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Educational Programming for Deaf Children with Multiple Disabilities

Abstract

Many deaf children have multiple disabilities. In this chapter the concept 'multiple disabilities' is explained. Subsequently etiology is discussed, followed by information about deafblindness, deafness and autism and deafness and intellectual disabilities. Educational accommodations, including assessment, access to communication and language (including cochlear implantation) and curricula for deafblind children, are the subject of the remainder of this chapter.

Key words: deaf- multiple disabilities- deafblind- autism- intellectual disability- assessment- education

Accommodating Special Needs

Among deaf children, there are many who have special needs.[1] Of particular interest in this chapter are children with a severe to profound hearing loss in combination with another disability. Such children generally need services beyond those provided for a child that is only deaf. Additional disabilities may include intellectual disability, autism, visual impairment, specific learning disorders (e.g., dyslexia), attention deficit disorders, emotional or behavioral

problems, or physical disabilities (see, e.g., Holden-Pitt & Diaz, 1998; Karchmer, 1985; McCracken, 1998). A major problem in describing the group of deaf children with special needs is the frequent use of generic definitions. These definitions "fail to explore the complex relationships that may exist between different conditions" (McCracken, 1998, p. 29). It is these complex relations that make these children special.

Definition and Etiology

One may wonder whether deaf children with special needs are inevitably multiply disabled. "Multiply disabled" does not mean the simple existence of multiple disabilities, but instead denotes a combination of two or more disabilities with an onset early in life for which, given help, education or intervention developed and suitable for children with one disability is not applicable. That is, in multiply disabled persons, the separate disabilities and the possible compensations for each disability influence one another (Gunther & de Jong, 1988; Nakken, 1993). It is the reduction in possibilities for compensation, whether spontaneously or after intervention, that makes a child multiply disabled. In this respect, deafblind, deaf, intellectually disabled children, and deaf children with autism or physical disabilities are truly multiply-disabled children. For these children, a unique situation evolves from the combined presence of two or more disabilities with great repercussions for communication, education, mobility, living skills, and learning.

A completely different situation is the case for teaching deaf children with learning disabilities or attention deficit disorders (Samar, Parasnis, & Berent, 1998). Although teaching these children most certainly will require adaptations, the intervention strategy is basically the same as is the case with a deaf child. In this chapter we focus specifically on multiply disabled

deaf children. We only briefly touch on the educational accommodations for deaf children with learning problems or attention deficits.

Multiple disabilities, including hearing disorders, are often consequences of the same conditions that may cause deafness (Das, 1996). These conditions may be divided into four categories, depending on the onset of the disability. Under the heading of "prenatal onset" we may categorize genetic syndromes, intrauterine infections (e.g., rubella and cytomegalovirus), and maternal illness. In 1985 these causes accounted for 40% of all cases of deafness in the United States. "Perinatal onset" includes birth trauma, anoxia/asphyxia, kernicterus, and prematurity and accounted in 1985 for 20% of all cases of deafness in the United States. Trauma, infections, and tumors may be categorized as causes with a "postnatal onset" resulting in acquired deafness or deafblindness, accounting for 10% of all cases. Finally, "idiopathic or unknown causes" accounted for 30% of all cases of deafness. In each case, these etiologies may result in either hearing loss alone or in hearing loss combined with a variety of disabilities. Even when deafness is hereditary, it may have syndromic (e.g., the syndromes of Usher's, Pendred, and Waardenburg) or nonsyndromic causes. It is estimated that 70% of hereditary deafness is nonsyndromic. In the 1995 publication of Gorlin and colleagues, more than 450 syndromes were described with hearing impairment as one of the main features (see also Arnos & Pandya, this volume). Some, but not all, of these hereditary causes of deafness associate with multiple disabilities. Examples are hereditary syndromes that lead to deafblindness such as Usher's syndrome and Zellweger syndrome.

Deafblindness

By far the best documented group of multiply disabled deaf children is the group of deafblind children (for a comprehensive overview about deafblindness and its educational consequences see Van Dijk, Van Dijk, Nelson & Postma, in press). The term deafblind came into use after 1990 instead of "deaf/blind" or "deafblind." The reason for using a single word is that it suggests a unique impairment, in which deafblindness is more than just deafness plus blindness (Aitken, 2000; McInnes, 1999; Van Dijk & Janssen, 1993). However, the label deafblind is still quite common, as well as the labels multi- or dual-sensory disabled.

McInnes (1999) gives several definitions of deafblindness, all essentially the same with respect to the following points. First, all definitions state that deafblind people have impaired vision and hearing, but are not necessary totally blind or completely deaf. Any degree and combination of hearing and vision impairment is called deafblindness. Theoretically speaking, there is no absolute threshold level for hearing or vision under which a person is labeled deafblind, in contrast to the thresholds in use for people who are solely visually or auditorally impaired (see also Aitken, 2000; McInnes & Treffry, 1982; Munroe, 2001). (For legislative purposes, definitional thresholds sometimes are established.) It is the deprivation of their distance senses that is the common feature of the group labeled as deafblind (McInnes & Treffry, 1982). Second, the two sensory impairments multiply and intensify the impact of each other, creating a severe disability, which is unique. Finally, because deafblindness is defined as not having sufficient vision to compensate for the loss of hearing and not having sufficient hearing to compensate for the loss of vision, deafblind people typically require services that are different from those designed exclusively for either blind or deaf people (McInnes, 1999).

In clinical practice, the definition of deafblindness occasionally is extended to all those who might benefit from being taught as a deafblind child. Thus, sometimes children with an

impairment to only one distance sense as well as additional (often multiple) impairments may be classified as deafblind (Aitken, 2000). This includes, for instance, children with congenital visual impairment plus additional disabilities and congenital hearing impairment plus additional disabilities.

Hearing and vision are the two major distance senses; these senses provide most of the information that is beyond what we can reach out and touch (Aitken, 2000). The combined absence of these two distance senses causes almost all deafblind people to experience problems with access to communication and information and with mobility (Aitken, 2000; McInnes, 1999; Van Dijk & Janssen, 1993). However, their specific needs vary enormously according to age, onset, and type of deafblindness. Onset of deafness and blindness may differ, which is of major importance for teaching, education, and individual support needs.

Munroe (2001) and Aitken (2001) classify deafblind people in four broad categories. The first comprises persons with congenital or early-onset deafblindness. They have minimal or no vision or hearing at birth or lost their hearing or vision before the age of 2. This condition is mostly caused by prenatal insults (e.g., maternal virus), prematurity, chromosomal abnormalities, or postnatal influences up to the age of 2. Studies (Admiraal, 2000; Munroe, 2001) indicate that the number of children in this group has increased since about 1980, due to higher survival rates of children born prematurely. According to Admiraal (2000), in reality the frequency of severe prematurity, leading to multiple disorders, including deafness, may be even higher, because of the under-diagnosis or the late diagnosis of deafness in this group, at least in the Netherlands. These premature children mostly receive medical care from pediatricians, and many of these children are not enrolled in hearing screening programs. If a lack of response to sound is

discovered, this is often attributed to intellectual disability instead of to a possible hearing impairment.

The second category of deafblindness includes people with congenital or early onset hearing impairment and acquired vision loss. These children become deaf or hard of hearing before the age of 3 and lose their vision at a later time. Causes of this type include Usher's syndrome types 1 and 2 and infections such as meningitis. (See Arnos and Pandya, this volume, for more information about Usher's syndrome.) The third category includes people with late-onset hearing and visual impairment. Children with this type of deafblindness acquire both vision and hearing loss, often separately, after the age of 3. Causes include several genetically inherited conditions (e.g., Usher's syndrome type 3), head trauma, metabolic conditions (e.g., diabetes), and in adults, stroke and aging.

