a special ed. specialist who was based at a little spec. ed. school near our home. At the time, the school was segregated but was at the beginning of a process to integrate with a nearby school. It was a relief for me to talk with a teacher who had experience teaching children with special needs. The teacher had the advantage of knowing Alistair's full diagnosis before he arrived in the school and was therefore able to plan for him. She told me that she needed to have everything in place so that his first day would be a success. The need to plan ahead for success was one of the most valuable things I learned from her. She realized that Alistair would need someone to help him attend and focus on school activities. The Board of Education agreed to hire an aide. (Apparently, after meeting Alistair, and seeing how active he was, the aide went straight out and bought herself a new pair of running shoes.) The teacher also realized that, as a deaf child, Alistair was going to need sign language. She and the rest of the staff enrolled for sign language classes, and my husband and I joined them.

The teacher developed a routine for Alistair, explaining that she felt that keeping to a routine helped the children "tell time." Even when Alistair had one of his "up/down" days at school, she would still stress that they had to be "flexible within routines" - she would let him have a break to run around but would then get him back to work again. I learned from this strategy that I needed to follow routines more at home and try, where possible, not to suddenly change plans. I also learned from the teacher to be more

consistent with Alistair with respect to his behaviour. At school, if Alistair didn't cooperate, he was always guided back to his classroom to sit in a chair for a few minutes before being allowed to join the group again. The response was always the same, and Alistair knew what to expect. The teacher also stressed the importance of preparing Alistair for an event that was out of his usual routine. He needed to be forewarned well in advance that something was going to happen, which could be done by pinpointing the date of the event on the calendar and describing with pictures what was going to happen.

Part of Alistair's daily routine was the time he spent working on concepts in his workbooks. Each workbook was allotted a specific time and, if the routine had been changed because of a trip, he would still be expected to do some work on the workbooks as soon as the students returned to the classroom. The work was clearly structured in small steps, and signs were included with the printed words and pictures. Alistair began to have great pride in his workbooks, which were really neat and tidy. Even though he was really delayed and the work he was doing was that of a younger child, he began to experience success, and we had the joy of seeing him succeed and move forward. Each workbook was sent home as soon as he had finished it with notes explaining how the teacher had helped him, e.g., "I guided his finger along sentence. Alistair checked with model at top and looked at color chart and wrote color word on his own." As a mother, I wanted to know these details. I wanted to see *how* he learned. The focus had moved off Alistair's difficulties and on to strategies that could be tried to help him succeed. I remember the teacher commenting that Alistair had had a difficult day and so the staff had joined together to discuss how *they* could have helped him have a better day. I realized that I could learn from the difficult days and find new ways to help Alistair.

Questions

1. Why do you think it was a relief for me to talk with someone who had experience of teaching children with special needs?
2. In what way do you think that developing a routine helps children with special needs tell time?
3. Why do you think Alistair needed someone to guide him to attend and focus on school activities?
4. Why do you think it was particularly important for Alistair's workbooks to be sent home as soon as they were completed?
5. Why do you think it was so important for me to realize that there were specific skills that I could learn to help Alistair at home?

7. How do schedules and calendars help Alistair?

It took us some time before we realized that schedules and calendars could make such a difference in Alistair's life. The special ed. teacher was very aware that Alistair needed visual schedules. The teacher convinced me that lack of information was the basis of many behavioural problems with Alistair when she deliberately took him to our local mall – the place where we had had so many difficulties with Alistair, the place where Alistair was known to be a very difficult child. She described to me how she was going to prepare Alistair for the visit and what was going to happen when they arrived at the mall. A few days before the trip she drew pictures of Alistair getting on the bus with his aide and then Alistair travelling in the bus and then he and his aide going into the mall. They made a list of the items they were going to shop for in the mall. There was then a picture of Alistair and his classmates having a treat in the little eating area at the end of the mall. Not only was Alistair shown what would happen in detail, but he was shown on the calendar WHEN it would happen. Apparently the trip was so successful that I heard later that storekeepers in the mall couldn't believe it was the same child.

The information that Alistair needed to be forewarned about events totally changed how we interpreted his behaviour. Before the special ed. teacher stressed to us that we needed to give Alistair more information we had misinterpreted his anxiety for an unwillingness to co-operate. On many occasions, in fact, we had concluded that Alistair absolutely hated what we were doing because he had looked so anxious and unhappy. We saw a very different child when we followed the teacher's advice and let him know what was going to happen in advance.

