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Deaf-Blindness and Autistic Spectrum Disorder

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Abstract

One factor that stands out regarding individuals who are deaf-blind and autistic is the dearth of literature and research about the condition. In addition to discussing the possible reasons for this, the paper covers the diagnosis of autism in those who are deaf-blind, some of the etiologies of the syndrome of autism and deaf-blindness, and some data on the current prevalence of the condition.

Keywords: Autistic Spectrum Disorder, syndrome, etiology, Applied Behavioral Analysis

Autistic Spectrum Disorder, often referred to as Autism, is currently an issue of increasing focus in the fields of mental health, special education, and disabilities in general (Gabriels & Hill, 2007; Jepson & Johns, 2007; Stabbe, 2007; Vernon Rhodes, 2009). Major publications in the popular press have also fostered articles on the topic (Erb, 2008; Park, 2008; Winerman, 2004).

Even in a relatively small field such as deafness, there has been a significant increase of studies by psychologists and psychiatrists on the relationship of autism to deafness (Miller & Funayama, 2008; Morton, 2008; Steinberg, 2008; Szymanski & Brice, 2008; Vernon & Rhodes, 2009).

The irony of all this is there have been almost no reports on adult deaf-blind persons who are autistic. Existing studies usually involve young deaf-blind children suspected of having autism (Andrews & Wyver, 2005; Dale & Alison, 2008).

It has been the author's experience that even individuals who have served clients who are deaf-blind for 25 years or more have yet to come across an adult who was deaf-blind and diagnosed as being autistic. Furthermore, in surveying the literature on deaf-blindness, almost no references on deaf-blind autistic adults are found.

Some Characteristics of Autism

Autism is characterized by impairment of social relationships, and lack of imaginative thoughts (Sicile-Kiva, 2004). The problems that develop from

these broad categories manifest in many specific atypical behaviors, among which are those listed in Figure I. In addition, persons with autism tend to have serious medical problems, including gastric disorders and immune deficiencies (Jepson & Johnson, 2007).

About a third of children with autism experience a major regression at around 18 to 24 months (Rapin, 1997). It involves language, social functioning, and overall behavior followed by prolonged plateaus and then eventual improvement. However, there is rarely a full recovery to previous levels of functioning (Rapin, 1997). Ten percent have pathological EEG patterns involving a later regression. This latter condition carries a poor prognosis (Rapin, 1997).

Figure 1
Some Symptoms of Autism *

1. Does not socialize with peers
2. Prefers to be alone
3. Makes little or no eye contact
4. Lacks the ability to sense the emotions of others
5. Does not develop language
6. Progresses normally during first year or so of life, then regresses. At around 24 months recovers some but not all of previous cognitive development
7. Obsessively odd play with toys or objects, e.g., lines them up or spins them
8. Eats only certain foods
9. Makes repetitive movements such as rocking back and forth or flapping hands
10. Poor motor skills
11. Hits or bites self or others
12. Removes clothes often
13. Frequent diarrhea and stomach problems
14. Resists changes in routine or surroundings
15. Intellectual disability

**(Data from Sicile-Kiva, 2006)*

Causes of the Syndrome of Autism and Deaf-blindness

There are very few studies specifically on the etiology of the syndrome of deaf-blindness and autism. However, there is considerable data separately

on the causes of each of the three conditions, autism, deafness and blindness, that make up the syndrome (Chess, Fernandez & Kern, 1972; Jepson & Johnson, 2007; Jure, Rapin & Tuchman, 1991; Rapin, 1997; Park, 2008). A partial list of these etiologies is provided in Figure II.

On rare occasions, the combination of two or three of the conditions listed in Figure 2 can affect an individual, resulting in the syndrome of deaf-blindness and autism. While the prevalence of this syndrome is not known, in view of the doubling of the rate of diagnosed cases of autism in school children over the past decade (Winerman, 2004), it is likely there has also been an increase in autism among persons who are deaf-blind.

