UCL

Intellectual Disabilities:
Raising Awareness and Combating Stigma

A Global Review

Leonard Cheshire Disability

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The voice of learning disability

Acknowledgements

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.

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We also thank Katalin Hajdú, Chloe Davies and Andre Strydom (UCL) for their input.

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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.* London: University College London. Available from:

https://www.ucl.ac.uk/ciddr/publications

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Contents

Executive Summary

This report presents the findings from a survey of informants who are active in the field of (intellectual) disability around the globe. We include date on the social inclusion of people with intellectual disabilities and attempts to raise awareness of intellectual disability and combat stigma. Furthermore, we provide a review of States Parties reports to the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) Committee relating to Article 8 of the Convention (awareness raising and combating prejudice and harmful practices). The aim of this project was not to produce an exhaustive account of such initiatives but rather to produce an overview of attitudes to intellectual disability around the world; of the range of initiatives implemented in different parts of the world; and to identify priorities for moving forward.

Other than Siperstein et al.'s (2003) *Multinational Study of Attitudes toward Individuals with Intellectual Disabilities* across 10 countries, and data on awareness raising campaigns collected as part of the World Health Organisation (WHO) *Atlas of Global Resources for Persons with Intellectual Disabilities* (2007), this is one of the most comprehensive global studies into attitudes to intellectual disability. It is also the first study to our knowledge to examine the range of actions in place around the globe to raise awareness, and combat stigma associated with intellectual disability. The key findings of our review of States Parties reports to the UN CRPD Committee, and survey responses from 667 experts and representatives of organisations active in the (intellectual) disability field from 88 countries, can be summarised as follows:

- While respect for diversity and the rights of minority groups are being taken very seriously in many parts of the world, despite the CRPD, in 2015 children and adults with intellectual disabilities are mostly still an invisible minority.
- People with intellectual disabilities are accorded low visibility, for example, in government action, in line with the duties placed on them under the UN CRPD. Of the 76 States Parties reports submitted to the CRPD Committee, only 16 specifically referred to intellectual disability in reporting efforts undertaken to raise awareness or combat prejudices. Intellectual disability mostly appears to be subsumed within general disability awareness raising, or overlooked entirely.

- In many countries the principle of inclusion for people with intellectual disabilities is accepted. However, among both the general population (and service providers) it is often viewed as impractical and unachievable, and there is often still concern that inclusion may have negative consequences for those without disabilities, particularly in school and work settings. Thus, the positive impact of inclusion not just for people with intellectual disabilities but for the general population should be stressed as part of awareness raising initiatives.

- In large parts of the world, particularly low and lower-middle income countries in Africa, Asia, Southern and Central America and in Russia, there is often still an active desire to segregate people with intellectual disabilities from society due to deep rooted prejudices or stigmatising beliefs about the causes of intellectual disability.

- This range of attitudes is 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 internationally, appears to have become more widespread around the globe. The use of derogatory terms such as 'mental retardation' appears on the decrease, compared to data collected around 11 years earlier for the WHO Atlas. However, in many places around the world highly negative 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.

- We identified continued segregation of people with intellectual disabilities in separate schools and institutions in all parts of the world; though its form and extent differ across countries and regions. Although the harmful effects and violation of fundamental human rights inherent in segregation has been widely recognised for five decades, closure of institutions and implementation of inclusive education settings that meet the needs of most persons with intellectual disabilities has been slow in most countries.

- 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.

- Around the globe, numerous initiatives are in place aimed at raising awareness of intellectual disability and combating stigma among children and adults in the general population, and among groups most likely to be in contact with people with intellectual

disabilities. Other than initiatives run by organisations with national and cross-national reach, similar efforts appear replicated within and across countries with little evidence of substantial cross-fertilisation. To encourage learning from initiatives that may be applicable elsewhere around the world and to illustrate the range of efforts underway, in this report we feature selected initiatives.

- The aims of many of the initiatives we encountered were poorly articulated. Whilst there appeared to be a lot of work aimed at raising awareness of disability generally and to a lesser extent of intellectual disability specifically, many of these appeared to be based on the implicit assumption that raising awareness would result in more positive attitudes and a reduction in discriminatory behaviour. Other projects did not express any specific aims for their work. Given that discriminatory behaviour is what is most likely to affect the life chances and well-being of people with intellectual disabilities, more attention should be given to initiatives that stand a chance of not just raising awareness but actively changing behaviour.

- Most of the initiatives we encountered aimed at raising awareness of intellectual disability and combating stigma had either not been evaluated at all or only informally so. We found few rigorously evaluated initiatives and thus little evidence regarding what works in raising awareness of intellectual disability and combating stigma. Given that research from other fields show that many attempts to change attitudes and/or behaviour fail to meet their aims and at best result in increased knowledge but little attitude or behaviour change, more efforts should be made to build rigorous evaluation into new initiatives. Adoption of an evidence based approach would also allow much more learning from others' efforts and avoid replication of efforts unlikely to lead to significant positive outcomes.

Chapter 1: Introduction

From attempts by the Eugenicists and the Nazi regime to eradicate people with intellectual disabilities alongside other groups deemed "undesirable", to playground taunts that use derogatory language associated with intellectual impairment, to being shunned because their disability is seen as a sign of evil forces at play, people with intellectual disabilities have been ostracised throughout history and across cultures, and are one of the most marginalised and excluded (social) groups around the world. Over recent decades much progress has been made towards improving the quality of life of people with intellectual disabilities and promoting their increased inclusion in the community in some parts of the world. However, even in these countries concerns are often expressed about the continuing presence of negative attitudes and discrimination directed at people with intellectual disabilities, and the lack of their actual *social* inclusion.

Information relating to inclusion and the wider societal context of attitudes to intellectual disability is fragmented and relates mainly to high income countries. There are very few comparative global data to judge what attitudes are commonly held towards people with intellectual disabilities, to what extent prejudice and discrimination are still realities for many people, 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 objective in this project was to begin to fill this gap by gathering data from informants who are active in the field of intellectual disability on indicators related to the social inclusion of people with intellectual disabilities, attitudes towards them within society, and what attempts are being made to improve attitudes.

Previous attempts to compile comparative data specific to intellectual disability from around the globe most notably include Siperstein et al.'s *Multinational Study of Attitudes toward Individuals with Intellectual Disabilities*, commissioned by Special Olympics and published in 2003, and the WHO *Atlas: Global Resources for Persons with Intellectual Disabilities*, published in 2007. The first of these comparative reports depicted how people across the world view the roles and capabilities of persons with intellectual disabilities in the workplace, the classroom and in daily social life. The study was conducted in late 2002 across 10 countries (Brazil, China, Egypt, Germany, Ireland, Japan, Nigeria, Northern Ireland (part of the UK), Russia and the United States). The findings, based on a survey of an average of

around 800 members of the general population per country, showed that at the time there was a definite presence of negative attitudes - both within and across the countries surveyed - toward persons with intellectual disabilities. The authors drew attention to the relationship between public attitudes toward people with intellectual disabilities and cultural norms, values and resources and services within countries.

The 2007 WHO Atlas set out to map resources and services for people with intellectual disabilities around the world. Data presented in the Atlas were based on 147 respondents from 143 WHO member states and territories. One response per country was obtained either from a representative of the government or a governmental advisory body, an NGO, or a university or research institution with expertise in the intellectual disability field. The Atlas highlighted the substantial lack of services available to people with intellectual disabilities worldwide. It also revealed differences between regions in efforts directed towards national awareness and the social inclusion of people with intellectual disabilities. While the Atlas' main focus was on resources, its authors did report briefly on efforts to raise awareness of intellectual disability. Of the 147 countries, 60.3% reported carrying out public awareness campaigns related to intellectual disability. As we note in this report, we estimate the actual figure to be much lower as intellectual disability is often not covered in the many general disability awareness campaigns conducted.

More recently, the *World Report on Disability* (2011) has brought out many of the issues and challenges around ID. First and foremost is the issue of definition. The CRPD does not define disability per se, but rather talks about it as an outcome of the interaction between an impairment and the environment. Such a definition highlights the heterogeneity of experiences, life chances, choices and preferences of adults and children with disabilities, shaped by a range of socio-economic, cultural and other factors, rather than focusing on a condition, Therefore, in line with the CRPD, in the *World Report on Disability* the term 'intellectual impairment' is preferred, and defined as follows:

> *"A state of arrested or incomplete development of mind, which means that the person can have difficulties understanding, learning, and remembering new things, and in applying that learning to new situations. Also known as intellectual disabilities, learning disabilities, learning difficulties, and formerly as mental retardation or mental handicap. (p. 305)*

This does highlight the issue of language and terminology, and how the language used to describe people can shape attitudes and practices. In the *World Report on Disability* examples of specific interventions and their impact on attitudes and practices are given, in particular the risks to persons with intellectual disabilities of violence and abuse; the need for carer support; challenges with accessing a variety of services, in particular healthcare, and linked to this, the issue of legal capacity. The aim of our report then is to summarise the current situation vis a vis attitudes and their grounding within inclusive or conversely segregationist practices. It is not an exhaustive study but rather an attempt to generate a comparative overview of attitudes and progress towards inclusion in some key areas around the world.

For people with intellectual disabilities to have equal rights and be fully included in their communities, there must be accessible services including education, health and social care; with legislation, policy and structures in place that promote inclusion, in addition to a population that is willing to accept and include people with intellectual disabilities. Achieving physical inclusion in local communities and wider society for children and adults with intellectual disabilities is central but not sufficient in itself to achieve acceptance and meaningful *social* inclusion. For this to happen, more direct action is needed to combat negative attitudes, and promote active engagement and regular social interactions between persons with intellectual disabilities and their fellow citizens without intellectual disabilities. At the same time we must be careful not to lose sight of the interaction between the underlying impairment in intellectual disability, personal, environmental and broader social factors, as well as the highly varying support needs individuals have, and risks that are inherent in social inclusion.

1.1   Background

The *World Report on Disability* (2011) produced jointly by the WHO and the World Bank concluded that more than a billion people around the world today experience some form of disability. Eighty per cent of these live in developing countries. Wherever they live, people with disabilities generally have poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities. It is estimated that around 2% of people in the general population have an intellectual disability, although estimates vary from 1 to 3%. Intellectual disability, like disability in general, is more common in developing countries due to poorer health and maternity care, and increased risk

of exposure to diseases, toxins and severe malnutrition. Persons with intellectual disabilities experience the same sources of disadvantage and inequities as 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 in the disability rights movement. Furthermore they frequently have to rely on parents, parents' groups and disability organisations to advocate for them and to support their rights.

Nevertheless, one of the key achievements of the disability rights movement inrecent decades has been the successful lobbying and eventual coming into being of the United Nations (UN) CRPD, which formally recognises the duty of governments around the world to promote and protect the full and equal enjoyment of all human rights and freedoms for persons with disabilities. The Convention was adopted by the UN General Assembly in December 2006, and entered into force in May 2008. To date, the Convention has been signed by 159 states and ratified (or acceded to)[1] by 154, see map below. By ratifying the Convention, states commit to enact domestic laws and measures to improve disability rights, and to abolish discriminatory legislation, customs, and practices.

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[1] The first step in becoming a party to the Convention is signing the treaty, which indicates a state or regional integration organisation's (ROI) intention to take steps to be bound by the treaty at a later date. The next step is ratification (or accession without prior signing), which signals the intention to undertake legal rights and obligations contained in the Convention. Further details including dates when states signed and ratified the CRPD can be found on the CRPD website: www.un.org/disabilities/countries.
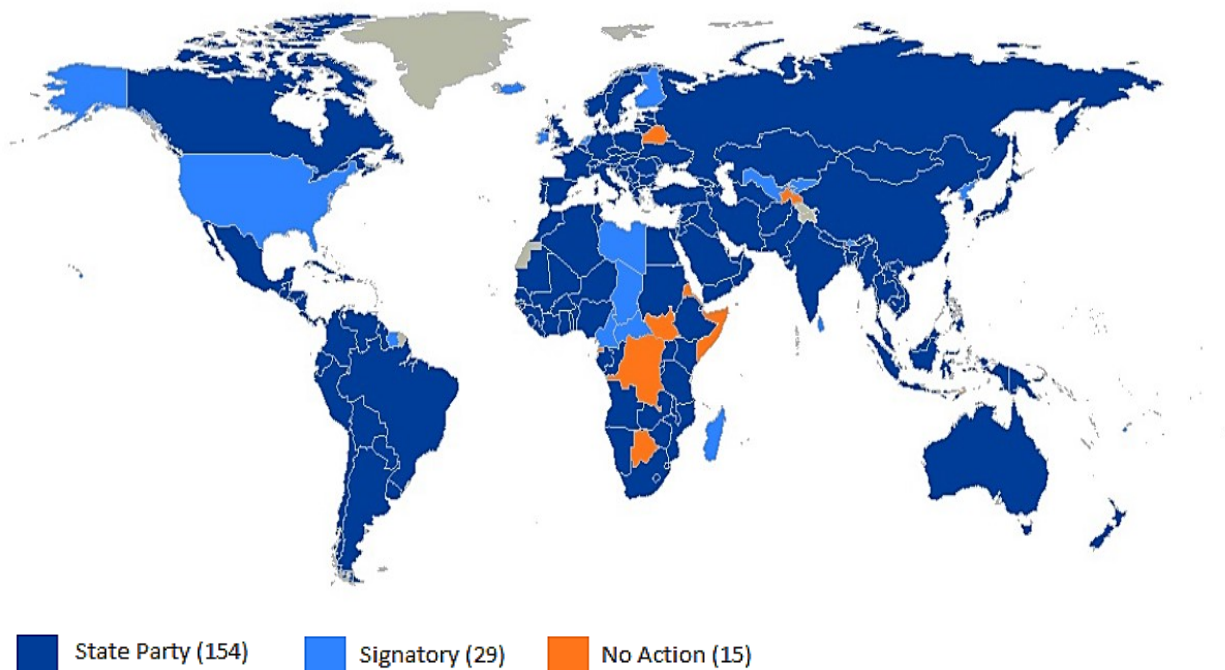
Source: www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx

In line with the reluctance to define disability outlined above, there is no specific article on intellectual disabilities, but of course all the articles of the convention relate to all persons with disabilities. Particularly relevant articles include Articles 5 (Equality and non-discrimination), Article 8 (Awareness raising and combating prejudice and harmful practices), and Article 12 (Equal recognition before the law) – the latter has specific resonance for persons with intellectual disabilities, many of whom are assumed not to have decision-making capacity or autonomy of choice. This has led to situations such as those highlighted in the aforementioned World Disability Report regarding sexual and reproductive health (in particular forced sterilisation), as well as more general issues regarding duty of care, independent living and access to justice. Policies and legislation in relation to Articles 5 and 12 play an important role in the recognition, physical integration and protection of people with intellectual disabilities, which may in turn in shape the attitudes of those governed by these laws. This does not necessarily translate into actual participation and social inclusion within societies though, particularly where social attitudes act as barriers. As our research examines attitudes and attempts to improve them, we have focused specifically on Article 8. This Article calls on governments to raise awareness of the needs of persons with disabilities, and to combat prejudices and harmful practices.

People with intellectual disabilities are part of the broader population of persons with disabilities covered under the Convention. They experience high levels of stigmatisation, social exclusion, and discrimination in many spheres of life. However, in a recent review of the research literature we identified only 75 articles on societal responses to this population, mainly reporting on North America, Europe and Asia (Scior, 2011). A further review of interventions aimed at tackling negative attitudes towards this population among lay people identified only 22 research-based published studies (Seewooruttun & Scior, 2014). Thus, our understanding of this area is very limited. This stands in marked contrast to concerted efforts directed at understanding and fighting stigma and discrimination relating to physical illness (e.g. HIV/AIDS) and mental health problems. Furthermore, anecdotal evidence suggests that action focused on people with intellectual disabilities in line with Article 8 (awareness raising and combating of prejudices and harmful practices) is highly variable across countries.

1.2 Definitions and Cultural Context

As noted above, the CRPD does not define disability per se, rather it talks of the interaction between an impairment and the environment. However, in countries and regions where definitions of disability – or at least identification of such – can lead to improved access to services and provisions, attempts have been made to try to categorise and define intellectual impairment. The most commonly adopted definitions are those published in the International Classification of Diseases (ICD-10, WHO, 1994) and the Diagnostic and Statistical Manual (DSM-5, American Psychiatric Association). They define **intellectual disability** as:

- Significant impairment of intellectual (cognitive) functioning, indicated by a full scale IQ below 70;

- Alongside significant impairment of adaptive (social) functioning that affects how a person copes with everyday tasks in three areas (American Psychiatric Association, 2013):
  - The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
  - The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
  - The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks."

These difficulties must be of early onset (i.e. they are not the result of trauma or deterioration experienced during adulthood). The most common causes of intellectual disability are genetic conditions, such as Down Syndrome or Fragile X; complications during pregnancy, such as rubella or foetal alcohol syndrome; complications around the time of birth; and exposure to diseases or toxins post-birth. It is important to stress that intellectual disability is a continuum; not only do those along the continuum vary hugely in their functioning and the volume and type of support they need, but they also differ hugely in their capabilities, personalities, and wishes.

In many places and countries around the world, particularly low and middle income countries, access to culturally appropriate diagnostic assessment and support services is very

limited or non-existent. As a result many children and adults who meet the aforementioned criteria for an intellectual disability are not formally identified or diagnosed. Lack of awareness, rights and responsibilities has led to significant prejudice against persons with intellectual impairments in most countries.

In highly developed countries, persons with intellectual disabilities were historically only deemed a concern when increasing industrialisation and the accompanying urbanisation led to the erosion of community support structures and gave rise to increasing state-based intervention and institutionalisation. Mixed accounts can be found in the literature regarding attitudes to intellectual disability in developing countries. Some note that in rural communities persons with intellectual disabilities are often an integral part of village communities and contribute according to their abilities (Ingstad & Reynolds Whyte, 1995). Others note that traditional beliefs and misconceptions about the causes of intellectual disabilities can lead to them being viewed with suspicion and to be ostracized from their communities (e.g. Mung'omba, 2008). Mckenzie et al. (2013) suggest that this apparent contradiction may be explained by the severity of intellectual disability and the competence of the person: where they are socially competent and can contribute to the household they may be more accepted. However, if they are highly dependent and seen as a burden on limited family resources, there may be less acceptance, especially in the absence of support services.

As is well established, all disabilities are culturally constructed and contextualised. Every society and culture has its own understanding of disability, and what may be seen as 'disability' in one is not necessarily seen as such in another. In part this reflects the CRPD definition of the interaction between impairment and environment. In theory, as the Social Model of disability has long posited, if a society is fully inclusive, then the negative and disabling consequences of impairment should be minimal. However, many now argue that a Rights Based model is better suited to tackling continuing barriers that prevent persons with disabilities from fully enjoying their rights.

Awareness, attitudes and stigma are concepts at the heart of this report and merit brief definition. Awareness refers to knowledge or perception of a situation or fact (Oxford dictionary). In the context of this report it refers to a basic understanding what intellectual disability is, and that it differs from other constructs such as mental illness and specific learning difficulties (e.g.,dyslexia). **Attitudes** are a psychological construct that refers to

favourable or unfavourable evaluations of people, objects, places or activities. They are made up of three aspects: a cognitive component (how we *think* about X), an emotional component (how we *feel* about X), and a behavioural component (how we *act* towards X). While contemporary psychological definitions encompass these three aspects, in common parlance the term 'attitudes' is mostly used to refer to the cognitive component alone, and less so to emotions and actions or behaviours. **Stigma** is a term used in preference to 'attitudes' in other fields, such as mental health and HIV/AIDS. The term originates in ancient Greek and was reintroduced into common parlance in the 1960s by Goffman[2] who defined stigma as the process by which the reaction of others spoils normal identity. More recently, stigma has been conceptualised as the co-occurrence of these stigma components: labeling, stereotyping (that is negative evaluation of a label), prejudice (that is endorsement of negative stereotypes), which lead to status loss and discrimination for the stigmatised individual or group [3][4]. Importantly, for stigmatisation to occur, power must be exercised (i.e., members of the stigmatised group are disempowered by having their access to rights, resources, and opportunities deterrmined by those invested with more power in the social hierarchy) - a condition that is clearly met in the case of people with intellectual disabilities.