For example, Alistair had always expressed an excessive dislike for going on a boat, much to the disappointment of my husband who loves to sail and is a sailing instructor. Only a little way out into the lake Alistair would indicate that he wanted to go home. One summer when I was visiting my family in England my husband decided to try the spec. ed. teacher's advice and prepare Alistair for a two-day sailing trip on the boat. He really wanted to go for a little sail and wanted to take Alistair with him. But it was a huge gamble. Would they even get out into the lake before Alistair begged to go home? So my husband made up a little calendar with the days clearly shown and signed that Alistair and Dad would go on the boat and they would have one sleep on the boat and then would return home. Everything was fine.

Another time we planned a few days going up the St. Lawrence River in the Thousand Island region. It is a very pretty area with lots of small family-owned islands in the river. This time our planning for Alistair got a little more detailed. We showed Alistair a calendar again with the days we would be out in the boat and clearly showed the day we would be back. This time, though, my husband scanned a copy of the map of the river. Each day, while we were out, he and Alistair plotted on the map where we were. We also showed Alistair at which point we were going to turn round and come back. He was fine, and we all had a wonderful holiday.

Even now, as an adult, Alistair relies on his calendar for information. He enjoys pointing out something that is coming up and making a comment about it so that he can double check that it is still going to happen. He insists on crossing off the day on the calendar each day before he leaves the house. Not only does the calendar prepare him for coming events, but it is also a tool to help us communicate with each other.

Questions

1. Why do you need planners, schedules, and calendars in your life?
2. How would you feel if an event suddenly happened and you were expected to participate without being warned in advance?
3. How do you think Alistair's social life was impacted by the use of calendars?
4. How does the insight of someone with experience of autism help lessen the stress for the mother of a deaf autistic child?
5. How do you think calendars can be used for a child with limited reading skills or other exceptionalities?

8. Why is Alistair's watch so important to him?

Alistair's life is intricately connected to his watch. He has had the same Timex watch for years, and we periodically buy a new wrist band and even once sent the watch back to the company to have a new glass put in. They don't make this particular watch any more and so we just keep recycling the old one. I think he probably would be able to cope with a change of watch but we haven't tried a new one because he loves this one so much. Sometimes I think our assumptions of Alistair's inflexibility get in the way of his making changes.

Alistair's need for his watch may not be so much an obsession but a real need to have some control over his day. He needs information on where he is in his day now and what the time lines are for events that come and go. If his dad or I have to go out he wants to know what time we are due back. We've learned to overestimate the time we are due back so that he is not confused if we take longer than expected.

This concern with the time can be misinterpreted by onlookers. Alistair does not have the social skills to know when NOT to look at his watch! When visiting friends he will suddenly look meaningfully at his watch as the evening goes on, which is interpreted by everyone to be an indication that Alistair is bored or tired and wants to leave – which, of course, may be the case. However it may also be that he simply wants some indication of what to expect and to have the information of when we will be going home. This need for time lines is not only in autistic people of course – I know lots of people who really need this way of scheduling things to feel at ease and in control. What is different about Alistair is his lack of inhibition when it comes to staring at his watch – not realizing that this action gives a message to others that he may well not mean to give. One really funny

example occurred one day at church. Every Sunday I take Alistair to a tiny church on a nearby island in Lake Ontario. We have to take the ferry over to the island and have to be back on the ferry exactly one hour later. The priest also needs to catch this ferry so all is well ... usually! One Sunday, the priest took a little longer with the homily, and the service was lasting longer than usual. After the communion, Alistair walked straight up to the altar and held his arm in the air for all to see and stared meaningfully at his watch and then up at the priest. Nobody needed to know sign language to know that Alistair was clearly saying “get a move on, some of us here have got a boat to catch.” The priest roared with laughter and said something to the effect of “yes I did go on a bit didn’t I!”

As Alistair’s obsession with the time developed, so did a need to make sure that everybody else’s clock or watch was accurate. If the time on someone’s clock didn’t match his, he thought nothing of reaching over and adjusting the offending timepiece. It never occurred to him that his watch might not be correct. One year, when it was time to move the clocks back one hour, my husband and I went round changing the time on every clock and watch in the house before Alistair woke up. Unfortunately, we had forgotten to change Alistair’s watch. Within hours we became aware that we appeared to be out of step with those around us. Our opinion regarding the current time didn’t seem to match the rest of the province. On seeing that his watch was different to the clocks in the house, Alistair had carefully changed every one forward an hour to match his. Now we only have to change one time piece, Alistair’s watch, and the rest of the house catches up very quickly.

