



Intellectual Disabilities: Raising Awareness and Combating Stigma A Global Review

Executive Summary & Recommendations



Acknowledgements

This project was funded by the UCL Grand Challenges Global Health Scheme



Dissemination of this project was funded by the Royal Mencap Society.



We thank UCL Grand Challenges, the Royal Mencap Society and Inclusion International for their support. We also thank IASSID, and Eric Emerson in particular, as well as Special Olympics for their invaluable help in distributing the survey which formed the central part of this project.

We wish to emphasise that the views presented in this report are those of contributors and the research team and do not represent the views of the organisations who have supported this project.

Research Team

Katrina Scior, Division of Psychology & Language Sciences, UCL (Principal Investigator)
Maria Kett, Leonard Cheshire Disability & Inclusive Development Centre, UCL
Richard Hastings, Cerebra Chair of Family Research, CEDAR, University of Warwick
Shirli Werner, Paul Baerwald School of Social Work & Social Welfare, The Hebrew University of Jerusalem
Aseel Hamid, UCL
Catherine Belton, UCL
Adebisi Laniyan, UCL
Maya Patel, UCL

We also thank Katalin Hajdú, Chloe Davies and Andre Strydom (UCL) for their input.
Report prepared by: Katrina Scior, Aseel Hamid, Richard Hastings, Shirli Werner, Catherine Belton, Adebisi Laniyan, Maya Patel and Maria Kett

Suggested Citation:

Scior, K., Hamid, A., Hastings, R., Werner, S., Belton, C., Laniyan, A., Patel, M., & Kett, M. (2015). *Intellectual Disabilities: Raising Awareness and Combating Stigma- a Global Review. Executive Summary and Recommendations*. London: University College London. Available from <https://www.ucl.ac.uk/ciddr/publications>

For queries relating to this document please contact: k.scior@ucl.ac.uk

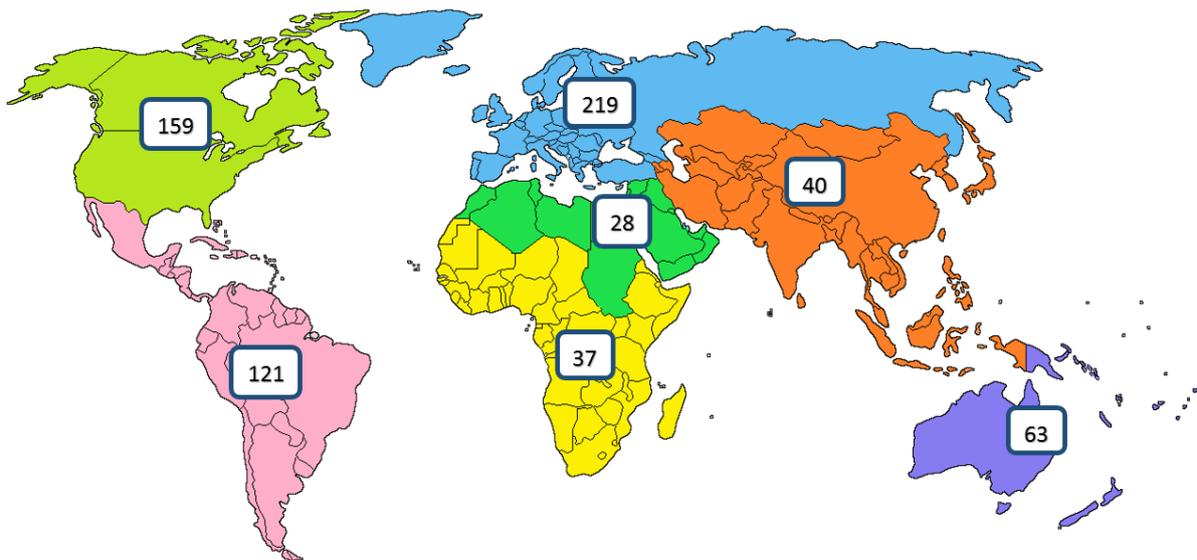
This Project

The physical inclusion of children and adults with intellectual disabilities is central but not sufficient in itself to achieve their meaningful social inclusion. The well-being and social inclusion of persons with intellectual disabilities is challenged by negative attitudes held among the general population and sub-sections of societies around the world. Yet information relating to inclusion and the wider societal context of attitudes to intellectual disability is fragmented and relates mainly to high income countries, despite a higher prevalence of intellectual disability in developing countries. There is very little comparative data to judge what attitudes towards adults and children with intellectual disabilities are held around the globe; to what extent prejudice and discrimination prevail; or what is being done to combat stigma associated with intellectual disability. For many countries worldwide, we have no access to published information on these issues. Our central objective in the current project was to begin to fill this gap by presenting global data on indicators related to the social inclusion of people with intellectual disabilities, continuing attitudinal barriers around the world, and attempts to address these.