1.3   This Project

In this project we set out to draw together empirical and anecdotal evidence from around the globe relating to actions undertaken to raise awareness of intellectual disability, combat prejudices and promote positive attitudes. As well as summarising published evidence, we engaged with researchers, statutory and third sector organisations, self-advocates, and advocates (often family members of people with intellectual disabilities) in collecting evidence addressing the following questions:

1a. What attitudes to intellectual disability prevail in different countries and world regions?

1b. What terminology is used among the general population and the media to refer to persons with intellectual disabilities?

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[2] Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity.* London: Prentice-Hall.

[3] Link, B.G. & Phelan, J.C. (2001). Conceptualizing Stigma. *Annual Review of Sociology, 27*, 363-385.

[4] Corrigan, P.W. & Watson, A.C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry, 1*, 16–20.

2. What structures and practices are in place to promote the inclusion of children and adults with intellectual disabilities?

3. What, if any, action has been taken within education settings, and at local, regional or national level to raise awareness, combat prejudices and promote positive attitudes intellectual disability?

4. What are the gaps in research, policy and action?

1.4 Method

Information presented in this report was gathered through:

a) A review of States Parties reports to the UN CRPD committee (the reports to the UN from countries that have ratified the convention on its implementation);

b) A large scale internet survey circulated by the two partner organisations (Inclusion International and Leonard Cheshire Disability) and with the support of IASSID and Special Olympics, as well as through contacts of the research team. The survey was made available in English, Arabic, French, German and Spanish. Respondents were encouraged to forward the survey to relevant people or organisations in their region.

We are mindful that there are many other sources of information about initiatives to raise awareness of intellectual disability, combat prejudices and promote positive attitudes. Summarising all these is beyond the scope of this report. However, we hope that in taking a global view in presenting selected initiatives, we are able to convey key messages about progress in this area, encourage further dialogue and enable interested parties to learn from one another.

Chapter 2: States Parties reports to the UN CRPD Committee

As noted in the introduction, when countries ratify the CRPD, they commit to uphold its legislation and promote its values. Countries must submit their first 'State Party Report' to the CRPD Committee within two years of ratification. This must give details of actions taken in line with the convention. Non-governmental organisations (NGOs) may also submit 'Shadow Party Reports' to the committee giving their perspective on the country's progress towards CRPD implementation.

The CRPD Committee meets twice a year for three weeks at the UN's Headquarters in Geneva to review these reports in detail and meet with a delegation from each country (this can include representatives of organisations for people with disabilities, persons with disabilities and their families). The committee then compiles a 'List of Issues', which detail concerns about a report and requests for additional information. The country's representative is invited to formally respond to these concerns and detail plans for action. After this inaugural review, subsequent reports must be submitted at least every four years or when requested by the committee.

2.1   Our research

To explore how frequently the rights of persons with intellectual disabilities are addressed in States Parties Reports or raised for consideration by the CRPD Committee, all reports and lists of issues submitted to date to the CRPD Committee were accessed through the CRPD website (http://www.un.org/disabilities/). The reports were examined in relation to three questions:

(1) To what extent are people with intellectual disabilities referred to across each State Party's report?

(2) How frequently are intellectual disabilities explicitly referred to in actions relating to Article 8?

(3) What type of actions relating to Article 8 with respect to intellectual disability are reported?

2.2   Findings

To date 76 countries have submitted a report to the CRPD Committee, all of which we accessed and analysed. (Oman is recorded as a 77th country to have submitted a report but this was not available via the CRPD website or secretariat at the time of this project).

2.2.1   Attention to Intellectual Disability in the Reports

All but one of the 76 States Parties reports examined referred to intellectual disability by this term or a synonym at least once. Armenia's report made not a single reference to intellectual disability (or a synonym). Across all reports, intellectual disability was mentioned on average 19 times (range: 1 to 76 times). Twenty-four of the 76 reports referred to intellectual disability fewer than 10 times. In comparison, physical disability and severe visual impairment/blindness were explicitly referred to with vastly greater frequency.

Although the UN's preferred term is 'intellectual disability', reflected in the terminology used in its 'Lists of Issues', it is of note that many reports used highly variable terminology to refer to intellectual disability. In 30 reports 'intellectual disabilities' was the predominantly used term, however the more common label given was 'mental disabilities' without distinction between mental illness or intellectual disability. Other commonly used terms included 'intellectual impairment', 'learning disabilities' and 'mental handicap'. Twenty-five reports referred to 'mental retardation'. This may be at least partly explained by the fact that this term is still used in the WHO's ICD-10. However, the term is now widely regarded as derogatory and the WHO intends to replace it with 'intellectual developmental disorders' in ICD-11 to be published in 2017.

2.2.2   Intellectual Disability in relation to Article 8

Within the section detailing their actions in line with Article 8, many States Parties reports gave details of initiatives aimed at raising awareness of disabilities as a whole or marking events such as 'International Day of Disability'. Whilst these projects may have incorporated awareness raising of intellectual disability, for the purposes of this research we focused only on those reports which specified the inclusion of intellectual disability in the country's actions.

Sixteen reports of the 76 submitted, explicitly referred to intellectual disability in the section addressing Article 8 (22%). In some cases this was a passing mention or details of a project not in fact specifically related to raising awareness. In some cases countries reported marking events such as World Autism Day or World Down Syndrome Day but did not describe how these occasions were used to promote awareness of intellectual disability in general. Some countries also described in this section their production of 'Easy Read' guides to raise awareness of the CRPD among people with intellectual disabilities but did not describe any steps taken to raise awareness of intellectual disability among the general public. A summary of the 16 reports that explicitly referred to intellectual disability in detailing actions taken in line with Article 8 can be found in Appendix 6.

Where specific and relevant projects were identified in the reports we followed up references using the internet to explore evidence of the project and evaluation data. In some cases, as the States Parties reports were in English and the names of projects had also been translated, we were unable to identify the initiative referred to. Several projects could not be located or were referred to with only limited information.

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 (7% of all States Parties reports) described initiatives to promote awareness which we could also trace via the internet. Of these projects, public information campaigns were the most common awareness-raising approach cited:

'Accept it and Accept me' (Hungary)

A road show run over the past six years by the Hand in Hand Foundation to raise awareness of disabilities in general, with some activities focused on intellectual disability.

'Life as a Safe Adventure' (Macedonia)

A campaign run by the PORAKA organisation to raise awareness of abuse directed at people (particularly children) with intellectual disabilities. It is aimed at the public, families of people with intellectual disabilities and professionals.

Awareness Campaigns by the Shafallah Centre (Qatar)

A centre for children with intellectual disabilities and autism from birth until the age of 27 years has run several public awareness campaigns about Down Syndrome and Autism.

Other projects made use of the creative arts to challenge attitudes:

'Some other stories' (Croatia)

A short film aimed at raising public awareness about the right to life of persons with Down Syndrome which was shown at several film festivals and was also screened in cinemas outside Croatia.

Social Theatre (Moldova)

Using young people as actors, Keystone Moldova have developed a show highlighting issues of exclusion of people with intellectual disabilities in schools. The show is performed in schools and pupils are invited to discuss its impact.

Whilst the examples of awareness raising initiatives taking place are encouraging to note, their limited number stands in sharp contrast to previously available global data on campaigns purporting to raise awareness of intellectual disability. In the 2007 WHO Atlas, of the 147 countries included, 60.3% reported carrying out public awareness campaigns related to intellectual disability. This figure was even higher for countries of high income (73.5%), and for South-East Asian countries, 80% of which reported having carried out such campaigns. Of the countries which reported running such campaigns to the WHO Atlas team, 15% said they were held annually.

The WHO Atlas' authors noted that in many cases awareness of intellectual disability was raised as part of more general disability awareness initiatives, which may in part explain the dramatic difference between these figures and our own findings. Some of these initiatives may have ended in the interim years of course. It is also important to consider that actually tracing these initiatives on the internet will have ruled out some which were small scale and may not have an internet presence. Nonetheless, we suspect that the WHO Atlas figure is an overestimate of the number of campaigns that actually do raise awareness of intellectual disability, and not just disability generally. We base this on the fact that in our survey 59% of

respondents replied 'yes' to the question of whether there are any national efforts, such as campaigns to raise awareness of intellectual disability. However, when we asked them to provide more details on such efforts, 54.5% provided further information but only 10.3% of the initiatives detailed in fact appeared to be efforts at raising awareness or changing attitudes that either clearly included or were specifically focused on intellectual disability once we had researched them in more detail.

2.2.3 Intellectual Disability in the CRPD's List of Issues

After consideration of the report submitted by a state party, the CRPD Committee compiles a 'List of Issues'. This list, typically around 4 to 5 pages in length, addresses any queries or concerns held by the committee in relation to each of the articles in the Convention.

We examined the 32 Lists of Issues available via the CRPD website, alongside 23 replies to them. Of the 32 Lists of Issues, 24 mentioned intellectual disability in relation to at least one of the articles of the Convention, with two mentions on average (range: 1 to 11 mentions). Typically queries in relation to intellectual disability sought to establish whether laws or initiatives described in the States Parties reports included those with intellectual disabilities or whether certain articles such as 'respect for private and family life' (Article 23) were being actively supported for people with intellectual disabilities. One notable query raised by the Committee in response to Mauritius' report, under Article 5 (Equality and Non-Discrimination), asked whether references such as 'persons of unsound mind' and 'state of imbecility' had been removed from their country's legislation.

None of the Lists of Issues included queries relating to intellectual disability under Article 8. Although it is worthy of note that in two replies to the respective List of Issues, Mexico and Belgium drew attention to projects conducted in their countries to raise awareness of intellectual disability, not included in the country's initial report to the committee:

Onze Nieuwe Toekomst (Transl.: Our New Future) (Belgium)

A project to increase political participation of people with intellectual disabilities whilst also raising the public's awareness of this issue.

Kipatla, para tratarnos igual (Transl.: Kipatla, to treat us as equals) (Mexico)

A TV series aimed at children addressing issues of discrimination. Four episodes have featured individuals with intellectual and motor disabilities.

2.3   Conclusions

Based on our examination of documentation submitted to the CRPD Committee and the Committee's response, several key points emerge:

- Despite intellectual disabilities being the preferred term of the convention, its use among States Parties to the Convention is inconsistent. Terminology is still an area of disagreement and if there is inconsistency among those compiling these reports it suggests even greater variation in the general population (see Section 4.1). Whilst some variation is perhaps inevitable, it is concerning that over a quarter of the reports still used the term 'retardation'. The level of inconsistency in terminology within the States Parties reports may arguably in itself be seen as an indication of the need to raise awareness of intellectual disability. Furthermore, considering the importance of terminology in reflecting attitudes, it is concerning that over a quarter of the reports still used the term 'retardation'.

- Within Article 8 of the States Parties reports, whilst many initiatives addressing the broad spectrum of disabilities were included, less than 20% mentioned intellectual disability and fewer again provided concrete examples of actions taken to raise awareness and combat prejudice in relation to intellectual disability. It appears all too often intellectual disability is subsumed under the general 'disability' label or overlooked entirely.

- It is encouraging that the majority of States Parties reports specifically discussed inclusion of people with intellectual disabilities. However, only 16 reports mentioned intellectual disability under article 8 and no List of Issues queried this absence. Thus, the subject of awareness raising and combating of prejudices specific to intellectual disability appears at risk of being overlooked.

- Finally, it is interesting to note that in the replies to the List of Issues two countries identified positive awareness raising initiatives related to intellectual disability, which had not been included in the country's original submission. This raises questions whether these reports give a comprehensive picture of initiatives taking place in the respective

country and indeed how those writing the reports make decisions about which initiatives to include.

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 lay people experience a lot of confusion about the concept of intellectual disability and the wide continuum of presentations subsumed under this label (Scior, 2011; Siperstein et al., 2003; Tachibana, 2006).

Future directions

A further aspect of the CRPD process is the submission of Shadow Party reports to the CRPD Committee. These are typically compiled by NGOs and supplement or criticise the information provided in States Parties reports. Due to resource limitations, Shadow Reports were not analysed for this research. Future studies should consider the alternative perspective these reports offer and the possible discordance between them and the state parties' account.

Chapter 3: Survey of Experts & Representatives - Method

To go beyond the published literature and engage directly with researchers, statutory and third sector organisations, and advocates, we asked their views on matters relating to the social inclusion of persons with intellectual disabilities in their countries and actions in line with the aims of Article 8 of the CRPD.

3.1 Survey Development

The questionnaire was designed by the project team to cover three broad areas: (1) information about the participant; (2) information relating to attitudes to intellectual disability and terminology commonly used by the public and the media when referring to intellectual disability, and contextual information relating to inclusion of people with intellectual disabilities in the respective country, including education provision for children with intellectual disabilities and the (continuing) existence of residential institutions for adults with intellectual disabilities; (3) information about initiatives aimed at: raising awareness of intellectual disability, encouraging respect for the rights of people with intellectual disabilities, recognising their abilities and (potential) contribution, promoting positive attitudes to intellectual disability; and encouraging more positive interactions between people without disabilities and people with intellectual disabilities.

The survey and covering invitation email were piloted with researchers in Europe, South America, the Middle East and East Asia as well as with representatives of Inclusion International to ensure that both the contents and language were appropriate to a range of contexts and respondents. Revisions were made to the survey in response to comments received during the pilot. The Arabic, French, German and Spanish versions of the survey were also piloted with at least one native speaker of the respective language, who was an expert in the field of intellectual disability, and revisions were made in line with their comments.

3.2   Data collection process

Information was collected through a web survey using the software Qualtrics. An invitation email informing potential participants about the project and the survey were available in five languages: English, Arabic, French, German and Spanish. On visiting the survey site, participants were able to choose their preferred language.

The survey was targeted primarily at researchers and representatives of organisations or advocacy groups in the intellectual disability field. Accordingly it was distributed via an email invitation (see Appendix 1) that contained a link to the survey (see Appendix 2) through mailing lists held by Inclusion International, IASSID and Leonard Cheshire Disability. The survey was also distributed with support from Special Olympics. In addition, respondents were invited to forward information about the survey to interested parties or to suggest potential respondents. Finally, information about the project together with a link to the survey was displayed on Inclusion International's website during January and February 2015. Responses were collected between January and March 2015.

Of 720 completed responses logged, 53 were removed because they were invalid[5] or the respondent completed the survey twice (in this case their responses were combined), leaving a final sample of 667. Of the 667 complete responses, 71% were in English (n=475), 21% in Spanish (n=142), 3.4% in each of French and German (n=23 each), and 0.6% in Arabic (n=4).

Of note, our criteria for data collection differed from the WHO Atlas. While both studies sought information through national respondents, we targeted experts/researchers and representatives of organisations and advocacy networks in the (intellectual) disability field. This was based on an expectation that they would know the field but be less likely than say a government representative to have a potential vested interest in presenting a certain picture and, above all, feel less pressured to paint a picture of their country that complies with the CRPD. In contrast, the WHO Atlas prioritised informants in this order: (1) the government or ministry responsible for intellectual disabilities; (2) a public organisation that advises the government in matters of intellectual disabilities; (3) a national NGO that deals with

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[5] Of the 53 responses removed from the dataset, 42 were removed because they described their role as neither an expert or representative in the (intellectual) disability field, and were not taken to the main part of the survey; a further 11 clearly tested the survey, e.g., by entering individual letters, to see what responses would be required.

intellectual disabilities; (4) and a reputable research or university institution that specialises in the field of intellectual disabilities. In addition, we sampled as widely from any country as possible and considered all responses in the analyses. Coversely, the WHO Atlas team only took account of one response from each country, where necessary prioritising the response from the preferred respondent. We expect there are benefits and shortcomings to both approaches to recruitment, some of which are considered in section 3.6.

3.3   Participants

The 667 respondents originated from 88 countries (or independent territories). They represented all UN defined regions, albeit with highly varying response rates.

Figure 1 - *Survey Respondents by UN Region*
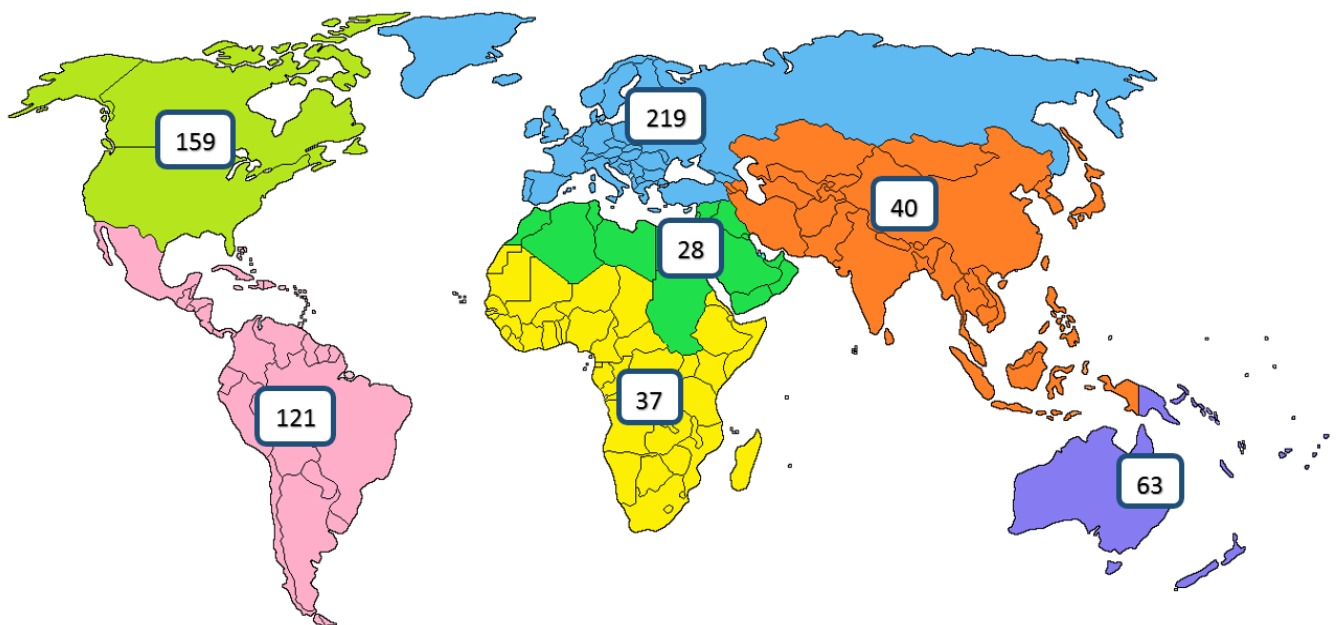
Respondents by UN region and sub-region are presented in Table 1. The respondents from Sub-Saharan Africa originated from 15 countries. MENA respondents were from 8 countries, with the majority from Israel (n=17). Asian respondents were from 16 countries or territories (including the territories of Hong Kong and Taiwan, now part of China, but treated as separate entities here). European respondents were from 27 countries [6]. South and Central America and the Caribbean were covered by respondents from 16 countries. North America,

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[6] Jersey is a self-governing territory and not part of the UK. However, as it is represented by the UK government in international affairs, Jersey has been subsumed under the UK in this report.

that is the USA and Canada had the highest number of respondents to the survey. And finally, respondents from Oceania were from four countries. For the full breakdown of respondents by country see Appendix 3. Thus while the present data cover almost half of the world's countries and spread across all world regions, different regions are not equally represented within the data.