Questions

1. Alistair has kept the same watch for many years because we were not sure he would accept a new one. Why is it important not to “presume” that Alistair is inflexible?
2. In what other areas might it be easy to presume that Alistair is inflexible?
3. How do you think I could use Alistair’s obsession with time to help him change his habit of being late for functions?
4. What do you think we could do to help Alistair not to appear rude when he keeps looking at his watch?
5. How could I use Alistair’s obsession with the time to benefit the rest of the family and make him feel he has a valuable contribution to make?

9. What did we have to do to ‘fill in the gaps’ to understand Alistair’s attempts at communication?

Sometimes I have totally misunderstood Alistair, and it has taken someone else to give me the essential piece of information that I was missing. When Alistair was approximately 7 years of age, he spent several days with a friend of mine while I took some exams. One day she proudly handed me a picture he had drawn. I felt deeply disturbed and disappointed with the picture. Alistair had drawn a man, but he had replaced the face with two lines across the eyes. I instantly presumed that this action was a really odd “autistic” thing to do and that Alistair was losing the little ground he had made. It was several days before I realized my mistake. Alistair had apparently drawn a picture of a knight in armour that was standing on top of an old clock on my friend’s mantelshelf. The two lines had been the visor. I had totally missed the shield and the spear in the knight’s hand. This incident taught me to realize Alistair did have something to say even though at first it seemed a little strange. There was always a logic.

Our not quite understanding Alistair was apparent in other ways too. Alistair had a tendency to sign a list of words based on something he had been thinking about, and it was very difficult for us to understand the context. We had to develop ways through which Alistair could give us more information. We had to “open doors” for him to be able to tell us what he meant. For example, just after Christmas when Alistair was 10 years of age, he started to carefully fill a cardboard box with books and began to sign a series of words that made no sense to me whatsoever. I could make out the sign for “owl” and “library,” “Christmas” and “light,” but couldn’t for the life of me imagine why he was putting such a disconnected list of words together. This obsessive signing went on

for several days until I felt so frustrated that I pointed to the car and indicated to Alistair that he should get in the car and that we needed to go somewhere. The only problem was, I had no idea where the “somewhere” was! I put the box of books on the back seat and signed “where?” Alistair pointed right and I turned right. He pointed left and I turned left, and I continued to follow his directions. Frustration was welling up inside me because I was confident that none of this driving about made any sense at all and that we were going on a wild goose chase. We ended up in front of a few odd little stores. Presuming we were about to turn round and go home, I signed angrily “let’s go home.” Alistair obviously had no idea where he was going and I had had enough – enough of the strange world we were living in. I pointed to the store in front of the car and signed “look that has nothing to do with owls or lights or ...” I stared in surprise at the store, which turned out to be a second-hand book store. Right above the door was their logo, an owl! Alistair was SO happy and picked up his heavy box of books and staggered into the store. He placed his books on the counter and pointed to the Christmas decoration in the window. It was a Mrs. Santa Claus and in her hand was the most beautiful light. Suddenly I knew what it had all meant. He had always been obsessed with unusual light bulbs and, because he had seen people enter the store with boxes of books, he had concluded that he could do a deal and exchange his books for the light in Mrs. Santa Claus’ hand. In Alistair’s mind it was perfect logic, perfect sense, and it had only taken me a week to understand him! All I could think of was that we would never have understood the reason for the books and the odd, seemingly disconnected, list of signs if I hadn’t taken the time to drive him around and follow his directions. My car was the door he needed to open the lines of communication again.

Questions

1. Why is it important to look past the diagnosis sometimes to see success?
2. What did I learn from this experience?
3. Can you think of any other ways you could help someone with a language disability express what he or she wanted to say?
4. What type of person do you think Alistair desperately needed in his life?
5. If Alistair was your child, how could you demonstrate to others that he is aware of his surroundings and needs to be included?