Figure 2
Diseases and Conditions Associated with or Known to be Etiological Factors in Deafness, Blindness, and/or Autism

- Genetics
- Congenital Cytomegaly Virus (CMV)
- Borneo Disease
- Measles Virus
- Measles-Mumps-Rubella Vaccine
- Rubella
- Prematurity
- Tuberous Sclerosis
- Fragile X Syndrome
- Perinatal problems
- Untreated Phenylketonuria
- Herpes Simplex
- Encephalitis
- Brain Lesions
- Bacterial Meningitis

References for this figure are Chess, Fernandez & Korn (1972); Jepson & Johnson (2007); Jure, Rapin & Tuchman (1991); Parks (2008); Rapin (1997); and Vernon, Grieve & Shaver (1980).

Psychodiagnostic Issues in Evaluating Deaf-blind Individuals with Autism

There is an almost total dearth of well-validated psychological tests to measure basic factors, such as intelligence and personality in persons who

are deaf-blind (Schum, 2008; Vernon & Hammer, 1996). The situation is almost as bad for those who have certain forms of autism only and even worse for individuals who are deaf-blind and autistic (Schum, 2008; Vernon & Rhodes, 2009).

Part of the problem is that one of the main features of both deaf-blindness and autism is defective communication skills in most persons having this syndrome. This severely limits or, in many cases, rules out, any linguistic interaction between the patient and the diagnostician. Consequently identification and psychological evaluation of deaf-blind autistic individuals tends to be relatively ineffective. One result of this is that we have no accurate account of how many deaf-blind autistic persons there are, although the population is probably small. Because it is small, commercial test developers are not interested in investing the money required to create and validate psychological tests of intelligence and personality for this as well as other low population disability groups.

However, some individuals and institutions have tried to adapt existing instruments for use with these populations. For example, the Haptic, a tactile performance IQ test for blind and deaf-blind adults exists and can be used with some adults who are deaf-blind and also autistic (Bauman, 1975). However, it has not been found to be very satisfactory (Vernon & Green, 1980). Thus, it is rarely used today.

There was also an attempt to adapt the TONI, a non-language performance IQ test for use with deaf-blind persons (Duncan, Wiedel, Prickett, Vernon, & Hollingsworth-Hodges, 1989). This was done by converting the line drawn designs of the TONI into conical raised lines, analogous to the raised lines in Braille. Had the TONI proved useful with those who are deaf-blind, it would probably have also been applicable with deaf-blind autistic individuals. However, administration time was excessively long. In addition, and, based on pilot test results, the investigators recommended against its use with blind or deaf-blind adults. The linguistic limitations of most, but not all, deaf-blind autistic adults precludes the use of verbal tests of IQ with most of this population (Duncan, Wiedel, Prickett, Vernon, & Hollingsworth-Hodges, 1989).

For deaf-blind children, the Collier Azasa Scale has been the most widely employed intelligence test. It was designed primarily for low functioning deaf-blind children ages zero to nine years (Stillman, 1978). To our

knowledge, it has not been attempted with deaf-blind autistic children, but would seem to have some potential with certain individuals in this group (Vernon, Blair & Lotz, 1979).

Starting about fifteen years ago, psychologist Wolf-Schein (1993) took a basically different approach to the evaluation of deaf-blind autistic children. The reasoning was that “the primary reason for testing should be to properly describe children’s current level of performance in order to point the way to the best intervention possible.” This is different from the conventional concept of psychological evaluations, which usually depend heavily upon IQ and personality tests. This measurement instrument is the Assessment of Developmental Levels by Observation (ADOL). It results in a description of how the child functions in the areas of “Relationship to Adults, Expressive Language, Receptive Language, Fine Motor Skills, Gross motor skills, and Self Help Skills (Wolf-Schein, 1998). The procedures, personnel and materials involved are too extensive to describe in this paper, but are provided in Wolf-Schein’s (1998) “Considerations in Assessment of Children with Severe Disabilities, Including Deaf-blindness and Autism”. This publication also provides a good overview of the other instruments of value in the evaluation of deaf-blind autistic children.

Diagnosis of Autism in Deaf-blind Individuals

Clinicians face awesome problems in diagnosing autism in clients who are deaf-blind for numerous reasons. For example, two of the major symptoms of autism are impaired capacity to socially interact with others and delayed or lack of functional language. Therefore, many individuals who are deaf-blind, especially the children, lack the language necessary to describe their symptoms or to communicate with the professionals making the diagnosis. While problems in some of these areas are present in the majority of those who are deaf-blind, the etiology of their disabilities is only occasionally autism (Vernon & Rhodes, 2009). Another difficulty in the diagnosis is that persons who are born deaf and become blind often lack intelligible speech, cannot hear conversation and have only limited socialization skills. For these individuals, their delay in or lack of language limits communication, which is also often a feature of autism.

