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Editorial

Intellectual Disabilities: Public Policy and Resources

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The prevalence of intellectual disability is estimated to be 1-4%. Etiological factors such as malnutrition, lack of perinatal care, and exposure to toxic and infectious agents, which are more common in low- and middle-income (LAMI) countries, possibly contribute to a higher prevalence of intellectual disabilities in these countries.¹⁻⁵ People with intellectual disabilities have a greater risk of experiencing physical and mental health problems and are vulnerable to chronic disease at an earlier age.^{2,6} While the disease burden due to intellectual disabilities has not been estimated, it is known that 1% of the global burden of diseases is due to lead exposure derived intellectual disability and cardiovascular diseases alone.⁷ In addition, persons with intellectual disabilities are frequently the most vulnerable group of the society and, on many occasions, are exposed to human rights violations and deprived of minimum services and dignity. They are often unable to access basic health and educational services, and are excluded from ordinary social relations.⁸ Intellectual disability is thus a problem of great importance for public health, education, employment and human rights.⁵

Inclusion and rights

Existing state-based resources for intellectual disabilities derive from treaty-based rights. Such rights are set out in binding international instruments, such as the International Covenant on Economic, Social and Cultural Rights (2000), the International Covenant on Civil and Political Rights (1994), and the Convention on the Rights of Persons with Disabilities (2007); non-binding instruments, such as the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993); and civil-society instruments, such as the Montreal Declaration on Intellectual Disabilities (PAHO & WHO, 2004). The Montreal Declaration on Intellectual Disabilities states that for persons with intellectual disabilities, the exercise of the right to health requires full social inclusion, an adequate standard of living, access to inclusive education, access to justly compensated work and access to community services. It is the right to non-discrimination that constitutes the fundamental element of the right to health.⁹

In India, the paradigm shift from the welfare and charity approach to rights based one towards the issues concerning persons with disabilities occurred with the enactment of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995; and the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999. The former was

aimed at non-discrimination and the latter at enabling and empowering persons with disabilities to live as independently and as fully as possible within or close to the community to which they belong.¹⁰ In keeping with the Persons with Disability Act, the central government and several states in India have begun providing many social security measures like disability pension, family pension, scholarships for special education, travel concession, income-tax relief and special insurance policies. The National Trust Act has provisions for parents to obtain guardianship (either partial or complete) for their adult offspring's with intellectual disability.

Resources

World: The World Health Organization (WHO) recently released the 'Atlas: Global Resources for Persons with Intellectual Disabilities' (Atlas-ID).⁸ This global report includes information from 147 countries, representing 95% of the world population. Indicators that intellectual disabilities have low visibility in some countries, and low priority on national political, economic, and social agendas, included the number of countries without any specific national policy (18.4%), protection law (28.8%), government benefits (22.6%), or public funding for intellectual disabilities (24%). Only about one third of countries had policy documents that covered human rights issues and just over half of the countries had special provisions for offenders with intellectual disabilities. When government benefits were provided, only about two fifths of participating countries had high access to such benefits (i.e. more than 75% of entitled individuals or families received some form of governmental benefits). It was noted that resources and services for intellectual disabilities seemed to be embedded within many fields (e.g. education, health, disability and social welfare), and scattered between sectors and authorities. Out of pocket funding (60.1% of countries) and financial support from NGOs (68.8% of countries) was equally as important as tax-based funding (76.0% of countries) in financing services for intellectual disabilities. The situation was especially worrisome in most LAMI countries.