10. What did we learn over the years about Alistair with regard to his receiving sign language?

Usually when young deaf children are exposed to regular signing, they will easily pick up the language and sign themselves. This was not the case with Alistair. Even though, as a young child, he was in a signing environment at the School for the Deaf and had a Deaf sister at home, he was having great difficulty developing sign language himself and wasn't even able to make eye contact with people consistently. The first thing that was needed was for all of us to realize that he was receiving more sign language than he could express. His teacher at the School for the Deaf was the first to notice this tendency. We then realized it was worth signing to Alistair even though he found it so difficult to comment on anything himself.

It was an interpreter who was working with Alistair a few years later who noticed something else about Alistair that might explain how he was managing to receive sign language even though he often appeared not to be looking directly at the person who was signing. She told us that she felt that Alistair had very good peripheral vision because he would not appear to have noticed her signing but then would go and do what she had asked. A well-developed peripheral vision was the only explanation as to how Alistair was able to receive information while not giving the signer direct eye contact. The same interpreter noticed something further about Alistair that would prove to be valuable. She was driving him to some function in the next town when she saw a train in the distance. She signed to Alistair that she had seen a train but Alistair did not react at all to her attempts at communicating with him. It was 10 minutes later when she glanced across at him and noticed, to her surprise, that he was signing the word "train"! Not only had he

appeared not to see the information but it had taken him many minutes before he had replied. Could it have been that he needed that time to process the information? The fact that Alistair was not consistent with his ability to make eye contact with people trying to communicate with him and the fact that there was sometimes a delay before he was able to respond put him at a huge disadvantage. By not appearing to pay attention to someone signing and not replying immediately, he gave the impression that he was not receiving communication and/or that he had no interest in social interaction. It makes me really sad as a mother to imagine Alistair trying to reply to someone's efforts to connect with him only to find that it was too late and the person had moved on.

Possibly, the most important thing we needed to learn about Alistair, with regard to sign language, was that he appeared to have more success understanding the communication of native Deaf signers. We found out this fact during a very traumatic time in our lives. Unbelievably, Alistair was diagnosed with cancer at the age of 10 years and spent a great deal of time hospitalized. A Deaf lady started to visit him, and we became very aware that Alistair was able to keep his attention on her as she signed to him. She had this wonderfully expressive face and body language that was really easy to understand – even for me. We began to request a “double interpretation” when Alistair needed an interpreter at an important appointment. A Deaf person would sit in front of Alistair and give him simple and beautifully expressive sign language from information relayed to her from a hearing interpreter sitting out of view of Alistair. To this day I have never forgotten her graphic visual description of the workings of the digestive system at an appointment with the dietician. Let's just say her description of gas going through the system was startlingly clear and left no room for misinterpretation.

Questions

1. Why was the inconsistency of Alistair's ability to make eye contact with people trying to communicate with him such a problem?
2. Why would Alistair's difficulty with acknowledging someone's signing immediately put him at such a disadvantage?
3. Why do you think a double interpretation for important appointments is so helpful to Alistair?
4. In what way would the information in this vignette be helpful to educators of deaf autistic children with regard to their planning?
5. Who else do you think might benefit from a double interpretation?

11. Is Alistair able to show empathy?

I had often wondered, when Alistair was young, if he had the ability to help me if there was ever a time I was in trouble and needed his assistance. For years I had had a vision in my head of myself collapsed on the floor in the house and trying to imagine if Alistair would actually realize I needed help and, even if he did, would he be able to emphasize and want to help? I got my answer one day when we were taking a walk together along a rather rough path near the shores of Lake Ontario. It was a beautifully sunny day, and we ambled along the path looking at the hedgerows and just taking the time to relax. The path took a sudden swing round to the left, and my foot got caught in a small hole in the mud. I suddenly found myself sprawling on the ground in great pain. I had landed so hard on the pebbles that my jeans had been ripped, and my knee was badly cut. I was in shock from the sudden fall; my knee was hurting me; I literally couldn't get up. I looked for Alistair who had walked on ahead. He started to turn in my direction and walked back towards me. He looked at me casually before his attention was taken with something else; he started to walk off again. I was in trouble and absolutely had to have his help as no one else was around. I was horrified at his apparent lack of concern and then saw him look back again. I threw my hands in the air and in exaggerated movements signed "HURT" and "HELP." This was one of those defining moments in my relationship with Alistair. To my relief, he suddenly dashed back to my side and carefully offered his hand to help me to my feet. He guided me back to the car, holding on to my arm as I stumbled along the path. When we got home, I collapsed into a chair trying to pull myself together and sort out what to do next. Alistair appeared from the bathroom with everything necessary to clean my wounds and bandage my knee. To say I was

surprised is an understatement. I stared at him in amazement. At that moment I realized how many times I had misunderstood my son and how he really felt. He hadn't been able to see that I needed help at first but that didn't equate with a lack of empathy. It would have been so easy to have concluded that he didn't care, which turned out to be far from the truth. He may not have been able to read the situation accurately but once I had clearly shown him I needed help, he had turned into the most caring nurse I could have wished for.