Table 1 – *Survey Respondents by UN Region and Sub-Region*

Region/Sub-Region	Number	Per cent
Sub-Saharan Africa	37	5.5
MENA (Middle East & North Africa)		
Northern Africa	1	0.1
Middle East	27	4.0
Asia (excluding MENA)		
Eastern Asia	12	1.8
South-Central Asia	13	1.9
South-Eastern Asia	15	2.2
Western Asia	2	0.3
Europe		
Northern Europe	91	13.6
Eastern Europe	15	2.2
Western Europe	70	10.5
Southern Europe	40	6.0
South & Central America & Caribbean		
Caribbean	3	0.4
Central America	9	1.3
South America	110	16.5
North America	159	23.8
Oceania	63	9.4
Total	667	100.0

Responses were also examined for the four income categories defined by the *World Bank* according to gross national income (GNI) per capita in 2013, see Figure 2. These categories are: low-income ($1,045 or less per year); middle-income ($1,046 to $12,745); high-income ($12,746 or more). Lower-middle-income and upper-middle-income economies are separated at a GNI per capita of $4,125. Low- and middle-income economies are sometimes referred to as developing economies. High income countries were over-represented in the data- while

15% of the world's population live in high income countries 70% of respondents came from such countries.

Figure 2 – *Responses by World Data Country Income Level*
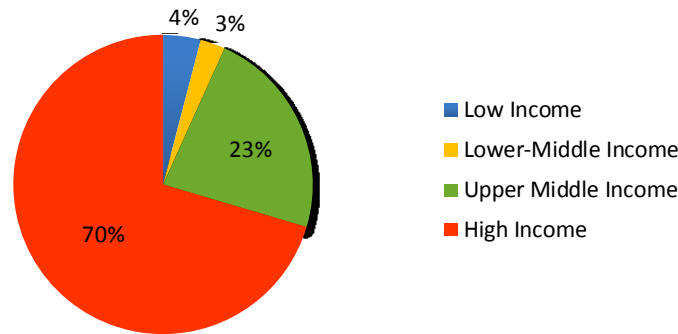
Of the respondents, 33.7% said the invitation to take part had been forwarded to them by an acquaintance, 27.1% said they had received it directly from the project team (we expect many of these actually referred to a message from IASSID but mistook the IASSID executive who circulated the invitation as a member of the project team, despite the project leads' names being clearly stated, see Appendix 1), 15.3% through Inclusion International, 10.9% through IASSID, 3.4% through Leonard Cheshire Disability, and 9.4% through another route including Special Olympics.

Finally, respondents were asked to indicate whether they completed the survey as an expert (or someone with a strong interest) in the (intellectual) disability field, or as a representative of an organisation or network focused on people with (intellectual) disabilities. The role of 71.5 per cent of respondents was focused on intellectual disability, with experts in this field making up almost 44 per cent of respondents (see Figure 3).

Figure 3 – *Respondents' Roles*

Pie chart legend:
- ID Expert — 44%
- ID Rep — 28%
- Disability Expert — 19%
- Disability Rep — 9%
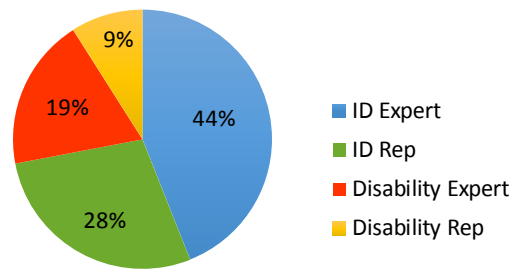
3.4   Quality of the Information Collected

To assess the quality of the information collected, the level of agreement between different informants in relation to key factual questions in the survey was examined. The responses to four factual questions were analysed for countries with a large number of respondents, pertaining to different respondent backgrounds: where children with intellectual disabilities attend school; whether residential institutions still exist and if so of what size they are; whether there are actions underway to close them; and whether disability hate crime is recognised in law. We reasoned that if agreement between respondents was found to be low, some types of respondents might have a better understanding of the issues under investigation, which would in turn call for caution in accepting all responses at face value and indicate a need to differentiate responses by informant role. Intraclass correlation coefficients (ICC) were calculated for the country within each UN region with the largest number of responses. It was not possible to calculate ICCs for countries in Asia or Africa, as there were too few respondents in the respective countries.

Table 2 shows the average measures ICC computed for all respondents from Argentina, Australia, Israel, the UK and the USA. ICC values of 0.40 to 0.75 are generally viewed as "fair to good". For three of the four questions, all ICCs were above 0.70, indicating a high level of agreement between respondents, irrespective of the respondent's role. Lower agreement between respondents was found for the question on hate crime legislation for Australia and Israel. As we note in section 5.1.1, in many countries we detected confusion whether disability hate crime is recognised as a distinct crime in law. In view of the generally high level of agreement between raters, we judged it appropriate to analyse responses to the

survey by country, rather than dividing them by respondent type, but have noted a need for caution regarding our findings in relation to disability hate crimes.

Table 2 - *Intraclass correlation coefficients for key factual information for 5 countries*

Country	N	UN Region	Schooling	Institution Presence	Institution Closures	Dis. Hate Crime Law
Argentina	44	Sth America	0.96	0.77	0.74	0.89
Australia	48	Oceania	0.99	0.82	0.98	0.58
Israel	17	MENA	0.92	0.95	0.70	0.56
UK	45	Nth Europe	0.99	0.74	0.94	0.99
USA	104	Nth America	0.99	0.98	0.99	0.92

3.5 Data analysis

Responses were analysed using Excel and the statistical software package SPSS. Descriptive statistics were completed to calculate frequencies and percentages. Cross-tabulations were computed according to the seven UN regions and four World Bank income categories.

3.6 Limitations

Surveys intended for a global audience are not without limitations. One limitation concerns definitions and terminology used which often varies between countries. To address this limitation, in the present survey we aimed to do justice to multiple definitions of intellectual disability available, in defining 'intellectual disability' as "*challenges some people face in learning and often communicating which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. Typically persons with intellectual disabilities experience these challenges from birth or an early age and usually require some form of lifelong support.*" We also expected that the term 'disability hate crime' would be open to misunderstanding and provided this definition at the point when the term was first introduced in the survey: "*A 'disability hate crime' refers to any criminal offence which is motivated by hostility or prejudice based on a person's disability.*" In asking about the current situation with regard to institutionalisation we were mindful that residential institutions can take many different forms and have a range of purposes. Hence rather than ask simply whether such institutions exist in the respective country, we divided the response

options by institution size, and also tried to account for residential accommodation for which the definition as an institution is controversial, namely units for short term assessment or treatment and forensic facilities. However, comments received from a small number of respondents indicated that this question and its associated response options were potentially confusing.

Similar to the CRPD, we did not define terms such as 'awareness raising' and 'promoting positive attitudes' but instead examined initiatives named by respondents in line with these concepts in detail to reach a judgement whether the initiatives mentioned did in fact seek to educate members of the general population or specific sub-groups about intellectual disability or to promote more positive attitudes (and behaviour) towards people with intellectual disabilities.

Another limitation pertains to the categorisation of countries by UN region. We diverted from the UN regional classification of countries in the Middle East which are classified by the UN as belonging in *West Asia*. Elsewhere, including by the UN High Commission on Human Rights, their commonalities with other countries in the greater Middle East and North Africa are recognised by clustering them together in the MENA (Middle East and Northern Africa region), a regional grouping we adopted in this project. Furthermore, where results are presented using the broad UN regions it should be borne in mind that the countries subsumed under these regions in many instances differ markedly in their cultural, religious and economic characteristics.

Although respondents had the option of skipping comments fields in the survey, they were required to respond to all other questions, where necessary choosing the 'not sure' or 'not applicable' response. This resulted in no missing data from the 667 respondents who completed the full survey.

Chapter 4: Survey of Experts & Representatives – Contextual Findings

Before we report on initiatives aimed at raising awareness of intellectual disability, combating prejudices and discrimination, we provide a broader context relating to attitudes to intellectual disability in the countries surveyed in this project. The contextual information presented relates to terminology employed, attitudes to intellectual disability commonly encountered, progress towards the aims of universal access to inclusive education for children with intellectual disabilities, and the current state with regards to institutionalisation.

4.1 Terminology used to refer to intellectual disability

Language not only reflects values and beliefs held within a culture, but also powerfully shapes attitudes. While diagnostic labels facilitate communication and are often used to regulate access to resources, such as welfare and specialist services, the power of labels to increase the separation between ''us'' and ''them,'' and to foster negative emotional reactions and discrimination has been noted in the stigma literature (e.g. Link, Yang, Phelan & Collins, 2004). It is not surprising then that labels are firmly rejected by the disability rights movement, epitomised by slogans such as *"label jars not people"*. To gauge the extent to which particularly derogatory labels are still in use when referring to 'intellectual disability', we asked survey respondents to tell us what term is most commonly used by lay people and in the media in their country when referring to the condition.

Terms in common use differed above all by income category of the country. Generally speaking, in higher income countries more progressive or acceptable terms such as 'intellectual disability' were reported to be in common use, whereas in lower income countries more derogatory terms such as 'mentally retarded' but also 'mad' and 'crazy' still appear to be in common use. Of note though, the relationship between income and adoption of more progressive terminology was not without exception, and in many high income countries very derogatory terms are still widely used.

4.1.1 Terminology by world region

In Sub-Saharan Africa, children with intellectual disabilities are usually referred to as 'slow learners'. Respondents said that many of the most commonly used terms among lay people are derogatory ones, such as 'mad' and 'retard'. In Kenya, terms such as '*mjinga*' (transl. 'fool'), *wazimu* (transl. 'madness/insane') are commonly used among lay people when talking about persons with intellectual disabilities. In contrast, in South Africa 'intellectual disability' is a commonly used term, and the media in both South Africa and Botswana use this term. However, even here derogatory terminology, including 'mentally retarded', is still often used among lay people.

In Asia a wide mix of terms are reportedly in use. In some East and South East Asian high income countries such as Japan and Singapore more progressive terms such as 'intellectual disability' are commonly used. However, negative terms such as 'mental retardation' and 'failure' are also still in common use in countries such as Taiwan.

The most commonly used term in South Central Asia is 'mental retardation'. In Bangladesh the media use the term 'intellectual disability', while lay people commonly use the term '*Pagol*' (transl. 'mad'). In South East Asia, the terms 'mental retardation' and 'slow learner' are reportedly most commonly used. In Malaysia '*Orang Kurang Upaya*' (transl. 'people less abled') is the most common term used by lay people.

The most common terms used in MENA countries include 'mentally retarded', 'people with special needs', and 'disabled'. The term 'intellectual disability' was reportedly used mainly in Kuwait, but not as often as the aforementioned terms. In Israel lay people and the media commonly speak of 'mental retardation', despite the government advocating the term 'intellectual disability'. There was only one response from North Africa (Egypt) where the term 'عقلى تخلف' (transl. 'intellectual infringement') is commonly used.

Almost all respondents from Oceania named 'intellectual disability' as the most commonly used term. In Australia it is occasionally still referred to as a 'mental disability'. In Fiji both 'intellectual impairment' and 'mental illness' are used when referring to intellectual disability, reflecting potential confusion between the two.

Across Northern Europe while most professionals use the term 'intellectual disabilities' or close synonyms, among the general public and the media a wide range of terms, many of them derogatory are in use. In the UK, 'learning disability' has been the most commonly used term for several decades, whilst in Ireland 'intellectual disability' is used alongside pejorative terms reportedly widely. In Finland and Norway, terms such as 'mentally retarded' and 'developmentally delayed' are still in common use. In Sweden the terms 'developmental disturbance', 'intellectual impairment/disability' and 'retarded' are in common use. In Iceland reportedly 'intellectual disabilities' and 'disabilities' are the most frequently used terms.

In Eastern European countries such as Bulgaria, Romania, Slovakia and the Czech Republic the terms 'handicapped' and 'disabled' are most commonly used. In Russia very pejorative terms are in use, including 'Downey', 'Moron' and 'Idiots'.

Across Western European countries, including Austria, France, Germany and Luxembourg, the terms 'mental disabilities' and 'mental handicap' are most commonly used by the public and media. In Switzerland, Belgium and the Netherlands reportedly the most commonly used terms is 'intellectual disabilities'.

In Southern Europe, 'intellectual disabilities' was named as commonly used term by some respondents for Malta, Slovenia and Spain. While this term is also used in some quarters in Croatia and Italy, the predominantly used terms in these countries are 'retarded' and 'person with disabilities' respectively. In Albania 'mental disabilities' is reportedly the most common terms. In Spain, alongside 'intellectual disabilities' many derogatory terms are also in common use, including 'subnormal', 'fool', 'retarded' and 'disabled'.

In the Caribbean, terms such as 'retarded', 'mad', 'mental', fool' and 'special needs' are commonly used in Jamaica.

In Central America, Mexican respondents named 'intellectual disabilities' as the term most commonly used. The same applied for Costa Rica, although alongside 'mental retardation'. In El Salvador, Honduras and Nicaragua pejorative terms such as 'mongoloid', 'mental retardation' and 'slow learner' are in common use.

In South America, in Argentina 'disabilities' is the most common term, alongside some use of 'intellectual disabilities' and 'mental retardation'. In Bolivia, 'mental retardation' and 'mental deficiency' were named as common terms, whilst it was acknowledged that many different terms would be used in rural areas. In Brazil, 'mentally deficient' is the most common term. In Chile, 'intellectual disabilities', 'retarded' and 'deficient' are all used by the public, with more derogatory terms common among the general population. In Colombia 'mentally disabled' or 'mentally retarded' are the most common terms, with 'intellectual disabilities' used in some quarters. In Ecuador, Peru and Venezuela, 'intellectual disabilities' is in use alongside 'special needs', 'mentally retarded' and '*tontito*' (transl. 'silly one'). The one respondent from Paraguay reported that 'mongol', 'defect' and 'silly/'stupid' are terms in common use.

Finally, in North America, 'intellectual disabilities' is commonly used, although largely refined to professionals, while in the general population terms such as 'developmental handicap' (Canada) and 'mental retardation' (USA) are still most commonly used.

4.1.2 Conclusions

This overview of terminology used across the countries surveyed suggests that 'intellectual disability' is gradually becoming the most accepted term. While the WHO Atlas reported 'mental retardation' as the most common term used around the world, the present data suggest that this term is increasingly viewed as derogatory and is slowly being replaced with more acceptable terms. According to the Atlas, just over a decade ago in 76% of countries around the world 'mental retardation' was the preferred term, or one of the preferred terms, to refer to intellectual disabilities. In contrast, in the present study a still concerning but much lower 40% of respondents reported that the term is still commonly used in their country to refer to intellectual disability (unlike the Atlas we asked about terms most commonly used by lay people and the media and not a "preferred" term). Of note, low and lower-middle income countries were underrepresented in our survey, and these are some of the countries where derogatory terms appear to be more commonly in use. Hence it is likely that our figure underestimates the continuing use of derogatory terms when referring to intellectual disability.

However, the findings also show that there is a long way to go to express respect and equality for persons with intellectual disabilities through the language used. In many countries

included in the present survey, pejorative terms are still in common use. Such terms appear to be most widely used in Sub-Saharan Africa, Russia, the Caribbean, and some (but by no means all) countries in Central and South America. This indicates that the need for awareness raising and asserting the rights of people with intellectual disabilities may be particularly acute in these countries. Furthermore, many respondents noted that while derogatory terms are no longer used among the media and service providers, they are still widely used among the general population. This suggests that more awareness raising is called for as well as greater efforts to establish subjective norms of acceptable language use among the general public in many of the countries covered in this project. Without doubt, policy makers and above all the media have a very important role in promoting the use of respectful and factual, rather than prejudicial, language. Countries where the R ('retard') word is reportedly still in common use are listed in Appendix 4.

4.2   Attitudes to Intellectual Disability

Participants were asked about general attitudes and beliefs relating to intellectual disability in their country. In their comments, there was a clear indication of progressive attitudes and an openness towards inclusion, but also evidence that negative and stigmatising attitudes prevail in many places and parts of the world. Below we have organised these comments into a number of overarching themes and sub-themes, see Figure 4, and present a brief overview of these, followed by a more detailed discussion of reference to the themes across different regions.

Figure 4 - *Thematic Map of Attitudes commonly encountered*
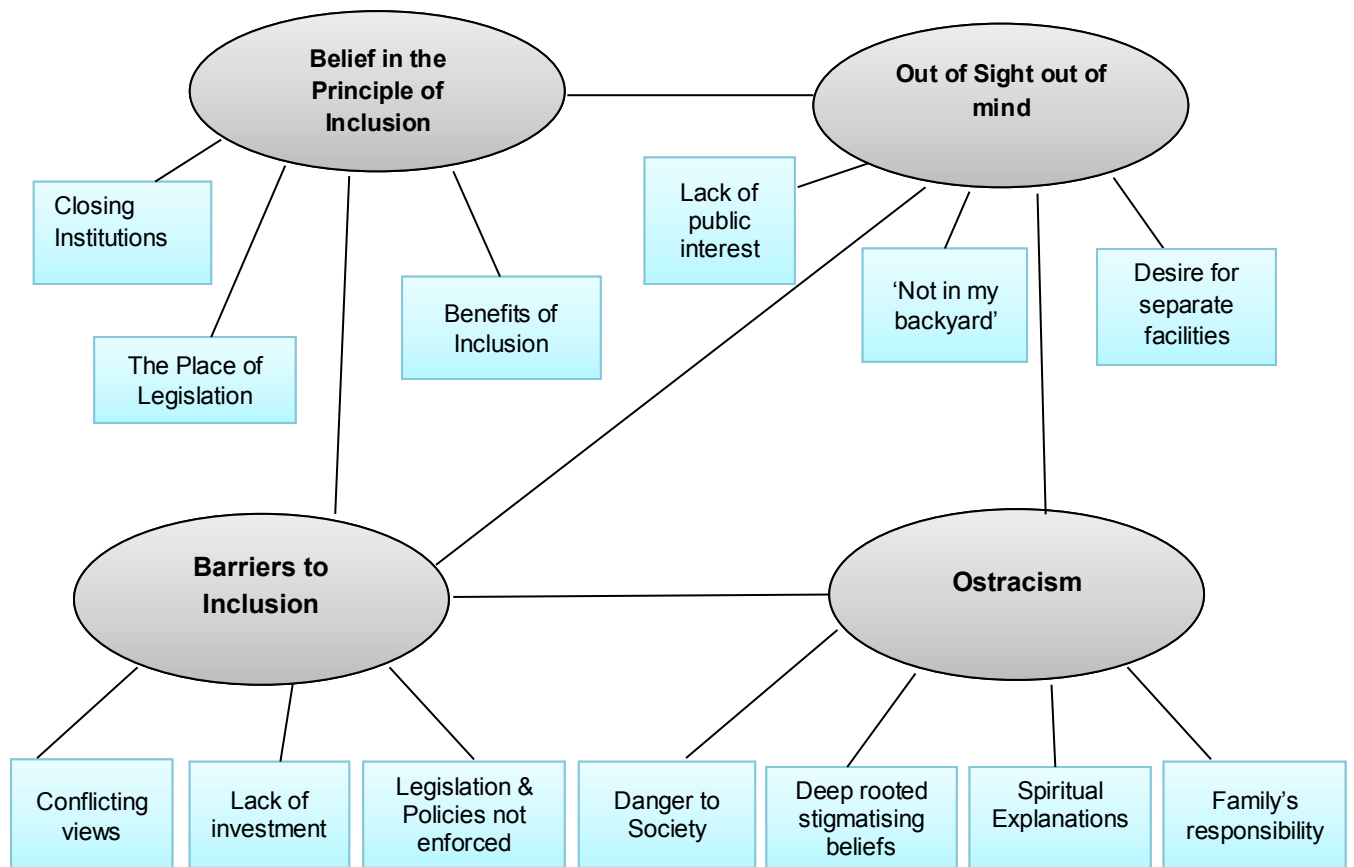
4.2.1   Belief in the Principle of Inclusion

This theme captures the many instances in the data where the public were reported as holding positive attitudes towards individuals with intellectual disabilities participating in the community, including the belief that they should have access to mainstream education and community housing. Support for the closure of institutions and for legislation advocating the rights of persons with intellectual disabilities were also an important aspect of this theme. 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.