Finally, the fourth category of deafblindness entails congenital or early-onset blindness with acquired hearing loss. This is a less common form of deafblindness than the other three categories. Causes include genetically inherited disorders (e.g., Alstrom syndrome and Norrie disease), birth trauma, and early postnatal infections.

Deafness, Intellectual disability, and Learning Disabilities

According to the American Association on Mental Retardation, intellectual disability is a disability characterized by significant limitations in both intellectual functioning and conceptual, social, and practical adaptive skills. The onset of this disability is before adulthood (Luckasson, 1992). One of the key elements in this definition is the concept of intellectual functioning, usually measured by a test of intelligence. The application of these tests with deaf children is an issue with pitfalls.

The assessment of the learning potential of deaf children may lead to misdiagnoses or over-identification of learning disabilities or intellectual disability (Marschark, 1993; Morgan & Vernon, 1994) because delays in spoken language and reading proficiency are often interpreted as resulting from intellectual disability instead of from a profound hearing loss, especially if the assessment is carried out by clinicians without experience in deafness. Deaf children's inability to obtain sufficient non-distorted information from the environment is often confused with the inability to process it (Mc-Innes, 1999). It therefore is important not to use regular norms for the general population with deaf and hard-of-hearing children and to use adequate test instructions (Braden, 1994; Morgan & Vernon, 1994; see also Maller, this volume). Deaf children should only be diagnosed as cognitively disabled when there is a significant retardation based on the norms for children with a severe to profound hearing loss. Unlike hearing children, deaf children's receptive and expressive spoken language competence often does not exceed their reading level very much. Therefore, written test instructions must be presented at the reading proficiency level of the child being tested. Alternatively, testing by means of sign language or, if appropriate, augmentative communication should be considered (Morgan & Vernon, 1994; Roth, 1991).

It is not always easy to differentiate between intellectual disability and learning disability in deaf children. A major problem is the fact that the concept of learning disability is not straightforward (Bunch & Melnyk, 1989; Mauk & Mauk, 1998; Samar et al., 1998). Often it is described in exclusionary language. As a consequence, learning disability is often defined as a condition that does not arise from intellectual disability, hearing disorders, emotional problems, or cultural or socioeconomic disadvantage. However, Laughton (1989) has re-defined the concept of learning disability in a way that includes the possibility of children with hearing

disorders having concomitant learning disabilities. Laughton states that these children have significant difficulty with the acquisition, integration, and use of language or nonlinguistic abilities.

As far as etiology is concerned, Admiraal and Huygen (1999), conducting a study of longitudinal patterns in the etiology of intellectual disability in deaf people, found that in 30% of all cases of combined deafness and intellectual disability the cause was unknown. This percentage is similar to the one for unknown etiologies of hearing loss in the general, not the multiply handicapped, deaf population. However, the proportion of hereditary deafness for children with intellectual disability was half of that reported for the general deaf population, with acquired causes much more prevalent in the population of deaf, intellectually disabled people. The most frequent etiologies among deaf and intellectually disabled persons older than 20 years of age were congenital infections (rubella, cytomegalovirus), severe prematurity, kernicterus, and meningitis. In younger people, rubella and kernicterus were less prevalent because of the start of rubella vaccination programs and the fact that kernicterus has almost disappeared in the Western world. Severe prematurity was the main cause of deafness and associated handicaps in deaf intellectually disabled children and youngsters.

As for possible causes of learning disorders in deaf children, Laughton assumed as the main causal condition a dysfunction of the central nervous system. Samar et al. (1998) stated that "pre-natal development misorganization can interact with abnormal experience or environmental trauma after birth to set up a recursive cascade of brain-environment interactions that leads to abnormal cognitive system development" (p. 207). In their view, learning disability and attention deficit disorders may result from different developmental disorganizations or environmental trauma, thus differing in presentation. This makes diagnosis difficult.

The claims of Laughton (1998) and Samar et al. (1998) received some support from a study by Zwiercki, Stansberry, Porter, and Hayes (1976). They evaluated 88 deaf and hard-of-hearing students from one school for the deaf in the United States (total population 286 students), who were referred for neurological examination. Referrals took place over a 5-year period. Thirty-five out of the 88 students had obvious organic signs of neurological dysfunction, primarily manifested in sensory or motor problems. Another 21 students were diagnosed as having minimal brain dysfunction. EEG data of 83 students showed abnormal sharp wave activity in 44 cases. These students generally did not exhibit any classical signs of epilepsy, but the authors felt that the learning and behavior characteristics of these students resembled those of epileptic children so much that in many cases preferred treatment was use of antiepileptic medication. Diffuse and focal slow-wave disorders were seen in 35 cases. These patterns support, according to the authors, a diagnosis of cerebral injury or dysfunction.

Deafness and Autism

Autism is a behaviorally defined syndrome with core characteristics such as inadequacies in the development and maintenance of social relationships, problems with the development of communication and language, stereotyped behavior, and problems with adaptation to environmental changes (Rutter, 1978). The pathogenesis of heterogeneous etiologies, however, may result in single outcomes such as autistic like behaviors. In the case of autism and hearing impairment with or without additional disabilities, the autistic like features might only be a single outcome superficially. That is, quantitatively, autism and deafness show overlapping characteristics such as delays in language acquisition, peculiarities in word use and (sometimes, or under certain conditions) social difficulties in peer relations.

Qualitatively, there are sometimes large but mostly subtle differences in cause, pathogenesis, manifestation, and persistence of these behaviors. Therefore, a classification of autism in deaf and hard-of-hearing children, especially in those with additional visual impairments and/or intellectual disability, should only be made by professionals familiar with deaf and hard-of-hearing, visually impaired, intellectually disabled, and autistic children, or misdiagnosis is likely.

Even more difficult is the diagnosis of autism in deafblind people. The prevalence of autism seems to be positively correlated to hearing impairments (Carvill, 2001), visual impairments (Cass, 1998) and intellectual disabilities (De Bildt et al., 2005). In a study involving 10 persons with congenital deafblindness and profound intellectual disability, five of whom were diagnosed as autistic by an expert panel, Hoevenaars-van den Boom, Antonissen, Knoors & Vervloed (2009) concluded that deafblind people with autism showed significantly more impairments in social interaction, in quality of contact initiatives and in the use of adequate communicative signals. It certainly seems possible to differentiate autism from behaviors specific for deafblindness, but a large overlap in overt behaviors between deafblind people and people with autism was also confirmed.

Jure, Rapin, and Tuchman (1991) suggested that because of overlapping characteristics, there may be an under-diagnosis of autism in deaf and hard-of-hearing children and of hearing impairment in autistic children.

Prevalence of Multiple Disabilities

In discussing the prevalence of multiple disabilities among deaf individuals, one can take two approaches. The first approach is to establish how many people with hearing disorders, more specifically deaf people, also show characteristics of other disabilities, such as vision disorders, intellectual disabilities, motor disabilities, learning disabilities, or autism. In the second

approach, one establishes what the prevalence of hearing disorders is among types of disabilities like intellectual disability or autism. In this section, we consider both perspectives, not only to highlight the incidence of multiple disabilities among those typically classified as deaf, but also to show the frequency of under-diagnoses of severe hearing disorders one often sees among many disabled people.

