In 1995 South Africa adopted the Convention of the Rights of the Child. Article 23 of the Convention states: 'A mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self reliance and facilitate the child's active participation in the community.'

Based on research done here in South Africa, I hope to illustrate not only the burden of disease of children with disabilities (in especially) rural communities, but also how much still needs to be done to achieve the objects of the Conventions of the Right of the (disabled) child. Until recently the main issues increasing paediatric mortality and morbidity included infections and malnutrition. Even though these are still prevalent today, issues regarding disabilities (especially intellectual disability) have begun to emerge and demand due consideration.

**Prevalence of disability**

The prevalence of childhood disability varies, according to local definition of disability and the various environmental factors, from 5% to 17% of the population. According to the last census, there are about 200 000 disabled children in South Africa under the age of 10, and another 300 000 between 10 and 20 years of age, representing between 2% and 3% of the population in these age groups (Census 2001). More than likely this represents an underestimation of the magnitude of the burden of disability. In these age groups physical, intellectual and hearing disabilities are the most prevalent.

In an epidemiological study of 6 692 children aged 2 - 9 years in the Bushbuckridge district a minimum prevalence of 35.6 per 1 000 of the childhood population was observed. The majority had mild intellectual disability (GIQ 56 - 80) and the ratio of mild to severe was 4.5:1. Epilepsy (15.5%) and cerebral palsy (8.4%) were the most commonly associated disabilities. The prevalence in this study was similar to that found in another South African study in the Western Cape.
More about...

In a study in KwaZulu-Natal, using a similar epidemiological approach, the prevalence of disabilities was found to be 60 per 1,000 children overall, 28 per 1,000 for motor disability, 20 per 1,000 for hearing disability, 9 per 1,000 for seizure disorders and 2 per 1,000 had visual deficits. The higher prevalence of disability may be due to the inclusion of perceptual disabilities.

The case for early detection and intervention

The importance of primary prevention of disability is universally accepted, even in the absence of an identified aetiology. Secondary prevention implies early identification of disability and intervention. Both the need for early diagnosis of abnormal development and the effectiveness of early intervention for actual or potential developmental disorders are treated with skepticism by many professionals. Some have a relatively hopeless or fatalistic attitude toward major disabilities (such as significant mental retardation). Relatively uninformed rural communities have even less insight into strategies that should be available to help their children with special needs, and therefore they would be less inclined to lobby for or even demand services and relevant interventions for their disabled children.

Another misguided notion is that children with milder developmental delay (such as early language defects) will ‘outgrow’ their problems. Both of these attitudes delay the treatment of young children and may diminish the eventual outcome of the intervention programmes.

It is widely accepted that early experience influences all areas of development. There may be critical periods for the achievement of certain skills (usually before the age of 4 years) and an inability to achieve these may lead to permanent deficits. Failure to provide early stimulation may not only lead to a discontinuation of normal development, but may cause actual atrophy of sensory ability (e.g. amblyopia associated with strabismus). Furthermore, failure to remediate one disability may multiply its effects in other developmental areas, and may produce secondary emotional handicaps. Parents also need a great deal of support, encouragement and knowledge to manage their children with disabilities. The prognosis for the child is often directly linked to the parents’ support, commitment and enthusiasm.

Identification of children with developmental disorders

A comprehensive paper is already published on this topic, but a simple approach is to consider 5 questions when a child is evaluated within the health system:

1. Can the child see?
2. Can the child hear?
3. Is language development adequate for age?
4. Could the child have motor delay?
5. Could the child have cognitive delay?

Some of these milestones have already been incorporated into the Road-to-Health charts. This is a step in the right direction. It behoves all health workers who come into contact with children to be alert regarding developmental issues. Perhaps developmental milestones should be included in the Integrated Management of Childhood Illnesses (IMCI) also.

Unfortunately it is not only the identification of these children that is a problem, but also the services available for support, intervention and rehabilitation. It is ethically questionable to screen for developmental delay and disabilities if there is no recourse to any intervention. It is in this area particularly that our children are poorly served. Services for children, beyond diagnosis, are obviously inadequate.

References


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Treatments for COPD do not appear to prolong survival

Treatments for chronic obstructive pulmonary disease (COPD) give symptomatic relief, but it’s hard to show that they actually save lives. Even more data are needed from even larger trials before frustrated specialists can tell if treatment is prolonging lives. The latest, supposedly definitive, trial recently ran into problems. The trial was large (N = 6,112) and compared 4 treatments (a long-acting beta-agonist, an inhaled corticosteroid, both of these combined, and neither of these) for 3 years in patients with COPD. Four out of 10 patients dropped out of the trial, so the findings were borderline and difficult to interpret. Combination therapy saved more lives than the placebo, but only just, and the difference was not significant in the strict statistical sense. Neither of the treatments alone reduced mortality compared with placebo.

So where do these results leave patients? Until there is better evidence, combined treatment with an inhaled steroid and a long-acting beta-agonist should probably be reserved for people with severe disease. Others should stick with a long-acting beta-agonist alone. Combined treatment reduced exacerbations, improved symptoms, and protected lung function in this trial. But patients given an inhaled steroid (alone or in combination) had a significantly increased risk of pneumonia.