Children With Cochlear Implants and Complex Needs: A Review of Outcome Research and Psychological Practice

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In recent years, the number of children receiving cochlear implants who have significant disabilities in addition to their deafness has increased substantially. However, in comparison with the extensive literature on speech, language, and communication outcomes following pediatric implantation in children without complex needs, the available literature for this special group of children is relatively sparse. This article reviews the available research on outcomes, grouping studies according to the nature of the additional disabilities and specific etiologies of deafness. The methodological problems relating to outcome research in this field are outlined, followed by some tentative conclusions drawn from the literature base while bearing these problems in mind. The remainder of the article focuses on the challenges for clinical practice, from a psychological perspective, of implanting deaf children with complex needs. Two groups of children are considered, those whose additional disabilities have been identified prior to implantation and those whose difficulties become apparent at some point afterward, sometimes many years later. A case example describing the psychological assessment of a deaf-blind child being considered for implantation is presented.

This article will focus on a special group of children with cochlear implants: those who have difficulties or disabilities in addition to their deafness which make the task of meeting their complex needs particularly challenging. A figure of 30%–40% of deaf children is consistently quoted as being the proportion with additional disabilities, although definitions of what constitutes an additional disability do vary. Gallaudet University (Gentile & McCarthy, 1973) defines them as “any physical, mental, emotional or behavioral disorder that significantly adds to the complexity of educating a hearing-impaired child”. The World Health Organization (1980) also provides a useful conceptualization in this context, proposing three levels: (a) impairment—any loss or abnormality of psychological or anatomical structure, (b) disability—the restriction or lack of ability to perform an activity considered normal for a human being, and (c) handicap—the disadvantages for an individual resulting from an impairment or disability that limits or prevents fulfillment of a role normal for that individual. Some deaf individuals would argue that deafness by itself is not an impairment and therefore does not result in either disability or handicap, as defined by the WHO. However, it is less contentious to consider many of the additional difficulties or impairments sometimes associated or coexisting with hearing impairment, as causing both disability and handicap. Such impairments include cognitive or learning difficulties, global developmental delay, visual impairment, language and communication disorders (autistic spectrum disorders [ASDs]), and other medical, physical, or motor problems. In addition, some deaf children may exhibit difficulties that are more psychological in nature, for example, behavioral or emotional disorders, which equally may prevent normal development and functioning. However, cognitive ability is a continuum, and all the other types of impairments mentioned above range in severity, so...
it is not always clear-cut when a deaf child should be considered to have “complex needs.”

In the early years of pediatric cochlear implantation, it was typical for children with known, significant additional disabilities to be considered unsuitable for the procedure. However, the criteria for candidacy have broadened in many respects in recent years, such that children with multiple handicaps and complex needs are now assessed, and many go on to receive implants. The aims of this paper are to review the literature on outcomes following cochlear implantation in children with complex needs and then to consider the challenges facing pediatric cochlear implant teams when working with this group of children, from psychological perspectives in particular.

Review of Outcome Research

There is now a very considerable body of evidence regarding the outcomes of cochlear implantation for deaf children in terms of speech perception, speech intelligibility, and communication and language development. To a much lesser degree, but slowly increasing, are studies reporting on the educational, psychological, and social consequences of implantation for the child and family (for a comprehensive review of studies published between 1994 and 2001, see Thoutenhoofd et al., 2005). However, the majority of these studies are of little relevance to those seeking information on the benefits (or otherwise) of cochlear implants for deaf children with complex needs. The reason for this is twofold. Firstly, as mentioned previously, children with additional difficulties were typically precluded from receiving an implant in the early years of the use of implants, and therefore historical data from such cases do not exist. Secondly, in more recent years, although many such children have been implanted, the vast majority of published empirical studies specifically exclude them from their samples, in order to try and make their groups as homogeneous as possible. As a result, there are only a very small number of papers that specifically focus on outcomes in children with additional disabilities.