Data of Holden-Pitt and Diaz (1998) show that an estimated 20–40% of all deaf and hard-of-hearing children have accompanying disabilities. For the 1996–1997 school year, the Center for Assessment and Demographic Studies of the Gallaudet Research Institute reported 50,629 deaf and hard-of-hearing children in special educational programs across the United States. This number represents approximately 60% of all deaf and hard-of-hearing children receiving special education in the country. Valid responses about additional disabilities were obtained for 47,760 children. Of these children, 34% were reported having one or more educationally significant disabilities in addition to deafness. The main problems mentioned were blindness or an uncorrected visual problem (4%); intellectual disability (8%); emotional/behavioral problems (4%); and learning problems (9%) (Holden-Pitt & Diaz, 1998).

The prevalence of deafblindness can only be estimated because official Census data were not available. Most prevalence rates are based on counts of deafblind people who receive help from service providers or schools. Based on a national survey of persons with deafblindness in Canada, Watters, Owen and Munroe (2004) estimated the deafblindness ratio in Canada to be 11/100,000, or a population of 3,306 persons of whom 67% had acquired deafblindness. Munroe (2001) cited widely differing figures from Norwegian and English registries. In Norway the most recent numbers indicate there are 302 persons with deafblindness, 203 with acquired deafblindness and 71 with congenital deafblindness. Prevalence for Norway is estimated to be

6.9/100,000 persons. In the United Kingdom the national deafblind organization SENSE has estimated there are 23,000 deafblind or dual-sensory impaired people, yielding an incidence rate of 40/100,000. For the United States there is the National Census for Deafblind Children and Youth, ages 0–21. The Teaching Research Division, Western Oregon University (Monmouth) maintains this census for the Federal Office of Special Education Programs. The census is produced annually, and information for December 1, 1999 indicated 10,198 persons aged 0–21 were on this registry (NTAC, 2001). The self-reported overall prevalence of concurrent visual and hearing impairments in a sample of over 195.000 adults in the United States was 3.3% and increased from 1.3% for participants aged 18-44 years to 16.6% for participants aged 80 years or older (Caban, Lee, Gomez-Marin, Lam, & Zheng, 2005).

Given the major problem of identifying deaf children with additional disabilities and handicapped children with hearing impairment, due to the fact that conventional assessment techniques often fail with these populations, and the fact that registration is mostly voluntary, the reported prevalence rates can only be a conservative estimate of the true prevalence rates. Jure et al. (1991) studied the prevalence of autism among deaf and hard-of-hearing children. In a sample of 1150 children, 46 (4%) met the criteria for autism. Further analysis of the charts of these 46 deaf or hard-of-hearing and autistic children revealed that 37 of them had a severe or profound hearing loss as opposed to a milder loss. With respect to cognitive functioning, data were available for 45 children who were both deaf and had autism: only 8 of the children had normal or near-normal intelligence. Seventeen children also showed signs of hyperactivity. Mauk and Mauk (1998) reported tremendously differing estimates of the prevalence of learning disabilities among deaf and hard-of-hearing children of 3–60%. These estimates are based on both clinical judgments and surveys among educators. As stated before, over-diagnosis clearly is

a problem, among other factors due to a lack of clearness in the conceptualization and problems in identification. Misdiagnosis of learning disability as a manifestation of intellectual disability is another serious error. On the basis of an analysis of four population studies in the United States regarding the incidence of learning difficulties in deaf children, Bunch and Melnyk (1989) concluded that since the early 1970s, approximately 6–7% of all hearing-impaired students had been reported as having concomitant learning problems that might be construed as learning disabilities. We now turn to the prevalence of hearing loss in two groups of handicapped children: children with autism and children with intellectual disability.

One of the features associated with autism is an inadequate modulation of sensory (including auditory) input. This raises the question of whether inadequate modulation of sensory input is caused by dysfunction of central auditory transmission or by peripheral hearing loss. Klin (1993) reviewed 11 studies of autistic children and youngsters, involving auditory brainstem measurements. Klin found no clear evidence for brainstem dysfunction in autism; however, the studies reviewed by Klin did provide indications for the manifestation of peripheral hearing loss in autistic people. Research into the prevalence of this hearing loss showed that the incidence in this group varies widely, depending on the inclusion criteria, the number of children taken into account, and the type and amount of hearing loss measured. Percentages of prevalence ranged from 13–44% (Klin, 1993). Rosenhall, Nordin, Sandström, Ahlsén, and Gillberg (1999) established a percentage of mild and moderate hearing loss (definitions by the authors) of 7.9% among a group of 199 autistic children and adolescents in Sweden. Pronounced (40–70 dB loss) or profound hearing loss (>70 dB) was found among 3.5% of the population studied. This is substantially higher than among children in the general population, where one finds profound hearing loss in no more than 0.1 or 0.2% of all children (Marschark, 1993).

Virtually all studies on hearing loss among intellectually disabled children and adults have focused on people with Down syndrome. One of the major causes of this hearing loss is otitis media, which occurs relatively frequently in this group. Conditions that can cause hearing loss, such as otologic abnormalities (e.g., relatively small external ear canal and shortened cochlear spirals), have been reported (Widen, Folsom, Thompson, & Wilson, 1987), as has sensorineural hearing loss due to premature aging (McCracken, 1998). Evenhuis, Van Zanten, Brocaar, and Roerdinkholder (1992) studied the prevalence of hearing loss among a group of 44 institutionalized subjects with Down Syndrome, aged 35 years or older, in the Netherlands. Twenty subjects had what the authors call a handicapping hearing loss—that is, a bilateral hearing loss of 40 dB or more. Evenhuis (1995) found that 4.3% of a group of aging intellectually disabled people had congenital or early and severe bilateral hearing loss.

Educational Accommodations

In general, specific approaches with respect to accommodations for educational programming tend to focus on deafblind children. Much less information, let alone empirical research into effects, is available with respect to deaf, intellectually disabled children, deaf, autistic children, or deaf children with learning disabilities. Professionals agree that for all groups of multiply-handicapped deaf children, educational programming cannot start without proper assessment (Chen & Haney, 1995; Roth, 1991; Van Dijk & Nelson, 2001).

Assessment

Proper assessment is a precondition for treatment and educational programming because multiply disabled deaf children vary enormously with respect to individual limitations, competencies, and potentials. Assessment should be carried out by people fluent in the ways of

communication preferred by the children such as sign language or forms of augmentative communication (Roth, 1991).

Because communication is the basis for education, the primary aim of assessment should be to study ways to access communication for a multiply disabled deaf child. Further, assessment should provide information about the likelihood of the child acquiring language, learning daily living skills, and possibly acquiring academic skills as a consequence of improved communication.

Unfortunately, formal psychoeducational testing of deaf and multiply disabled deaf children often presents considerable challenges. Reliable and valid assessments with respect to vision, hearing, cognition, and overall development are problematic (see, e.g., Chen, 1999; Jones, 1988; McCracken, 1998; Mauk & Mauk, 1998; Rönnberg & Borg, 2001; Roth, 1991; Van Dijk & Janssen, 1993), and there is a tremendous lack of adequate tests and normative data in these areas. Systematic observational assessment of the strength and weaknesses of children in the domains of perception, behavior, language, and motor skills is thus very important to educational planning. At present, however, it appears that the only observational instruments especially designed to assess the development of deafblind children are the Callier Azusa scales (Geenens, 1999; Stillman & Battle, 1986) and for adults aged 18 and older the interRAI Community Health Assessment and Deafblind Supplement (Dalby, Hirdes, Stolee, Strong, Poss et al., 2009). Even with the help of assessment instruments, much still depends on the expertise of assessors, especially on their ability to integrate the results of the different assessments. Nevertheless, this should not be seen as an excuse to refrain from assessment. Given the numerous difficulties severely multiply handicapped children face, a multidisciplinary holistic assessment and intervention approach is required (Chen, 1999; Eyre, 2000; Van Dijk & Janssen, 1993).