4.2.2   Barriers to Inclusion (and Implementation)

In many countries the general public may believe in inclusion as a theoretical principle, but view it as impractical and unachievable for most persons with intellectual disabilities, and thus expect segregated facilities as the default. Whilst legislation may exist to assert the right

to inclusion of people with disabilities, in many countries such legislation is not fully implemented. Instead intellectual disability is often a low government priority with poor investment. Whilst the closure of institutions was typically viewed positively, respondents raised concerns about their replacement with inaccessible and inadequate support services such as poorly resourced group homes or even housing of people with disabilities in homes serving the elderly or homeless. In some countries, lack of government support means access to facilities for individuals with intellectual disabilities is governed by their family's financial resources, with those of low income entirely reliant on family care. These circumstances leave the public and media in many countries expressing doubts about inclusion.

Many respondents noted a firm belief in their country that persons with intellectual disabilities should be cared for in separated facilities. In some instances, preference for separate facilities appears to be informed by a desire to provide optimum support, and an expectation that specialist educational and residential settings best serve the needs of persons with intellectual disabilities. In others, the preference for segregated facilities was clearly related to a desire to ostracise people with intellectual disabilities (see 4.3.4).

4.2.3   Out of Sight Out of Mind

Despite many countries and regions purporting a firm belief in inclusion, a lack of interest in those with intellectual disabilities and their widespread invisibility were central to many responses. A further common barrier to inclusion, noted in all regions, was the ignoring of the needs of those with intellectual disabilities and in some cases a fear that inclusion would negatively affect the wider community. In higher income countries, despite a public endorsement of the principle of inclusion, a 'Not in my Backyard' attitude if often encountered, such as local resistance to the opening of a community home or fears that children in inclusive schools would be 'held back' by peers with intellectual disabilities.

In many countries persons with intellectual disabilities are viewed as the responsibility of their family. In some countries, particularly low income ones, this view goes hand in hand with societal rejection and the stigmatisation of children and adults with intellectual disabilities. It also leaves individuals with intellectual disabilities vulnerable when there are changes in the family structure such as serious illness or death of the main caregiver.

Their invisibility is accompanied by low expectations of people with intellectual disabilities and the use of segregated facilities to 'warehouse' them with no view to support their aspirations or goals. In many countries they are still widely viewed as incapable, unable to live independently or contribute to society. Respondents also noted that in many places support and acceptance of those with intellectual disabilities is often age dependent; children are often accepted into mainstream education and viewed with sympathy, but as adolescents they are often confined to segregated 'special' schools or have little or no access to post-elementary and further education, means to earn a livelihood, or other activities in adulthood.

4.2.4 Ostracism

In many countries an active desire to ostracise people with intellectual disabilities from society was reported. Deep rooted prejudices and negative beliefs towards those with intellectual disabilities perpetuate their segregation, and in some low and middle income countries they may be feared, often as a consequences of (intellectual) disability being attributed to highly stigmatising causes. They may be viewed as a danger to society, either because they undermine the social fabric of society (as in Russia)[7], or because they are viewed with great suspicion resulting from deep rooted beliefs that disability is the result of God's will, evil forces at play, a curse or angered spirits, as in some traditional communities in Asia and Africa (Hartley et al., 2005; Mckenzie et al.,2013; Miles, 1992; Mung'omba, 2008). Such misconceptions and stigmatising beliefs can lead to the person and their family being shunned by the community. In many other instances poverty and a complete lack of support leave families few options but to view segregation and, where available, institutionalisation as desirable.

4.2.5 Reference to these Themes across different World Regions

Reference to the aforementioned broad themes varied between and within regions. Respondents also noted that views regarding inclusion can vary by location within their countries; pro-inclusion attitudes may be more common in urban areas while awareness on intellectual disability and inclusion was described as lower in rural areas.

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[7] For an article that traces the historical and political origins of intense prejudice towards people with disabilities in the former Soviet Union we point the reader to Phillips, S.D. (2009). "There Are No Invalids in the USSR!": A Missing Soviet Chapter in the New Disability History. *Disability Studies Quarterly, 29*(3).

4.2.5.1 Sub-Saharan Africa

Responses from Sub-Saharan Africa (SSA) indicated only very limited support for the principle of inclusion. Support is very much seen as the responsibility of the family and in many countries in the region people with intellectual disabilities have few rights:

> *"People with ID remain dependent and have very little opportunity to exercise their right to freedom of choice, citizen participation, or respect for privacy." (Mauritius, transl. from French)*

SSA respondents depicted unfavourable attitudes towards persons with intellectual disabilities. In Kenya they are generally "*undervalued*" and ostracised. In Uganda they are typically referred to as "*lepers"* and *"outcasts*". A firm belief that they should be marginalised from mainstream community and *"taken very far from their community in an institution or special schools for people like them"* (Kenya) was widely reported. Some also noted that carers may be ostracised due to their affiliation with a person with an intellectual disability. In Nigeria:

> *"The general attitude/belief is that people with ID should be segregated or locked away to avoid the family being stigmatised."*

Attribution of intellectual disability to spiritual causes, such as curses or possession, was reported for several SSA countries, and reported to not only lead to segregation but in some cases, as mentioned in Togo, exorcism by "Voodoo Priests" and even death:

> *"Children with ID are killed at a young age due to their ID." (transl. from French)*

Discrimination and stigmatisation were evident in lower *and* middle income countries and said to be "entrenched in communities". One respondent noted a common belief in Madagascar that it is "*not necessary to invest anything for people with ID*" as the general perception is they are incapable of learning.

The discourse however changed in southern parts of the region, which presented more progressive attitudes with a desire for change and inclusion. A respondent from South Africa spoke of a *"new upsurge in mainstreaming"* education, evident in an "inclusive education

programme for the entire country". In Tanzania educational inclusion is also actively pursued, mainly through pressure from parents and religious groups in the country.

4.2.5.2 Asia

Responses from Asia illustrated a divide in attitudes, based mainly on countries' income and an urban/rural divide. In upper middle and high income countries and sections of society, and in urban environments more progressive attitudes are generally found compared to lower income countries and sections of society and in rural areas:

> *"People in Japan tend to think that living in their hometown is the happiest scenario for both people with ID or without ID''.*

In Nepal, among middle income and more wealthy families inclusion friendly attitudes are more common. In contrast, lower income families, especially those in rural areas, "*want the institutions with accommodation so that they can work freely for income generation*" and among the wider community "*intellectual disability is treated as caused by a past life's curse. Thus, persons with disabilities are mistreated.*"

In Pakistan, in line with traditional beliefs, persons with intellectual disabilities are often believed to be "*under the influence of evil forces*" and '*dangerous*', but if they are "*silent, not active or aggressive are considered saints*".

Generally, stigmatising views of persons with intellectual disabilities as "*dangerous and aggressive and best kept at home*" still prevail in many parts of Asia. In Cambodia lack of understanding regarding the causes and consequences of disability can "*cause these children to be shunned by their neighbours, peers, and even family members*".

4.2.5.3 Middle East and North Africa (MENA)

Mixed attitudes were reported for this region. Whilst their inclusion was said to be generally favoured, stigmatising and discriminatory beliefs prevail. One respondent noted that national data show that 20% of Israelis do not want to live next to people with intellectual disabilities, another noted a common belief that there should be "*an institute so they [the public] are not in daily contact with the family and surroundings*". In countries such as Kuwait and Lebanon two predominant views were expressed; persons with intellectual disabilities are to be cared

for at home or in specialist institutions. Respondents from both countries highlighted their governments' push towards institutional care and in Kuwait. There was only one respondent from North Africa (Egypt), who stated there was a general desire for institutionalisation, but as a form of protecting those with intellectual disabilities from *"ill-treatment and cynicism, exploitation"* as opposed to as a means of segregation.

4.2.5.4 Europe

Europe presented mixed views and attitudes. One of the most common themes identified in this region was a dichotomy between officially sanctioned acceptance and inclusion versus the reality of ingrained prejudice. Within Northern Europe, despite increasing integration of people with intellectual disabilities in the wake of deinstitutionalisation, there are very mixed attitudes to inclusion in practice.

> *"Opinions [toward inclusion] are split, even amongst members of organisations like the Norwegian equivalent of Mencap and National Autistic Society." (Norway)*

> *"It's as if everybody really likes the concepts associated with full inclusion, but things get stuck at the implementation level." (Ireland)*

A respondent from the UK noted widespread confusion about the concept:

> *"I don't believe that people in general have a clear idea about who is being talked about when they hear 'learning disabilities' [British term for intellectual disability]. Essentially I don't believe that the general population are able to make a decision as I don't think they understand how broad the spectrum of ID is." (UK)*

Specialist services are typically used across European countries (in some alongside mainstream services), and were described as being seen by many as both of greater benefit to the individual but also desired by the public in an 'out of sight, out mind' mentality.

> *"A large number of parents feel that having children with ID in mainstream classes holds their own children back, from an academic standpoint." (Ireland)*

"Sadly there are still people who raise objections when they find out there is to be a community house nearby for people with a learning disability & possibly other complex needs." (UK)

Positive actions towards inclusion were described such as companies in the UK and Austria being encouraged to hire people with intellectual disabilities. In Sweden inclusion was described as an accepted reality:

"Sweden has no institutions since more than a decade back. Most people that were born in the 70s or later have gone to daycare/school together with children with ID. Maybe not in the same class at school but at the same daycare centre or school." (Sweden)

Regional variation was also described, for example in some urban areas of Austria such as Vienna and Graz inclusive education is far more accepted and practiced as default than in other parts of the country. Although across many European countries there is a desire for change and active steps towards achieving inclusion have been taken, many respondents felt stigmatising attitudes, limited resources and a real conviction that inclusion is possible continue to pose barriers to inclusion.

"Most 'average' citizens are very happy that they have little to come into contact with people with ID." (Germany)

"Overall the belief is that people should be living in the community but the supports are not available and this halts any growth for the individual." (Ireland)

In Eastern Europe attitudes to intellectual disability seem to be much more negative and there are much greater barriers to inclusion and equal rights.

"Because for 45 years, during the communism time, the people with ID officially didn't exist, most people believe that ID people need to be schooled only in special schools, not the mainstream ones. But little by little the mentality toward ID people is changing and they are more accepted than before." (Romania)

A respondent from Albania noted that people with intellectual disabilities are at risk of physical attack and *"verbal degrading provocations"*, and that "g*irls are especially*

threatened by sexual assault and misuse (lured by maleficent adult males for sex)". As a result many girls with intellectual disabilities *"are kept home without education at all"*.

4.2.5.5 South and Central America & the Caribbean

Across this large region, people with intellectual disabilities are generally viewed as the responsibility of their families, both by governments and the public – their families receive little support and there are few opportunities for education or meaningful activity. Many specialist facilities are privately owned and often out of families' economic reach.

> *"In Colombia people with ID as other situations disabilities have been and are the responsibility of families. The state and society have not been guarantors of the rights of participation and enjoyment of these people and their families. The spaces and initiatives that have been established segregate and stigmatise." (Colombia- transl. from Spanish)*

> *"I think the general population (and parts of government) think that people with ID are the responsibility of families and have to live with them for life." (Chile, transl. from Spanish)*

Two other respondents commented on vulnerability to abuse from families and lack of government protection for the person:

> *"Many of them are abused by the family, or go completely neglected." (Ecuador, transl. from Spanish)*

South American respondents suggested that whilst professionals, NGOs and some members of the public support inclusion, instances of inclusion are infrequent. While legislation and policies exist to promote inclusive education and equal rights, these are rarely enforced.

> *"There is no penalty to the state agencies that violate standards. It is as if there were a great and good library that everyone reads but it is not applied." (Argentina, transl. from Spanish)*

In general, across much of this region, respondents noted that the general public and governments view people with intellectual disabilities as incapable.

"People generally do not see a person with ID as having a chance at education and integration in the society unless they are somewhat familiar with one such person or they work in the disabilities sector." (Jamaica)

Respondents from Central America reported that there is still a considerable way to go in their countries to achieve greater inclusion. Respondents from Nicaragua and Costa Rica mentioned some availability of inclusive education and access to day time activities (though not employment oriented ones). The general picture however was one of separate facilities that are often few in number. Family care is favoured for people with intellectual disabilities, leaving them vulnerable to changes in family structure and tight family finances when trying to access specialist services.

"Most people with ID don't attend school whether regular or special school – the latter are regrettably very few in number and not available in all parts of the country. In addition, their family's poverty places limits." (El Salvador, transl. from Spanish)

"Prejudice still prevails, there is still much to do within the public and private system. In the way our society is structured, people with ID in general live with their families. There is a centre in the capital that welcomes children with disabilities abandoned by their families, funded through the Ministry of Family and private donations." (Nicaragua, transl. from Spanish)

It was commonly reported that the public lacked knowledge, awareness and interest in equal rights and inclusion for people with intellectual disabilities, and that the same often applied to government.

"There is a total lack of interest in people with ID in our country." (Argentina, transl. from Spanish)

This near complete disinterest was reflected in the note by two respondents from Mexico who said they felt unable to comment on public opinion towards people with intellectual disabilities as this is not a matter that receives any attention in the public sphere. A similar comment was made by a respondent from Argentina:

"There is widespread ignorance on this subject. It is only discussed among specialised professionals."(transl. from Spanish)

Against this pessimistic picture, many respondents reported that attitudes are slowly changing and that NGOs are doing valuable work to turn things around, but felt there is still a long way to go.

"It's a long and slow process - change takes time." (Argentina, transl. from Spanish)

"In Colombia we are in diapers, as well as all third world and underdeveloped countries, and we are missing help." (Colombia, transl. from Spanish)

4.2.5.6 North America

The responses from the USA and Canada suggested a high level of educational inclusion and available support services, although respondents felt their country was still a long way from full inclusion or having systems in place which meet the needs of all with disabilities.

"The overwhelming attitudes and beliefs would be that people with intellectual disabilities should attend regular (mainstream) schools and participate in fully inclusive settings and that they should live in community with family as children and as adults in homes of their choosing with supports necessary to afford social inclusion." (Canada)

"We have been working for 40 years on the philosophy and implementation of inclusive practices and the change has been small. The message needs repetition and all too often the successes happens one family at a time." (USA)

"I feel that this country has a very long way to go. It is 2015 but individuals with disabilities still struggle for competitive employment, housing, quality health care, accessibility, and respect." (USA)

"In terms of beliefs about where individuals with ID belong, I think there is a strong belief that individuals with ID cannot learn, cannot benefit from education (e.g. reading instruction), and too often, we observe "instruction" in segregated classrooms more resembles custodial care and behaviour modification than real education based on the belief in the students' ability to learn. I have also observed this in so-called habilitation programs, that are also boring, repetitive, punitive, and inhumane, Individuals with ID are not seen as "real" employees and their opportunities are at most "make-work." (USA)

The public may also have concerns that the presence of children with intellectual disabilities in mainstream classrooms holds other pupils back. Respondents in both countries said there is a 'Not in my Backyard' attitude held by many in the population.

"I think people are very open and happy to integration, but not at any price." (Canada-transl. from French)

"When people with ID are "nice" and don't disrupt Society, people's opinions are that they should live in the community and go to special schools. The opinion is then that a special school will provide better suited supports to the person with ID, while not disrupting the education of their children (with no ID)." (Canada)

"Policy is moving towards an inclusive educational setting but not every school is inclusive, not everybody is accepting of having an inclusive school environment due to perceived negative impacts for other children." (USA)

Despite countries reporting a growing public belief in inclusion, there is still prejudice in these societies – not least because the traditional belief has been that people with intellectual disabilities are incapable, meaning many people assume inclusion to be an impossible goal. There is a lack of awareness, knowledge and indeed interest in intellectual disability.

"Many people still seem to have a difficult time understanding that people with disabilities, including people with significant disabilities, can live and participate in their communities and that they can actually contribute to society through work, volunteering and other activities." (USA)

As mentioned in other regions, experiences of inclusion in education and residential settings are also often age-dependent. There is regional variation across North America in the closing of institutions, with some are still in use and cases of those with intellectual disabilities being housed in facilities for different groups such as the elderly. Respondents drew attention to the need for greater funding and resources, there were concerns about low quality of homes and institutions with poorly supported staff.

"In so far as institutionalization is concerned, there are 14 states in the US that have closed their state institutions completely. On the other end of that same continuum,

there are states with high numbers of people still living in institutions (in Texas, for example, there are about 4000 people living in state-run institutions)." (USA)

Whilst inclusion is gaining favour, opinions are still mixed and concerns prevail about what this would mean in practice.

"We have a long way to go for people who have an intellectual disability to be accepted as contributing members of society. However, we are moving away from institutional models and towards true community involvement." (Canada)

"This is a divided issue - there are proponents for inclusion as well as segregation." (Canada)

"The beliefs of people in the community vary from very willing to include people with disabilities to discriminatory." (USA)

"Beliefs range from right to full inclusion in living arrangements, education, employment, leisure activities, etc. with supports and services where needed to enable the individual to participate ..all the way to beliefs that people with intellectual disabilities should be housed in institutions away from the general public." (USA)

4.2.5.7 Oceania

The overall view of intellectual disability in Oceania was described as one of progression and inclusion. The introduction of the National Disability Insurance Scheme in Australia is an explicit example of moves toward integration and inclusion. Despite such initiatives and general public support for inclusion, an '*out of sight out of mind*' attitude was also reported frequently in Oceania, in particular Australia. Some felt that "*widespread discrimination and resistance to inclusion in regular schools*" are still quite prevalent.

The response from Papua New Guinea stressed the lack of understanding of the needs of people with intellectual disabilities and the lack of national resources:

"There is only one psychiatric hospital in the country, one disability centre and one Cheshire home for other disabilities for a population of seven million."

4.2.6 Conclusions

Discussions concerning the general public's "not in my backyard" style of thought was prevalent amongst participants everywhere. Respondents mentioned the various negative consequences the public believe could arise if people with intellectual disabilities were integrated in school and work settings. Such beliefs will clearly need challenging as part of awareness raising efforts, and the positive consequences not just for people with intellectual disabilities but everyone should be emphasised.

4.3   Education for Children with Intellectual Disabilities

Prior to the CRPD, the *Education for All* initiative launched in 1990 was meant to include children with disabilities. The principle of inclusive education was adopted at the Salamanca World Conference on Special Needs Education (UNESCO, 1994) and was re-stated at the Dakar World Education Forum (2000). The Salamanca Statement and Framework for Action defined inclusive education thus: *"schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions"*. Therefore 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, these rights are frequently not implemented. Not only are many children with intellectual disabilities often 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 (UNESCO, 2015).

As part of the survey we asked all respondents to provide the following information:

- where children with intellectual disabilities typically receive schooling in their country;
- whether special schools exist in their country;
- comments on the schooling provided for children with intellectual disabilities and attitudes generally.

Here we provide a summary of the responses, and highlight countries where education for all children with intellectual disabilities seems to be far from a reality, as well as countries that

appear to be furthest ahead in providing inclusive education for children with intellectual disabilities.[8]

4.3.1 Where are Children with Intellectual Disabilities typically schooled?

Responses to this question are presented in Table 3. In the survey the term 'special schools' was defines as schools where children with intellectual disabilities are educated separately from their peers who do not have a disability.

Table 3: *Where children with intellectual disabilities are typically schooled*

Where Schooled	Number of Responses	Proportion of Responses
All/most in mainstream schools	108	16.2%
In both mainstream & special schools	385	57.7 %
All/most in special schools	136	20.4 %
Either special school or not sent to school at all	13	1.9 %
Typically not sent to school at all	18	2.7 %
Unsure	7	0.1 %
Total	667	100%

Countries where respondents said children with intellectual disabilities are often not sent to school at all are the following: Congo, Hong Kong, India, Liberia, Nepal, Nigeria, Sierra Leone and Uganda. Countries where respondents said children with intellectual disabilities either attend special school or are often not sent to school at all: Albania, Bangladesh, Bulgaria, Iran, Kenya, Paraguay, and Russia. Some respondents in Argentina, Colombia and South Africa also reported that such children are often not sent to school at all but the majority of respondents from these three countries did not say this, suggesting regional and likely urban/rural variation. Of 51 respondents from Colombia, 28 noted that children with intellectual disabilities attend both inclusive and special schools, but nine noted that they typically either attend special school or are often not sent to school at all. For Argentina, 26 of the 43 respondents said children with intellectual disabilities are schooled in both special

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[8] The findings reported here were also submitted to the CRPD Committee for consideration as part of its Special Day on Education in April 2015.

and inclusive schools, 14 that they are mostly sent to special schools, but three noted that they are often not sent to school at all.