Cognitive/Learning Disabilities

In one of the earliest papers to be published on this topic, Pyman, Blamey, Lacy, Clark, and Dowell (2000) examined speech perception outcomes in 75 children aged up to 5 years, comparing the results of children with and without cognitive and/or motor delays. They found that the former group was significantly slower in developing speech perception skills following implantation. Interestingly, there was no significant association between outcome and the etiology of deafness per se. Thus, they speculate that the wide variety of outcomes among children with the same syndrome or etiology of deafness are individual variations in the functioning of higher centers of the brain.

Fukuda et al. (2003) provided a case study on a 10-year-old congenitally deaf child described as having moderate mental retardation, who received a cochlear implant at 4 years of age. Before implantation, his language development was delayed by 34 months in comparison with his chronological age. This gap had narrowed to a 23-month delay, 2 years after surgery, but the extent of his cognitive delay remained unchanged at around 15 months delay. The child was able to use intelligible three-word sentences within 2 years of implantation. They recommended that multiply handicapped children be considered for cochlear implantation under certain preoperative conditions, including that the child responds to signed communication and produces at least two-word sentences (in sign).

Recently, Holt and Kirk (2005) reported the results of a retrospective study examining the speech and language outcomes of children with cochlear implants who have a cognitive delay, defined as scoring more than one standard deviation below the mean on tests of cognitive function and/or identified as developmentally delayed by a psychologist. Children with any additional disabilities other than cognitive delay were excluded. They compared 19 children with cognitive delays (average estimate of cognitive functioning in the borderline to mildly impaired range) with 50 children with no additional disabilities, up to 2 years after implantation. Both groups demonstrated significant improvements in speech and language skills over time, but the children with cognitive delays had significantly lower scores on two of the three measures of receptive and expressive language and slower rates of auditory sentence recognition development compared with their normally developing implanted peers. Children with cognitive delays made relatively good progress in
developing speech perception skills but struggled with the tasks involving higher level language skills such as sentence recognition and receptive and expressive language. They concluded that cochlear implantation in children with a mild cognitive delay does produce sufficient benefit to make it an appropriate intervention for this group, but also question how benefit should be defined, and highlight the need for appropriate assessment measures for children with additional disabilities.

Although these three studies (and others on implanted children without complex needs, e.g., Moog & Geers, 2003) do suggest a strong association between cognitive ability and outcomes, as yet it is not possible to confidently define the level of ability below which a cochlear implant may be considered nonbeneficial.

Global Developmental Delay

Generalized developmental delay frequently also entails some degree of cognitive or learning delay, but in young children, particularly those with limited language skills, it is difficult to accurately determine the level of cognitive functioning using traditional standardized assessments. Consequently, a global index of development is a more suitable measure of additional difficulties in young implant candidates. To date, one published study has explicitly examined outcomes following cochlear implantation in relation to developmental status before implant. Edwards, Frost, and Witham (2006) found that children implanted before the age of 3.5 years who had a mild developmental delay did make gains in speech perception skills and in speech intelligibility over a 2-year period, but at a slower rate than their normally developing implanted peers. However, a small group of children whose general development was significantly delayed (by around 12 months or more) made almost no progress in terms of speech perception or speech intelligibility.

Visual Impairment

Saeed, Ramsden, and Axon (1998) described the progress of two visually impaired children who received cochlear implants, one of whom was congenitally deaf–blind due to rubella infection. The authors described modest gains in identification of speech sounds and the ability to follow simple auditory instructions 2–3 years after implantation. El-Kashlan, Boerst, and Telian (2001) also reported positive results in two pediatric cases where deafness was accompanied by significant visual impairment. The first child, who had Usher’s Syndrome Type 1, was implanted at 3.5 years and started losing her sight at 7 years of age. She developed excellent open-set speech recognition skills and attended a mainstream school. The second child, a little boy with multiple medical problems and delayed general development, had only had his implant for 6 months at the time the authors made the report, so gains were minimal at that time.