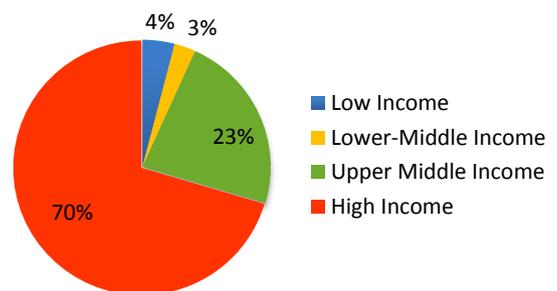
This report presents the findings from a review of UN States Parties reports and a survey of informants who are active in the field of (intellectual) disability around the globe on key indicators related to the social inclusion of people with intellectual disabilities, attitudes towards them, and attempts to raise awareness of intellectual disability and promote positive attitudes towards intellectual disability. In identifying actions undertaken to this effect, we asked about initiatives within education settings, those at local or regional level, and any initiatives on a national scale. The aim of this project was not to produce an exhaustive account of such initiatives but rather an overview of their range, objectives, and impact, and to identify priorities for moving forward.

The study was funded by University College London's Grand Challenges Global Health scheme. The dissemination of the findings was funded by the Royal Mencap Society, the largest non-governmental organisation providing advocacy and support for people with intellectual disabilities and their families in the UK. In carrying out this research we had generous support from Inclusion International who advertised the study on their website during January and February 2015, and also circulated information about it via their affiliate organisations around the world. The International Association for the Scientific Study for Intellectual Disabilities (IASSID) and Special Olympics also supported the study by distributing an invitation to complete our survey to their respective networks. Sampling targeted experts/researchers and representatives of organisations in the (intellectual) disability field as they were deemed well placed to observe attitudes within their own

country and likely to be aware of initiatives aimed at raising awareness and combating intellectual disability stigma. Parent advocates, in their frequent role as leads of non-governmental disability networks or organisations, and some self-advocates were among the respondents. Data were collected between January and March 2015 through a web administered survey, available in five languages. In total 667 complete and valid survey responses were received pertaining to 88 countries and covering all main world regions. This map shows the number of respondents per world region.



Countries from all four income categories defined by the *World Bank* according to gross national income (GNI) per capita are included in the data, albeit high income countries were over-represented.



The findings provide a comprehensive, global picture of attitudes to intellectual disability, both within and across countries and world regions. Above all, they provide the first overview of the range of initiatives in place around the world designed to raise awareness of intellectual disability and combat stigma. Where available, evidence on the effects of such initiatives was examined.

Overview of Findings

This review yielded a wealth of information about attitudes to intellectual disability around the globe. Here we present a summary of information extracted from States Parties reports to the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) Committee and of responses to the survey. The full report presenting the detailed findings and case studies of selected initiatives aimed at raising awareness or combating stigma is freely available at www.ucl.ac.uk/cidrr/publications.

States Parties Reports to the UN Convention

The CRPD, which has been ratified by 154 states within the last seven years, places a duty on governments to do more to promote respect for the rights and equality of people with disabilities. The Convention includes a duty to raise awareness of disability and combat prejudice and discrimination (Article 8). We have focused on Article 8 as the focus of this project is closely aligned with this Article of the Convention. States Parties to the Convention, that is countries that have ratified the Convention, report on actions taken in line with the Convention in a State Party Report. One aim of the present study was to examine what action, if any, governments have taken to raise awareness of intellectual disability and combat prejudice and discrimination towards people with intellectual disabilities.