Providing Access to Communication

Speech is often beyond the grasp of multiply disabled deaf children. Even if their hearing loss is mild, perception and comprehension of speech can be difficult. Especially when children have additional problems in the cognitive domain, their potential to compensate for the loss of information by speech reading or residual hearing through the use of context information is often limited.

In most cases, establishing access to communication first means selection of a proper communication device based on assessment data about perception, cognitive processes (e.g., memory, attention), and motor skills. One may then select a means of communication that ultimately proves to be useful to the child.

In recent years deaf children with multiple disabilities receive a cochlear implant. Research into the effectiveness of implantation for this specific group of children is still limited. Daneshi and Hassanzadeh (2007) conducted a retrospective study focusing on auditory perception in 60 deaf children with additional disabilities. Among these were three congenitally deafblind children and four deaf children with autism. According tot Daneshi and Hassanzadeh (2007) all deaf children with multiple disabilities showed improved speech perception one year after implantation except the deafblind and deaf and autistic children.

Donaldson, Heavner and Zwolan (2004) studied the effect of implantation on auditory perception in 7 deaf and autistic children, varying in age between 3 and 16. Four children showed improved auditory perception after implantation. However, progress was limited compared to deaf children without additional disabilities.

Holt and Kirk (2004) studied retrospectively the development of speech and language in 69 deaf children with mild intellectual disability. All these children shows progress in speech and in

language proficiency, but, again, progress was significantly lower compared to deaf children without intellectual disability. Speech intelligibility five years after implantation was studied in 67 deaf children with learning problems or multiple disabilities by Nikolopoulos, Archbold, Wever and Lloyd (2008). 70% of all these children developed intelligible speech, but compared to deaf children without additional disabilities a significantly lower number of children could speak intelligible to all people. Deaf children with several combined additional disabilities showed the poorest performance.

Finally, Dammeyer (2008) describes a study into the effect of implantation on auditory perception and communicative development in 5 congenitally deafblind children. Through rating of video observations and parental interviews Dammeyer established that cochlear implantation in these children led to an increase in attention and responsiveness. Improved communication, but not spoken language, was the most noticeable outcome of implantation in this small group of children.

In a review of the existing literature Edwards (2007) concluded that establishing general conclusions about the effect of cochlear implantation in deaf children with multiple disabilities is extraordinary difficult given the small number of studies, the small number of children involved and the huge variation between these children. Nevertheless it seems that deaf children with relatively mild intellectual disability may profit from implantation, not only in speech perception but also in spoken language development. Severe intellectual disability or autism however seem to be a contra-indication for implantation if one expects beneficial effects for speech perception and spoken language development.

Sign language may also be appropriate as a communication tool if visual perception and motor production are relatively intact and if the child or adult functions cognitively near normal.

If deaf children or adults are intellectually disabled, communication through sign language may be too difficult (Kahn, 1996). It is therefore essential to determine whether the grammatical structure of a sign language will be transparent enough for a child to comprehend and acquire it, even if at a slower pace. If sign language grammar proves to be too difficult, a set of selected signs (i.e., high-relevance vocabulary) may be more appropriate.

Apparently, the only available research concerning training deaf people with intellectual disability in understanding and producing sign language is a study by Walker (1977). That study involved 14 hard-of-hearing and deaf, intellectually disabled adults, in a systematic training of a set of 110 signs for 9 months; a large gain in comprehension ability was observed. Although it is not clear from that report whether British Sign Language or Sign Supported English was used, expression through signs increased, and comprehension increased even more. More than half of the group members learned 90% of all the signs taught. It is important to note, however, that no signs were learned spontaneously.

Research by Jure et al. (1991) showed that learning sign language is promising for deaf children with autism, but is, according to the authors, certainly not a solution for all deaf children with autism. None of the children studied was judged to be a fluent signer, and a considerable proportion of the children did not sign at all. Unfortunately, Jure et al. gave no information about the intensity of the training, the language input during the day, and whether a created sign system or a natural sign language was used. Therefore, it might be that more intensive input of sign language during daily communication and in training sessions could lead to better results. The authors pointed out that not all children with autism may be able to produce signs adequately because of the interference of pragmatic deficits with the communicative use of signs. Sometimes, the behavior of deaf, autistic children may be so disruptive that access to

communication can only be established after the implementation of a behavior modification program (Brimer & Murphy, 1988).

Research on congenitally deafblind or severely intellectually disabled children shows that the use of signs might be too demanding in the early stages of communication. Children may need the use of more permanent symbols such as objects (real size or miniaturized) or graphic symbols or natural gestures representing actions with objects (Stillman & Battle, 1986; Van Dijk, 1986). Even if ultimately some signs may be used by deafblind children, the fact that dual sensory impairments may involve profound visual impairments means that access to communication should be established by tactile means. Tactile Sign Language may be necessary (Miles, 1999, Reed, Delhorne, Durlach & Fisher, 1995).

If a multiply disabled deaf child has severe difficulties with motor skills, sign language still may be good as input for communication and language acquisition, but augmentative devices, such as those based on pointing to pictographs or sign drawings, might be more useful (Aiken-Forderer, 1988). In all cases, if communication is adapted and the specific means of communication are selected, it is important to make sure that the people in the environment are able to use the selected means of communication. Training people in the environment and coaching them in the use of sign language or augmentative communication during important communicative activities during the day is as essential as training the children.

Providing Access to Language

Providing children access to communication does not necessarily lead to the acquisition of language. First, acquisition of language is dependent on the structure of the input. If the input consists of a set of signs without grammar, of course no acquisition of language would be expected, unless the child goes beyond the input given. In some cases, even deaf, intellectually

disabled persons restructure the input according to processing demands, as shown by Van Dijk, Van Helvoort, Aan den Toorn, and Bos (1998). Second, the communicative patterns in the environment should allow for language acquisition. This means that the child should gain insight into the reciprocal nature of communication. Turn-taking behaviors, for example, have to be developed, so the child should be allowed time to perceive and comprehend utterances by adults. This means that adults in the environment have to remain patient when a child tries, often with great effort, to produce a communicative message. In other words, the pace of communication should be slowed down so that the child can properly perceive, comprehend, and produce the sign. This is not easy, especially when deaf children are severely cognitively impaired or if they show a large asymmetry between their perception and production capabilities (e.g., if they have severe physical disability; Vervloed, Van Dijk, Knoors & Van Dijk, 2006).

In general, even if multiply disabled deaf children have the potential to acquire language, the ultimate proficiency levels are often low compared to the ones attained by deaf children (Grove, Dockrell, & Woll, 1996). Sometimes, it is necessary to fulfill certain preconditions before children gain access to communication and language at all. This is especially the case with multiply disabled deaf children who have severe behavior problems. Sometimes these behavior problems are not so much typical of a specific syndrome (e.g. Charge syndrome) or disability, but rather related to medical conditions of the children involved (Vervloed, Hoevenaars-van den Boom, Knoors, Van Ravenswaaij & Admiraal, 2006).

In extreme cases, it is necessary to regulate behavior before communication can take place. Sometimes communication itself can lead to a decrease of disruptive behavior patterns, because these patterns (e.g., self-mutilation, acting-out behavior) are thought to serve as communicative signals when others are not available (Durand, 1990; for children with Charge syndrome see Van

Dijk & De Kort, 2005)). However, reduction of disruptive behavior patterns can sometimes only be achieved by means of medication or by intensive psychotherapy or intensive behavior modification programming (Brimer & Murphy, 1988; Glenn, 1988).