Autistic Spectrum Disorders

ASDs remain one category of additional difficulties where great caution is exercised by cochlear implant teams when considering a child for an implant. Hearing children with autism generally have major difficulties communicating effectively and in developing spoken language skills and may have sensory integration difficulties. It is therefore not surprising that deaf autistic children are not usually considered good candidates for cochlear implantation. Thus, in the past, a confirmed diagnosis of autistic spectrum disorder has typically been given as a contraindication to implantation. However, with the steady decrease in age at which children are being assessed and implanted, the number of children in whom autism is only diagnosed after they have received an implant is slowly increasing. Also, as the term ASD implies, there is a range of level of disabilities in autistic children, with some relatively minor social communication difficulties and little or no general cognitive impairment, through to severe language, cognitive, and behavioral difficulties. Therefore, careful assessment of the extent of impact of ASD in each individual case is essential in deciding whether a cochlear implant may be an appropriate intervention. Having said all this, at present there is only one paper that specifically reviews the progress of children with ASD who have cochlear implants. Donaldson, Heavner, and Zwolan (2004) described the progress of seven children, aged between 3 and 9 years at implantation, who had been using their implants for between 6 months and 5 years. Four children were diagnosed with...
autism and two with pervasive developmental disorder, with a range of severity of presentations and disabilities. Many of the children were unable to complete some of the standard speech and language measures due to their developmental level. However, where data were available, they indicated modest gains, but these were small compared with a normal implant population. In addition, these authors used a survey to explore parents’ perceptions of the impact of the implant on their child’s functioning. This revealed benefits in terms of improved eye contact, awareness of the environment, reaction to music, vocalization, use of sign language, and response to requests. Overall, most families said they would recommend an implant to other families in a similar situation. The authors stress the importance of counseling parents about the potential benefits of an implant, emphasizing that the implant is likely to have little or no impact on the diagnosis of ASD and that oral communication is unlikely to be a realistic goal.

Two other studies have included children diagnosed with ASD in their sample. However, because these studies did not focus specifically on these children, they will be described in the next section.

Mixed Additional Disabilities

In one of the largest studies of implanted children with multiple handicaps, Waltzman, Scalchunes, and Cohen (2000) documented the progress of 29 children with disabilities ranging from attention-deficit disorder, dyspraxia, or central auditory processing disorder to autism, learning disability, or cerebral palsy. Many of the children were unable to perform the standardized tests either preoperatively or at many of the time intervals after implant. However, some children did gradually become able to attempt the tests and go on to slowly develop the ability to perceive phonemes, words, and sentences using audition alone. Just over half of the children used oral communication, rather than total communication or sign. They concluded that “multiply handicapped children obtain demonstrable benefit from cochlear implantation,” but the rate of development of auditory perceptual skills is slower than for other deaf children with implants. Although these results are encouraging, unfortunately they tell us little about whether the children have been able to use their improved perceptual abilities to also develop their communication and language skills.

In a smaller study of 10 multiply handicapped children, Hamzavi et al. (2000) used the Evaluation of Auditory Responses to Speech (EARS) battery to assess progress following implantation. Again a range of disabilities are represented, including severe learning difficulties, blindness, hyperactivity, psychomotor retardation, and autism. Similarly they report a wide range of outcomes, from no speech recognition or production through differentiating voices and using some vocalizations to communicate, through to the ability to use simple sentences. These authors also concluded that multiply handicapped children (and their parents) do benefit from cochlear implantation despite not being considered traditionally “good” candidates.

Vlahovic and Sindija (2004) described an even smaller sample, of four children with additional disabilities including communication disorder, moderate psychomotor retardation, and attention-deficit hyperactivity disorder, following implantation. They used the Categories of Auditory Performance and Speech Intelligibility Rating scales, the Listening Progress Profile, and part of the EARS test to monitor progress. They reported better than anticipated perception skills but less satisfactory speech development (speech was mainly unintelligible).

Filipo, Bosco, Mancini, and Ballantyne (2004) assessed outcome from a different perspective in their study that included 18 deaf children with additional disabilities or associated problems (bilingualism or family problems in 10 of the cases). They focused on psychosocial as well as audiological and/or communication outcomes, examining the child’s self-help skills along with social and family relationships using a mixture of observation, questionnaires, analysis of drawings, and structured interviews. They reported gains in listening, communication, and self-sufficiency while family and social relationships remained stable and concluded that in such special cases cochlear implantation is a positive intervention.

