

Changing patterns of visual impairment

One of the benefits of working with a single disability over many years is to be able to observe the epidemiological, clinical and other trends over time. At the beginning of my career the main causes of blindness were eye diseases and only a few professionals were specifically interested in the care of totally blind but otherwise normal children. Today a large number of specialists are involved in this dynamic field and the major causes of visual disorders are found to be neurological rather than ocular. Furthermore, most patients have residual sight and multiple neurodevelopmental disabilities. Although this shift in the types of visual disorders and associated disabilities became evident in the early 1980s, a disproportionate number of service providers, researchers, and publications still focus on the relatively few totally blind children who are otherwise without neurological impairment.

As time has passed, during my involvement in the field of visual impairment for the past 30 years, new frontiers have appeared and disappeared. Our current knowledge of what vision is and how its disturbance or absence affects the development of a child has vastly increased. These and many other advances have been made as a result of hard work by dedicated professionals worldwide. Much credit goes to ophthalmologists who have improved the diagnosis and medical management of ocular disorders, and thereby have frequently prevented or reduced visual loss. Other medical and non-medical specialists have played equally important roles.

Perhaps the most important step forward in the study of visual impairment was the acceptance of scientific concepts which recognize that optimal neurodevelopment of young children, including their complex visual sense, is dependant on active, healthy interaction with the environment¹. Thus, the environment for children with disabilities must be enriched and modified. Intervention techniques are essentially based on this principle. Today the need for early intervention services for those afflicted with neurodevelopmental disabilities is widely accepted, although this may not be uniformly provided.

Three to four decades ago, it was not uncommon for us to meet neglected blind individuals with learning disabilities* whose lives had been permanently damaged by lack of early intervention². This is much less common nowadays, which gives intense satisfaction to those of us who are old enough to remember those earlier days. We must not forget the past in order to avoid making the same mistakes over again.

Many challenges still remain. For example, almost no advances have been made in the prevention of optic nerve hypoplasia which is one of the leading causes of ocular visual impairment in children living in Western countries³. Although major progress has been made in the genetic aspects of

congenital retinal disorders, the related therapeutic advances have been disappointing. There is a need for improved diagnosis and management of visual disorders due to neurological causes. In order to achieve this objective, a simple, practical, widely acceptable, and sound classification system of these conditions is urgently required. Clinical research into the various aspects of visual disorders must be encouraged because it greatly benefits the children and their families. Another important task for clinicians is the constant searching of the literature for advances made in visual disorders, and then applying the new knowledge to the treatment of children at a practical level.

How times have changed! The field of visual impairment is now recognized as a speciality of its own yet it has become too complex for a single specialist. Today, around half the children who are referred by ophthalmologists to our Visually Impaired Program in British Columbia come with an incomplete or sometimes an incorrect visual diagnosis; even for well-trained, experienced paediatric ophthalmologists it can be difficult to make an accurate ocular diagnosis without a series of tests, including DNA testing in sophisticated genetic laboratories. The identification of visual disorders due to neurological causes is still more difficult. As a result, the diagnosis and management of visually impaired children is most effective when differently-trained professionals work together in teams.

Although there have been many advances, those of us who participate in the habilitation of children with visual impairment should remain vigilant. Just as people with visual impairments must continually prove themselves to the sighted in order to gain acceptance, professionals also need to prove the usefulness of their therapeutic efforts and must continually educate their colleagues and the public.

James E Jan

References

1. Wiesel TN. (1982) The postnatal development of the visual cortex and the influence of environment. (Nobel Lecture, 1981) *Bioscience Reports* 2: 351–77.
2. Hellstrom A, Wiklund LM, Svensson E. (1999) The clinical and morphologic spectrum of optic nerve hypoplasia. *Journal of American Association for Pediatric Ophthalmology and Strabismus* 3: 212–20.
3. Warren D. (1984) *Blindness and Early Childhood Development*. 2nd edn. New York, American Foundation for the Blind.

Professor Jan has contributed many papers to DMCN over 30 years and has also been a major referee for us in the field of visual disorders. He has recently asked to be relieved of his burden, hence, I invited him to write this editorial. MCOB.

*UK usage. US usage: mental retardation.