Curricula for Congenitally Deafblind Children

A unique feature in educational programming for congenitally deafblind children is that teaching and learning has, above all, to take place by touch. It is because of the combined impairments in hearing and vision that deafblind children face problems in profiting from modeling, imitation, and incidental learning. They often experience difficulties in anticipating coming events, lack curiosity, have difficulty in setting up an emotional bond, and run a serious risk for learned helplessness whenever an individualized development/education plan is not developed (McInnes, 1999). Without proper intervention, congenitally deafblind individuals may spend much of their time in self-stimulation (Nafstad & Rødbroe, 1999). Moreover, they may be passive and rarely take the initiative to make contact with other people, to show exploratory play, or to share their feelings, thoughts, and experiences with others. Because of these serious risks, careful and deliberate educational programming is essential for deafblind children.

Professionals working with deafblind children first attempted to copy the teaching strategies so successfully used with adventitiously deafblind children such as Helen Keller (Enerstvedt, 1996). These strategies, however, did not always work with congenitally deafblind children. Although deafblind children did learn signs, they were rarely used communicatively—that is, to share feelings, thoughts, and experiences (Rødbroe & Souriau, 1999). From 1970 on, interest in the role of attachment in development gave new impetus to research on communication in congenitally deafblind children. Establishing emotional bonds with significant people, mostly the parents, was considered to be crucial for the origination of initiatives to

explore the world, because access to the significant person was obtainable (Nafstad, 1989). Emotional bonding and attachment are still seen as important aspects in the education of deafblind children, as outlined in the approaches of McInnes and Treffrey (1982), Van Dijk 1986; Van Dijk & Janssen, 1993), and the early intervention strategies of Chen (Chen, 1999; Chen & Haney, 1995).

Van Dijk was among the first to design an educational approach for deafblind children. This approach is not solely directed at improving communication but takes into consideration all aspects of the development of deafblind children. Van Dijk's work, also known as the "conversational method" or "movement-based approach" is probably one of the best-known programs in the field of deafblind education. It has been described extensively by Writer (1987), Enerstvedt (1996), and by Van Dijk (Van Dijk, 1983, 1986; Van Dijk & Janssen, 1993). MacFarland (1995) and Wheeler and Griffin (1997) give concise descriptions of Van Dijk's teaching strategies. Most of his approach is based on his work with children handicapped as a result of rubella (see, e.g., Van Dijk, 1983, 1986), but it is also applicable to other congenitally deafblind children.

Van Dijk's work can best be characterized as an educational approach based on theories of sensory deprivation, psychology (i.e., attachment and social learning theory) and communication. The curriculum should not be carried out in isolation but should be used to establish the structure of the child's daily activities (Writer, 1987). In Van Dijk's approach, the need is stressed for initiating activities in natural contexts during times when they would normally take place. The approach is movement-based and distinguishes four levels of communication. The first one is the resonance level, in which the deafblind child's reactions to stimuli are seen as reflexive and preconscious. The second level, co-active movement, extends

the resonance level because the child is more consciously aware of the turn-taking aspect of communication. Turn-taking is introduced by making movements together with as much physical help as needed to expand the (mostly limited) movement repertoire of the child: co-active movement. An extension of the co-active movement level is the level of imitation, the third level. The child is now able to follow the actions of the teacher without physical support and to imitate these actions. A first step toward symbolic communication is the fourth level, the one of referencing, whether it is by pointing, using objects cues (i.e., objects used in an activity or associated with a person) or objects of reference (i.e., three-dimensional objects referring to actions, objects, or people). When a child is able to understand that people can participate in each other's actions and thoughts by means of a symbolic system, a system for symbolic communication has to be chosen: speech, fingerspelling, or tactile sign language. Setting up routines is one of the key aspects of Van Dijk's educational curriculum. Deprived of sensory input, a deafblind child has great difficulty in organizing and structuring events in daily life. By building daily routines, activities become predictable with respect to time, places, and persons. Knowing what is going to happen, with whom they are going to happen, and where they are going to happen are important prerequisites for the feeling of security to emerge, which in turn is important for the deafblind child's social-emotional development. Well-known tools introduced by Van Dijk to aide the establishment of routines include daily and weekly calendars and calendar boxes, association books to assist recognition and memory of important life events, and activity planners to simplify and decode complex tasks.

Although books on the development and educational programming for the deafblind were published before (see, e.g., Freeman, 1975; Walsh & Holzberg, 1981), McInnes and Treffrey (1982) were probably the first authors to publish a comprehensive book on the development,

teaching, and education of deafblind children. Their work builds on that of Van Dijk, but extends it by including a comprehensive curriculum, based on a sound theoretical and methodological framework.

McInnes and Treffry (1982) noted that deafblind children often appeared to be either hypoactive or hyperactive as a result of sensory deprivation. For both groups of deafblind children, the goal of their program, during the first 3 years, is to make contact and to establish an emotional bond with the child. In order for that bond to be an enduring emotional one, it will need to involve frequent reciprocal interaction around activities that are challenging to the child. The second stage in their program is to create, in addition to strengthening the emotional bond, a need to use residual vision or hearing, integrate sensory input, and a need to communicate with the teacher. Further, in this stage one should provide experiences that help the child establish a positive self-image. General activities, which make up the child's day, are suited to developing these needs and to solve problems. According to McInness and Treffry (1982), the child first has to integrate sensory input and use information to solve problems before one is able to implement a formal developmental or educational program in stage three. In this stage the teacher can begin a total program approach with regard to cognition, social, emotional, motor, and perceptual development, as well as life skills and orientation and mobility.

McInness and Treffry emphasize that the program should be activity based and implemented in a reactive environment—that is, an environment that stimulates the child to interact, to solve problems, and to communicate, and at the same time attempts to provide every effort of the child with success. According to McInness and Treffry, most deafblind children will spend considerable time in this third stage of programming. As they progress in the various program areas, elements of traditional academic and vocational programs of non-handicapped

peers can be introduced in the fourth stage. The program then becomes more formal, made up in large part by reading, writing, and mathematics.

With regard to learning, McInnes and Treffry (1982) discerned three stages in each of the four program stages described above. First the teacher and child work co-actively; that is, they work as one person together. Second, they work cooperatively, with the teacher providing the child with sufficient support to ensure success. Finally, in the reactive stage the child completes the task independently. With respect to the interaction, McInnes and Treffry anticipated that, until the child is confident enough, eight specific stages will occur in each new interaction with the environment. First, the child might resist the interaction, and then the child will tolerate the interaction in the second stage before he or she passively cooperates with the teacher in stage three. From this stage on, realistic goals for intervention can be constructed. In the fourth stage the child will enjoy the interaction because of the teacher. In the fifth stage the child will work cooperatively with the teacher. The child will follow the lead of the teacher with little direction or need for encouragement. In the sixth stage the child will lead the teacher through the activity once the initial communication has been given. In stage seven the child is able to imitate the action of the teacher upon request. Last, in stage eight the child is able to initiate the action independently.