While two thirds of countries provided services, training and support that were specifically related to intellectual disabilities (e.g. screening, early intervention, work-skills training, assistive technology, family education and counseling); fewer than half the countries offered residential services; literacy programmes; and adult education programmes. Services for intellectual disabilities that involve asylums remained very important in half of the countries. Socioeconomic status, rural-urban setting and geographical location were important barriers to access to services in more than half of countries surveyed. There was a coexistence of segregated and inclusive education worldwide. Just over half the countries had programmes designed to prevent intellectual disabilities. These strategies included supplementation of diet by iodination of salts or folic acid in bread (in 67.1% of countries); programmes for prevention of alcohol or drug abuse during pregnancy (61.6%); genetic counselling and prenatal testing (61.0%); and tests to detect phenylketonuria, lead, or hypothyroidism (57.5%). Only 32.4% of countries could rely on epidemiological trends or on information systems to obtain data about services. There was a clear economic gradient in provision and access to services among the countries surveyed.

The five main groups of professionals who provided services for persons with intellectual disabilities were special educators (85.6% of countries), social workers (80.1%), psychiatrists (78.1%), psychologists (75.3%), and teachers (76.7%). In-service training (69.5% of countries) offered to professionals who work with persons with intellectual disabilities was the most common form of training, whereas graduate training was rare, and concentrated in high-income countries. Although primary care services were felt as important to persons with intellectual disabilities, few respondents mentioned primary health care workers among the providers who worked with such persons, and few countries seemed to offer training to these workers.

Non-Government Organizations (NGOs) were present in 88.2% of responding countries, and international organizations in 62.2% of them. Although both NGOs and international organizations focused their activities on advocacy and education, international organizations were also involved with policy and system development and human rights training, whereas NGOs concentrated on support, self-help, empowerment, and rehabilitation services. The roles of NGOs and international organizations tended to differ according to the income levels of the countries in which they operated. In high-income countries, NGOs focused on advocacy and development of policies and systems; whereas in other countries they devoted more effort to education, rehabilitation, support, self-help, empowerment, and provision of direct services. In low-income countries the contribution of NGOs to financing services for persons with intellectual disabilities was highest.

India: The government has made an effort to include disability rehabilitation as an area of critical social development responsibility and accountability of the national planning process from the 8th Five Year Plan onwards. During the 10th Five Year Plan, the outlay was 14,541 million Rupees, and the 11th Five Year Plan will focus on early intervention, education, and employment, and aim at a barrier free and inclusive society.¹⁰ Recently, Ministry of Social Justice and Empowerment has come out with National Policy on Disability. In addition, there is a National Program for Rehabilitation of Persons with Disabilities (NPRPD).² However, till now, the care for persons with intellectual disability has largely been limited to the area of social and educational services and social welfare.

Education is seen as a fundamental right of every child. The Government of India envisages that every child with a disability should have access to appropriate preschool, primary and secondary level education by 2020. The Sarva Shiksha Abhiyan (Education for All) for children in the age group of 6 to 14 years has a special focus on education of children with disabilities. In keeping with the principle of inclusion the national policy is committed to educate each child, to the maximum extent appropriate, in the school and classroom the student would otherwise attend. The concept involves bringing the support services to the child, rather than moving the child to the services, and requires only that the child benefit from being in the class, rather than having to keep up with the other students. However, constraints involved in implementation may require provision of special setting for more severely disabled children.¹⁰ The programme elements of Sarva Shiksha Abhiyan include: early detection and identification, functional and formal assessment, educational placement, provision of aids and appliances, support services,

teacher training, resource support, individualised education plan, parental training and community mobilization, planning and management, strengthening of special schools, and removal of architectural barriers. A revised plan for Inclusive Education of Children and Youth with Disabilities (IECYD) will target persons with disabilities in the age range of 14-18 years.¹⁰

The establishment of the National Institute for the Mentally Handicapped led to improvements in availability of trained personnel, models of service, and resource materials adapted to the needs of intellectually disabled individuals; and the consequent growth of special schools for children with intellectual disability. About 200,000 intellectually disabled people have been helped through various programmes of the National Institute for the Mentally Handicapped.¹⁰ While this is a laudable achievement indeed, it is contrasted against the presence of over 10-60 million persons with intellectual disability in India if one makes projections based on available epidemiological data.²⁻⁴

Vocational training and employment are major areas in the empowerment of persons with intellectual disabilities. The Rehabilitation Council of India is attempting to standardize human resource development programs. At present 83 centres provide special education and vocational training programs.¹⁰ The Central Government also provides for District Disability Rehabilitation Centers (DDRC's) and the National Handicapped Finance Development Corporation.² Community based rehabilitation (CBR) is now considered a viable and sustainable method for improvement of the quality of life of disabled persons, and some centres in India have taken initiative in this area.