We are mindful that in at least some of the countries detailed above many children without disabilities are not regularly sent to school for a host of reasons. This is particularly the case in rural and/or disadvantaged areas, as one respondent in Nepal commented: *"Only 10% [of children with ID] have access to school. Others in rural parts of the country are not sent to school."* However, other comments provided by respondents indicate that children with intellectual disabilities are particularly marginalised, and are often subject to a failure to recognise their fundamental human rights and their right to education due to their disability.

Countries where children with intellectual disabilities reportedly attend both mainstream and special schools include: Austria, Australia, Chile, Costa Rica, Iceland, Ireland and Israel.

Of note, 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 (mainstream) schools. A respondent from Italy noted: *"According to the Italian Constitution any person has the right to (mainstream) education."* In Canada, according to the 53 Canadian respondents to our survey, only a small minority with complex needs attend special 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."*

4.3.2 Where do Special Schools still exist?

Responses to this question are presented in Table 4.

Table 4: *Where special schools still exist*

Special school existence	Number of Responses	Proportion of Responses
Yes, special schools exist	525	78.7%
No special schools exist, but special units within mainstream schools	118	17.7%
No special schools or units exist	16	2.4%
Unsure	8	1.2%
Total	667	100%

The majority of respondents reported that special schools still existed in their country. Italy is one of the very few countries where reportedly no special schools are in existence, due to a commitment by the Italian government to provide all children, regardless of (dis-)ability, with a good quality and inclusive education. In the other three countries the lack of special schools is due to resource limitations rather than a strong commitment to inclusion. In Liberia reportedly there are no special schools but, as noted above, this appears to be because children with significant intellectual disabilities are excluded from schooling altogether.

A mixed picture was reported for Canada, Colombia, Nepal and the USA. For Canada over half of respondents reported that special units within mainstream schools exist, and a small number of special schools still appear to be in existence. For Colombia 40 of 52 respondents noted that special schools still exist. For Nepal one of four respondents said there are special schools and special units. For the USA (which signed the CRPD in 2009 but as yet has not ratified it), 65% of the 104 respondents noted that special schools still exist. In the UK a small number of special schools exist alongside special units attached to mainstream schools and an inclusive education model.

4.3.3 Qualitative Data

Respondents also provided general comments regarding attitudes to schooling for children with intellectual disabilities in their countries. Below we present key themes that emerged

from these comments, together with participants' comments (in italics) and the respondent's country.

4.3.3.1 Continuing Segregation in Education Settings

In clear contrast to Article 24 of the CRPD, and despite international legislation and policy that emphasise every child's right to attend an inclusive school as default, in many countries there is a continuing, clear preference for children with intellectual disabilities to be sent to special schools.

"The majority (of the population) are in favour of special schools." (Austria)

"People prefer people with intellectual disabilities to be schooled in special schools and to live with their family." (Argentina)

"In Argentina there is still a very high proportion of pupils who attend special schools. This modality has a lot of power in decision-making and there is clearly a double discourse: 'yes to integration, but we have to decide where this child with disabilities goes to school.' There have been changes to the quantity but not the quality of inclusive education." (Argentina)

"Many in mainstream schools are still segregated in special units and there is limited inclusion particularly in high schools." (New Zealand)

"People believe that people with intellectual disabilities should go to special schools." (Tanzania)

"Despite ratification of Article 24, special school is still recommended most of the time." [9] *(Germany)*

"The vast majority of children with mild intellectual disabilities attend mainstream schools. Some go to special schools. Children with severe and profound intellectual disabilities are often excluded from the educational system." (South Africa)

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[9] Authors' comment: In Germany parents receive a recommendation where their child should be schooled following primary education, and although theoretically possible, it is notoriously difficult to go against this recommendation.

4.3.3.2 Exclusion from Education

In some countries, as noted in section 3.1, children with intellectual disabilities are typically excluded from education altogether, or are included only if family means and regional availability allow.

"Most times children with intellectual disabilities do not go to school." (Sierra Leone)

"Special Schools have very little capacity to accommodate all children with intellectual disability, and many of them are at home." (Albania)

"Governmental special schools in Hong Kong are free for students with mild learning difficulties. For children who are more severely affected, or who have more challenging impairments (such as an intellectual impairment, cerebral palsy, Down's Syndrome, autism, etc.), private international (fee paying) day-centre placements are available. However, for some years, these services have been few, are only available in the inner metropolitan areas, and as they incur high tuition fees, are really only available to the more affluent families." (Hong Kong)

"The quality of special education in Malaysia is very poor. Most teachers are not trained to handle children with learning disabilities and poor support and resources are given to the teachers and students. Parents who have the financial means often send their children to international schools or pay privately to have their children attend special private services." (Malaysia)

4.3.3.3 Moves towards Change

There was clear evidence of a desire for change in line with Article 24 in some countries.

"Our organisation is seeking inclusiveness. That is why the government has allowed people with intellectual disabilities to go to normal schools by establishing classes within those schools at primary level and total inclusion at secondary level. After primary school, those who exhibit some improvement are enrolled in centres where skills development lessons and practicals are taught. Such centres are funded by the government but others are funded by religious organisations." (Tanzania)

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"For 45 years, during communism, people with intellectual disabilities officially didn't exist and most people believed that children with intellectual disabilities need to be schooled only in special schools, not mainstream ones. But little by little, the mentality toward people with intellectual disabilities is changing and they are more accepted than before." (Romania)

Despite progress though, responses indicated that in many countries inclusive education for all children with intellectual disabilities is still not viewed as realistic or appropriate, or that children are included in name but in fact still educated in settings that are entirely or largely segregated:

"Special school can offer more adequate support than mainstreaming practices producing the natural second exclusion." (Poland)

"Most attend mainstream schools, however, in the state where I work, most students with intellectual disabilities are educated in segregated settings- typically a classroom apart from their typically developing peers and those classrooms are often physically separated from the general education classrooms, either in a different part of a building, in a different building, or sometimes, on the same schools grounds, but in a separate "campus" (a school within a school)." (USA)

4.3.3.4 Guided by the Needs of the Individual Child

Some countries appear to be clearly driven by the needs of the individual child and the wishes of their parents.

"All children have the right to education, independent of what disability the child has. There are different alternatives for schools, but many are included in mainstream schools. Many times this is on the basis of discussions of what parents want for their child." (Finland)

"Only students with a moderate-severe/profound intellectual disability or complex disabilities attend a special school in my state." (New South Wales, Australia)

"Depending on the severity of intellectual disability. If it is mild-moderate then they are sent to integrated schools and if severe/profound they are sent to special schools, some of which are based in residential care centres." (Israel)

"As far as schools are concerned, most people would say that it depends on the needs of the individual child. Where they can benefit from mainstream schools they should have the right to attend those schools." (Wales, UK)

But, it seems there are constant fluctuations and regional variation even within the most progressive countries, and many parents do not feel that inclusive education, as provided, meets their child's needs :

"Numbers in special schools have been increasing since 2010." [10] (UK)

Very importantly, we must not lose sight of children's needs, which are often poorly met in inclusive schools unless it is carefully considered how to make reasonable adjustments to the curriculum, the social and physical environment, and to teaching methods to provide actual inclusion for these children rather than physical presence but by no means inclusion. This recognition was reflected in this comment:

"Only mainstream schools who have received some awareness training on inclusive education enrol children with intellectual impairments." (Fiji)

"Some children have transferred from special schools to mainstream but this is not often successful. The children have encountered bullying from peers without intellectual disabilities, this has been one of the main reasons they wanted to return to a special school. In some special schools some students with intellectual disabilities have asked to join mainstream schools but this has been discouraged by staff. The reasons given by staff are to protect the children from children at mainstream schools." (UK)

"There are diverse views. There has been a strong movement for inclusion in schools and communities led by parent organisations. However, there is also a strong pull

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[10] Authors' comment: This statement is confirmed by recent UK data which show an increase in the number of pupils in special schools and the proportion of children educated in such settings since 2007, indicating a reversal of a 30-year trend towards inclusion, which has been attributed at least in part to an emphasis on academic results (Times Educational Supplement Connect 10/8/2014).

toward exclusion as people with intellectual disabilities might not be seen to be safe or protected in regular schools and communities." (South Africa)

"Inclusive education has been supported for physical and sensory disabilities but special education is still considered as a better option for children with intellectual disabilities…Prejudice towards people with intellectual disabilities continues to prevail. There is plenty to do, within the public and private system." (Nicaragua)

"Some mainstream school staff believe that children with an intellectual disability are better catered for in a special school, but I believe this is due to the lack of support offered in the mainstream school for the child with intellectual disabilities." (Australia)

However, the fact that in many countries a two tier system exists raises the question how the decision to send some children with intellectual disabilities to inclusive schools and others to special schools is reached, and to what extent it is based on evidence about the scenario likely to promote the best outcomes for the individual child. This seems particularly indicated in some countries where clear criteria underpinning such decisions have been reached yet without any discernible basis in research evidence.

"The situation will change in September: children with an IQ greater than 65 will be sent to mainstream schools."[11] (Belgium)

4.3.4 Conclusions

Overall, our findings concur with the conclusion of the latest report on progress relating to the Millennium Development Goals (UN, 2014) that: *"disadvantaged children, such as those with disabilities, are also at risk. These children often require education adapted to their needs. However, in many developing countries, such personalized approaches are either deficient or unavailable, which either prevents these children from going to school, or slows their progress. Inclusive education requires increased attention to be paid to children with disabilities"*.

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[11] Authors' comment: The Flemish government has approved a decree to prevent students "with slight mental disabilities" from being referred to the special education system too quickly. However, if this were interpreted as only applying to children with an IQ of 65 or above, in our view, it would exclude a large number of children from inclusive education settings who with reasonable adjustments may well be able to benefit from inclusive education.

At least in some countries there appears to be a clear willingness on the part of the government and the education system to ensure that children with intellectual disabilities attend inclusive schools as default, and that reasonable adjustments are made to inclusive learning environments to accommodate the needs of such children. However, at present such countries appear to be very much in the minority. Instead in many countries the right of children with intellectual disabilities not only to education, but also to inclusive education as the default firmly enshrined in international policy for two decades, is frequently still violated. Not only are many children with intellectual disabilities 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, and to inclusive education.

In countries where such children are educated within inclusive learning environments, low quality support delivered by poorly trained teaching assistants, and a general lack of resources to make effective reasonable adjustments has resulted in some parents preferring special education settings over mainstream settings in countries where they have a choice. Overall, it seems the provision of 'effective individualised support measures' referred to in Article 24, provided "in environments that maximise academic and social development, consistent with the goal of full inclusion" needs much more careful attention where children with intellectual disabilities are concerned. Their disabilities are often 'invisible' and poorly understood relative to children with physical or sensory disabilities, indicating a need for more awareness raising. As a result, they are often not provided with the necessary support or excluded from inclusive education, or in some countries, as well as in many rural regions of developing countries, excluded from education altogether.

A reversal of progress towards inclusive education in some countries, possibly as a result of parental concerns about the quality of what is delivered in inclusive learning environments, cut-backs and an educational culture that emphasises results, is deeply worrying. A respondent from Ireland noted: *"There are moves towards support in mainstream education although recent cutbacks have halted this progression."* A respondent from the UK also commented: *"While the general principle of inclusion is stated in most schools, it is not unusual for inclusion to be a secondary concern, below the desire for other students to achieve high grades."*

In some countries, policies do not appear to clearly favour inclusive education, as indicated by a respondent in Taiwan: "*Both special schools and institutions are still welcomed by parents and policy makers.*" In others, such as Tanzania, there seem to be concerted efforts at grass roots level to push for inclusive education. However, in some countries there may be a wide gap, at least at present, between will and resources available to support effective inclusive education.

Finally, access to inclusive activities appears to be very age-dependent. Several respondents described inclusive education being available for primary school age children but becoming more segregated at secondary level. Adults are extremely unlikely to access inclusive educational activities.

Evidence presented elsewhere indicates that children with intellectual disabilities who are educated in inclusive schools often experience name calling, bullying and rejection by their peers, and not infrequently negative attitudes from teachers [12] [13]. Action aimed at combating bullying of children with disabilities in inclusive schools is being taken in many places and countries. However, in line with Article 24 and Article 8 (awareness raising and combating prejudice and discrimination) of the CRPD, more needs to be done to raise awareness of the needs of children with intellectual disabilities, to combat negative attitudes towards such children among their peers and teachers, and to work actively towards the social, not just physical, inclusion of such children within school environments

4.4   Progress on 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. However, many people with intellectual disabilities continue to be placed in residential care institutions with little choice and few freedoms. Historically the large scale institutionalisation of people with intellectual disabilities is a phenomenon largely confined to higher income countries and Eastern Europe, while the family has always been viewed as the primary or only place of residence for

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[12] Frederickson, N. (2010). Bullying or Befriending? Children's responses to classmates with special needs. *British Journal of Special Education*, *37,* 4-12.
[13] Mencap (2007). *Bullying wrecks lives: The experiences of children and young people with a learning disability*. London: Mencap Publications.

children and adults with intellectual disabilities elsewhere. It can be traced as much to a belief that their needs were best met in specialised institutional environments as to a desire to segregate them from society. It has been recognised for several decades 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. Nonetheless in many countries children and adults with intellectual disabilities continue to be institutionalised, often for large parts of their lives.

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 5.

Table 5: *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

When asked whether there is an active programme underway at closing larger institutions where they remain, 35.7% (n=238) said yes, 20.7% (n=138) that no such closure plans are underway, and 30% respondents (n=200) stated that this question was not applicable as no (large) institutions remained or were unsure. These responses indicate that 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.

A few countries have closed all larger institutions. Italy was one of the first beginning their closure in the late 1970s[14]. In Norway the last large institutions were closed in the early 1990s, and in New Zealand and Australia within the last 10 years. In the UK, all large institutions in England were closed in the 1990s but some institutional settings remain in other parts of the UK, and new "mini" institutions have taken their place in the form of 'Assessment and Treatment Units'. In the USA reportedly 12 states no longer have any large institution, most other states are downsizing or actively closing them, but respondents noted that some states are highly resistant to closing remaining institutions. In Canada similarly variation by province was noted- while the last institution closed in Ontario in 2009, in some other provinces institutions remain. In other countries institutions have been reduced in size but the political will and investment needed to close them is lacking:

"While the two ID hospitals in the Western Cape have decreased in size, the financial resources and political will to relocate service users to community-based residential services are not in place." (South Africa)

In many countries the closure of large institutions has been very slow, with thousands of citizens still living in such places:

"In Israel we know about 7,000 in 62 residential care centers (on average 112 persons per center (range 21-324). (In the next 3 years) we plan to move 300 per year from residential centers into small apartments in the community (6 people per unit)."

"There is a programme but it is not what could honestly be called active. There are 4000 people in institutions and the timeframe for closure/moving people to communities has been moved by more than 15 years." (Ireland)[15]

In other places institutions are being closed down but are often being replaced with new, smaller institutions where residents similarly have little choice and control over their lives. This was evident in the following comments:

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[14] Although it is commonly reported that Italy was one of the forerunners of deinstitutionalisation, two of the five Italian respondents said that institutions for 10 to 20 residents still exist, and one that an institution for >100 residents exists.

[15] Authors' note: Another respondent from Ireland noted that plans are underway to move all 4000 remaining residents to community homes by 2018.

"State institutions are actively closing down but people are being moved to facilities run by not for profits. Many of these are quite big." (South Africa)

"Finland has a government decision to close all institutions by 2020, circa 1400 persons will be moved out to the local community."

"Norway closed down all long stay hospitals in 1991. Sadly, some councils have rebuilt institutional services locally (with more than 20 residents). The local decision makers' most common argument for this is that it is more financially viable, despite research showing that this might not be the case. There is a gap between what central and local government are saying. Last year the Norwegian government ratified the UN convention. The principles in the Convention are in stark contrast with the principles of how local services are run."

Many countries in Asia, Africa and South and Central America never had large institutions, care for people with intellectual disabilities always having been seen as families' and not the state's responsibility. Some such countries, in the process of intense development and urbanisation and the associated intense pressures on families, may seek to establish institutions, at times paying insufficient attention to their harmful effects and violation of people's rights:

"Only a few NGOs like us are working very hard against building larger institution by government. We are relatively small and weak compared with government agencies and most family members of people with intellectual disabilities [who prefer institutions]." (China)

Of note, the lack of institutional or other care in these countries 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, as this respondent from Malaysia noted:

"There are still a lot of individuals with ID who are being abandoned by the family members."

Chapter 5: Survey of Experts & Representatives – Actions aimed at Raising Awareness and Combating Stigma

5.1 Actions to combat Acts of Abuse, Harassment and Violence against People with Intellectual Disabilities

In the WHO *Atlas of Global Resources for Persons with Intellectual Disabilities* a respondent from Iran is quoted: *"It must be pointed out that there are lots of written laws regarding the rights of the disabled persons, including those who have intellectual disabilities; unfortunately there is not any type of sanction and supervision on execution of the laws." (p.27).* The UN CRPD at last provides supervision, and where called for sanctions, to ensure legislation assuring equal rights for people with disabilities is put in place and implemented at national level. The extent to which the CRPD does live up to this promise and apply sanctions in reality remains to be seen[16].

As part of our survey we sought to ascertain to what extent, by the time of our survey in early 2015, seven years after the CRPD came into force, people with intellectual disabilities have recourse to the law when they are the victims of abuse, harassment and violence directed at them *because* others perceive them to have a disability. Responses to disability hate crimes – including punishments (or lack thereof) - should be seen in the broader context of the law enforcement and judicial systems of each country.

For the purposes of the survey we adopted a definition of disability hate crime as 'any criminal offence which is motivated by hostility or prejudice based on a person's disability', a definition agreed by the UK Crown Prosecution Service and Association of Chief Police Officers. Whether such offences 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 the present project as it

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[16] The CRPD Committee has the power to launch an inquiry if it receives reliable information that grave or systemic violations have been committed by a country signed up to the CRPD and its optional protocol. It is rumoured that the UK is or may be subject to an inquiry by the CRPD over cuts to benefits available to persons with disabilities. The inquiry procedure is detailed at http://www.ohchr.org/EN/HRBodies/TBPetitions/Pages/HRTBPetitions.aspx.

reflects a willingness on the part of governments to take action to prevent and punish the most extreme acts informed by prejudice.

5.1.1 Recognition of disability hate crime

Respondents to the survey were asked whether disability hate crime, in line with this definition, is recognised as a criminal offence in their country. Overall, nearly half of all respondents thought that disability hate crime is recognised as a criminal offence in their country, around a fifth reported it is not, and a third were unsure. These proportions varied considerably across the regions, see Table 5.

Table 5: *Recognition of Disability Hate Crime as a Criminal Offence by Region*

Region	Yes	No	Unsure	Total
Sub-Saharan Africa	60.0% (21)	11.4% (4)	28.6% (10)	35
MENA (Middle East & N. Africa)	28.6% (8)	25.0% (7)	46.4% (13)	28
Asia (except MENA)	26.3% (10)	42.1% (16)	31.6% (12)	38
Europe	54.0% (114)	14.2% (30)	31.8% (67)	211
South/Central America & Caribbean	42.7% (50)	31.6% (37)	25.6% (30)	117
North America	49.7% (78)	9.6% (15)	40.8% (64)	157
Oceania (Aus, NZ, Pacific)	41.9% (26)	22.6% (14)	35.5% (22)	62
Total	47.4% (307)	19.0% (123)	33.6% (218)	648

Of note, there was a high proportion of 'unsure' responses and in some instances respondents from the same country frequently disagreed on this item, as noted in section 3.4. The countries with the most marked split in responses to this question were Argentina (number of 'yes' versus 'no' responses: 26:11), Australia (22:10), Colombia (15:18), Ireland (7:5), Israel (4:3), and the Netherlands (10:6). While the lack of clarity regarding this factual question may seem surprising, there are a number of possible explanations for it. In many places such crimes appear poorly defined in law, or relevant legislation may be inadequately advertised and/or implemented. For example in the USA, where four in ten respondents were unsure, the Shepard/Byrd Hate Crimes Prevention Act was passed as federal legislation (thus applying to all 50 US states) in 2009 and includes offences motivated by a victim's disability but only a handful of cases have been prosecuted under this Act. A respondent from South Africa noted: "*Hate crime is an offence but our over stretched, under-trained and resourced police*

have many, many other challenges." In any case, the inconsistency in responses pertaining to several countries indicate that our findings relating to legal recognition of disability hate crime should be viewed with considerable caution.