Finally, Wiley, Jahnke, Meinzen-Derr, and Choo (2005) also moved away from the usual methodology for assessing outcome of pediatric cochlear implantation, to examine the qualitative benefits for children with additional disabilities using a mixture of
open- and closed-ended questions that were then coded by themes. Fifteen families were recruited whose child had had at least 6 months of cochlear implant use with additional disabilities including visual impairment, mild motor disabilities, cognitive disabilities (nonverbal IQ of 75 or lower), specific learning disability, and language or behavioral disorders. Some of the disabilities were diagnosed after implantation. All the families felt that their child had made progress in developing communication skills and was more attentive and interested in the world around them, and all parents were happy with their decision to have their child implanted. However, the authors recognized that the qualitative methodology used may have led to bias in reporting of skills and inconsistencies in interpreting communication behaviors.

Specific Syndromes/Etiologies of Deafness

In contrast to the studies described above where samples have been heterogeneous in terms of the etiology of deafness and additional disabilities, in this section the papers to be considered have focused on groups of children with the same cause of deafness. Two studies have reported on the outcomes following cochlear implantation in children with CHARGE association. Bauer, Wippold, Goldin, and Lusk (2002) described variable degrees of objective benefit from the procedure for five children. In a single case study report, Au, Hui, Tsang, and Wei (2004) described the progress of a boy with CHARGE association who received a cochlear implant at the age of 2.5 years. At 7 years of age, after “intensive rehabilitative training,” his receptive and expressive language age equivalents were 2.05 and 2.04 years, respectively. Speech perception performance did improve, although even at 4 years after implant he was unable to correctly identify the Ling sounds, number of syllables, vowels, or consonants with 100% accuracy.

Both Lee, Lustig, Sampson, Chinnici, and Niparko (2005) and Ramirez Inscoe and Nikolopoulos (2004) noted that children whose cause of deafness is human cytomegalovirus (CMV) contracted perinatally are at risk of experiencing developmental neurological deficits, including learning difficulties. Ramirez Inscoe and Nikolopoulos compared 16 children deafened by CMV with 131 children with all other etiologies and found a wide range of speech perception and speech intelligibility outcomes, which were, on average, poorer in the former group. Lee et al. (2005) also found improvements in speech perception in 13 children with CMV-related deafness and describe these as being within the range established by their overall pediatric implant population.

The last group of children to be considered here is that of children with hearing impairment secondary to meningitis. In some ways, they constitute a very different group from the others as these children will have experienced sound prior to the meningitis and, depending on their age, may have well-developed oral language skills. However, as a result of the infection, this group is at high risk of having additional difficulties, particularly in the cognitive domain. Isaacson, Hasenstab, Wohl, and Williams (1996) reported that of the 10 pediatric cochlear implant patients in their sample, five had documented learning disability. This group showed slower progress in developing auditory perception and receptive language skills, as well as sequential organization abilities, and lower overall test scores, compared with postmeningitic children with no learning difficulties. More recently, Francis et al. (2004) compared 30 postmeningitic children with children deafened by other causes, matched for age at diagnosis, age at implantation, age of first hearing aid use, and method of communication at home or school. Cognitive abilities were assessed before implant, and speech perception skills were measured within the first 2 years following implantation. They found no difference between the groups on overall cognitive or speech perception performance, but the authors did note that where there had been postmeningitic hydrocephalus, the gains in speech perception were significantly smaller.