In recent years, Janssen and colleagues have developed a curriculum to foster harmonious interaction between deafblind children and educators (Janssen, Riksen-Walraven & Van Dijk, 2003a, 2006; Janssen, Riksen-Walraven, Van Dijk, Ruijssenaars, Vlaskamp, 2007; Janssen & Rodbroe, 2007; Souriau, Rodbroe & Janssen, 2008, 2009). Building on the assessment procedures developed by Van Dijk, Janssen designed a diagnostic intervention model that aims to enhance the communicative competence of deafblind children and their caregivers. Three

elements constitute the core characteristics of harmonious interactions: mutual attention (e.g., eye contact and joint attention), reciprocal attunement (e.g., contingent responding, turn taking, sense of feeling felt by the other person), and adequate emotion regulation. In the case of deafblind children it is mostly the caregiver who is responsible for the creation and maintenance of harmonious interactions. For this reason the intervention is directed on the caregivers. By means of video interaction analysis they are trained to create opportunities for the child to communicate, to attune their behaviors to those of the child and to adapt the interactional context to promote the opportunities for interaction. With the help of video interaction analysis a video interaction coach translates the question for help into a limited number of intervention aims by focusing on four features of the interaction. First, the individual signals of the child and caregiver are described in terms of eight core categories of behavior, that is: taking initiative, confirming that an initiative has been noticed and recognized, positive and negative reactions to utterances of the interaction partner, turn taking and turn giving, attention, regulation of intensity of the interaction, affective involvement, and independent acting without focus on the partner. Second, interaction characteristics are determined along with their strengths and weaknesses. Third, analysis of the interactional context in order to see what can be adapted to promote interaction. Last, establishing intervention goals in terms of the eight core categories of behavior. In a series of single case studies on 14 children and 44 caregivers Janssen and colleagues were able to improve the communicative skills of the children and their caregivers with regard to the eight core categories of behavior (Janssen, Riksen-Walraven & Van Dijk 2002, 2003b) with sufficient long term follow up effects (Janssen, Riksen-Walraven & Van Dijk 2004).

Accommodations for Other Subgroups

There is little published information concerning educational accommodations for deaf, intellectually disabled and deaf, autistic children. In general, apart from the use of touch, many of the same principles of curricula for deafblind children seem to be used. But, the individualized programs developed for such children do not appear to have been well documented.

Compared to multiply disabled deaf children, deaf children with learning disabilities need fewer major accommodations. On the one hand, strict classroom management is advocated in order to have the attention of these children focused on educational content and to prevent undesirable behavior. Creating a sense of community and responsibility is a key element, as is discipline (Stewart & Kluwin, 2001). On the other hand, several authors stress the importance of individual, sometimes revised, instruction and support. It may be necessary to adapt the curricular content. Much emphasis should be put on experiential learning. Reduction of cognitive demands (memory) may be accomplished by means of visualization, structuring (advance organizers), and the use of specific examples. Test instructions may be modified. Also, support for the home environment is an important element (Samar et al., 1998; Stewart & Kluwin, 2001). Samar et al. (1998) point to the potential of interactive multimedia remediation, especially for deaf children with learning disability or attention deficit disorders. They claim that approaches like the ones developed by Merzenich et al. (1996) for dyslexic children who are hearing and for children with speech and language impairments could, though in adapted formats, also be used for certain multiply disabled deaf children. Currently, however, no empirical research is known into the effects of adaptations of didactic techniques or curricula content.

Summary and Conclusions

In this chapter “multiply disabled” has been used to denote a combination of two or more disabilities for which given methods of intervention and support, developed for children with

only one disability, are not applicable because of the presence of another disability. A child is multiply disabled because of the reduction of the possibilities for compensation for each of the separate disabilities.

Although prevalence estimates vary, especially with respect to deaf children with learning disabilities and with autism, it is safe to state that deaf children and adults with multiple disabilities constitute a relatively large subgroup of the entire deaf community. The etiology of multiple disabilities, specifically studied for deafblind people and deaf people with intellectual disability, shows a trend toward an increase of acquired causes, especially due to severe prematurity.

For the entire group of deaf children and adults with multiple disabilities, the appearance of their disabilities, their related developmental limitations, and their remaining potentials differ widely. Thorough assessment by professionals familiar with deafness and multiple disabilities is an absolute precondition for the design of an appropriate educational program. Accommodations in educational programming for deafblind children have been described and are most comprehensive for any group of deaf children with multiple disabilities. Research literature on educational programming for other groups of deaf children with multiple disabilities is largely lacking. This is typical for the research literature on deafness and multiple disabilities in general: in spite of the considerable number of children and adults concerned, there is, with the exception of several single case studies in deafblindness, almost no research published on proper forms of assessment, educational outcomes, or the effects of educational accommodations. The sole recommendation that needs to be made here is that a comprehensive research program focusing on deaf children and adults with multiple disabilities is very much needed.

Note

1. We use the term “deaf” in an audiological sense, indicating a mean hearing loss of at least 70 dB for the better ear.

References

Admiraal, R.J.C. (2000). *Hearing impairment and associated handicaps. An aetiological study.* Unpublished doctoral dissertation, University of Nijmegen, Netherlands.

Admiraal, R.J.C., & Huygen, P.L.M. (1999). Causes of hearing impairment in deaf pupils with a mental handicap. *International Journal of Pediatric Otorhinolaryngology, 51,* 101-108.

Aiken-Forderer, M. (1988). Home and school support for physically handicapped deaf children. In H. T. Pricket & E. Duncan (Eds.), *Coping with the multi-handicapped hearing impaired* (pp. 29-36). Springfield, IL: Charles C. Thomas.

Aitken, S. (2000). Understanding deafblindness. In S. Aitken, M., Buultjens, C., Clark, J. T. Eyre, & L. Pease, (Eds.), *Teaching children who are deaflind* (pp. 1-34). London: David Fulton.

Braden, J. P. (1994). *Deafness, Deprivation, and* IQ. New York: Plenum Press.

Brimer, J., & Murphy, P. (1988). Autism and deafness: a case study of a deaf and autistic boy. In H.T. Pricket & E. Duncan (Eds.), *Coping with the multi-handicapped hearing impaired* (pp. 37-44). Springfield, IL: Charles C. Thomas.

Bunch, G.O., & Melnyk, T-L (1989). A review of the evidence for a learning-disabled, hearing-impaired sub-group. *American Annals of the Deaf, 134,* 297-300.

Caban, A.J., Lee, D.J., Gómez-Marín, O., Lam, B.L. & Zheng, D.D. (2005). Prevalence of Concurrent Hearing and Visual Impairment in US Adults: The National Health Interview Survey, 1997–2002, *American Journal of Public Health, 95,* 1940-1942.

Carvill, S. (2001) Sensory impairments, intellectual disability and psychiatry. *Journal of Intellectual Disability Research, 45*, 467-483.

Cass, H. (1998) Visual impairment and autism: Current Questions and Future Research. *Autism, 2*, 117-138.

Chen, D. (Ed.) (1999). *Essential elements in early intervention. Visual impairment and multiple disabilities*. New York: AFB Press.

Chen, D., & Haney, M. (1995). An early intervention model for infants who are deafblind. *Journal of Visual Impairment and Blindness, 89,* 213-221.

Dalby, D.M., Hirdes, J.P., Stolee, P., Strong, J.G., Poss, J., Tjam, E.Y., Bowman, L., & Ashworth, M. (2009). Development and psychometric properties of a standardized assessment for adults who are deaf-blind. Journal of Visual Impairment and Blindness, 103, 7-16.

Dammeyer, J. (2009). Congenitally deafblind children and cochlear implants: effects on communication. *Journal of Deaf Studies and Deaf Education, 14, 2*, 278-288.

Daneshi, A. & Hassanzadeh, S. (2007). Cochlear implantation in prelingually deaf persons with additional disability. *Journal of Laryngology and Otology, 121*, 635-638.

Das, V.K. (1996). Aetiology of bilateral sensorineural hearing impairment in children: a 10 year study. *Archives of the Diseases of Children, 74,* 8-12.

