Disability in children and adolescents must be integrated into the global health agenda

Alarcos Cieza and colleagues argue that services for children and young people with disability need greater priority

Disability has low priority in the general agenda of child and adolescent health. Although one billion people have some form of disability, people with disability are among the world’s most marginalised and discriminated against groups. Driven by global goals, most countries have focused primarily on reducing childhood mortality, leaving disability low in their priorities. Few countries provide adequate quality services. There are at least three good reasons why countries urgently need to tackle this.

Firstly, the number of people living with disability is set to increase dramatically because of epidemiological and demographic trends, such as the relatively young populations of low income countries. These trends are usually considered in terms of increasing disability among older people with chronic conditions, rather than among children. With child survival increasing but not all children who survive being able to thrive, more children will need health services to optimise their developmental outcomes. However, most health systems lack capacity to deal with current needs of children with disability, let alone meet the rising demand.

Secondly, children with disability often need specific rehabilitation services related to their impairment or disability. Rehabilitation interventions—which can tackle impairments, functioning limitations, and restrictions such as mobility, vision, and cognition—can have a profound impact on functioning and wellbeing. Rehabilitation is often required for considerable periods of time. The limited evidence available shows major gaps and unmet needs for such services, particularly in low income countries.

Lastly, access to appropriate care is a fundamental human right. Children with disability repeatedly face barriers to care, including physical ones, causing much suffering, hardship, and isolation. But the greatest obstacles they encounter are negative or ill informed attitudes. Without a shift in attitudes, it is likely that they will continue to be denied access to care by health providers.

Growing numbers of children with disability

The low priority accorded to disability is reflected in the lack of data. One recent global analysis estimated that 291 million children and adolescents experience disability due to epilepsy, intellectual disabilities, or sensory impairments. But the real impact of childhood disability is not yet known.

Epidemiological evidence so far has been fragmented, limited to prevalence data for specific health conditions. The only source of global evidence, the World Report on Disability, found that about 5% of children experience disability, but the report relied on data from 2004. A comprehensive perspective is vital: it should consider a broad list of chronic health conditions with high levels of associated disability that profoundly affect children’s functioning and wellbeing. This will enable appropriate provision of health services.

We explored trends in prevalence and associated disability of a number of common non-communicable diseases and injuries using the Global Burden of Disease as a data source, comparing data from 1990 to 2019. Since the list of conditions can be broad, we adopted an approach that limited the number of conditions but was still representative without being exhaustive. We selected the 20 impairments and health conditions with the highest number of years lived with disability, which reflected the level of disability according to Global Burden of Disease data. Infectious diseases, such as malaria, and conditions driven by prevalence rather than disability, such as micronutrient deficiencies, were excluded.

RESULTS show that for most of the conditions the estimated global prevalence remained virtually unchanged during this period (table 1), but the numbers of children and adolescents living with disability rose substantially owing to demographic trends: in low income countries, particularly in sub-Saharan Africa, children under 14 years typically constitute more than 40% of the total population. Already, there are nearly 500 million more children and adolescents today than in 1980.

Health systems lack capacity to tackle needs

Despite the numbers needing care, services for children and adolescents with disability are woefully inadequate. Health systems...
Child care. Yet in reality, even basic healthcare provide for all children to be entitled to barrier, but the invisibility of children hinders policy making. Another critical deficiencies. A lack of evidence and data with disability is the root problem of many equipment. Limited resources are a key barrier, but the invisibility of children with disability is the root problem of many deficiencies. A lack of evidence and data hinders policy making. Another critical issue is the lack of qualified healthcare professionals and medical equipment to tackle specific needs. For example, in Ethiopia, many children with autism and intellectual disability do not receive the care they need because of the lack of training and knowledge of healthcare professionals and the absence of referral mechanisms.

| Long term impairment/chronic condition | Proportion of population (%) | No of people (millions) | Years lived with disability (millions) |
|----------------------------------------|------------------------------|-------------------------|---------------------------------------|
| Developmental intellectual disability  | 3.4                          | 73.1                    | 3.8                                   |
| Hearing impairment                     | 4.3                          | 102.3                   | 3.3                                   |
| Vision impairment                      | 1.4                          | 29.9                    | 1.5                                   |
| Congenital anomaly*                    | 1.3                          | 28.2                    | 3.3                                   |
| Epilepsy                               | 0.6                          | 12.0                    | 4.6                                   |
| Migraine                               | 7.5                          | 159.5                   | 5.8                                   |
| Conduct disorder                       | 1.5                          | 32.7                    | 4.0                                   |
| Dermatitis                             | 3.3                          | 90.4                    | 3.8                                   |
| Anxiety                                | 2.4                          | 50.0                    | 5.0                                   |
| Injuriet                               | 7.5                          | 158.1                   | 5.7                                   |
| Asthma                                 | 4.4                          | 93.1                    | 3.7                                   |
| Depression                             | 0.9                          | 18.6                    | 3.5                                   |
| Autism                                 | 0.4                          | 9.4                     | 1.5                                   |
| Attention deficit/hyperactivity disorder| 2.1                          | 44.8                    | 0.5                                   |

Data from Institute for Health Metrics and Evaluation http://ghdx.healthdata.org/gbd-results-tool.

*The Global Burden of Disease includes in this category congenital heart defects, neural tube defects, oral clefts, congenital anomalies of the urogenital system, congenital anomalies of the gastrointestinal tract, musculoskeletal congenital anomalies, Down’s syndrome, Turner syndrome, Klippel–Feil syndrome, and other chromosomal abnormalities, genetic syndromes, and microdeletions.

**Injuries from 30 causes, including transport injuries, falls, drowning, self-harm, interpersonal violence, and animal contact.**

Watch survey with respondents from 54 countries found children with disability among the hardest hit, as services for them often fall by the wayside.34

The way forward

Disability urgently needs far higher priority in the child and adolescent health agendas. Low and middle income countries especially need to tackle the huge unmet need for services, which will only escalate with demographic changes. While services need to be built up, a lack of interventions is not the inherent issue. Numerous effective options for children with disability currently exist (see supplementary file 2), but they are not made available in most countries. For example, a recent analysis on hearing aids found that only 17% of the 400 million people “in need” of hearing aids have one.35 To move forward we need a shift of attitudes and the commitment of all relevant parties in the disability and health sectors.

Governments need to scale up service delivery with a strong focus on primary healthcare. This will help widen access and meet rising demand from the growing number of children with disability, many of whom will require services close to home. Primary care can become an essential platform and starting point for the care needed beyond and above the health sector. Some children might otherwise never receive the care they need.

Also, rehabilitation services need to be expanded to reach all children in need. This can happen only through integration into the health system and specifically at the primary care level. Providing early access to
rehabilitation services is crucial to ensure optimal outcomes and mitigate the risks of ongoing complications that may affect health and overburden health systems. Evidence shows that early intervention at the primary care level can significantly reduce the prevalence of many chronic conditions and delay the onset of conditions, such as for cerebral palsy. Timely prevention interventions that target risk factors can also prevent conditions associated with high levels of disability. Stepping up rehabilitation services will entail sensitising and training the health workforce, who need the necessary information and skills to provide specific services. In addition, families can be given support and education, including on stigma and discrimination, which are at the root of many barriers.

Governments need to look at children with disability with fresh eyes and bring them out of their invisibility to inclusion. Countries need to commit to prioritising children who are among the most disadvantaged in many societies.

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Web supplements: Prevalence and years lived with disability attributed to different long term health conditions and impairments

Web supplements: Evidence on effectiveness of prevention, treatment, and rehabilitation interventions for long term health conditions

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