Comment

Given the small number of studies available, the typically small numbers of cases in those studies and the wide variety of types and severity of additional disabilities, drawing conclusions about the outcome of cochlear implantation in children with additional disabilities is a challenge. The confounding variables are particularly difficult to account for when considering
specific etiological groups, when the number of cases becomes even smaller, or when single cases are reported. Also, even in these defined groups, the range and severity of additional disabilities may be great. Thus, the generalizability of the findings is probably low. Methodologically, the studies are also heterogeneous. Those that follow a specific group longitudinally provide interesting information about the development of certain skills, usually in the first few years following implantation. Most of these focus primarily on speech perception skills or speech intelligibility, which, although important, do not tell us much about the children’s communication skills in the “real world” or their language abilities. Is the progress of these children meaningful, or simply measurable? Studies that have employed a comparative design give a clearer indication of the gains made by the children with complex needs relative to the general pediatric implant population. However, these are few and far between.

More generally in terms of methodology and evidence-based practice, pediatric cochlear implantation is not a procedure that lends itself to conducting randomized, controlled, double-blind trials for a variety of ethical and practical reasons. Cohort studies, with or without an appropriate control group, are rarely large enough to allow sufficient power for the results to be interpreted confidently.

To date, there are no published studies (let alone ones which are methodologically robust) that specifically explore the progress of children whose additional difficulties have only been identified after they received their cochlear implant. Such children would include those who were implanted at a very young age or have autistic spectrum disorders or other communication or language disorders that could not be diagnosed before implantation. Other groups could include those diagnosed with dyslexia or dyspraxia, which often occurs many years after receiving their implant. In terms of outcome research, there is a danger of becoming tautological here as the lack of progress in developing language and literacy skills is often the trigger for these children being assessed and diagnosed, and therefore, by definition they will show poorer outcomes compared with the general cochlear implant population. Research by David Pisoni and his colleagues since the late 1990s has sought to identify what factors distinguish “star” implant performers from those who struggle to develop oral language skills, focusing on cognitive functions such as working memory. This is a particularly promising area of research, which has the potential to both increase our understanding of how children learn to decipher the electrical stimulation provided by a cochlear implant and also to devise remedial activities for those children who are having difficulty making sense of the auditory input.

Despite the methodological issues, a few tentative conclusions may be drawn and a number of important themes have arisen from the work described above. Overall it appears that where there is a cognitive or global developmental delay, when this is mild, the children can make measurable progress, and outcomes may be within the same range as those of the pediatric implant population overall. However, where there are significant learning disabilities or a severe global developmental delay, outcomes are much less favorable; although children may develop some speech perception skills, there is less evidence that they progress to using this information to improve their oral communication and language skills. It also appears that it is probably the severity of any cognitive deficits that is predictive of outcome rather than etiological factors per se.

Almost all the authors emphasize the importance of a comprehensive, multidisciplinary preimplant assessment and the need to consider the appropriateness of cochlear implantation for each child on a case-by-case basis. Many authors also stress the need to broaden the nature of outcome measures to include indices of subjective benefits such as improved quality of life and family relationships. Finally, preimplant counseling for the parents of pediatric implant candidates regarding likely benefit and outcomes is strongly advised for children with additional disabilities by many authors. However, it has to be acknowledged to parents that although there are some factors that are known to be associated with better outcomes, it is not possible to precisely predict the degree of benefit based on the empirical evidence available to date.

Challenges for Clinical Practice

The following sections will consider the practical implications and challenges of implanting children with
additional disabilities, particularly from a psychological perspective.

Children Whose Additional Disabilities Are Identified Before Implant

There are two main groups of children who come under this category—those whose complex needs have been well documented in their medical histories prior to being referred for cochlear implant assessment and those whose additional difficulties are identified as part of the cochlear implant assessment process. This latter group is not as rare as one might expect as many difficulties may be relatively subtle in nature, particularly in young children, yet potentially have a profound negative impact on the benefit to be gained from a cochlear implant. For example, emerging autistic spectrum disorder, language disorders, or attention-deficit/hyperactivity disorder may only be formally recognized when the child is undergoing the multidisciplinary assessment of hearing, speech and language skills, cognitive abilities, behavior, and general development. Up until that point, it may be that the child has not been put in a situation where such difficulties are likely to be apparent, and subtle additional difficulties are frequently attributed to the child’s deafness and lack of understanding of communication and language, rather than being considered additional difficulties in their own right. In many children, the etiology of deafness is known and additional disabilities are common, as for example in CHARGE association, CMV infection, significant prematurity, rubella, meningitis, and toxoplasmosis infection. However, the range and severity of the disabilities are wide, and the assessment for cochlear implantation can be useful in identifying and describing these difficulties more fully. In particular, the psychological assessment may clarify the extent of any general developmental delay or identify specific cognitive deficits that have implications for rehabilitation, outcome with the implant, and development generally.