In many countries respondents noted that hostile actions against someone with a disability are covered under (disability) discrimination legislation. However, this means that they are not recognised as crimes in their own right and only provide a civil course of action. In addition, underlying hostile attitudes towards those with disabilities may well be overlooked.

In some countries people with intellectual disabilities appear to have very little recourse to legal protection if they are victimised because of their disability, as noted by these two respondents:

"It might be so in the law (not sure) but nothing usually comes out of such cases. Persons with ID are not protected." (Jamaica)

"In Pakistan people think nobody can hate people with disabilities, actually that is a wrong concept. This is the main reason there is no such law." (Pakistan)

Of note, in some countries, respondents said they had never heard of any such acts:

"I'm not aware of any such deeds in Austria." (Austria)

"This crime doesn't really exist. It is prosecuted like any other crime." (Germany)

And a respondent from Bahrain responded to this question:

"Yes, on paper. The issue is that persons with disability rarely are seen hence it is hard to answer this question."

In contrast, in some countries such as the UK, disability hate crime is recognised in law and provides for enhanced sentencing of offenders, and there are active efforts by the judiciary and police to tackle such crimes. Furthermore, a respondent from the UK noted that the public are becoming increasingly aware of such crimes due to reports and campaigns mounted by not for profit (charity) organisations such as Mencap and Scope[17]. In New

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[17] In the UK a ground-breaking report in 2008 by Katherine Quarmby written for Scope also gained a lot of media attention: *Getting Away with Murder: Disabled people's experiences of hate crime in the UK.*

Zealand, under the Sentencing Act 2002 higher sentences are given to those convicted of crimes whose hostility is because of disability, as well as race, religion etc. In the Netherlands Article 137c of the Criminal Code (Wetboek van Strafrecht) makes it punishable to insult a member of a minority group, including their having a disability. Detailed responses to this question by country can be found in Appendix 5.

5.1.2 Actions to combat disability hate crime

When asked whether there are active efforts underway in their country to tackle disability hate crime by the courts or criminal justice system, the proportion of respondents answering in the affirmative dropped compared to the question regarding recognition of such crimes, in many places by a large margin, see Table 6. So, while in Africa 60% said that disability hate crime is recognised in law, only 27% were aware of any action by the courts or justice system to combat these crimes. In South and Central America and the Caribbean similarly 43% said that it is recognised in law but only 33% reported that active steps are being taken to combat it. In other regions the figures suggest that disability hate crime may not be recognised in law as a distinct offence but that action is taken nonetheless by the courts and criminal justice system to tackle crimes against people with disabilities that are informed by prejudice or hostility. 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, which may have limitations in the first place.

Table 6: Action by Courts/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 & the 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

Action by the police or other law enforcement agencies to combat disability hate crime was generally deemed similarly or considerably less likely compared to action by the courts or criminal justice system. The proportion who said 'yes' to the question of whether the police or other law enforcement agencies make active efforts to tackle disability hate crime were: Sub-Saharan Africa: 27%; MENA: 25%; Asian: 17.5%; Europe: 38.1%; South & Central America and the Caribbean: 22.1%; North America: 23.8%; and Oceania: 23.8%. These figures paint a worrying picture of the extent to which, in practice, people with intellectual disabilities have recourse to legal protection when they are the victims of abuse, harassment or violence directed at them *because* of their disability and associated vulnerability. Respondents from Canada and Australia commented that they had never heard of any prosecution in relation to such crimes committed against someone with an intellectual disability.

In the UK, considerable efforts have been made to tackle disability hate crime, both through collaboration between the police and judiciary, and national campaigns aimed at increasing public awareness of such crimes. There has been a consistent increase in reports of disability hate crime in the UK since 2011, likely as a result of awareness raising and better monitoring[18]. Nonetheless a respondent noted:

> *"The current definition of disability hate crime is seen as problematic by the [police] officers having to work with is as it relies on perception and sometimes third party perception and in achieving the evidence to demonstrate the hostility was a motivating factor. "* (UK)

This is supported by UK Home Office statistics which reveal that the police recorded 1,841 reports of disability hate crime for 2012-13, with 810 incidents going to court. This led to 349 convictions, but only seven of these resulted in an increased sentence with the victim's disability being considered an aggravating factor. Despite these reservations, we thought it useful to illustrate some of the work undertaken in the UK, where a lot of attention has been given to disability hate crime over recent years, via two selected case examples.

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[18] For more detailed figures see http://www.report-it.org.uk/files/home_office_hate_crime_data_201314.pdf

Case Example: mcch Jigsaw project (UK)

As a result of the 3-year 'Living in Fear' research project into hate crimes against people with autism and/or intellectual disabilities, mcch is now tackling the issues of disability hate crime head on through the Jigsaw project, in partnership with people with intellectual disabilities and autism. Working closely with Kent Police, Medway Council and Victim Support, the mcch Jigsaw project is raising awareness of disability hate crimes to encourage people to report crimes, to give police officers the skills to support people with intellectual disabilities when reporting and to advise potential perpetrators (such as school pupils) about the consequences of offending. They also work with other agencies like transport, General Practitioners, businesses, and health and social cares staff. They do this through joint working and presentations, often with people who have been victims of disability hate crimes, in an interactive format. With funding from the Kent Police and Crime Commissioner, they were able to employ specialist Community Bridge Builders, working in partnership with Victim Support, who were trained specifically to work with people with autism and intellectual disabilities. They have also worked with young people from Medway Youth Trust to develop a film to take to schools.

Case Example: Intellectual Disability Awareness Training for Police Officers (UK)

In the London Borough of Hammersmith & Fulham, 45 minute training sessions were delivered by members of the specialist Clinical Psychology Team for people with intellectual disabilities, at the request of the local Police Commander. These sessions were delivered as part of mandatory training for the local police force. It was delivered in four separate sessions across two days to a total of 500 police officers of all ranks. The sessions covered: what is intellectual disability; the main features of autism spectrum conditions; hate crimes; communicating with people with an intellectual disability; and how to gain support from local intellectual disability services. Officers were also shown a 4 minute film of four self-advocates with intellectual disabilities talking about their experiences of contact with the police, and were given handouts to take away. A formal evaluation of the impact of the training sessions indicated that officers' knowledge of intellectual disability increased, as did their confidence in interacting with someone with an intellectual disability, and in communicating with someone with an autism spectrum condition.
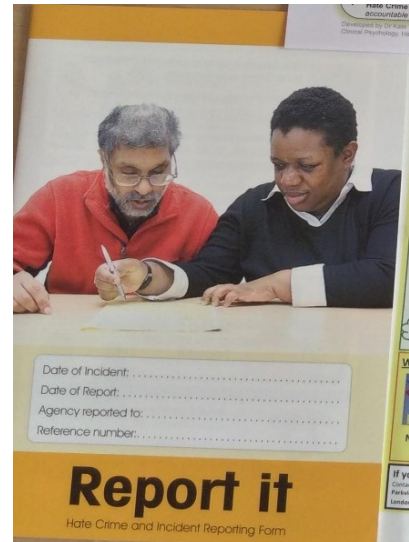
5.2 Actions to raise Awareness of Intellectual Disability and promote Positive Attitudes

In this section, we present an overview of initiatives designed to raise awareness or promote positive attitudes that we identified through the survey. We also present details of selected initiatives to illustrate the range of actions undertaken to raise awareness and combat intellectual disability stigma. Our focus was mainly on society at large, and thus on children and adults in the general population, and not on initiatives targeting groups more likely to have contact with individuals with intellectual disabilities, such as carers, teachers or health professionals. In the survey and presentation of the findings we have classified initiatives according to whether they target: (1) children within education settings; (2) the wider community through local or regional initiatives; (3) society through initiatives implemented at national level, as we did in the survey, Appendix 1. Of note, we only counted initiatives that were clearly relevant to intellectual disability. Accordingly, we excluded from our analyses initiatives that were specific to autism, in view of the fact that only around 40-50% of those with autism have an intellectual disability. We also excluded initiatives that were not primarily targeting the wider community or specific target populations thereof- many respondents identified projects providing support to people with intellectual disabilities and their families, increasing access or informing them of their rights - all important activities but not the focus of this project. We should stress that what is presented here likely only scratches the surface of the broad range of initiatives in place around the world. However, we believe it is worthwhile to provide a sense of the range of initiatives in place, where these are most and least likely to be carried out, and gaps. Given that we received a large number of responses from some countries, in Figures 5 and 6 below, we report the number of initiatives by country and region and not by number of respondents to account for the same initiative being named by multiple respondents.

Figure 5 - *Number of educational, local/regional and national initiatives by UN region*
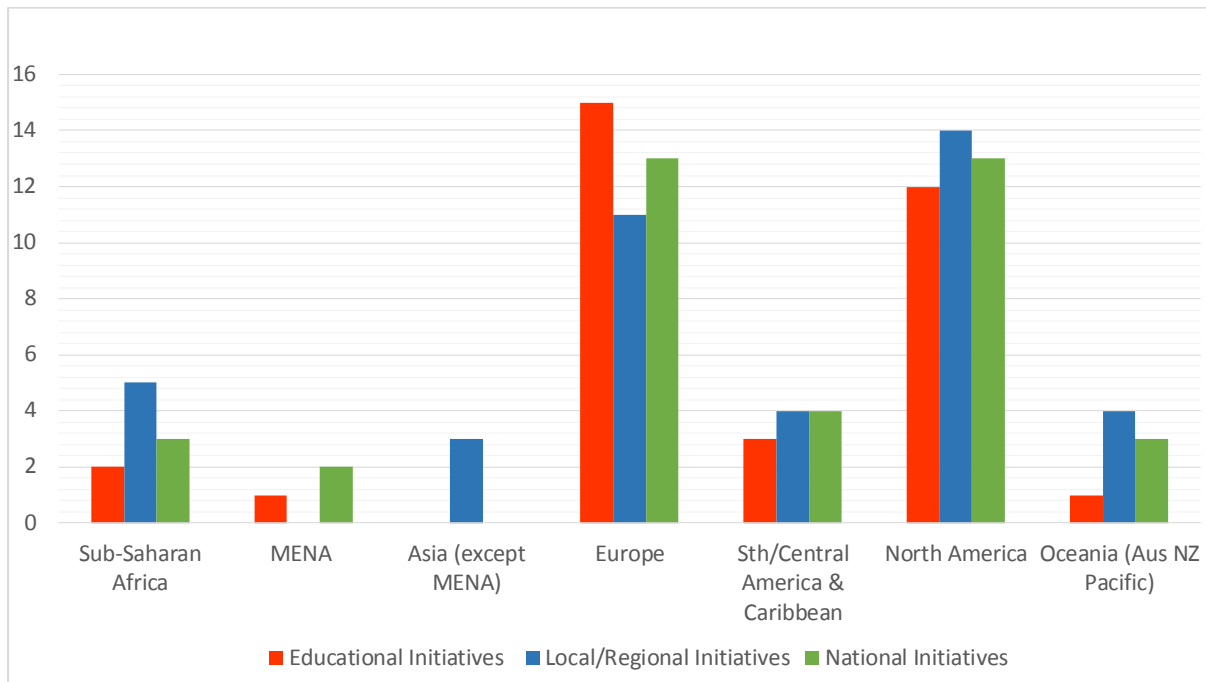
The extent to which respondents from the different country income categories were aware of specific initiatives aimed at raising awareness of intellectual disability and promoting positive attitudes is shown in Figure 6.

Figure 6 - *Number of educational, local/regional and national initiatives by country income*
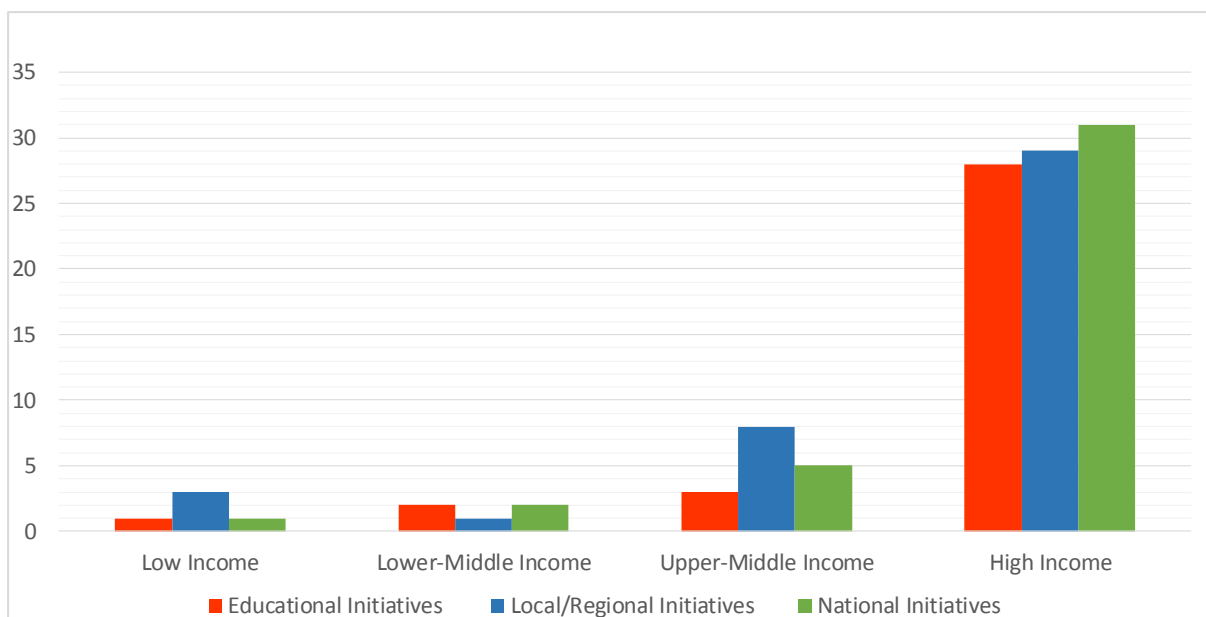
We must stress that, as noted in section 3.3, UN regions were not equally represented within our data and high income countries were overrepresented. Therefore the small number of initiatives identified in Africa and Asia, as well as in low and lower-middle income countries is at least partly explained by the smaller number of respondents from these regions/countries. However, we did receive 122 responses from South and Central America and the Caribbean, 63 from Oceania and 28 from MENA countries, which suggests that the rather small number of initiatives identified for these regions may not simply be attributed to insufficient data.

5.2.1 Actions within Education Settings directed at Children

5.2.1.1 Overview of Initiatives within Education Settings

Of the 667 survey respondents, 72 (10.8%) named at least one specific project targeting children within education settings. A further 94 (14.1%) indicated that there were educational initiatives in their region but were not able to name any specific project. In some high income countries (Australia, Germany, UK, USA), several respondents stated that there have been many such initiatives but did not name any specific ones. Many respondents named initiatives but once we looked at these more closely, they were either not specific to intellectual disability or were general disability-related initiatives that did not make any reference to intellectual disability (such as disability awareness resources that do not feature anyone with an intellectual disability).

We identified 29 initiatives targeting children or young people within education settings, some of which were carried out in several countries (hence the number shown in Figure 5 exceeds 29). The majority of these educational initiatives took place in Europe (15) and North America (12), see Figure 5. In contrast, the 122 respondents from 16 countries surveyed across South and Central America and the Caribbean, identified only three initiatives. The 37 respondents covering 15 African countries named two initiatives and the 28 respondents from the eight MENA countries identified one initiative. The 40 respondents from 16 Asian countries did not identify any initiative targeting children in school settings. Finally, the 63 respondents from four countries in Oceania named one initiative.

Furthermore, as shown in Figure 6, the majority of the 29 education setting initiatives identified were undertaken in high income countries. Although the number of respondents

from low, lower-middle and upper-middle income countries comprised only 29.5% of the sample, the number of respondents who specified an initiative in those regions was still disproportionately low (six initiatives were identified in these regions compared to 28 in high income countries). In view of reports noted in sections 4.1 and 4.2 that stigma in lower income countries 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 initiatives appear to be small in number and entirely dependent on the efforts of parent run organisations and NGOs.

Of the 72 respondents who named initiatives that clearly aimed at raising awareness and/or promoting positive attitudes, 22 (29.3%) mentioned Special Olympics as an organisation that runs such initiatives, indicating the high profile this organisation has in this field.

We identified some initiatives, such as The Early Years Organisation in Ireland (www.early-years.org), that do important work with young children between the ages of 3-5 in laying the foundations for respecting difference. Their work focuses on physical, social and cultural differences, i.e. differences that may be more salient for children at that age. However, we identified few initiatives targeting primary or secondary age children that extend such work to promote greater acceptance of peers with intellectual disabilities.

Below we have listed all of the initiatives mentioned and the country in which respondents to our survey referred to these as taking place. We wish to emphasise that we have only listed named initiatives. The many general descriptions provided by respondents, such as 'raising disability awareness in schools' without details of any specific initiative or organisation running the initiative, were not included. Furthermore, several participants mentioned integrated learning and social activities involving children with and without intellectual disabilities in local nurseries or schools. These undoubtedly have an important role in raising awareness and reducing prejudice but have not been detailed here as they are large in number and usually based on local agreements rather than part of a broader initiative. The initiatives identified, in alphabetical order, were:

o Anti-bullying Alliance SEND (Special Educational Needs and Disabilities) Programme (UK)
o Awareness raising (specific to Down Syndrome): Downside Up charity (Russia)
o Awareness raising workshops in schools: ASNIC (Nicaragua)

- Awareness raising workshops in schools: Fundown Caribe (Colombia)
- Awareness raising workshops in schools: Special Olympics (Belgium, Ireland, USA)
- Awareness raising workshops in schools: Touch of Understanding (USA)
- Awareness raising workshops and training for teachers, social workers and administrators: Open Doors for Special Learners (Nigeria)
- 'Best Buddies' (Canada, USA, Venezuela)
- 'Circle of Friends' programmes in schools: Extend-a-Family (Canada, USA)
- Disability Awareness training: Down Syndrome Association - (UK, USA) (specific to Down Syndrome)
- Disability Matters (UK)
- 'Disabling Segregation': Canadian Association for Community Living (Canada)
- 'Every Disabled Child Matters' campaign (UK)
- 'Everyone Everyday' Disability Awareness Program (Australia)
- 'Get Into It': Special Olympics (Hungary, Ireland)
- Integrated Play: Esdégé-Reigersdaal (Netherlands)
- 'Jigsaw Project' (UK): Videos related to disability hate crimes shown in schools
- 'Kids on the Block' (USA) (specific to Down Syndrome and Autism)
- Peer Buddy programmes (USA)
- Peer to Peer programme: Bauleni Street Kids Centre (Zambia)
- 'PEER training': WALK (Ireland)
- 'Play With Me' (Slovenia)
- Speaking Up - Making schools better places for people with intellectual disabilities: People First New Zealand (New Zealand)
- 'Special Olympics Unified Strategy for Schools' (previously, 'Project UNIFY') (USA, UK)
- 'Spinclusion' (Canada)
- 'Spread the Word to End the Word' School Based Activities (Canada, USA)
- Talks in Schools and Inclusive Summer Programme: Extend-a-Family (Canada)
- 'The Other is Me' (Israel)
- Workshops by actors with intellectual disabilities in schools: Eskalibur (Netherlands)

Of note, Special Olympics Unified Strategy for Schools (previously, 'Project UNIFY') was mentioned by 13 respondents, Spread the Word to End the Word by 10 respondents, and Best

Buddies by eight, indicating the high profile of these initiatives within education settings. These initiatives are outlined in sections 5.2.1.3 and 5.2.3.3 below.