Of the 76 States Parties reports submitted to the CRPD committee, all but one made explicit reference to intellectual disability at least once. Twenty-four reports referred to intellectual disability less than 10 times. In comparison, physical disability and severe visual impairment/blindness were explicitly referred to with vastly greater frequency. Although the term 'mental retardation' is now widely regarded as highly pejorative, 24 reports used this term when reporting to the UN. Of the 16 reports that explicitly referred to intellectual disability in their account of actions taken in line with Article 8 of the Convention, only five described initiatives to promote awareness which we could also trace via the internet.

Examination of the 32 Lists of Issues (LOIs) compiled by the CRPD Committee in response to its examination of States Parties reports indicates that the Committee holds people with intellectual disabilities in mind- we identified 24 references to intellectual disability in the 32 LOIs. Typically these were queries seeking to establish whether laws or initiatives described in the States Parties reports included people with intellectual disabilities. None of the LOIs included queries relating to intellectual disability under Article 8.

Overall, within the States Parties reports, whilst programmes to raise awareness of disability in general appear to be common, intellectual disability is rarely identified as a specific focus. This is concerning given that research suggests that lay people experience a lot of confusion about the concept of intellectual disability and the wide continuum of presentations subsumed under this label, and that people with intellectual disabilities frequently face hostile and negative attitudes and discrimination.

Public Attitudes to Intellectual Disability

We organised respondents' comments about attitudes to intellectual disability typically observed in their country into four themes: Belief in the Principle of Inclusion; Barriers to Inclusion (and Implementation); Out of Sight Out of Mind; and Ostracism. In many countries the fundamental principle of inclusion appears to find broad support, as do the closure of institutions and legislation advocating the rights of persons with intellectual disabilities. Across regions, positive public attitudes towards inclusion were typically described as developing over recent decades, thanks to marked changes and actions aimed at improving integration, and the work of NGOs and parents to raise awareness and advocate for inclusion. However, despite broad agreement with inclusion in principle, in many countries the general public view inclusion as impractical and unachievable, and view specialist educational and residential settings as best placed to meet the needs of persons with intellectual disabilities. Even in high income countries negative attitudes persist, particularly 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.

In many middle and low income countries, children and adults with intellectual disabilities often still face high levels of stigma and have their fundamental rights and freedoms denied. 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 contribute to society. Respondents noted that in many parts of Africa and Asia, in Russia, and in some parts of South and Central America there is often still an active desire to segregate people with intellectual disabilities from society due to deep rooted prejudice or stigmatising beliefs about the causes of intellectual disability.

This range of attitudes is also reflected in the language commonly used among the general population and media when referring to intellectual disability. Use of terms such as 'intellectual disability', currently deemed more acceptable, appears to have become more widespread around the globe, particularly in higher income countries, and use of derogatory terms such as 'mental retardation' appears on the decrease, compared to data collected

around 11 years earlier for the WHO’s ID Atlas. Nonetheless in many places around the world highly pejorative terms such as ‘retard’, ‘downey’, ‘moron’, ‘mongol’ and ‘fool’, that indicate fundamental disrespect and a failure to recognise the equal rights of people with intellectual disabilities, are still widely in use.

Inclusive Education

The right of children with intellectual disabilities not only to education, but also to inclusive education as the default has been firmly enshrined in international policy for two decades. However, not only are many children with intellectual disabilities still educated in segregated learning environments but in many countries they are denied the right to education altogether and are among the most marginalised of children ¹. As part of the survey we asked respondents where such children typically receive their schooling in their country, see Table 1.

Table 1: *Where children with intellectual disabilities are typically schooled*

| Where Schooled | Number of Responses | Proportion of Responses |
|--|---------------------|-------------------------|
| All/most in mainstream schools | 108 | 16.3 % |
| In both mainstream & special schools | 385 | 58.1 % |
| All/most in special schools | 136 | 20.6 % |
| Either special school or often not sent to school at all | 13 | 2.1 % |
| Typically not sent to school at all | 18 | 2.7 % |
| Unsure | 1 | 0.2 % |
| Total | 661 | 100% |

In some countries in Asia, Africa and South America, children with intellectual disabilities are often not sent to school at all, indicating the very negative effects the interaction between disability and poverty can have on children’s life chances (UNESCO, 2015). Canada and Italy were the only countries where all (Italy) or most (Canada) respondents to our survey reported that children with intellectual disabilities typically attend inclusive schools. However, even here there seems to be regional variation as one Canadian respondent observed: “*In the English sectors, mainstream is favoured. In the French sectors, special schools are favoured.*”

¹ UNESCO (2015). *Fixing the Broken Promise of Education for All*. Montreal, Canada: UNESCO Institute for Statistics.

