Deaf-Blind Perspectives

Volume 12, Issue 3 Spring 2005

A Personal View of Changes in Deaf-Blind Population, Philosophy, and Needs

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During the past quarter century there have been significant changes in the population of children who are deaf-blind. At the same time there has been a steady increase in understanding and knowledge of effective educational strategies to help this group of children. As deaf-blind education specialists, we have experienced firsthand the influence of these changes on our work with children and their parents, teachers, and other service providers. In this article we relay some of our own experiences and offer our personal perspective on changes that have occurred in the field.

Changes in Population

In 1983, a national survey of the population of children with deaf-blindness in the UK suggested that Congenital Rubella Syndrome was declining as a leading cause of deaf-blindness, while the number of other identified etiologies was steadily increasing, as was the proportion of children with additional severe disabilities. The author of the survey made the point that, "If this apparent change in population is a long-term one then it has implications for the provision of placements, staffing and the development of appropriate teaching techniques and appropriate measures for assessment" (Best, 1983, p. 11).

Subsequent writers (Collins, Majors, & Riggio, 1991; Riggio, 1992; Brown, 1997; Chen, 1998; McInnes, 1999; Miles & Riggio, 1999) have confirmed that the change in population has, indeed, been long-term, and has gone further than could have been imagined 20 years ago. This is also supported by data from the 2003 National Deaf-Blind Child Count, which lists more than 70 possible causes of deaf-blindness and identifies characteristics that underscore the complexity of these children. Of the approximately 10,000 children on the census, 60% also have physical impairments, 68% have cognitive impairments, and 40% have complex health care needs (National Deaf-Blind Child Count Summary, 2004).

Explanation of these changes is complex, and there are many contributing factors (Brown, 1997). The availability of a rubella vaccine and associated public health campaigns drastically decreased the incidence of Congenital Rubella Syndrome. Advances in medicine have increased survival rates for infants with severe disabilities and for premature infants (approximately 10% of children on the national child count are deaf-blind as a result of complications of prematurity). There has also been a growing awareness of the prevalence of sensory impairments and sensory processing difficulties in the population of children with multiple and profound disabilities. Two decades ago, many of these children would probably have been perceived simply as having "severe brain damage" or "mental retardation" without any consideration of their sensory status.

In This Issue

As the needs of deaf-blind children have become more complex, educators, especially those working in an advisory capacity with young children, have had to familiarize themselves with an increasingly complex array of medical and therapeutic procedures and equipment. Of course, significant levels of complexity and learning difficulty, as well as a very wide range of ability, have been a feature of the population since the early days of deaf-blind education. Then and now, educators have been introducing teachers and parents to long-standing educational methods and techniques in the specialty of deaf-blindness, supporting children who are following academic curricula in regular classes, training staff and family members in techniques like tactile signing and adapted orientation and mobility, and helping vision specialists to adapt Braille instruction. They have also supported children who are functioning at the earliest stages of awareness and communicative ability. But now, these same educators are increasingly likely to be involved in cases where it may seem that their primary role is to help a family to implement an early educational program entirely within the confines of overwhelming medical, nursing, and therapy routines that fill up most of the child's day. These include the use of ventilators, suctioning, gastrostomy tube feedings, techniques for monitoring oxygen saturation, hormone treatments, a growing range of drug therapies, sensory integration therapy, physical therapy, and technological innovations like cochlear implants.

Many of the questions put to educators by parents as primary concerns these days are related to medical and therapy issues that are not (and have not traditionally been) within the area of competence and responsibility of teachers. Medical issues influence not only how we teach children but sometimes even what we teach. In order to help a child gain an understanding of his own environment and activities, early vocabulary that is part of a communication and language program might include ways to represent such things as "oxygen mask," "suction tube," and "G-tube button cleaning." In a small number of cases, a child's "natural environment" might be a special room built on to the family home, complete with everything to be found in a hospital room including round-the-clock nursing, with peers, and even siblings, excluded because of the risk of infection.

Accurate predictions of developmental progress are increasingly confounded by episodes of regression that result from recurrent illnesses and hospitalizations. It is often difficult to ascertain the exact cause of significant distress, loss of function, or behavioral problems in children with this level of complexity.