Over the years there have been instances of Alistair, unexpectedly, reaching out to help someone. One particularly memorable example happened when he was at the special ed. school. The children had all been given bowls of beads to thread on a length of string. Alistair finished his quickly and then walked over to a boy who was blind and also had cerebral palsy. Alistair put his hands over the boy's hands and guided him to thread the beads too. I had always thought that communicating with someone inevitably involved eye contact, but Alistair was helping someone who couldn't give him eye contact. He had seen someone in need of help and had reached out to him. I was so moved to hear this story that I made it the last scene in a play I was writing about Alistair for my university drama department. An actor, pretending to be Alistair, reached out to help the other child and then we shone a light on the two children's hands and blacked out the rest of the stage. Sometimes we need to "black out" the preconceptions we have about special needs children and open our eyes to those moments when we are given another chance to understand who they really are.

Questions

1. How do you think we could help Alistair to read someone's facial expressions more accurately?
2. When Alistair walks through a door he has the tendency to throw the door shut regardless of who is behind him. What do you think we could do to demonstrate to Alistair that the person behind him could get hurt by a door closing on her or him?
3. Alistair has needed a great deal of help over the years. Do you think that having the opportunity to help others is essential for the human condition – if so, why?
4. Alistair is deaf and has no voice. How do you think we can guide people to encourage some interaction with him when they have no sign language?
5. How do you think we can help Alistair learn how to show others that he is aware of them?

12. Why did I need the support of other parents?

When Alistair was ten-and-a-half years of age, it became apparent that he was very ill. For months he had been hitting his head, but this action just appeared to be yet another “autistic” movement. It is so easy when you have a child with a diagnosis like autism to see everything in the light of that one diagnosis. I was to learn the lesson that, even though Alistair sometimes made odd jerky movements that looked so strange, they were always a response to something – an odd response maybe, but still a reaction to something. Alistair became extremely congested and ill. The paediatrician admitted him to hospital for investigations. One thought was that Alistair had stuffed something up his nose that had become lodged. There *was* something behind his nose but it wasn't something he had pushed in himself – it was a tumour. He had a very rare cancer that had spread. He was given a 30% chance of survival. I was paralysed with fear.

I clung on to my husband, children, and family in England and prayed like never before. Once Alistair's treatment began, I became very aware of the presence and support of other parents in the hospital. We were not artificially brought together in discussion groups; we were just there as a natural consequence of our children's treatment. At our weekly visits to the cancer clinic my husband and I would talk with the other parents in the play room while volunteers helped our children make crafts. We didn't need to constantly dwell on the topic of cancer. It was enough that we were together. I didn't need to tell the other moms and dads that I was terrified and sick to my stomach – they already knew. We met in the clinic, and we met in the hospital when our children were admitted, too sick to stay home. We smiled in joy at the Christmas party and grieved with each other when a child died. It was the first time in years that I felt I had something in

common with other parents. For several years, I had not been able to identify with parents of deaf children because my child had so many more challenges. I would go to meetings of the Autism Society and feel exactly the same – they didn't understand because my child wasn't just autistic. But with the parents of the cancer children, none of that mattered. All they saw was a boy fighting for his life and that we were parents frightened to death that we would lose him.

Regularly meeting other parents reminded me of many years earlier when Alistair was just 2 years of age. We had been living in the U.S. at the time and had enrolled Alistair in a Hearing and Speech centre that supported young children with a hearing loss and their families. I took Alistair there three mornings a week. A teacher of the deaf taught the little children while we, the parents, sat in a room behind a one-way mirror. We gradually made these sessions a time for us to have a coffee and chat. I didn't realize how very much I needed this support until my husband was suddenly transferred to Canada. I really grieved for the loss of the centre, the teacher, and the regular meeting with the other parents. I was deeply homesick and lost without my friends to support me.