Overall, at present countries where the government and education system offer inclusive schooling as default, and are willing to make reasonable adjustments to inclusive learning environments to accommodate the needs of children with intellectual disabilities, appear to be a tiny minority. Not only are many such children still educated in segregated learning environments, but in many places they are denied the right to education altogether. Clearly, much more needs to be done to assert the right of children with intellectual disabilities to education more generally, and to inclusive education specifically, in line with the CRPD.

Deinstitutionalisation

Under the Universal Declaration of Human Rights everyone has the right to life, liberty and security of person. The CRPD explicitly states that all persons with disabilities have equal rights and the fundamental right to freedom. It is now widely recognised that institutional environments are damaging to a person’s development and well-being, make them more vulnerable to abuse and violate their right to freedom. However, many people with intellectual disabilities continue to be placed in residential care institutions with little choice and few freedoms. Respondents to our survey were asked whether residential institutions for adults with intellectual disabilities are still in existence in their country and how big the largest such institutions are, see Table 2.

Table 2: *Largest Residential Institutions for Adults by Size*

| Size of Remaining Institutions | Number of Responses | Proportion of Responses |
|---|---------------------|-------------------------|
| >100 residents | 240 | 36% |
| 50 to 100 residents | 82 | 12.3% |
| 20 to 50 residents | 70 | 10.5% |
| 10 to 20 residents | 41 | 6.1% |
| < 10 residents | 57 | 8.5% |
| Only for short term assessment/treatment or as secure accommodation | 58 | 8.7% |
| There are no (remaining) residential institutions | 104 | 15.6% |
| unsure | 89 | 13.3% |

Note: Numbers exceed 667 as some respondents indicated that two of the response options applied

That their country has no plans for closing remaining large institutions was noted by 21% of respondents. Despite the intensely harmful effects of institutionalisation having been

recognised since the 1960s, the question should perhaps not be where large institutions still exist but rather where they no longer exist. Only a few countries that historically built large institutions have closed all, including Italy², Norway, the UK, New Zealand and Australia. In the USA and Canada all institutions have closed in some states/provinces yet some remain in others. In many countries the closure of large institutions has been very slow, with 1000s of citizens still living in such places, including in Ireland, Israel and Finland³. In others, institution closure has been followed by the establishment of new smaller institutions, often under a different name and purportedly different function, such as 'Assessment and Treatment Units' in the UK.

In some countries in South and Central America and Asia, where people with intellectual disabilities invariably live with their families, the lack of institutional or other care leaves many people with intellectual disabilities utterly unsupported when their parents die. Of note though, in countries where families are expected to care for their relatives with disabilities and where no or few support services exist, family support is by no means guaranteed and many individuals with intellectual disabilities are abandoned by their families.

Actions to tackle Disability Hate Crimes

Whether offences motivated by hostility or prejudice based on a person's disability are recognised as criminal offences, and the extent to which persons with intellectual disabilities who view themselves as having been the victim of a disability hate crime have recourse to legal action, is relevant to this study as it reflects a willingness on the part of governments to take action to prevent and punish the most extreme acts informed by prejudice. Responses to disability hate crimes – including punishments (or lack thereof) - should also be seen in the broader context of the law enforcement and judicial systems of each country.

Respondents were asked whether disability hate crime is recognised as a criminal offence in their country, and whether the courts or criminal justice system take action to tackle such crimes, see Table 3. The large number of respondents who were unsure regarding the answer to this question suggests that work is needed even among those with expertise in this field (and thus likely to be in a position to advise and support people with intellectual

² Although it is commonly reported that Italy was one of the forerunners of deinstitutionalisation, there was disagreement among the five Italian respondents whether all institutions have in fact closed.

³ All 3 countries have plans in place for the closure of their institutions: In Ireland plans are underway to move all 4000 remaining residents from institutions to community homes by 2018. In Israel 7,000 remain in institutional settings (average size 112 residents, range 21-324), with plans to move 300/year into small apartments in the community. Finland's government plans to close all institutions by 2020, ca 1400 persons will be moved out to the local community.

disabilities) to raise awareness about the law affecting people with intellectual disabilities even perhaps where there are legal provisions in place.