Thus, one of the major challenges for the psychologist on the implant team is to tailor their assessment to the specific presentation and needs of the child. For the majority of pediatric implant candidates, it is possible to follow an assessment protocol, which is likely to be broadly similar between implant programs. The areas typically explored would include the child’s general development, nonverbal cognitive abilities (if old enough to complete a standardized test), emotional and behavioral factors, learning style, communicative intent, social skills, play skills, and family expectations and support. In older children, the assessment would also explore issues around academic achievement, peer relationships, and self-concept. A central part of the protocol is the assessment of nonverbal cognitive abilities using standardized measures appropriate for hearing-impaired children, such as the Leiter International Performance Scale-Revised (Roid & Miller, 1997) or the Snijders-Oomen Non Verbal Test Revised (Snijders, Tellegen, & Laros, 1989). For very young children, that is, those under 2 years of age, a developmental test such as the Griffiths Scales of Mental Development (Griffiths, 1984) or the Schedule of Growing Skills II (Bellman, Lingham, & Aukett 1996) may be used to assess functioning in domains not related to hearing, speech, or language (as these will be covered in depth by the implant team Speech and Language Therapist). The main problem with all these tests when considering a child with complex needs is their reliance on adequate vision and fine motor skills for their completion. Although the manual for the Leiter R states that it is acceptable for the testee to respond using eye pointing if necessary, in practice this is an extremely difficult response to interpret reliably and is a method of communication encountered only very rarely. Therefore, gaining an accurate impression of the child’s cognitive abilities and learning capacity may not be possible, in those very children where this information may be central to deciding whether a cochlear implant is an appropriate intervention. Although it is important to identify significant learning difficulties where they do exist, it is equally, if not more, important to demonstrate the child’s normal cognitive capacity where this may be obscured by overwhelming physical difficulties, as in severe cerebral palsy.

As a result of the problems administering standardized tests, it becomes necessary for the psychologist to think creatively about how to assess the child’s learning capacity. One way to do this, which has proved useful on a number of occasions in the author’s experience, is to devise one or more learning “tasks” for the child to

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tackle during the assessment period. The task should be set at an appropriate level of difficulty such that it is just beyond the child’s current level of achievement, based on careful observation of the child’s current skills and information from parents and other professionals involved, along with clinical judgment. Many young deaf children with additional disabilities have not been explicitly taught early skills such as matching (color, shape) or sorting (by size, color, shape), often as a result of emphasis on self-help or daily living skills. Parents typically require explicit instructions on how to teach their child these sorts of cognitive skills, including what materials to use, how to get their child to indicate choices, and how to monitor progress. At another level of cognitive functioning, it is very informative to focus on the child’s development of symbolic understanding. Parents may be asked to keep a note of any example of when their child has indicated that he/she realizes that a picture of an object represents a real thing (e.g., the child may be looking at a picture of a cat in a book and then points to the family pet cat). If the parents are unable to identify any example of symbolic understanding from the child’s everyday behaviors, it may be necessary for the psychologist to devise an appropriate task or activity to see if the child is able to develop this skill. At a more sophisticated level, it is very helpful to be able to show that the child is able to learn that signs such as those used in BSL are symbols representing real objects, even if the signs have to be adapted in some way to accommodate the child’s visual or motor disabilities. If this level of learning and understanding can be reliably demonstrated, it might indicate that the child has the learning capacity to associate spoken symbols (i.e., words) with real objects, thus beginning the development of oral language. However, it must be noted that this is a risky assumption to make, and a large number of other factors will determine whether the child is able to learn to interpret the auditory input provided by a cochlear implant. This is an area that clearly requires further study.