There are nearly 200 parent associations in the country with a membership of over 40,000 parents. A national federation called *Parivaar* functions as a central organ for these associations under the guidance of National Institute for the Mentally Handicapped.¹⁰

Health needs and response

Intellectual disability is a very significant public health problem, because of its prevalence, the costs to the public health system, the families and society in general; and due to related health complications. It has high rates of physical as well as psychological comorbidity through out the lifespan, with a morbidity pattern that is often related to the cause of the disabilities.^{2,15} Seizure disorder has been reported in 15-30% and psychiatric disorders in up to 40% of persons with intellectual disability.² A small proportion of children with intellectual disability have multiple disabilities.²

It is estimated that around 25% to 30% of intellectual disability is potentially preventable, since many cases are related to the consumption of neurotoxic agents such as lead, nutritional deficits, or problems during gestation, childbirth or premature development.^{2,15} The impact of health policies aimed at correcting the causes of intellectual disability, e.g. nutritional support, immunization and proper maternal and child care could be enormous.^{1,11-13} For example, folic acid fortification in the diet of pregnant women can reduce the occurrence of neural tube defects by half. Salt iodization is the most cost-effective way of delivering iodine and of substantially improving cognitive development.¹³ Enormous advances in the field of prenatal diagnosis of

conditions leading to intellectual disability have also occurred, e.g. ‘triple test’ screening for Down syndrome, chorionic villous biopsy for chromosomal and metabolic disorders, ultrasonogram for nuchal thickness measurement at 11-14 weeks of gestation and genetic amniocentesis.² Available literature (including that from LAMI countries) also seems to suggest that techniques such as play and cognitive stimulation in the form of reading and possibly music or massage are important and useful to neuro-cognitive and sensori-motor development, and in the process reduce neuro-cognitive deficits.¹⁴ In that sense, it can be expected that the Integrated Child Development Service programme in India for children in the age group of 0 to 6 years would serve a preventive role for intellectual disabilities and help in the promotion of cognitive development. The National Rural Health Mission is expected to cover early identification and intervention for children at risk.¹⁰

There is a large gap in healthcare for persons with intellectual disability. Health service providers often have little knowledge of and little interest in the special needs of this group of patients. This lack of care is reflected in the lack of education in health professions with respect to intellectual disability. The time dedicated to training medical students about intellectual disability is less than one elective hour in the majority of countries.¹⁵ The mainstream health services would have to be equipped to support the specific health needs of intellectually disabled patients with primary care providers playing a central role. For this to happen, health providers in mainstream health services will need to develop competencies to deal with some of the more specific health problems of people with intellectual disabilities (e.g. etiology-related health problems, legal and ethical aspects, communication). Health professionals who are specialized in the specific health needs of individuals with intellectual disabilities should be available as a back-up to mainstream health services. It should be remembered that health care for individuals with intellectual disabilities often needs a multidisciplinary (e.g. visual and hearing impairment, mental health care, care for people with multiple and complex disabilities, etc.) and proactive (e.g. participation in screening programmes, investigations of anticipated visual and hearing impairments) approach; hence, training and services need to be geared towards this.¹⁶