Further complicating the diagnostic problem in individuals who are deaf-blind and autistic is that there are few IQ or personality tests adequately validated on deaf-blind people (Vernon & Hammer, 1996). Nor are there

medical tests to detect the presence of autism in one who is deaf-blind. Perhaps the most severe diagnostic problem is the dearth of psychologists and psychiatrists who have any experience with the syndrome of deaf-blindness and autism (Vernon & Hammer, 1996).

Because autism often involves complex physical disorders, a major aspect of a thorough diagnosis of autism in deaf-blind patients is medical. Physical symptoms may include painful gastric pathology, conditions affecting multiple organ systems, a weakened immune system, epilepsy, etc. (Jepson & Johnson, 2007). Until the more severe of these physical disorders are addressed, the extreme pain and discomfort they cause makes successful treatment and education impossible (Jepson & Johnson, 2007; Vernon & Rhodes, 2009).

Because the autism component of the syndrome of deaf-blindness and autism involves such complex medical issues, few physicians have the specialized knowledge needed to diagnose and treat these kinds of autistic patients. Thus, parents are advised to contact an autistic center to get the name and address of the nearest physician who specializes in these medical issues (Jepson & Johnson, 2007). Figure 3 contains a partial list of centers that can provide this information.

Figure 3
Resources for Parents and Professionals

1. Autism Research Institute
4182 Adams Avenue
San Diego, CA 92116

2. Autism Society of America
7910 Woodmont Avenue, Suite 200
Bethesda, MD 20814-3067

3. Center for the Study of Autism
P.O. Box 4538
Salem, OR 97302

4. National Alliance for Autism Research (NAAR)
99 Wall Street, Research Park
Princeton, NJ 08540

Prevalence

Before 1980, autism was found in only 2 to 5 per 10,000 children in the United States. By 2007, the Centers for Disease Control determined the rate of autism in the U.S. to be 1 in 150 children. It is now considered to be a major social and medical crisis (Jepson & Johnson, 2007). Among children who are Deaf, autism occurs in 1 per 76 children, or almost twice as often as with children in the general population (Szymanski & Brice, 2008; Gallaudet Research Institute, 2007).

However, little data is found on the prevalence of autism in adults who are deaf-blind and autistic. Yet the information on an increase among children who are Deaf and autistic is a strong indicator that the increase in the percent of autism among those who are deaf-blind would be greater than is the case with children in the general population or children who are Deaf. The reason for this is that so many of the causes of deafness, blindness and autism tend to overlap (Figure II).

The accuracy of the few available statistics on autism and on autism and deafness has been questioned (Wing & Potter, 2002). However, the data as it exists has been cited in this paper. Among the questions that have been raised about the accuracy of the statistics are the changes in the criteria for the diagnosis of autism over the last decade, the lack of rigor of the diagnoses of autism made by psychologists, psychiatrists, and others, and the lack of psychological tests for autism validated on deaf-blind samples. (Wing & Potter, 2002; Vernon & Hammer, 1996).

Despite these problems, the preponderance of the evidence appears to indicate there has been a steady increase in the syndrome of autism and deaf-blindness over at least the last three decades (Vernon & Rhodes, 2009).

Autism in the Blind Population

Most of the research on autism among those who are blind was done in England on children. It has been summarized by Andrews and Wyver(2005) and Dale and Alison (2008). For example, Keeler (1958) and Wills (1979) documented the presence of autistic features in young and older children with serious congenital blindness. They concluded that blind children were definitely at risk for autistic-like behaviors.

Further evidence of symptomology of autism in congenitally blind children comes from the work of Case, Sonksen, & McConachie (1994). They found that out of 102 children having varying levels of vision impairment and documented normal development in their first year of life, 11 percent showed the same kind of regression at around two years of age that had been reported in children who have autism.