5.2.1.2 Objectives of Identified Initiatives within Education Settings

An important question is what the objective of these initiatives is (and whether these are in fact achieved). We asked respondents to detail the aims of initiatives they were aware of. We also examined further available information about initiatives (e.g. on project websites) to classify these aims. Of note, for many the objectives were not clearly defined, or where stated in some cases did not appear to match the actual work undertaken. The objectives of the 26 initiatives targeting children within education settings can be summarised thus:

- 11 initiatives appeared to aim to raise awareness, and change both attitudes and behaviour;
- 8 initiatives appeared to aim mainly to raise awareness and educate children and young people about intellectual disability;
- 6 initiatives appeared to aim for a combination of both awareness raising and attitude change;
- 4 initiatives appeared to aim for a combination of attitude and behaviour change.

Of note, none of the initiatives appeared to have behaviour change, for example by increasing interaction and reducing discrimination, as their primary objective. This is concerning given that children and adults with intellectual disabilities often identify stares in public, name calling and discrimination in education, social and health as a major concern.

5.2.1.3 Illustrative Examples of Initiatives within Education Settings

In order to give a flavour of the range of initiatives targeting children and young people within education settings that are in place around the world, we provide an overview of some of the initiatives we identified below.

Case Example: Special Olympics Unified Strategy for Schools (formerly known as Project UNIFY) (USA and other countries)

With sports as the foundation, this programme offers a combination of programmes that equip young people with tools and training to combat exclusion, segregation and isolation. The Unified Strategy creates sport, classroom and community experiences that aim to reduce bullying and exclusion, promote healthy activity and interactions, combat stereotypes and stigma, eliminate hurtful language in schools, and engage young people in pro-social activities that lead to improved behaviour and school climate. Schools employ the Strategy to promote social inclusion by fostering student leadership, combining students with and without intellectual disabilities on school sports teams (Special Olympics Unified Sports), through inclusive student clubs, and together in school-wide initiatives, helping to create a school climate where students without disabilities are accepting of their peers with disabilities both in the classroom and school overall. Supported in large part by funding from the U.S. Department of Education, currently, over 3500 elementary, middle and high schools across 45 states are employing the Special Olympics Unified Strategy for Schools, and as many as 1.7 million youths are experiencing messages of inclusion and acceptance.

Photo courtesy of Special Olympics Washington DC

Case Example: The Spinclusion Game (Canada)

This classroom based game was designed by Community Living Toronto. It is a fun, interactive game that aims to create a welcoming and inclusive environment for children of all abilities and cultures. This multi-activity package has a variety of activities for children and youth (grade 2 to high school) that teaches them that everyone is different and has different abilities. While the version for children focuses on diversity and disability in general, the youth version includes specific scenarios and activities relating to intellectual disability and how to include peers who may experience communication and cognitive differences. The full game pack can be purchased or downloaded for free.
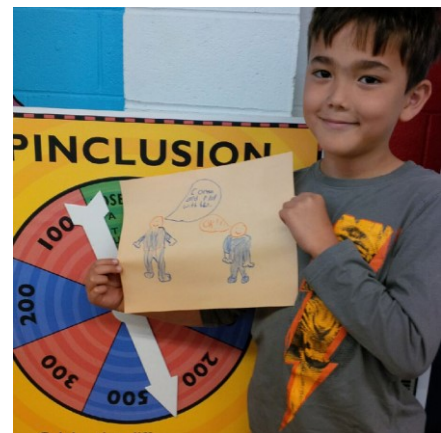
Photo courtesy of Community Living Toronto

Case Example: Best Buddies® (Worldwide)

Best Buddies was founded in the USA in 1989 to foster one to one friendships between people with intellectual disabilities and those without. Through creating opportunities for peer mentoring, employment and leadership development, Best Buddies work towards their goal of an inclusive society. Having grown from one original chapter, Best Buddies now has almost 1,900 middle school, high school, and college chapters in 50 of the United States and a presence in over 50 countries around the world.

Best Buddies has eight formal programs, including peer-mentoring in middle schools, high schools and colleges, corporate settings or local communities and online. Best Buddies' Ambassadors and Promoters programmes also encourage young people with intellectual disabilities to become self-advocates and develop leadership skills. The work is estimated to have a direct positive impact on almost 900,000 individuals with and without disabilities worldwide. As a result of their involvement with Best Buddies, people with intellectual disabilities secure rewarding jobs, live on their own, become inspirational leaders, and make lifelong friendships.

Best Buddies is continuously looking to grow and expand. Programmes in Japan, Morocco and Sri Lanka are currently under development. Best Buddies UK was set up in 2014; there are now six active Best Buddies chapters in the UK with plans to create a further 100 local initiatives by 2017.

Photo courtesy of Best Buddies UK

Case Example: Disability Matters (UK)

The Disability Matters e-learning programme aims to positively change attitudes towards disabled children and young people among the children's workforce, and to equip them with the knowledge, confidence and skills to welcome and include disabled children and young people. All Disability Matters resources are freely available, and include 57 online e-learning sessions alongside two resource packages that support face-to-face group learning. All the online resources have been co-produced by disabled children, young people, parent carers and other experts across statutory and voluntary sectors. They are full of real stories of lived experiences and top tips from disabled children, young people and their families for all that work or volunteer with them. The core themes within the programme are: understanding disability; person to person working; family and society; decision making and growing up; health and well-being; and behaviour and emotions. The vignettes and information provided explicitly include young people with intellectual disabilities, and there are specific e-learning sessions such as 'Learning Disabilities Matter'.

Photo courtesy of Disability Matters

Case Example: Awareness Workshops by Fundown Caribe (Colombia)

The Foundation hopes to produce long-term change in attitudes and ensure that individuals with Down's syndrome are included in their communities. An important aspect of this is getting rid of the preconception that people with cognitive disabilities should always be placed in 'special' institutions.

Since 2010, Fundown Caribe has been promoting awareness workshops towards inclusion in the Colombia-Caribbean coast. Up until December last year they completed 234 workshops at 120 schools with the participation of 7800 students. This experience informed the development of a new project, 'It´s a myth and it´s not permitted', created to bust myths about persons with Down's syndrome and intellectual disabilities. 5000 free books were distributed during workshops. Interactive wall murals in universities, museums, and shopping centres were placed. 20,000 placemats with the same message were located in restaurants. These have been used as tools to raise awareness about the potential of this population.

Photo courtesy of Fundown Caribe

Case Example: People First New Zealand, Ngā Tāngata Tuatahi (New Zealand)

People First New Zealand is a Disabled Persons Organisation run by and for people with intellectual disabilities. The "speaking up about making schools better places for people with intellectual disabilities" project was run in 2014 as part of leadership development within the regions. It was the idea of young people with intellectual disabilities who decided to speak to students and teachers about: what they liked at school, what they didn't like at school, being bullied at school, wanting to have non-disabled friends at school, and what their achievements were at school.

The leadership group did 8 presentations that included universities, training centres, vocational day bases and high schools. As part of their work they emphasise that young people with disabilities want: to be in classes with the rest of the students; to be in the senior common room; teachers to understand their learning needs better; to have non-disabled friends; and other students to understand that they just want to be like everyone else.

Photo courtesy of People First New Zealand

Case example: Everyone, Everyday Programme (Australia)

The Everyone Everyday programme promotes changing attitudes towards children with any type of disability, with a particular emphasis on children with intellectual disabilities. It is a resource for teachers to explicitly teach mainstream students concepts and behaviours relating to inclusion so they can take action to foster an inclusive environment in the classroom, school and the broader community. The programme is about changing attitudes and focuses on themes including positive communication, being mindful, taking action, embracing and valuing difference, building strong communities, everyone having a role to play, rights and responsibilities, benefits of inclusion etc.

The resource includes four programmes (or units of work) targeting different age groups from 4 ½ to 12 years and consists of sequenced lesson plans, freely available via the programme webpage. The lessons provide links to the Australian Curriculum to assist with programming, assessment and reporting. An important component of the program is the professional learning session that gives teachers an update on current perspectives in disability and inclusion (i.e. emphasis on asset based approach as opposed to deficit based and the 'social model' of inclusion), and aims to help build teacher confidence to foster an inclusive learning environment.

Photo courtesy of Everyone, Every Programme

Case Example: Workshops to promote acceptance in inclusive schools (Nicaragua)

ASNIC (Nicaraguan Association for Community Living) work to promote inclusive education in Nicaragua and to change attitudes towards the inclusion of children and youth with disabilities in the economic and social life of the country. As part of their work, they run seminars for pupils (without disabilities) and parents to promote acceptance and support for inclusive education in classrooms, workshops with key officials in the education sector on curriculum reform and resource development, and campaigns in the media. They also produced a documentary about positive experiences of inclusive education in Nicaragua. A key aim was to achieve increased awareness of the benefits of the inclusion of children with disabilities in schools. The work is funded by the IAF and the UK Big Lottery Fund.

Photo courtesy of ASNIC

5.2.2 Actions at Local or Regional Level

5.2.2.1 Overview of Local/Regional Initiatives

Actions carried out at local or regional level, often on a small scale and as one-off events, are unlikely to be widely known about. Hence our earlier note that what we present is likely to only scratch the surface of initiatives in place to raise awareness of intellectual disability and combat stigma applies in this section perhaps even more than elsewhere.

Of the 667 survey respondents, 57 (8.5%) named at least one initiative conducted at a local or regional level. A further 88 (13.2%) indicated that there were local initiatives in their region but did not name any specific project. As long as an initiative was named, or the organisation and some details of the work carried out were provided, and the initiative's focus was clearly on either awareness raising or combating intellectual disability stigma at local (and not education or national level), it has been included here.

Given that we received a large number of responses from some countries, as for initiatives in education settings, we looked at initiatives reported by country and region and not by number of respondents to account for the same initiative being named by multiple respondents. As shown in Figure 5, the majority of the 41 local/regional initiatives identified took place in Europe (11) and North America (14). In contrast, the 122 respondents from 16 countries surveyed across South and Central America and the Caribbean, identified only four initiatives. The 37 respondents covering 15 African countries named five initiatives. The 28 respondents from the eight MENA countries identified no local/regional initiatives. The 40 respondents from 16 Asian countries identified three initiatives. Finally, the 63 respondents from four countries in Oceania named four initiatives. The small number of initiatives identified in these regions can be partly attributed to the smaller number of respondents from these regions. However, it should be borne in mind that MENA and Asian respondents reported from 24 countries, which raises concerns about the fact that only four local or regional initiatives were identified collectively from these regions.

In addition, Figure 6 shows the vast majority of local/regional initiatives identified took place in high income countries. Although respondents from low, lower-middle and upper middle income countries made up 29.5% of the entire sample, the number of local/regional initiatives reported in their countries was still disproportionally low (12 in comparison to 29 in high income countries).

We identified many local and regional level efforts that were spearheaded mainly by parents of people with intellectual disabilities, churches and NGOs. Below we have listed all of the local/regional initiatives identified and the country in which they were reported to have taken place. We were informed of several projects aimed at matching people with intellectual disabilities with buddies or befrienders – while such projects have an important role to play on a 1:1 level, we have not included them as they are large in number and not generally aimed at wider community change.

- o 'A Chromosome is Not a Border' (Un Cromosoma no es una Frontera): Campaign and interactive inclusive activities (Venezuela)
- o 'AllBornIn' (USA)
- o Ambassador Programme: Special Olympics and Youth Sport Trust (UK)
- o AVESID 'Carrera de los PANAS DOWN': Sports inclusive activity (Venezuela)
- o Awareness raising: Aprosuba-4 (Spain)
- o Awareness raising: ARC organisation at county and state level (USA)
- o Awareness raising: ASDOWN (Colombia)
- o Awareness raising: Best Buddies (Canada)
- o Awareness raising: DINCAT (Intellectual Disability Catalonia) (Spain)
- o Awareness raising: Down Syndrome Association of Nepal (Nepal)
- o Awareness raising: Down Syndrome Association of South Africa (South Africa)
- o Awareness raising: Down Syndrome Association Wales (UK)
- o Awareness raising: Equity Works (Australia)
- o Awareness raising: Fundación Tempo de Integrarse (Argentina)
- o Awareness raising: Madrid Down Syndrome Foundation (Spain)
- o Awareness raising: Pietermaritzburg Mental Health Society (South Africa)
- o Awareness raising: Special Olympics (Canada)
- o Awareness raising: The Children's Developmental Centre (Nigeria)
- o Awareness raising and promotion of employment: Rong Ai Rong Le (China)
- o Boy Scouts and Girl Scouts work to promote inclusion of children with disabilities (USA)
- o 'Buddy Walk®' (USA)
- o Community awareness: New South Wales Council for Intellectual Disability (Australia)
- o Community awareness activities and seminars: University of Kentucky (USA)
- o Community based education and awareness raising: The BOLD Network (Australia)

o Community Sensitisation and Rehabilitation: Kaoma District Forum for the Disabled (Zambia)

o COMPASS Advocacy Network (Northern Ireland)

o Disability awareness training for schools and employers: Centres for Independent Living (USA)

o Documentary Film 'Ein Gewinn Fuer Alle' ('Everyone's a winner') promotes employment of people with (intellectual) disabilities: Elbe Werkstaetten (Germany)

o Summer Open Air – Annual Inclusive Music Festival: Stiftung Mensch (Germany)

o Law enforcement training: ARC New Jersey (USA)

o 'One to One Day': The Western Cape Forum for Intellectual Disability (South Africa)

o 'Partners Club': Local branches of Special Olympics (USA)

o 'Project SAFE' aimed at preventing crimes against people with disabilities (USA)

o Promotion of interaction: Prokkel (Netherlands)

o Public presentations on disability: Yooralla Speak Tank (Australia)

o Quebec Intellectual Disability Awareness Week (Canada)

o 'Start with Hi': Canadian Ass. For Community Living (British Columbia, Canada)

o 'The Drama Group', play performed by the Bake Bean Company and guest star Hugh Grant, January 2015, Sadlers Wells Studio Theatre, London (UK)

o United Church of Canada inclusion efforts (Canada)

o Valuing People Big Day Network: Transport for London (UK)

o Workshops, seminars, campaigns and awareness programmes: GFPID (Nepal)

5.2.2.2 Objectives of Identified Local/Regional Initiatives

The objectives of the 41 local and regional initiatives identified here can be summarised thus:

- 21 focused on raising awareness and educating the public on intellectual disability;

- 9 focussed on a combination of both awareness raising and changing attitudes;

- 4 explicitly set out to increase interaction and reduce discrimination;

- 3 focussed on raising awareness, challenging attitudes and prejudices and changing behaviour;

- 3 focused on raising awareness and promoting inclusive behaviour;

- 1 focused on changing attitudes and behaviour;

5.2.2.3 Illustrative Examples of Local/Regional Initiatives

In order to give a flavour of the range of initiatives at local or regional level that are in place around the world, we provide an overview of some of the initiatives we identified below.

Case Example: Valuing People Big Day Network (UK)

This group was established in February 2007, linking Transport for London (TfL) with the Government's Valuing People programme for individuals with intellectual disabilities in the London region. TfL have funded it since April 2011.

The group gets together three times a year, with additional events and projects also taking place. Meetings regularly have representation from more than 20 London boroughs. At the meetings, members and supporters of self-advocacy groups for people with intellectual disabilities have the opportunity to talk to TfL managers about transport services they use as either independent travellers, or with support. It is also an opportunity for TfL to have continued dialogue with advocates on a variety of issues and to gain understanding of the experiences of those with intellectual disabilities when using the transport system. The Network has become increasingly high profile within TFL, leading to greater awareness of intellectual disabilities among drivers and managerial staff.

Through the Network links between self-advocacy groups and local bus companies have also been developed. Several visits to local bus garages have been held at which self-advocates and bus drivers have the opportunity to chat and learn from each other's experiences.

Photo courtesy of John Hersov

Case Example: The Drama Group (UK)

As part of the launch of the book 'The Drama Group', 25 actors with intellectual disabilities from the London based Bake Bean Company and guest star Hugh Grant, gave two sell-out performances at the Lilian Baylis Theatre at Sadlers Wells, London. 'The Drama Group' is part of the series 'Books Beyond Words', co-authored by actor Hugh Grant, Baroness Sheila Hollins and her son Nigel Hollins. It tells the story of Dean who loves going to the theatre and decides to join a drama group. The performances gained wide attention and were featured on BBC television news, indicating the potential of high profile individuals joining with people with intellectual disabilities to raise awareness and highlight their capabilities.

Photo courtesy of The Drama Group

Case Example: Prokkel (Netherlands)

Prokkels are 'exciting encounters' between people with and without intellectual disabilities. They aim to challenge negative stereotypes about people with intellectual disabilities and their capabilities.

'Prokkel Week' takes place annually during the first week of June and aims to demonstrate the skills persons intellectual disabilities possess. Initially, beginning as a two day event with a few towns participating in 2008, the event now spans to a week full of activities with over 400 participating towns throughout the Netherlands. Local communities, workplaces, schools, care homes and other settings are encouraged to host and organise Prokkel events; activities vary from arts and crafts workshops, community lunches, sporting activities to music concerts. All activities are collaborative between persons with intellectual disabilities and those without.

Not only does this week act as a forum to raise awareness of intellectual disability, it has also fostered more positive interactions between people with intellectuals and members of their local communities through the various collaborative activities.

Photo courtesy of Prokkel

Case Example: Start with Hi (Canada)

Community Living British Columbia (CLBC) is a provincial Crown agency in British Columbia, Canada that funds supports and services to help adults with intellectual disabilities and their families achieve their goals and live the life they want.

CLBC started a social media awareness campaign called, 'Start with Hi'. The aim? To inspire people to be more welcoming towards people with intellectual disabilities by starting a conversation with a simple greeting. The idea came out of feedback from people with intellectual disabilities who said a small act, like saying hi, has a huge impact and can help a person feel included and safer in their community.

The campaign encourages everyone, in all communities, to become aware of people with intellectual disabilities as they go about their daily lives and to encourage them to acknowledge and connect with someone by simply saying "hi", with the hope that further and future conversation and awareness will occur.

Photo courtesy of Start with Hi

Case Example: Children's Developmental Centre (Nigeria)

This centre in Lagos was established to provide services to children with intellectual disabilities and their families. They offer practical support with medical assessments and schooling, as well as opportunities for employment through their own catering company and candle-making business.

In addition to running training events for professionals on the topic of intellectual disabilities, CDC are passionate about raising awareness of intellectual disability and fighting stigma throughout Nigeria. They have run awareness raising roadshows by travelling to different parts of Nigeria, holding rallies in towns on arrival and hosting events to engage the public, raise awareness and highlight the capabilities of people with intellectual disabilities. Since 2007 they have also run a 'Ride 4 Life' cycling event, for participants from their centres and the public. At the end of the bike ride, a talk show is held to stress the right of people with intellectual disabilities to a full role in society.

Photo courtesy of Children's Developmental Centre

5.2.3 Actions at National Level

5.2.3.1 Overview of National Initiatives

Of the 667 survey respondents, 70 (10.5%) named at least one specific national project aimed at either raising awareness of intellectual disability, or combating stigma, prejudices and/or discrimination against people with intellectual disabilities. A further 53 (7.9%) indicated that efforts to raise awareness or combat stigma had taken place in their country but were not able to name any specific initiative. Of note, many respondents named national projects and efforts, some of which we have not included here given that they aimed to raise awareness of disability in general but did not include any specific focus on intellectual disability.