Table 3: Action by Criminal Justice System to tackle Disability Hate Crime by Region

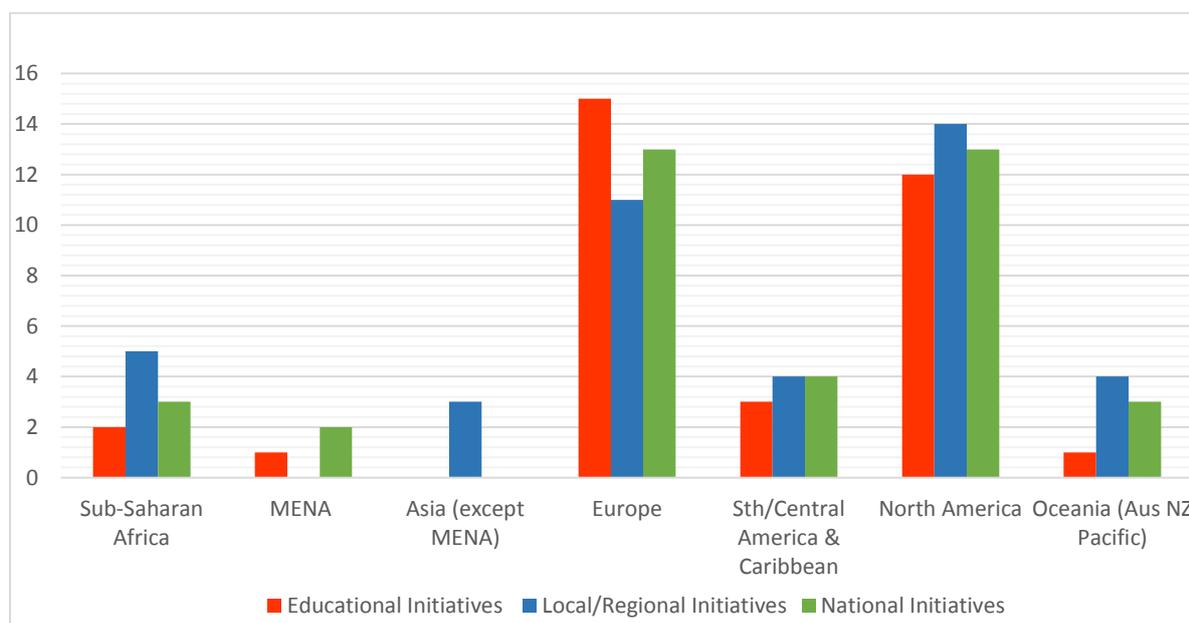
| Region | Yes | No | Unsure | Total |
|-----------------------------------|-------------|-------------|-------------|-------|
| Sub-Saharan Africa | 27.0% (10) | 37.8% (14) | 35.1% (13) | 37 |
| MENA (Middle East & N. Africa) | 39.3% (11) | 25.0% (7) | 35.7% (10) | 28 |
| Asia (except MENA) | 12.5% (5) | 42.5% (17) | 45.0% (18) | 40 |
| Europe | 42.2% (92) | 12.8% (28) | 45.0% (98) | 218 |
| South/Central America & Caribbean | 32.8% (40) | 30.3% (37) | 36.9% (45) | 122 |
| North America | 45.3% (72) | 10.1% (16) | 44.7% (71) | 159 |
| Oceania (Aus, NZ, Pacific) | 33.3% (21) | 20.6% (13) | 46.0% (29) | 63 |
| Total | 37.6% (251) | 19.8% (132) | 42.6% (284) | 667 |

In many countries respondents noted that hostile actions against someone with a disability are covered not as forms of hate crime but under (disability) discrimination legislation. However, this means that they mostly only provide a civil course of action and that underlying hostile attitudes towards those with disabilities may well be overlooked. In some countries people with intellectual disabilities appear to have very little protection in law if they are victimised because of their disability.

