



Consigned to the margins: a call for global action to challenge intellectual disability stigma

Stigma as an important public health concern has been recognised in relation to conditions as diverse as HIV, leprosy, and mental illness. Little attention has been paid to date, however, to the pernicious effects of stigma on the wellbeing and life chances of one heavily stigmatised population: people with intellectual disabilities. Of the 15 billion people globally affected by disability,¹ an estimated 2%, or 300 million, have an intellectual disability. They experience the same disadvantages and inequities as do people with other types of disabilities, but often face the additional disadvantage of having their needs inadequately understood and met, having limited recourse to assert their rights, and being poorly represented, including within the Disability Rights movement. The majority live in low-income and middle-income countries where there is little impetus or resource to assess or diagnose their struggles in meeting the cognitive, social, and economic demands of everyday life. Whether labelled intellectually disabled or not, they are generally among the most marginalised groups within society, experiencing high levels of health, social, and financial inequities.^{1,2}

The 2008 UN Convention on the Rights of Persons with Disabilities (CRPD) requires governments to raise awareness of disability and challenge prejudice and discrimination (Article 8), and to ensure equal and effective legal protection against discrimination (Article 5). Earlier global comparative data on attitudes to intellectual disability is limited to a study from 2003, which included ten countries across four continents, and to a 2007 WHO Atlas, focusing on resources but including some indicators of attitudes.^{3,4}

To determine current issues related to persons with intellectual disabilities, we undertook a global study, examining government action as reported to the CRPD Committee and gathering data from 667 disability experts and organisations from 88 countries regarding the extent to which low awareness of intellectual disability and stigma are continuing concerns, and what is being done to tackle these concerns.⁵ The results indicate that in many (mostly high-income and upper-middle-income) countries the general public agrees with

inclusion in principle, but often view it as impractical and unachievable. A “not in my own backyard” attitude and a fear that inclusion of people with intellectual disabilities may affect the resources and achievements of those without disabilities, particularly in school and work environments, persists.

Of equal concern, in many middle-income and low-income countries, children and adults with intellectual disabilities still face high levels of stigma and denial of fundamental rights and freedoms. Their invisibility is accompanied by low expectations of people with intellectual disabilities—in many countries they are still widely viewed as incapable, unable to live independently or to contribute to society. Furthermore, throughout Africa and Asia, in former states of the Soviet Union, and in some parts of South and Central America, an active desire to segregate them from society continues because of deep rooted prejudice and stigmatising beliefs about the causes of intellectual disability.

Our data suggest that efforts to combat intellectual disability stigma in such countries are small in number and entirely dependent on parent organisations and non-governmental organisations. The imbalance between the world regions where intellectual disability stigma is of greatest concern and where efforts are underway to tackle such stigma is evident the figure, which categorises interventions reported to us by world region.

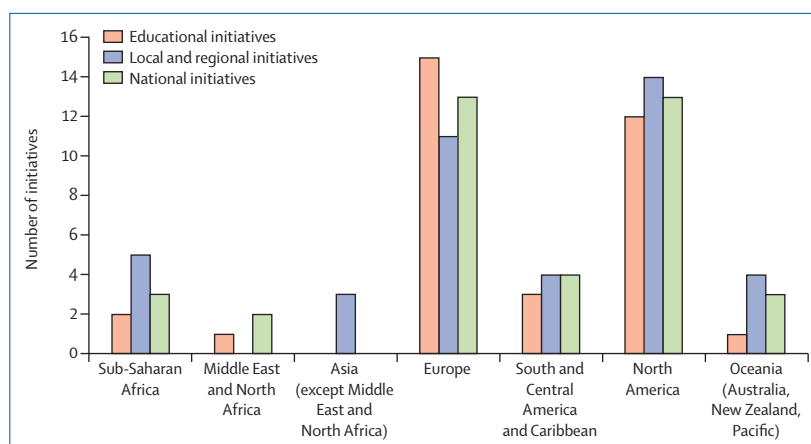


Figure: Number of educational, local and regional, and national initiatives, by UN region

Our analysis of UN CRPD committee reports indicates that people with intellectual disabilities, despite their substantial numbers, continue to be low priority in government policy and programmes worldwide. Although governments report initiating many programmes to raise disability awareness, these rarely include intellectual disability. Of particular concern, whereas global public awareness of many health conditions and disability issues has grown, public understanding of intellectual disability is still frequently rife with confusion and misconceptions.

This poor understanding is due in part to the wide continuum of disabling conditions subsumed under this label and the frequent lack of outward signs of an intellectual disability. However, lack of public education and anti-stigma programmes are at least equally to blame, as is the assumption implicit in disability awareness programme that education about other types of disability will also lead to a better understanding of intellectual disability.

In conclusion, there is a need for greater recognition among policy makers and programme leaders of the detrimental effect stigma has on the life chances of children and adults with intellectual disabilities. Findings from our study show that the voice of people with intellectual disabilities is often unheard and their visibility in society and the Disability Rights movement is generally low. Much more action is needed to achieve their equal rights. The crucial role of parent

advocates, particularly in low-income and middle-income countries, merits greater support, and greater prominence must be given to self-advocacy as powerful means of reducing stigma. Given the large number of individuals with intellectual disabilities and their families, this is an issue no longer to be ignored.

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- 2 Emerson E, Hatton C. Health Inequalities and People with Intellectual Disabilities. Cambridge: Cambridge University Press, 2013.
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