Alistair was 15 years of age before I met another parent of a deaf autistic child. I would have liked to have compared notes with another parent with a similar child when Alistair was young. If I had known that there was another parent out there, going through similar experiences to me, I wouldn't have felt so alone. We could have shared those things that had helped our own children and learned what else we could try. It would have been particularly helpful to have met a parent of an adult deaf autistic person so that I would have had some idea of what to expect for the future. What bigger support could there be than meeting other parents going through a similar experience?

Questions

1. Do you think that it might be easier to bring parents together to talk when they meet as a natural consequence of their child's programming or treatment rather than arranging a date for a meeting – if so, why?
2. When we find ourselves challenged in life, why do you think it is so helpful to meet others who have lived through the same experience?
3. Why do you think it would have helped me to have met another parent of a deaf autistic child when my son was young?
4. Apart from another parent, who else do you think would be a great support for a parent of a child with a disability or disabilities?
5. Do you have any ideas on how parents of deaf autistic children could support each other?

Where are we now?

I am so very grateful that Alistair was healed of his cancer and is with us today. Ever since that time, I've seen his deafness and autism in a very different light. I knew that we were very fortunate to still have our son in our lives and suddenly all the other challenges didn't seem so insurmountable any more. Alistair has grown up to be a deaf autistic adult which, I have to admit, was a shock at first because I had hoped for so long that he might be able to grow out of his autism if only I could find the right help. I now see Alistair as "Alistair," a young man with his own personality and talents.

While developing this project I've been surprised to notice that many of the traits in Alistair that I found so odd and difficult when he was young are the very strengths that I am so proud of now. Alistair is now 24 years of age and his fascination with parts of objects has turned into a real talent for assembling things. Anything that arrives in our house now bearing the words "some assembly required" is quickly passed on to Alistair. Over the years our family realized that we had to make opportunities for Alistair because he was not going to be able to move around in the world on his own and create his own life. For example, realizing that Alistair loved to make things and was obsessed with anything Japanese, my husband found a Japanese doll maker on the internet and ordered some of her doll kits for Alistair to make. He learned quickly how to work on the dolls and has made some really beautiful dolls over the years. By introducing Alistair to the craft of doll making, we were no longer crying over what Alistair couldn't do, we were celebrating what he *could* do! Later we started to look into what else we thought Alistair might enjoy making. We heard of a local studio that made stained glass and started him with classes. By the time he graduated from the School for the Deaf (which he had

returned to for his high school years) he had become so accomplished with stained glass that he was able to make a stained glass “I Love You” sign for them to hang from a window (the “I Love You” sign is a hand shape that has become closely associated with the Deaf community).

As I’ve written these vignettes I’ve become very aware that this was not just my story; it was the story of our entire family. I am so proud of all my family and the amazing patience each of them has had with Alistair and how much they love him. As my daughter once said to me, “we have to learn to love Alistair just the way he is.”

CHAPTER 4: DISCUSSION AND CONCLUSIONS

This chapter begins by listing five recommendations to help teachers of the deaf autistic. These recommendations are followed by a section discussing what I have learned during my research. These recommendations and reflections on my learning aim to increase awareness of the difficulties faced by parents of deaf autistic children and thereby lead to greater support for all concerned.

Recommendations to Help Teachers

The following five recommendations are aimed to help teachers of the deaf and autistic. They were developed from my documentation gathered over 10 years of my experiences as the mother of a deaf autistic child and from information I found in the literature. The recommendations are as follows: (a) recognition of parental stress, (b) culturally Deaf signers for deaf autistic children, (c) an autism workshop for teachers of the deaf, (d) inclusion of autism in training for teachers (particularly teachers of the deaf), and (e) research plan of action in deaf autism.

Recommendation 1: Recognition of Parental Stress

Teachers need to understand that parents of deaf autistic children are coping with a great deal of stress. In addition to the deafness, these parents are trying to cope with the challenges that autism brings. As Siklos and Kerns (2006) point out, ASD is a difficult disorder for many parents to adapt to. Many of those parents have very difficult behaviours to cope with, no way to communicate with their child, and are not able to socially interact. Therefore, they do not receive the same sort of “reinforcement” from

parenting compared to other parents. Teachers should be aware of these stressors and be willing to provide extra support to these parents.