The increasing importance of medical issues has also been noted in older children and adults. As the population identified as having deaf-blindness back in the 1960s and 1970s has matured, a further change and challenge has been the discovery of late-onset health problems, fluctuations in sensory status, and resulting behavioral changes.

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Many of these developments appear to be neurologically determined, though there is still insufficient understanding of precise causes and appropriate remediation techniques. As a consequence of this ongoing process, our field has evolved very different, more complex, and comprehensive pictures of syndromes such as Congenital Rubella Syndrome and CHARGE Syndrome.

Changes in Educational Philosophy

During the past quarter century there have also been significant changes in educational philosophy, sometimes imposed by changes outside our narrow specialty and sometimes originating from our own experiences and research. Rodbroe and Souriau (1999) chronicle a major change in the emphasis of deaf-blind education, from the tight "behavioristic approach" of the 1960s, when children were taught primarily by having things done *to* them, to a strong focus beginning in the late 1980s on "reciprocal social togetherness," which encouraged following a child's lead and building positive relationships in order to foster the development of communication and other skills. Increasing awareness of the importance, for all children, of developing attachments and forming positive relationships has been accompanied by growing evidence of the negative impact of stress on early brain development. Jan van Dijk has been an outstanding advocate for the consideration of stress as an inherent feature in deaf-blindness (Nelson & van Dijk, 2001) and its extremely deleterious impact on the development of children who are deaf-blind. He has also advocated for the need to consider these children at a biobehavioral level if assessment and teaching is to be successful, a view shared by other recent writers (Blaha, 1996; Brown, 2001). As a result, we now place a much greater emphasis upon meticulous observation and upon individualization of assessment and teaching approaches than we did 25 years ago.

At the 13th Deafblind International World Conference on Deafblindness in 2003, Tony Best presented a view of this history from a different perspective. He described how ways of defining or thinking about deaf-blindness as a medical condition have changed over the years. According to Best (2003), in the early days of deaf-blind education, collaboration between educators and medical experts was based on a narrow medical model that focused primarily upon the combination of vision and hearing loss. In this context, educators often worked with pediatricians; ear, nose, and throat specialists; audiologists; and ophthalmologists. Later, there was a move away from this view of deaf-blindness as primarily a medical condition and toward a more social model—evident also within the broader field of disability—which was concerned with environmental adaptations and staff training needs. The emphasis shifted from the degree of vision and hearing loss of the children to their academic ability levels.

Because of changes in the population of deaf-blind children, and advances in the field of genetics and neurology, Best proposed that it was time, once again, to consider the influence of the medical aspects of conditions causing deaf-blindness on children's educational needs. He stated that, "the neurological involvement of the vast majority of deafblind people under the age of 10 makes it a medical condition as much as a sensory disability," and he proposed a "new medical model," that emphasizes collaboration between educators and specialists in genetics and neurology (Best, 2003, p. 1).

It would be fascinating to study to what extent the evolution of the various educational models described by Rodbroe and Souriau and by Best, occurred as a result of changes in the identified population, and to what extent the advent of the new models themselves have altered our perception of who exactly constitutes the population of "children with deaf-blindness." Since deaf-blindness is a spectrum disability, it seems inevitable that the field will continue to experience these periodic significant changes of emphasis and focus, manifested most clearly in the persistent search for a satisfactory and comprehensive definition of deaf-blindness.

What Have These Changes in Population Meant for the Field?

Although the impact of these population changes has been immense it is important to remember that we never worked with a homogeneous and noncomplex group of children, even though some of us might have viewed our caseloads in precisely that way a long time ago. It is true that the vastly expanded range of etiologies has removed the old certainties derived from teaching a class or supporting a caseload predominantly of children with Congenital Rubella Syndrome (to know a lot about Congenital Rubella Syndrome used to be synonymous with knowing a lot about deaf-blindness, and vice versa). How many of us can claim similar facility and familiarity in working with children with Cockayne Syndrome, Cogan Syndrome, Turner Syndrome, Klippel-Fell Sequence, Trisomy 18, or even a quar-

ter of the other 70 or so etiologies included in the national census? It is also now unusual to find teachers with the high level of facility in adapted sign language and finger-spelling found among longer-standing, "pioneer," teachers in this field, since an increasing proportion of the younger (but surviving and growing) children in the current population are at a pre-language or very early level of language development. Even with appropriate teaching, this group's subsequent progress is often extremely slow. One need not travel far to hear complaints that these more complex and medically involved children are excessively challenging, develop slowly and inconsistently, and are using up an unfair proportion of the scarce resources that our services have available.