Initiatives aimed at Raising Awareness & Combating Stigma

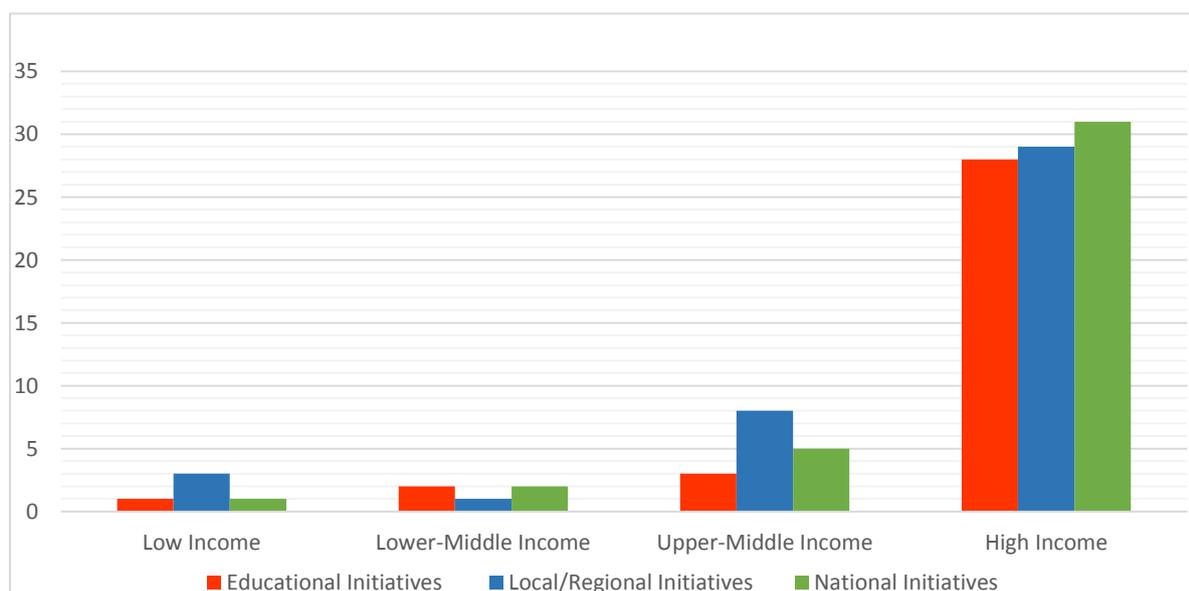
One key objective of this study was to identify what, if any, actions are being taken around the world to raise awareness of intellectual disability and combat stigma, in line with the duties laid on governments under Article 8 of the CRPD. We classified initiatives according to whether they target (1) children within education settings; (2) the wider community through local or regional initiatives; (3) wider society through initiatives implemented at national level, see Figures 1 and 2 for breakdowns by region and country income category.

Figure 1: Number of educational, local/regional and national initiatives by UN region



The majority of the 29 educational initiatives identified took place in Europe and North America (the numbers in Figure 1 exceed 29 as some initiatives were carried out in several countries simultaneously). Similarly, the majority of the 41 initiatives carried out at local or regional level and of the 29 national initiatives (again some were carried out in several countries simultaneously) took place in Europe and North America. Across all three types of initiative, we identified only 10 in Sub-Saharan Africa, 11 across the whole of South, Central America and the Caribbean, three across the MENA region, and three across the whole of Asia.

Figure 2: Number of educational, local/regional and national initiatives by country income



Of all initiatives identified, 88 took place in high income countries yet only 26 in low, low-middle and upper-middle income countries, see Figure 2. In view of reports noted earlier that stigma in some lower income countries and in large parts of Asia, Africa, and South and Central America is often very high, the urgent need to raise awareness and combat stigma in such countries does not appear to be in any way matched by initiatives to this effect. Instead, such efforts appear to be small in number and entirely dependent on the efforts of parent run organisations and NGOs.

Almost a third of respondents named initiatives aimed at raising awareness and/or promoting positive attitudes run by Special Olympics, indicating the high profile this organisation has in this field. Other than this, similar efforts appear replicated within and across countries with little evidence of substantial cross-fertilisation. Most of the initiatives identified aimed to raise awareness, about half also set out to change attitudes. Few aimed to actively change behaviour, which is concerning given that being treated as different and discriminated against is a common concern for people with intellectual disabilities. Only a few of the initiatives identified have been formally evaluated using pre- and post- measures, and none, to our knowledge, have been evaluated through a randomised controlled trial.

