Intellectual disability

Peter Mittler

The needs of people with intellectual disabilities have often been overlooked in programmes designed to reach disabled people in general. They themselves are calling for their needs to be met.

The term intellectual disability is increasingly accepted as appropriate by the main international professional and scientific associations. Mental retardation is still the official terminology of WHO, as well as of the United States; other countries use terms such as mental handicap, learning disability, intellectual impairment. Mental deficiency or mental subnormality are no longer in use and language which appears to encourage stereotypes and generalizations is discouraged, such as references to the “retarded”.

According to the American Association on Mental Retardation (AAMR), “Mental retardation refers to substantial deficits in certain aspects of personal competence. It is manifested as significantly sub-average abilities in cognitive functioning, accompanied by deficits in adaptive skills”. For an individual to be regarded as having an intellectual disability, both cognitive functions and ability to function in society must be impaired; neither is sufficient on its own. The AAMR definition also emphasizes the nature and intensity of the supports that an individual may need to function in society. In other words, the current approach to mental health is not limited to identifying deficits in the individual; it underlines the importance of interaction with the environment and the support that is needed to do so.

People with a mild intellectual disability may be accepted in schools and in the local community, though the threshold of acceptance will vary with social and economic circumstances and also with local attitudes. Most people with more significant degrees of intellectual disability will require support from their families and from social service agencies.

It is estimated that one in ten of all disabled people has a significant intellectual disability – over 50 million in the world at the present time or up to 1% of the population. Mild forms will affect up to 3%. By 2025, three-quarters of them will live in developing countries, mainly as a result of much more rapid population growth and also because many children who would previously have died at an early age are now surviving and needing services.

Stimulating learning and development

The families of infants identified at an early age as having an intellectual disability will need practical advice and personal support in stimulating the learning and development of their children. Home-visiting schemes have been used in many developing countries. The essence of this approach is that the parent and a home visitor jointly assess the developmental level of the child and on that basis plan a programme of teaching which the parent carries out at home.

Inclusive education involves schooling for all children and ensuring that ideally, people with an intellectual disability:

• have the same basic rights, needs and responsibilities as all other citizens to be fully included in society and social institutions;
• can contribute to and enrich society;
• can learn, provided they are properly taught and are given time to do so;
• will be supported by persons and services within the community;
• should be able to make their own choices and decisions;
• should be able to live with their families or in the community with appropriate support, and should not be segregated or placed in institutional settings.

Plans can be developed to enable teaching to be carried out at home.
Efforts should be made to educate children with intellectual disabilities in their neighbourhood schools.

ing that the teaching and the activities of the school are accessible to all children in the community. Surveys by UNESCO suggest that although most children with intellectual disabilities in developing countries are excluded from any form of schooling, an increasing number of children are being successfully educated in their local schools.

The United Nations' goal of a Society for All by the year 2010 applies not only to education but also to health, housing, employment, recreation and leisure, public transport—indeed to all social amenities and institutions. In many countries, progress is being achieved through a new approach to community-based rehabilitation, one that involves much closer collaboration between health, education and vocational training. People with intellectual disabilities are now beginning to gain access to rehabilitation programmes from which they were previously excluded. In future, this approach will need to be much more closely integrated, with access to local educational and work opportunities.

Better community understanding

The needs of people with intellectual disabilities have often been overlooked in programmes designed to reach disabled people in general. But we now have enough knowledge and skill to ensure that their needs are more fully met in the future. They themselves are calling more clearly and with greater persistence for their needs to be met. Their representatives have addressed the UN General Assembly. Human rights organizations such as Inclusion International (formerly the International League of Societies for Persons with Mental Handicap) are disseminating examples of good practice and protesting at examples of discrimination and abuse. Family members throughout the world are insisting on better support and better community understanding. Many local and national voluntary organizations are insisting on the rights of all citizens with an intellectual disability to contribute to society and to live in a more inclusive society.

Here are some practical steps that can be taken by health workers at field level and also by those involved in policy and planning.

- Offer to meet and work with local voluntary organizations and parents' groups concerned with this problem. If these do not exist, offer to support parents and volunteers who may be prepared to start a small group.

- Help to ensure that families are supported when a child is identified as likely to have an intellectual disability. This can be done by ensuring that guidelines are available on initial communication with parents (such as the WHO behaviour science learning module entitled Introducing parents to their abnormal baby), or by providing accurate and reliable information to parents, in written or pictorial form, which includes guidance and suggestions on what the family can do to stimulate and support the child's development.

- Work with other professionals—especially teachers, social workers and staff of day centres—to develop a joint, multidisciplinary approach, using WHO's guidelines on community-based rehabilitation.

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