Case Example: A Congenitally Deaf–Blind Child

Michael, a 4-year-old child congenitally deaf and blind as a result of severe prematurity, was assessed for the possibility of cochlear implantation. He attended sessions over a 6-month period, during which time he was seen by a consistent set of implant team members, and established testing/session routines with the various professionals involved. The aims of the psychological assessment were as follows:

- To gain an impression of the child’s learning capacity and learning style
- To assess his/her ability to adapt to novel situations
- To assess the relationship between his/her behavior and learning capacity/style
- To gain an impression of the child’s motivation to learn and explore
- To attempt to establish whether there are learning difficulties over and above those to be expected given the level of dual sensory deprivation

To this end, Michael’s interactions with his parents, implant team members, and educational staff were observed in the clinic, home, and educational settings. Appropriate sections of the Reynell-Zinkin Scales for Young Visually Handicapped Children were administered (social adaptation, sensorimotor understanding, and exploration of environment; Reynell, 1979), bearing in mind that these were not developed or standardized on children with a hearing as well as visual impairment. Although it was not possible to give any instructions to Michael, it was possible to encourage him to explore and manipulate the test materials (primarily everyday objects) and demonstrate through touch what was required of him. Results of the psychological assessment indicated that Michael is a highly enthusiastic explorer of his environment (gaining great satisfaction and enjoyment from dismantling objects and then trying to reassemble them), he shows a high level of communicative intent and symbolic representation through the use of both home-made and official signs and joint attention, he has the ability to persevere with an activity until he has achieved his goal, and he has the ability to transfer learning from one setting and session to another. On this basis, it was felt that there was sufficient positive evidence of learning capacity to recommend cochlear implantation for Michael, from psychological perspectives. Michael received an implant around a year ago and has developed an oral expressive vocabulary of around 25 words and is
beginning to join two words together. He understands many more spoken words and is also further developing receptive and expressive vocabulary in sign.

Although the assessment of deaf children with complex needs is a major challenge, it is not the only one to be faced before implantation. Parents who are considering a cochlear implant for their child naturally want to know what degree of benefit their child will receive and the potential risks. For many parents with multiply handicapped children, whose medical problems may put them at greater than normal risk under anesthesia, any potential benefit has to be weighed against the risks. However, as the research literature described above indicates, advising parents on likely outcomes in children with additional disabilities is a very inexact science at this point in time. Communicating the highly complex, often technical information needed to allow parents to make a fully informed decision is a skill that all team members need to acquire. Parents may need help arriving at realistic expectations for their child’s potential progress with a cochlear implant. Some parents also need help coming to terms with findings of the assessment, where the extent of the child’s difficulties may not have been fully realized previously.

Children Whose Additional Disabilities Are Identified After Implant

A wide variety of disabilities or complex needs can be included in this group: social communication-autistic spectrum disorders, language disorders, auditory processing disorder, dyslexia, dyspraxia, progressive visual impairment, and behavioral or emotional problems. Some difficulties may have been present all along but masked by the deafness (e.g., language disorder or dyslexia), and others (e.g., behavioral or emotional problems) may arise as a result of a variety of factors, related to deafness or coincidental to it. The majority of children who fall into the first category are identified after a period of implant use, often of many years, who are failing to make the progress expected in developing oral and later written language skills, given their age at implant, cause of deafness, nonverbal cognitive abilities, and rehabilitation input. Unfortunately, this group is a very difficult one to identify early, but the problem is often compounded by a “wait and see” attitude by some professionals. Although some children do initially make slow progress, only to “take off” and make rapid progress after a period of time, others seem to remain stuck at the earliest stages of language development or simply make inordinately slow progress. Thus, one of the major challenges for implant programs is to identify these children as early as possible, a process which can now be operationalized using a system of “clinical red flags,” raised when a child has not achieved certain benchmarks for average auditory progress at intervals during the first year after implant (Robbins, 2005). The benchmarks were established independently for three groups of children depending on age at implant, residual hearing, communication mode, and hearing aid use prior to implant, based on research findings and clinical experience.