Mental health: Literature suggests a 3-5 times greater prevalence of psychiatric disorders in persons with intellectual disability than in general population. The entire range of psychiatric disorders has been described in children and adults with intellectual disability. Impairment in development of the brain, associated problems such as seizures and speech disorders, limited intellectual potential with consequent vulnerability to environmental influences and stress, and adverse conditions of upbringing such as understimulation, overprotection and inconsistent disciplining often combine to contribute to this excess prevalence. However, psychiatric disorders are commonly under-diagnosed or misdiagnosed in persons with intellectual disability owing to erroneous beliefs or narrow focus of clinicians (e.g. psychiatric disorders cannot be diagnosed in the presence of intellectual disability; focus on disruptive behaviours and symptomatic treatment rather than treatment of disorders), diagnostic masking (manifestations of the psychiatric disorders may be modified or masked by intellectual disability), diagnostic overshadowing (tendency to write-off symptoms of psychiatric disorders as ‘mere’ expressions of intellectual disability) and difficulty in interviewing

persons with intellectual disability.. Also these children are likely to be rejected in social and educational settings.

Fortunately, a change in the tendency to neglect the health care needs of intellectually disabled has occurred in recent years, e.g. evaluation and diagnostic instruments such as the Psychiatric Diagnostic Manual on Intellectual Disability have been made available.¹⁷ Recently, a few standardized instruments to screen for psychiatric and behavioral disorders in persons with intellectual disability have also been developed such as Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD), Reiss Screen for Maladaptive Behavior, Psychopathology Inventory for Mentally Retarded Adults (PIMRA), and Developmental Behavior Checklist (DBC). Also, evidence base on interventions that address specific health care needs of persons with intellectual disability is accruing.^{2,12,13} Management often needs to be multi-modal. The available data suggests that persons with intellectual disability respond to various psychotropic medications in ways similar to the typically developing population. Studies have established the efficacy of methylphenidate in attention deficit hyperactivity disorder comorbid with intellectual disability. However, rates of response tend to be poorer and the occurrence of side effects tends to be more frequent. Studies have also shown the efficacy of risperidone in aggression and stereotypies, clonidine in hyperactivity and impulsivity, and serotonin specific reuptake inhibitors in dysphoria, self-injurious behaviour and stereotypies. Pharmacotherapy needs to be combined with psycho-social forms of treatment to obtain optimum and sustained improvement. These include parent counseling, parent training, behavior modification, skills training, and environmental changes. Individual counseling with appropriate modifications in language and approach could be attempted wherever it is necessary and feasible.^{2,12,13}

Miles to go

The issue of intellectual disabilities has had a low position in many related fields, such as mental health, rehabilitation, public health, and primary care. There is thus a need for advocacy to help prioritize intellectual disabilities on government agendas and to increase civil-society awareness of intellectual disabilities; for mechanisms for coordinating the actions of the many constituencies, government departments, and agencies that are responsible for intellectual disability; and implement existing policies in a way that intellectual disabilities gain parity with other disabilities. One challenge will be to ensure that recent attention on human rights issues can be translated into policies, programmes, and actions that will improve underlying conditions necessary for health and especially for intellectual disabilities. Accordingly, persons with intellectual disability and their caregivers should be actively involved in policy and service decisions so as to promote the organization of community-based services that guarantee the enforcement of these rights.

Any planning effort geared to scale up resources must recognize that there is a paucity of financial resources and should mobilize all existing resources in the community, whether from public, private, or third sector sources, and try to maximize the efficiency of their use, without duplication of services. There should be an emphasis on

downsizing of asylum-type facilities and establishment of services that are community-based and integrated into the national networks of services. Development of services must consider access as a major issue. Capacity building for intellectual disabilities must be prioritized within primary care. Professionals should be trained to support families, informal caregivers, and community leaders, and to provide consultations to primary health care workers.

Public health programmes that target environmental factors (e.g. iodine, mercury, and lead), living conditions (poverty), behaviours (tobacco, alcohol, and drug abuse), provision of services (mother and child care and vaccination) could reduce the incidence of intellectual disabilities. General practitioners (physicians), primary-health workers, midwives, and skilled birth attendants should get training and guidance in prevention and identification of intellectual disabilities, and in early intervention for such disabilities.

Finally, though recently there have been efforts to develop government programs to meet the needs of the intellectual disability population in LAMI countries, the effectiveness of these programs needs to be evaluated.

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