De Bildt, A., Sytema, S., Kraijer, D., & Minderaa, R. (2005) Prevalence of pervasive developmental disorders in children and adolescents with mental retardation. *Journal of Child Psychology and Psychiatry, 46*, 275-286.

Donaldson, A.I., Heavner, K.S & Zwolan, T.A. (2004). Measuring progress in children with autism spectrum disorder who have cochlear implants. *Archives of Otolaryngology—Head and Neck Surgery, 130*, 666–671.

Durand V. M., (1990). *Severe behavior problems: a functional communication training approach.* New York: Guilford Press.

Edwards L.C. (2007). Children with cochlear implant and complex needs: A review of outcome research and psychological practice. *Journal of Deaf Studies and Deaf Education, 12*, 258–268.

Enerstvedt, R. T. (1996). *Legacy of the past, those who are gone but have not left, some aspects of the history of blind education, deaf education, and deafblind education with emphasis on the time before 1900*. Dronninglund, Denmark: Forlaget Nord-Press.

Evenhuis, E.M. (1995). Medical aspects of ageing in a population with intellectual disability: II. Hearing impairment. *Journal of Intellectual Disability Research,* 39(1), 27-33.

Evenhuis, E.M., Van Zanten, G.A., Brocaar, M.P. & Roerdinkholder, W.H.M. (1992). Hearing loss in middle-age persons with Down Syndrome. *American Journal on Mental Retardation,* 97(1), 47-56.

Eyre, J. T. (2000). Holistic assessment. In S. Aitken, M., Buultjens, C., Clark, J. T. Eyre, & L. Pease, (Eds.), *Teaching children who are deafblind* (pp. 119-140). London: David Fulton.

Freeman, P. (1975). *Understanding the deaf/blind child.* London: Heinemann Health Books.

Geenens, D. L. (1999). Neurobiological development and cognition in the deafblind. In J. M. Mclnnes (Ed.), *A guide to planning and support for individuals who are deafblind* (pp. 150-174). Toronto: University of Toronto Press.

Glenn, S. L. (1988). A deaf re-education program: a model for deaf students with emotional and behavioral problems. In H. T. Pricket & E. Duncan (Eds.), *Coping with the multi-handicapped hearing impaired* (pp. 7-18). Springfield, IL.: Charles C. Thomas.

Gorlin, R.J., Toriello, H. V., & Cohen, M. M. (1995). *Hereditary hearing loss and its syndromes.* Oxford: Oxford University Press, 1995.

Grove, N., Dockrell, J., & Woll, B. (1996). The two-word stage in manual signs: Language development in signers with intellectual impairments. In S. von Tetzchner & M. H. Jensen (Eds.), *Augmentative and alternative communication: European perspectives* (pp. 101-118). London: Whurr.

Gunther, F. A, & de Jong, C. G. A., (1988). Meervoudig gehandicapt [Multiple handicapped]. Doorn, Netherlands: Vereniging Bartiméus.

Janssen, M.J., Riksen-Walraven, J.M., Van Dijk, J.P.M. (2002). Enhancing the quality of interaction between deafblind children and their educators *Journal of Developmental and Physical Disabilities, 14* , 87-109.

Janssen, M.J., Riksen-Walraven, J.M., Van Dijk, J.P.M. (2003a). Toward a diagnostic intervention model for fostering harmonious interactions between deaf-blind children and their educators. *Journal of Visual Impairment and Blindness, 97* , 197-214.

Janssen, M.J., Riksen-Walraven, J.M., Van Dijk, J.P.M. (2003b). Contact: Effects of an intervention program to foster harmonious interactions between deaf-blind children and their educators *Journal of Visual Impairment and Blindness, 97* 215-229.

Janssen, M.J., Riksen-Walraven, J.M., Van Dijk, J.P.M. (2004). Enhancing the interactive competence of deafblind children: Do intervention effects endure? *Journal of Developmental and Physical Disabilities, 16* , 73-94.

Janssen, M.J., Riksen-Walraven, J.M., Van Dijk, J.P.M. (2006). Applying the diagnostic intervention model for fostering harmonious interactions between deaf-blind children and their educators: A case study. *Journal of Visual Impairment and Blindness, 100),* 91-105.

Janssen, M.J., Riksen-Walraven, J.M., Van Dijk, J.P.M., Ruijssenaars, W.A.J.J.M., Vlaskamp, C. (2007) Team interaction coaching with educators of adolescents who are deaf-blind: Applying the diagnostic intervention model. *Journal of Visual Impairment and Blindness, 101*, 677-689

Janssen, M. & Rødbroe, I. (2007) Contact and Social Interaction. Communication and Congenital Deafblindness. Handbook 2. Sint-Michielsgestel: VCDB/Viataal.

Jones, C. J. (1988). Evaluation and educational programming of deafblind/severely multihandicapped students, sensorimotor stage. Springfield, IL: Charles C. Thomas.

Jure, R., Rapin, I., & Tuchman, R. F. (1991). Hearing impaired autistic children. Developmental Medicine and Child Neurology, 33(12), 1062-1072.

Hoevenaars-van den Boom, M.A.A., Antonissen, A.C.F.M., Knoors, H., & Vervloed, M.P.J. (2009). Differentiating Characteristics of Deafblindness and Autism in People with Congenital Deafblindness and Profound Intellectual Disability. *Journal of Intellectual Disability Research, 53,* 6, 548-558.

Holden-Pitt, L. & Diaz, J. (1998). Thirty years of the Annual Survey of Deaf and Hard of Hearing Children & Youth: a glance over the decades. *American Annals of the Deaf,* 143(2), 72-76.

Holt, R.F. & Kirk, K.I. (2004). Speech and language development in cognitively delayed children with cochlear implants. *Ear & Hearing, 26, 2*, 132-148.

Kahn, J. V. (1996). Cognitive skills and sign language knowledge of children with severe and profoundly mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 31,* 162-168.

Karchmer, M.A. (1985). A demographic perspective. In E. Cherow (Ed.), *Hearing-impaired children and youth with developmental disabilities* (pp. 36-58). Washington, DC: Gallaudet College Press.

Klin, A. (1993). Auditory brainstem responses in autism: brainstem dysfunction or peripheral hearing loss? *Journal of Autism and Developmental Disorders,* 23(1), 15-31.

Luckasson, R. (1992). *Mental retardation: definition, classification and systems of supports*. Washington, DC: American Association on Mental Retardation.

Marschark, M. (1993). *Psychological development of deaf children.* Oxford: Oxford University Press.

Mauk, G. W., & Mauk, P. P. (1998). Considerations, conceptualisations, and challenges in the study of concomitant learning disabilities among children and adolescents who are deaf or hard of hearing. *Journal of Deaf Studies and Deaf Education,* 3(1), 15-34.

McCracken, W. (1998). Deaf children with disabilities. In S. Gregory, P. Knight, W. McCracken, S. Powers, & L. Watson (Eds.), *Issues in Deaf Education* (pp. 28-37). London: David Fulton.

MacFarland, S. Z. C. (1995). Teaching strategies of the van Dijk curricular approach. *Journal of Visual Impairment and Blindness, 89,* 222-228.

Miles, B. (1999). Talking the language of the hands. *DB-Link,* 1-11.

Mclnnes, J. M. (1999). Deafblindness: a unique disability. In J. M. Mclnnes (Ed.), *A guide to planning and support for individuals who are deafblind* (pp. 3-33). Toronto: University of Toronto Press.