However, having identified that a child is not making the anticipated progress, the next challenge is to identify the reason for this. Although a specific learning disability, communication disorder, or other diagnosable difficulty may play a significant role, other factors must also be taken into consideration. These include family and social issues and educational and rehabilitation input (e.g., speech and language therapy). Where an additional disability is likely, assessment of its nature should be multidisciplinary. In most cases, it is advisable that a psychological assessment is part of the protocol. One of the first steps is always to assess the child’s nonverbal cognitive abilities, in order to rule out generalized learning difficulties as a potential cause of the child’s problems developing language skills. Having done this, there is a wide range of possible assessment tools available to explore and define the nature of the child’s difficulties, the choice of which depends on the presenting difficulties, the age of the child, and pragmatically, whether the child has the language skills necessary to undertake the test in the first place. It must also be remembered that commonly used psychometric tests are not standardized on hearing-impaired children, and only occasionally does the manual include data on a small number of deaf children for comparison. Therefore, such tests must be administered by a psychologist who is experienced in working with deaf children, and even then the results should be interpreted with great caution.
Diagnosis of an additional disability should not be made solely on the basis of results from formal, structured psychometric assessments. Observation of the child in a variety of settings, questionnaires for parents and/or teachers, and semistructured interview schedules can be highly informative, particularly where the problems are, for example, behavioral or emotional, autistic spectrum disorders, or executive function disorder.

Having discovered an additional disability or difficulty, the next challenge may be overcoming family resistance to the diagnosis. Understandably, many parents feel a sense of shock, anger, or grief that their child has yet another hurdle to overcome in terms of reaching his/her potential, and in some cases additional difficulties are vehemently denied. More surprisingly, some professionals working with the child at a local level may also contest the diagnosis of an additional disability, perhaps due to fears that they will not have the skills needed to meet the child’s complex needs. It is clear that these children require highly specialized teaching and that at the present time there is often a lack of training or support for teachers and other professionals in this field, working with children who are deaf and have another significant disability. Consequently, the challenge is to raise awareness of the wide variety of presentations and types of difficulties children with cochlear implants may experience and of the need to diagnose and intervene as early as possible. Sometimes the diagnosis confirms the belief held by parents and/or teachers that the child is not placed in the most appropriate educational provision to meet his/her needs. It may be that their hearing impairment is no longer their primary impairment, and their needs could be better met in a school or setting for children with language disorders, social communication disorders, or moderate learning difficulties. This can be challenging both in terms of parental expectations and acceptance and in finding appropriate provision within the area in which the child lives.

Conclusions

The available published literature on outcomes following cochlear implantation in children with additional disabilities suggests that cognitive functioning is one of the strongest predictors of progress in developing speech perception and speech production skills. Unfortunately, this is also one of the most difficult areas to accurately assess before implant in those children with the most complex needs. However, as with diagnosing additional disabilities after implantation, it is not acceptable to avoid these issues simply because they are so challenging. It is only through clinical practice and experience, leading to audit and research, that a sufficiently large body of evidence may be accumulated in order to develop guidelines for best practice and provide parents (and where appropriate children) with the information they need to make an informed choice about cochlear implantation or the most effective interventions for children requiring additional support to achieve their potential. Currently, there is no research that compares the outcomes of children with complex needs using cochlear implants with children with similar disabilities but who use conventional hearing aids. It could be argued that for cochlear implantation to be appropriate in children with known additional disabilities, there should be demonstrable differences in outcome between these two groups.

At a broader, more philosophical level, we need to consider what the aims and objectives are when offering a cochlear implant to a child (and their family) who has multiple disabilities. At what level are we hoping for change—speech perception, communication, language, educational attainment, or employment? Alternatively are the priorities in psychological well-being, mental health, or quality of life? How do we define these concepts and operationalize the changes hoped for or realized after implantation? Finally, who should be the judge of whether the intervention was successful—cochlear implant professionals, parents, or the children themselves? These are all questions for future study.

References


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