Less frequently discussed is the abundance of evidence that working with the more complex and profoundly disabled children has helped educators to develop skills and insights that also improve the quality of their work with the whole population of students with deaf-blindness and children with other disabilities. These benefits include increased creativity and flexibility, improved observation skills, greater empathy, more genuinely holistic and multisensory approaches to assessment and teaching, a stronger emphasis on individualized programs, and a more urgent awareness of the need for collaborative approaches. Above all, working with these most challenging children has helped to expand the parameters of what we previously thought possible for people with deaf-blindness in all areas of development, including adaptive skills, compensatory abilities, short- and long-term memory, social awareness, and differentiated behaviors. And just think, for example, how much even the most academically gifted child with deaf-blindness benefits from being considered from a biobehavioral perspective and how much more effectively we could have supported every child on our caseloads had we enjoyed these many invaluable insights decades ago.

Where Next?

What are the implications of all of these changes? What should specialists in deaf-blindness, parents, and others involved in the education of deaf-blind children do in the light of this knowledge? Along with our colleagues in California, we have had many discussions on this topic. Although we would not wish to return to a time when deaf-blindness was considered primarily a medical condition, increased collaboration with neurologists and geneticists, as Tony Best suggests, is essential. There are already exciting examples of this process at work. For example, within the CHARGE Syndrome Foundation there is a long-standing collaboration among medical specialists (with a significant representation of geneticists), families, psychologists, and teachers that has led to a rapid increase in knowledge about this condition. Except where they step forward though, it is probably unrealistic to expect much from most medical specialists in terms of engaging with developmental or educational issues, which are, after all, our prime focus and concern. An exception to this, however, may be the physicians and researchers involved in developmental and behavioral pediatrics, pediatric neurology, and neuropsychology, or rehabilitative medicine. For example, at the 2003 Deafblind International World Conference, Jude Nicholas, a neuropsychologist in Norway, spoke about cognitive neuroscience and how it "helps us to understand the communication in the nervous system and is the scientific key in understanding how the brain processes information" (Nicholas, 2003, p. 4). His comments on neuroplasticity (how the brain modifies itself in response to sensory deprivation), on the possible role of emotion in cognition, and on the emotional aspects of the communication process suggest a tantalizing new perspective that reinforces some of the more recent changes in our educational philosophy mentioned above.

It is also apparent that we need to read, research, document, and discuss far more about recent discoveries and developments in the fields of neurology and genetics and make our own inferences and decisions, while also becoming better able to formulate more appropriate questions to pose to the relevant medical specialists. Experts within the field of deaf-blindness are beginning to become more involved with these issues. At the 2004 NTAC Topical Workshop on Early Intervention, the presentations on early brain development and on the impact of the neonatal intensive care unit (NICU) on the early sensory development of premature babies were well attended and of great relevance for anyone working with the current population of children with deaf-blindness aged birth to ten. And increasingly, newer literature intended for teachers in our own and in closely associated fields has included a focus on neurological development, multisensory perspectives, health issues, and sensory integration difficulties that would have been very unusual 15 years ago (Liefert, 2003; Alsop, 2002; Orelove, Sobsey, & Silberman, 2004). Research into the patterns of change in the annual national deaf-blind census

and a planned forum for discussion of the findings seems an urgent necessity, particularly since our perception is that the changes in the nature of the population described in this paper are most marked among infants and young children. Issues about the changing population of deaf-blind children are often raised and debated, but in casual ways resulting from specific local events such as a new referral, the death of a child, or an inquiry about a rare syndrome. The time and opportunity to examine these issues in any kind of depth rarely presents itself.

As a field, it is important to regroup and reexamine what we are doing and with whom. As deaf-blind specialists, we are uniquely placed to take a holistic view of children. Creating opportunities to explore and discuss the nature of the changing population, the history of deaf-blind education, and the implications of these on our current work should now be a priority for the field.

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