Mclnnes, J. M., & Treffry, J. A. (1982). *Deafblind infants and children, a developmental guide.* Toronto: University of Toronto Press.

Merzenich, M. M., Jenkins, W. M., Johnston, P., Schreiner, C., Miller, S. L., & Tallal, P. (1996). Temporal processing deficits of language-learning impaired children ameliorated by training, *Science, 271,* 77-80.

Morgan, A., & Vernon, M. (1994). A guide to the diagnosis of learning disabilities in deaf and hard or hearing children and adults. *American Annals of the Deaf,* 139(3), 358-370.

Munroe, S. (2001). *Developing a National Volunteer Registry of Persons with Deafblindness in Canada: Results from the study,* 1999-2001. Brantford, Canada: The Canadian Deafblind and Rubella Association.

Nafstad, A. (1989). *Space of interaction.* Dronninglund, Denmark: Nordic Staff Training Centre for Deafblind Services.

Nafstad, A., & Rodbroe, I. (1999). *Co-creating communication.* Dronninglund, Denmark: Forlaget Nord-Press.

Nakken, H. (1993). Meervoudig gehandicapten, een kwestie van definitie [Multiple handicapped, a matter of definition]. In H. Nakken (Ed.), *Meervoudig gehandicapten* (pp. 13-33). Rotterdam: Lemniscaat.

Nikolopoulos, T.P., Archbold, S.M., Wever, C.C. & Lloyd, H. (2008). Speech production in deaf implanted children with additional disabilities and comparison with age-equivalent

implanted children without such disorders. International journal of pediatric otorhinolaryngology 72, 12,1823-8.

NTAC Teaching Research Division (2001). *National deafblind count.* Monmouth, OR: Western Oregon University.

Reed, C. M., Delhome, L. A., Durlach, N.I., & Fisher, S.D. (1995). A study of the tactual reception of sign language. *Journal of Speech and Hearing Research, 38,* 477-489.

Rødbroe, I., & Souriau, J. (1999). Communication. In J. M. Mclnnes (Ed.), *A guide to planning and support for individuals who are deafblind* (pp. 119-149). Toronto: University of Toronto Press.

Rönnberg, J., & Borg E. (2001). A review and evaluation of research on the deafblind from perceptual, communicative, social and rehabilitative perspectives. *Scandinavian Audiology, 30,* 67-77.

Rosenhall, U., Nordin, V., Sandström, M., Ahlsén, G., & Gillberg, C. (1999). Autism and hearing loss. *Journal of Autism and Developmental Disorders,* 29(5), 349-357.

Roth, V. (1991). Students with learning disabilities and hearing impairment: issues for the secondary and postsecondary teacher. *Journal of Learning Disabilities,* 24(7), 391-397.

Rutter, M. (1978). Diagnosis and definition of childhood autism. *Journal of Autism and Developmental Disorders, 8,* 139-161.

Samar, V.J., Paranis, I., & Berent, G.P. (1998). Learning disabilities, attention deficit disorders, and deafness. In M. Marschark & M.D. Clark (Eds.) *Psychological perspectives on deafness* (Vol. 2, pp. 199-242). Mahwah, NJ: Lawrence Erlbaum Associates.

Souriau, J., Rodbroe, I., & Janssen, M (2008). *Meaning Making. Communication and Congenital Deafblindness.* Handbook 3. Sint-Michielsgestel: VCDB/Viataal.

Souriau, J., Rodbroe, I., & Janssen, M (2009). *Transition to Cultural Language. Communication and Congenital Deafblindness.* Handbook 4. Sint-Michielsgestel: VCDB/Viataal.

Stewart, D.A., & Kluwin, T.N. (2001). *Teaching deaf and hard of hearing students. Content, strategies, and curriculum.* Boston: Allyn and Bacon.

Stillman, R. D., & Battle, C. W. (1986) Developmental assessment of communicative abilities in the deafblind. In D. Ellis (Ed.), *Sensory impairments in mentally handicapped people* (pp. 319-335). San Diego, CA: College-Hill Press.

Van Dijk, J. (1983): *Rubella handicapped children.* Lisse, Netherlands: Swets & Zeitlinger.

Van Dijk, J. (1986). An educational curriculum for deafblind multi-handicapped persons. In D. Ellis (Ed.), *Sensory impairments in mentally handicapped people* (pp. 374-382). San Diego, CA: College-Hill Press.

Van Dijk, J., & Janssen, M. (1993). Deafblind children. In H. Nakken (Ed.), Meervoudig gehandicapten (pp. 34-73). Rotterdam: Lemniscaat.

Van Dijk, J., & Nelson, C. (2001). Child guided strategies for assessing children who are deafblind or have multiple disabilities (CD ROM). Sint-Michielsgestel, the Netherlands: Instituut voor Doven & AapNootMuis Productions.

Van Dijk, J.P.M. & De Kort, A. (2005). Reducing challenging behaviors and fostering efficient learning of children with CHARGE syndrome. American Journal of Medical Genetics Part A, vol.133A, 3, 273-277.

Van Dijk, R., Van.Helvoort, M., Aan den Toorn, W., & Bos, H. (1998). Niet zomaar een gebaar. [Not just a sign]. Sint-Michielsgestel, the Netherlands: Publication Instituut voor Doven.

Van Dijk, R. Nelson, C., Postma, A., & Van Dijk, J.P.M. (in press). Deaf Children with Severe Multiple Disabilities: Etiologies, Intervention, and Assessment. In Marschark, M. & Spencer, P. E. (Eds.), *Oxford Handbook of Deaf Studies, Language, and Education, Volume 2*. New York: Oxford University Press

Vervloed, M.P.J., Hoevenaars-van den Boom, M.A.A., Knoors, H., Van Ravenswaaij, C. &, Admiraal, R.J.C. (2006). CHARGE Syndrome: Relations between Behavioural Characteristics and Medical Conditions. *American Journal of Medical Genetics, part A*, 140A, 851-862.

Vervloed, M.P.J., van Dijk, R.J.M., Knoors, H., & van Dijk, J.P.M. (2006). Interaction between the teacher and the congenitally deafblind child. *American Annals of the Deaf, 151*, 3, 336-344.

Walker, M. (1977). Teaching sign language to deaf mentally handicapped adults. In *Institute of Mental Subnormality Conference Proceedings* (vol. 3, pp. 3-25). Kidderminster, UK: British Institute of Mental Handicap.

Walsh, S. R., & Holzberg, R. (1981). *Understanding and educating the deafblind/severely and profoundly handicapped, an international perspective*. Springfield, IL: Charles C. Thomas.

Watters, C., Owen, M., & Munroe, S. (2004). A Study of Deaf-Blind Demographics and Services in Canada. North York, ON: Canadian National Society of the Deaf-Blind

Wheeler, L., & Griffin, H. C. (1997). A movement based approach to language development in children who are deafblind. *American Annals of the Deaf,* 142(5), 387-390.

Widen, J. E., Folsom, R. C., Thompson, G., & Wilson, W. R. (1987). Auditory brainstem responses in young adults with Down syndrome. *American Journal of Mental Deficiency,* 91(5), 472-479.

Writer, J. (1987). A movement-based approach to the education of students who are sensory impaired/ multihandicapped. In L. Goetz, D. Guess, & K. Stremel-Campbell (Eds.), *Innovative program design for individuals with dual sensory impairments* (pp. 191-224). Baltimore, MD: Paul H. Brookes.

Zwiercki, R. D., Stansberry, D. A., Porter, G. G., & Hayes, P. (1976). The incidence of neurological problems in a deaf school age population. *American Annals of the Deaf, 121,* 405-408.