Children with CHARGE, a medical syndrome with both physical and psychological effects indicating a non-random pattern of congenital defects that occur together more frequently than would be expected by chance, are often diagnosed as having autism, (Hartshorne, Grialou & Parker, 2005). The cause of CHARGE is usually genetic, but not always. The diagnosis is frequently made by clinical judgment and the syndrome usually involves coloboma, congenital heart defects, hearing loss and a number of nervous system anomalies that vary to some extent depending on the individual patient. (Hittner, H.M.; Hirsch, N.J.; Hreh, G. M. & Rudolph, A.J., 1979) The autistic-like behavior in children with CHARGE is different in some respects from children who have the single diagnosis of autism or of deaf-blindness. This raises the question of whether children with CHARGE may also be autistic or whether their behavior should be attributed to other causes unique to CHARGE (Hartshorne, Grialou & Parker, 2005).

In summarizing these and other studies, Dale (2005) and Sanksen & Dale (2007) concluded that blind children whose etiology of blindness was multiple brain lesions, whose onset of visual loss was under 10-16 months and who were male were most at risk for also developing symptoms associated with autism.

Andrews and Wyver (2005) among others maintain that while many blind children who have specific features of Autism Spectrum Disorder (ASD) they should not be considered to have Austistic Spectrum Disorder because the neural pathways involved may be different for the two groups.

Summary

Deaf-blindness is among the most severe of all disabilities psychologically and educationally. When it is compounded by autism and its physical and emotional components, the problems are exponentially magnified. For these reasons, it is critically important that we develop far better diagnostic tests and techniques to identify autism in deaf-blind persons who are also autistic.

Although autism is currently thought by many to be incurable (Jepson & Johnson, 2007), there are psycho-educational techniques, such as Applied Behavior Analysis and tactile sign language (Lovaas, 1987; Moores, 2001), which have the potential to alleviate some of the adjustment issues deaf-blind autistic individuals face. Equally important is there is an abundance of knowledge on how to address the medical conditions associated with the autistic component of the syndrome (Jepson & Johnson, 2007). One of the main reasons so little has been done to treat the syndrome of deaf-blindness with autism maybe because of the complex nature of the diagnosis (Vernon & Hammer, 1996).

The point to be made from these data and the author's review and interpretation of the literature is that the education, treatment and diagnosis of deaf-blind persons with autism is currently and has always been little understood and grossly ignored, leaving these individuals without the help they need. In a way, this is understandable because the deaf-blind autistic population is extremely small and is not in a position to articulate their needs. At the same time, the problems that they pose, medically and psychologically, are extremely complex and difficult to resolve.

Coupled with the general lack of awareness of the public to these issues, it is understandable, but unfortunate, that more effort is not put forth to resolve the issues this population faces.

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References

- Andrews, R. & Wyver, S. (2005) Autistic tendencies: Are there different pathways for blindness and Autistic Spectrum Disorder? *British Journal of Visual Impairment*, 23, 2, 52-57. doi: 10.1177/0264619605054776
- Bauman, M.K. (1975) Guided vocational choice. *New Outlook for the Blind*, 69, pp. 257-360.
- Case, H. Sanksen, P.M. & McConachie, H.R. (1994) Developmental setbacks in severe visual impairment. *Archives of Disease in Childhood*, 70, 192-199.
- Chess, S.; Fernandez, P., & Kern, S.J. (1972) *Psychiatric Disorders in Children with Congenital Rubella*. New York: Brunner/Mazel, Inc.
- Dale, N. (2005) Early signs of developmental setbacks and autism in blind infants; In Pring.L. (Ed.) *Autism and Blindness: Research and Reflections*. Londong: Whurr.
- Dale, N. & Alison, S. (2008) Social identity, autism, and visual impairment (VI) in the early years. *British Journal of Visual Impairment*, 26, 135-146. doi: 10.1177/0264619607088282
- Duncan, E., Wiedel, H., Prickett, H., Vernon, M., & Hollingsworth-Hodges, T.(1989) The tactile TONI, a possible new performance IQ test for deaf-blind adults. *Journal of Visual Impairment and Blindness*, 85, 510-511.
- Erb, R. (2008) Autistic students find a place in college. *Florida Times-Union*. D-3, March 26, 2008.
- Gabriels, R.L. & Hill, D.E. (2007) *Growing up with Autism*. New York: The Guilford Press.
- Hartshoren, T.S., Grialou, T.L., & K.R. (2005) Autistic-like behavior in CHARGE syndrome. *American Journal of Medical Genetics*, 133A, 257-261. doi: 10.1002/ajmg.a.30545