Recommendation 2: Culturally Deaf Signers for Deaf Autistic Children

Children with autism have difficulty with language including sign language. My son appeared to have better understanding when he was signed to by a Deaf person. I recommend that deaf autistic children have educators who are native Deaf signers. When there is a need to get important information from a hearing person, such as doctors, the deaf autistic person should have the addition of a deaf interpreter who works with a hearing interpreter so that the information is clearer. This recommendation is also supported by the literature. According to Forestal (2005), Deaf interpreters may work with deaf persons who have limited ASL skills or limited communication skills.

Recommendation 3: An Autism Workshop for Teachers of the Deaf

A 1- or 2-hour autism workshop should be provided for all teachers who are currently teaching deaf children and for early intervention teachers of the deaf who visit young pre-school deaf children and their parents in the home. The purpose of this workshop would be to familiarize teachers with the symptoms of autism (early and subsequent) and to provide information on the techniques that can be used to teach children with autism more effectively. The workshop should include information about the challenges and rewards of working with deaf autistic children, as well as the strategies for working with these children.

Recommendation 4: Inclusion of Autism in Training for Teachers of the Deaf

Parents have expressed the need for school personnel to be better trained in how to teach their children effectively (Starr et al., 2006). Furthermore, as Easterbrooks and

Handley (2005) point out, teachers of the deaf are not able to get guidance from the literature on how to teach deaf children with a dual diagnosis. Until there are more studies in this area, I recommend that the teacher training programs for teachers of the deaf include the same level of training in the area of autism that is available for special education teachers.

Recommendation 5: Research Plan of Action in Deaf Autism

To help deaf autistic children and their families more effectively, there needs to be a great deal more research in this area. Graduate students interested in special education need to be informed that there is very little research in this area and that they have the opportunity to make a difference in this area. This research-based information could be most useful in helping teachers understand deaf autistic children.

What I Have Learned

Working on my M. Ed. degree has been a huge challenge for me. It had been many years since I had studied in university. I knew it would be hard but I had no concept of just how hard it would be. Nothing came naturally to me, not the academic writing and certainly not the searching for studies on the computer. I felt like I had landed in a foreign land and had no understanding of the rules and traditions of the society. It has been the faculty, fellow students, and my family that has patiently guided me through the process and encouraged me to keep trying and not to give up.

The first major thing I have learned about myself is that I find it very hard to follow instructions. “When all else fails, read the instructions” seems to have been my motto! I have spent a lifetime struggling to work things out through trial and error when

the process could have been finished in half the time by following the instruction leaflet or finding someone who could guide me through the process. This tendency to go off in my own direction and not follow direction was strikingly evident when I began writing my literature review for the project. My supervisor knew that this process was going to be exceedingly challenging for me and arranged to meet with me on a regular basis to guide me through the process. He would carefully work through each paragraph giving me instructions on what needed to be added or deleted but then I would go off and change the very sentences that he had corrected. I have had a major lesson on learning to accept that others have expertise and that I should learn to trust them – which is what I did in the end!

The second thing I have learned about myself is that there is a distinct possibility that I have Attention Deficit Hyperactivity Disorder (ADHD)! I truly do find it very hard to keep my attention focussed on one thing. This tendency has been apparent in my academic writing. It has been hard for me to focus in on studies that demonstrate a particular point and not add a great deal of additional interesting, but largely irrelevant, information. I have started to curb this tendency but I still have a long way to go.

Third, I've learned to forgive myself for many events in my life that I have considered failures. I have always felt particularly badly that I was never able to contribute fully to the financial base of our family. I have worked for many years on a part-time basis as a supply teacher because I felt I couldn't cope with the stress of a full-time teaching position on top of the challenges I experienced, and continue to experience, in my family. Researching my story has helped me to realize that I have done the best I could in the circumstances, and that my life experience does have value in that it adds to

the data base for deaf autism and may, in turn, help other parents cope more successfully than I did. I am realizing that my experiences happened at a time when my son was one of the first deaf autistic children in the provincial schools for the deaf system. I can now look back and realize that everyone was struggling to understand my son and help him, and that they too were doing the best they could in the circumstances. Reflecting on my story has helped me see how far my son has progressed despite his limitations and how far I have progressed despite mine! I couldn't be prouder of my son and of all of my family and of myself!

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