Summary of the Findings

Overall, it seems in many countries around the globe there is agreement with the fundamental principle of inclusion and the rights of people with intellectual disabilities. Compared to earlier multinational studies⁴, this suggests a shift in a welcome direction in many countries. This can be evidenced by the gradual reduction in the use of pejorative language to talk about intellectual disabilities, particularly in some (high and middle income) countries. However, in many parts of the world, particularly countries in Africa, Asia, some part of South/Central America and the Caribbean, and former member states of the Russian Federation, highly stigmatising beliefs about intellectual disability and hostility to the concept of full inclusion are still a huge concern and a real barrier to the well-being, rights and life chances of people with intellectual disabilities. While this indicates an urgent need to raise awareness and combat stigma in such countries, initiatives to this effect appear to be small in number and entirely dependent on the efforts of parent organisations and NGOs.

Intellectual disability still appears to be of low priority in government action around the world, evident in the relatively few references in States Parties reports to the UN CRPD Committee. Furthermore, we found little evidence of governmental recognition that

⁴ Siperstein et al.'s (2003) *Multinational Study of Attitudes toward Individuals with Intellectual Disabilities conducted in 10 countries* (Brazil, China, Egypt, Germany, Japan, Nigeria, Ireland, Russia, Northern Ireland and the USA) noted a definite presence of negative attitudes towards people with intellectual disabilities.

awareness of intellectual disability needs raising either explicitly as part of general disability awareness raising or in its own right.

Few countries formally recognise extreme acts informed by hostility and prejudice against those with intellectual disabilities through a separate category of disability hate crime. In some countries people with intellectual disabilities appear to have very little recourse to legal protection if they are victimised because of their disability.

Overall, there appears to be relatively limited action to actively combat stigma directed at children and adults with intellectual disabilities. With the exception of Special Olympics and Best Buddies programmes, which are run in many countries, the numerous initiatives we encountered are often small in scale and can be relatively short lived (even though it is widely recognised that changing attitudes takes a long time). They also often appear rather disjointed and we found little evidence of learning from one another.

The initiatives identified were accompanied or backed up by very little evidence as to what works in combating intellectual disability stigma. Few initiatives have been evaluated, and even fewer have been evaluated using sufficiently robust scientific methods that would render findings on the initiative's impact valid and reliable. We found no evidence of any randomised controlled trial (RCT), the gold standard for evaluating interventions. Without such robust evaluation it is impossible to conclude reliably that any effects observed are due to the work undertaken and not to other factors.

This project's findings can serve as a baseline against which to measure the volume and impact of future initiatives.

Recommendations

Children and adults with intellectual disabilities need to experience greater inclusion in societies and in the public sphere, and have their fundamental rights and freedoms respected. One of the best ways to achieve this is for them to have greater visibility and voice in all areas of public life, through measures including: inclusive education; closure of all institutional facilities; work with the media; and supporting their louder voices in the disability rights movement and beyond.

More efforts are required to raise awareness of intellectual disability and combat stigma, including in low and middle income countries where awareness is often low and stigma can be high. Such efforts are likely to call for collaboration between governments and NGOs, many of which are parent led, and allocation of funding to support activities of NGOs. Governments, in collaboration with the media, have an important role to play in raising the profile of people with intellectual disabilities.

While awareness raising may well be conducted as part of broader disability awareness initiatives, without explicit attention to intellectual disability it is a fallacy to assume that education about other types of disability will necessarily lead to a better understanding of intellectual disability.

Language not only reflects values and beliefs held within a culture, but also powerfully shapes attitudes. To avoid the adverse consequences of using inconsistent and (potentially) derogatory vocabulary, the terminology used by states reporting to the CRPD requires harmonisation, preferably using the term 'intellectual disability'.

Closer attention is needed in most countries globally to ensure that persons with intellectual disabilities who are the victims of criminal acts informed by hostility or prejudice towards people with disabilities have proper recourse to the law and law enforcement. Very few countries have legislation in place that recognises such crimes as hate crimes on a par with racially motivated crimes, and that provides for harsher sentencing.

As there is very limited evidence as to what works in combating stigma associated with intellectual disability in different settings and cultural contexts, evaluation should be built into initiatives from the outset. In evaluating what is seen as 'good' or 'best' practice it is important to be cognisant of challenges in lower/middle income countries. In any case, evaluation and more broadly evidence production is likely to be achieved only through much closer collaboration between disabled people's organisations, NGOs and other disability organisations with academics and researchers, and through increased collaboration between those seeking change.