- Hittner, H.M.; Hirsch, N.J.; Kreh, G.M. & Rudolph, A.J. (1979) Coloboma tous microphthalmia, heart disease, hearing loss, and mental retardation—a syndrome. *Journal of Pediatric Ophthalmology and Strabismus*, 162, pp. 122-128.
- Jepson, B. & Johnson, J. (2007) *The Changing Course of Autism*. Boulder, CO: Sentient Publications.
- Jure, R., Rapin, I., & Tuchman, R. F. (1991) Hearing impaired autistic children. *Developmental Medicine and Child Neurology*, 33, 1062-1072. doi: 10.1111/j.1469-8749.1991.tb14828.x
- Keeler, W.R. (1958) Autistic patterns and defective communication in blind children with Retrolental Fibroplasia; in Hoch, P.H. & Zubin, J. (Eds.). *Psychopathology of Communication*. New York: Grune & Stratton.
- Lovaas, O.I. (1987) Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Consulting Clinical Psychology*, 155, 1, 3-9.
- Miller, M. & Funayama, S. (2008) Life after high school for deaf youth with autism. *Odyssey*, 19, 1, pp. 32-37.
- Moores, D.F. (2001) *Educating the Deaf: Psychology, Principles and Practices*, 5th ed. Illinois: Houghton, Mifflin Co. pp. 29-55.
- Morton, D.D. (2008) Deafness and autism. *Odyssey*, 9, 1, pp. 4-5.
- Park, A. (2008) How safe are vaccines? *Time Magazine*, 171, 22, pp. 36-41.
- Rapin, I. (1997) Autism. *New England Journal of Medicine*, 337, 97, pp. 94-104.
- Sanksen, P. M. & Dale, N. (2002) Visual impairment in infancy: Impact on neurodevelopmental and neurobiological processes. *Developmental Medicine and Child Neurology* 44, 782-791.

- Schum, R. (2008) Psychological assessment of children with multiple handicaps who have hearing loss. *The Volta Review*, 104, 4, 234-255.
- Stabbe, M. (2007) Special ed funding fuels surge in autism diagnoses. *Florida Times-Union*, November 5, 1907, p. B 2
- Steinberg, A. G. (2008) Understanding the need for language. *Odyssey*, 9, 1, pp. 6-9.
- Stillman, R. (1978) The Collier Azusa Scale-G-Scales for the assessment of communications abilities. Dallas TX: University of Texas at Dallas, Collier Center for Communication Disorders.
- Szymanski, C. & Brice, P.J. (2008). When autism and deafness coexist in children. *Odyssey*, 9, 1, pp. 10-15.
- Vernon, M. , Bair, R. & Lotz, S. (1979) Psychological evaluation and testing of children who are deaf-blind. *School Psychology Digest*, 8, 291-295.
- Vernon, M. & Green, D. (1980) A guide to the psychological assessment of deaf-blind adults. *Visual Impairment and Blindness*, 74, 6, 229-230.
- Vernon, M. & Hammer, E. (1996) The state of evaluation and diagnosis of deaf-blind people: Psychological and functional approaches. *Journal of Vocational Rehabilitation*, 6, 2, 133-141. doi: 10.1016/1052-2263(96)00176-6
- Vernon, M. & Rhodes, A. (In press) Deafness and Autistic Spectrum Disorders. *American Annals of the Deaf*.
- Wills, D. (1979) Early speech development in blind children. *Psychoanalytic Study of the Child*, 34, 85-117.
- Winerman, L. (2004) Effective education for autism. *Monitor on Psychology*, 35, 11, 46-49.

Wing, L. & Potter, D. (2002) The epidemiology of autistic spectrum disorders: Is the prevalence rising? *Mental Retardation Disability Research Review*, 32, 207-215.

Wolf-Schein, E. (1993) Assessing the “untestable client. ADLO. *Developmental Disabilities Bulletin* 22, 1, 35-54.

Wolf-Schein, E.G. (1998) Considerations in assessment of children with severe disabilities including deaf-blindness and autism. *International Journal of Disability: Development and Education*, 45, (1), 35-55. doi: 10.1080/1034912980450104