We identified 29 initiatives carried out at national level, some of which were carried out in several countries (hence the number shown in Figure 5 exceeds 29). Similar to educational and local initiatives, as shown in Figure 5, the majority of these initiatives identified took place in Europe and North America. Therefore, as before, we looked at the initiatives reported by country and region and not by number of respondents to account for the same initiative being named by multiple respondents. Where the same initiative was reportedly

carried out in several countries we counted it for each of the countries mentioned. Most of the national initiatives took place in Europe (13) and North America (13). Despite there being 122 respondents from South and Central America and the Caribbean, only four initiatives carried out at national level were identified for this region. Similarly only three national initiatives were identified for Sub-Saharan Africa, despite 37 respondents being from this region. From the four countries in Oceania surveyed three national initiatives were reported. There were only two national initiatives from the MENA region but none could be identified for the 16 Asian countries surveyed.

In addition, Figure 6 shows the vast majority of national initiatives identified took place in high income countries. Although respondents from low, lower-middle and upper middle income countries made up 29.5% of the entire sample, the number of national initiatives reported in their countries was still disproportionally low (8 in comparison to 31 in high income countries).

Below we have listed all of the initiatives mentioned and the country in which respondents to our survey referred to these as taking place. Organisations such as Special Olympics have a presence in many of the countries surveyed. Two of their programmes were named repeatedly and are run not only at national level, but internationally and also within education settings: 'Special Olympics Unified Strategy for Schools' (previously, 'Project UNIFY'), and 'Best Buddies'. Most of the Special Olympics campaigns are presented as focused on awareness raising (and as this is their explicit aim were coded as such). However, campaigns such as 'Stop the Word to End the Word' play an important role in not only raising awareness, but also in challenging negative attitudes and ultimately one would hope result in behaviour change (in encouraging the audience to refrain from using the term 'retard(ed)').

FEAPS, the Spanish Federation for People with Intellectual Disabilities, was also identified as running several national campaigns and projects, including 'Nosotros También' (transl. 'We Also') campaign and 'Iguales' (transl. 'Equals'), which are social media campaigns targeting diverse audiences, including young people in schools and members of the wider community.

The national initiatives or organisations that run them (where the initiative does not have a name or title), in alphabetic order, were:

- 'Best Buddies' (Canada)
- Canadian Association of Community Living (Canada)
- 'Death By Indifference': Mencap (UK)
- Down Syndrome Association of Argentina (Argentina)
- Down Syndrome Association Romania (Romania)
- Equal in Uniform: Ministry of Social Affairs & Social Services and AKIM (Israel)
- FEAPS (Spanish Confederation of Organisations for Persons with Intellectual Disability and Development) (Spain)
- FIDES (Foundation for the Investigation and Development of Special Education) (Colombia)
- Fundacion Quiereme Como Soy (Love me as I am Foundation) (Dominican Republic)
- Hear My Voice Campaign: Mencap (UK)
- IHC: In Your Community (New Zealand)
- Inclusion Ireland (Ireland)
- KAIH (Kenya Association for the Intellectually Handicapped) (Kenya)
- Lebenshilfe Österreich (Austria)
- National Down Syndrome Day: Down Syndrome Foundation (Nigeria)
- PACER Center (USA)
- People First (Canada, New Zealand, USA)
- Special Olympics Unified Strategy for Schools (previously, "Project UNIFY") (Ireland, USA)
- REDempleo Campaign: FEAPS (Spain)
- 'Spread the Word to End the Word' (Canada, USA)
- SOLE: Special Olympics Law Enforcement Training Programme in collaboration with Special Olympics Ireland with An Garda Síochána and the Police Service of Northern Ireland (PSNI) (Ireland)
- Special Olympics (Canada, El Salvador, Finland, Ireland, Israel, New Zealand, USA)
- The Arc (USA)
- The Western Cape Forum for Intellectual Disability (South Africa)
- Think Differently Social Campaign (New Zealand)
- USA Games: Special Olympics (USA)
- Workfit Initiative - Down Syndrome Association Wales (UK)
- World Games: Special Olympics (USA)

- ○ ZAK Initiative (Zesummen Aktiv) brings together people with and without disabilities to participate in sports and cultural events (Luxembourg)

5.2.3.2 Objectives of Identified National Initiatives

The objectives of national initiatives identified here can be summarised thus:

18 aimed to raise awareness and provide information about intellectual disability;

6 aimed for a combination of awareness raising, attitude and behaviour change;

2 aimed for a combination of both awareness raising and changing attitudes;

1 explicitly aimed to change attitudes and behaviours;

1 aimed to raise awareness and change behaviours;

1 held behaviour change as the main aim.

5.2.3.3 Illustrative Examples of National Initiatives

In order to give a flavour of the range of initiatives at national level that are taking place around the world, we provide an overview of some of the initiatives we identified below.

Case Example: Hear My Voice Campaign: Mencap (UK)

This campaign aimed to increase the voice of people with intellectual disabilities in the run up to the 2015 UK general elections. It was based on the fundamental belief that people with intellectual disabilities have a right to take part in the political process, but then politics are often inaccessible for them. Mencap's campaign focused around an accessible microsite, encouraging people with intellectual disabilities to share their stories directly with their election candidates, and asking them to publically sign up to the campaign (over 800 did). Acknowledging that there has been real progress for people with intellectual disabilities and their families, the manifesto set out what needs to happen before people with intellectual disabilities are recognised – and treated – as equal and valued members of society, focusing on six key areas: health, early years, social care, hate crime, education, and benefits and welfare reform.

The manifesto has been used widely to lobby politicians to ensure they have a better understanding how these issues affect the lives of people with intellectual disabilities and their families. Prior to the election, all major political parties worked with Mencap to produce accessible versions of their manifestos, which Mencap then promoted, along with guides on the voting process for people with intellectual disabilities – all developed to encourage them to take part in the democratic process.

Photo courtesy of Mencap

Case Example: Spread the Word to End the Word ® (Special Olympics) (USA)

Through engagement with schools, organizations and communities, the Spread the Word to End the Word® campaign urges young people around the world to take a stand in their own communities and help change the conversation by eliminating the use of the R-word and replacing it with 'respect.'

The Spread the Word to End the Word grassroots campaign was created in February 2009 by youth who participated in the Special Olympics Global Youth Activation Summit, held in conjunction with the Special Olympics World Winter Games in Idaho. Led by Soeren Palumbo and Timbo Shriver (son of Special Olympics Chairman Timothy Shriver), the campaign evolved out of a united passion to promote the positive contributions people with IDD make in communities around the world. It was combined with a simple call to action to take the pledge and inspired thousands of K-12 schools and universities across the country to hold rallies enlisting young people to take the pledge. To date, nearly 600,000 people across the country have taken the pledge online to end the use of the R-word and millions more have signed banners and petitions throughout the world. In terms of social media presence, in 2014, Special Olympics had over 10.5 million Twitter impressions on all of our handles. In 2015, during the same time period, we generated nearly 30 million social media impressions with tweets from celebrities, partners and ambassadors alike. The success of the Spread the Word to End the Word campaign is due in part to how participation in the campaign can vary both in scope and implementation, as well as the strong message of inclusion and acceptance that is universal.

Photo courtesy of Special Olympics Washington DC

Case Example: Papas Viajeros *(Travelling Dads)* (Argentina)

The Papas Viajeros are a group of fathers of persons with Down's syndrome. As part of ASDRA, the Down's syndrome Association of Argentina, they travel the country giving seminars and talks on Down Syndrome, inclusion and rights. They aim to raise awareness of the importance of inclusion in education, the labour market and society, the rights of persons with disabilities, and to challenge negative attitudes and perceptions regarding the capabilities of persons with Down's syndrome.

Photo courtesy of Papas Viajeros

Case Example: Western Cape Forum's March on Government to demand right to education (South Africa)

On 18 March 2004 more than 500 parents, children and staff from 22 special care centres in Cape Town marched on government demanding their right to education.

Western Cape Forum advocates for the constitutional rights and needs of children and adults with intellectual disabilities in many spheres. One of their success stories relates to their work lobbying for the right to education for children with severe and profound intellectual disabilities, leading to a ground breaking High Court judgment (Case no: 18678/2007). After 13 years of lobbying, judgment was delivered in the High Court of South Africa (Western Cape High Court, Cape Town) Case no:18678/2007 in November 2010.The judgment stated that: *"... every child in the Western Cape who is severely and profoundly intellectually disabled has affordable access to a basic education of an adequate quality..."*. This ruling has been a landmark judgment, both nationally and internationally, however of even greater significance has been the provincial implementation thus far, largely in response to post judgment collaboration and relationships of the NGO sector and government. At a national level there is a "Draft South African policy framework for the provision of quality education and support to children and youth with profound intellectual disability" and a "Draft learning programme for children and youth with profound intellectual disability".

Photo courtesy of Western Cape Forum for Intellectual Disability

Case Example: Quiéreme Como Soy (Dominican Republic)

Founded in 2011, the Foundation Quiéreme Como Soy (*Love me as I am*), works to promote the inclusion of people with intellectual disabilities and a culture of acceptance in Dominican society. They run awareness raising campaign, deliver multi-media sessions in schools for 10-17 year olds, and put on large events such as a Basketball match involving the national Special Olympics team attended by 4000 spectators. They also work closely with national television and radio channels to raise awareness and deliver their message of acceptance and inclusion.

Case Example: Equal in Uniform (Israel)

As part of AKIM Israel's ongoing efforts to include people with intellectual disabilities in community life, a unique partnership was created with the Israel Defence Forces (IDF).

This project, funded by the Division of Intellectual & Developmental Disabilities in the Ministry of Social Affairs and Social Services, enables Israel's young citizens with intellectual disabilities (18 years old) to complete national service, as do all Israeli citizens when they reach adulthood. Serving in the IDF is a crucial part of growing up in Israel, which reinforces connections to the land and its people and enhances values of camaraderie, intuition, and leadership. Under this project young adults with intellectual disabilities are no longer automatically excluded from IDF service but can serve in a range of roles.

Photo courtesy of AKIM

Case Example: Campaigns run by FEAPS (Spain)

The mission of the FEAPS Movement is to provide support and opportunities to enable each person with intellectual or developmental disabilities and their families to develop their quality of life and to promote their inclusion as fully-fledged citizens in a just and fraternal society. Among their many efforts they run two national campaigns:

#SomosSusMayoresFans (Transl. 'We're Your Biggest Fans')

This is an awareness campaign launched by FEAPS Madrid. The campaign aims to encourage the general public to support inclusion and participation in society. Several well-known personalities and celebrities have publicly declared their support for the campaign.

#InclusoYo (Transl. 'Including Me')

Another public awareness raising initiative by FEAPS is the #InclusoYo project, which involves young people with and without intellectual disabilities in achieving joint challenges, through rights training, awareness raising and participation. The result of this project has been a rap, entitled Iguales (Transl. *Equals*). This song offers a message of inclusion, as a result of what the contributors have learnt through working collectively as active agents of social change.

Photo courtesy of FEAPS?

5.2.4 Impact of these Initiatives

In order to examine whether initiatives identified through the survey have been effective in raising awareness of intellectual disability, promoting positive attitudes or changing actual behaviour, we asked survey respondents to provide information about any evaluation of initiatives named that they were aware of. In many cases respondents either did not indicate or know whether the projects they listed had been evaluated. Some noted that the projects they identified were either too small or in their early stages and so had not (yet) been evaluated. Several responded 'yes' to the question of evaluation but provided no further details; in these cases the research team explored project websites for further information. In addition, in contacting the organisations or teams conducting the initiatives featured as case examples in section 5.2 to seek their approval, we asked whether any evaluation had been completed and requested further details if this was the case.

Most of the 99 initiatives detailed in this report either do not appear to have been evaluated, or any evaluation consisted solely of informal participant feedback. As we sought evidence on the effectiveness of said initiatives in meeting their targets, here we do not consider information on impact that does not provide information on a project's effectiveness, such as anecdotal evidence on how well a project was received, how many people had taken part or web traffic to project websites.

We traced evaluation data that provide at least some indication whether the project achieved its aims for ten of the 99 initiatives listed (seven education setting initiatives and three national initiatives). We were unable to identify evaluations for any of the regional initiatives listed - this is not to say that they were definitely not evaluated; evaluation efforts may not have been brought to our attention and/or we may well have been unable to access them. Furthermore, given that many initiatives identified (particularly local/regional ones) were small scale and run by parents or local groups, it is unsurprising that evaluations could only be traced for a limited number. We also recognise that many evaluations taking place are not disseminated externally to the organisation and thus much harder to trace. Furthermore, several survey respondents mentioned evaluations such as small surveys following a one-off seminar or teaching session, which were beyond our reach in this research.

Evidence on the effectiveness of the ten initiatives for which we were able to access such data is summarised below.

5.2.4.1 Impact of Initiatives within Education Settings

Best Buddies (International)

Since its inception in 1989, Best Buddies (see section 5.2.1.3) has grown to a presence in over 50 countries around the globe, aiming to support relationship building and mentoring between people with intellectual disabilities and those without in education settings, workplaces and local communities. A formal evaluation by Prinstein and Aikins (2005) used questionnaires at two time points and observation sessions, and concluded that 'Best Buddy' relationships were similar to friendships with best friends, with additional levels of support, nurturing and 'scaffolding' in skill development.

The most comprehensive evaluation of Best Buddies is the annual electronic survey distributed via Best Buddies to all stakeholders. In 2014, the survey was completed by 6497 volunteers completed alongside 1973 people with intellectual disabilities who participated in Best Buddies' Citizens projects (working with adults), e-Buddies projects (supporting online friendships) and programmes in middle schools, high schools and colleges [19]. Participants without disabilities ('volunteers') reported very positive attitudes, including over 85% who reported being more aware that people with intellectual disabilities can hold down jobs in the community since being involved in the programme; over 96% who said they would support people with intellectual disabilities living as their neighbours; and a similar proportion who said they would like their child to attend school alongside children with intellectual disabilities. While apparently very promising, such data do not reliably measure change in attitudes as a result of participation in Best Buddies. It is conceivable that persons who volunteer for participation in Best Buddies hold very positive attitudes to start with and that these attitudes undergo no or only limited change; or that they may feel inclined to give positive feedback given their involvement with Best Buddies.

Of Best Buddies participants with intellectual disabilities, 65 to 71% of those completing the 2014 survey reported feeling more accepted by their friends and in their communities, and 55% reported feeling more confident in engaging with other online social networks as a result of their participation with Best Buddies. Perhaps the strongest support for the programme is

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[19] Best Buddies International: 2014 Annual Survey Results. Retrieved from http://www.bestbuddies.org/our-programs/why.

that about 93% of volunteers and a similar proportion of participants with intellectual disabilities said they would recommend the programme to others.

Everyone Everyday (Australia)

The Everyone Everyday Programme (see case example, section 5.2.1.3) was piloted in five primary schools in the Canberra area, involving 14 teachers and 350 students from Years 3 and 4. The pilot was evaluated by the University of Canberra using pre and post surveys of teachers and students, classroom observations, and interviews/focus groups with participating teachers. (Report sent as personal communication, summary of evaluation available at http://www.communityservices.act.gov.au/disability_act/everyone-everyday-program).

The evaluation concluded that the programme resulted in positive attitude change; after exposure to the programme, children spoke of treating people with disabilities as equals, focused less on supposed 'deficits' of peers with disabilities, and their language became more positive and respectful. They were also more likely to say they interacted with or were friends with peers with disabilities, and reported feeling more knowledgeable and confident as to how to include someone with a disability. The programme also resulted in more positive teacher attitudes. Observation confirmed that the classroom learning generalised to positive actions elsewhere.

Spinclusion (Canada)

Evaluation of Spinclusion (see case example, section 5.2.1.3) is limited to very specific indicators of self-reported change. During 2014, children were asked "How many of you know what inclusion means?" before playing the Spinclusion game and again at the end of the session (personal communication from Spinclusion team). Of pupils, 19 % understood the idea of inclusion before the game and 84% after. In 2012, a further evaluative question targeted at inclusive attitudes asked: "After having played Spinclusion, how many of you think you would be more likely to include someone with differences?" Out of 2063 children, 91% (1879 children) said they would be more likely to include someone with differences. While such efforts to evaluate projects should be commended, it is conceivable that the data overestimate positive change. After playing a game on inclusion of peers with disabilities, children may have been more aware of the desirable answer and more likely to

respond accordingly. Furthermore, children may well have been inclined to respond in line with most of their peer group.

Kids on the Block (USA)

Kids on the Block (KOB) is a puppet show devised by the Children's Institute to teach school children about the importance of diversity and inclusion. Each show features life-size puppets in three scenes which illustrate different disabilities, including intellectual disabilities. After each scene, children are invited to ask the puppets questions. Teachers are also provided with supplementary activities for use throughout the year. Several studies into the effects of KOB were summarised by Dunst (2012), who also conducted a meta-analysis of the effects of puppet shows on children's attitudes and knowledge to disability (Dunst, 2014). He concluded that KOB and the other puppet show reviewed (Count Me In) had a small effect in changing children's attitudes towards people with disabilities and a small to medium effects in increasing their awareness of disabilities; the effect sizes were moderated by a number of intervention- and non-intervention related variables. Of note, the results relate to attitudes and knowledge regarding disability in general and are not specific to intellectual disability – hence it is impossible to say whether children's awareness of or attitudes to intellectual disability are affected by KOB.

ASNIC (Nicaragua)

To evaluate the effects of ASNIC's schools based work (see case example, section 5.2.1.3), workshop leaders administered questionnaires to 111 people in newly inclusive schools, including 17 children with disabilities, 44 children without disabilities, and 50 teachers and school staff (personal communication from ASNIC team). The evaluation concluded that the project was well received and created a positive impact. Children with disabilities reported feeling treated more positively at school and more included in games and activities. All said they now received help from other children in school, although they still reported experiencing difficulties in their homes and local communities. Children without disabilities displayed a greater acceptance of peers with intellectual disabilities, and a greater sense of unity with them. Teachers reported increased awareness of the benefits of inclusion, not only for children with disabilities, but for all of society, and a greater willingness to implement inclusion. Two limitations of the evaluation conducted should be noted: information about

the measures used was unavailable and evaluation was conducted retrospectively only, hence some of the limitations noted for Spinclusion apply.

Touch of Understanding (USA)

This organisation runs interactive sessions in schools to raise awareness of different types of disabilities, including intellectual disability and autism. In 2013/14 they reached 7465 students across 82 schools (personal communication from Touch of Understanding team)[20]. According to their annual report for that year, 95% of pupils who completed a survey after participation in a session said they would now find it easier to make friends with someone with a disability, and 96% said they would now be more comfortable interacting with someone with a disability. A survey of teachers found that 90% reported improved peer interactions following the sessions, and 96% reported increased student awareness/sensitivity to others. The evaluation did not collect any baseline data (data collected before the sessions), thus the evaluation data is entirely based on retrospective self-reported change, with aforementioned risks of socially desirable responses being elicited.

For the period 2008 to 2011, an evaluation of the programme was carried out through an independent consultant, Dr Borbely[21]. The evaluation administered the Chedoke-McMaster Attitudes Towards Children with Handicaps (CATCH) questionnaire before and after the sessions. In total 967 students participated in this evaluation, including 778 matched pre/post pairs. The key outcome was that 70.1% of students showed an increase in positive feelings, intentions and beliefs towards people with disabilities.

Special Olympics Unified Strategy for Schools (prev. 'Project UNIFY') (International)

The outcomes and processes of the Youth Unified Sports programme of Special Olympics with regards to its value in promoting social inclusion were evaluated by McConkey et al. (2013). The programme combines players with intellectual disabilities ('athletes') and those without intellectual disabilities ('partners') of similar skill levels in the same sports teams for training and competition. Alongside the development of sporting skills, the programme offers athletes a platform to socialise with peers and to take part in the life of their communities.

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[20] Report of Activities 7/1/13-6/30/14. Retrieved from www.touchofunderstanding.org/home/annual-reports

[21] Report of Activities 7/1/11-6/30/12. Retrieved from www.touchofunderstanding.org/images/stories/Reports/2011-2012.pdf

The evaluation focused on unified football and basketball teams from five European countries: Germany, Hungary, Poland, Serbia and Ukraine. Individual and group interviews were held with athletes, partners, coaches, parents and community leaders, totalling around 40 informants per country, retrospectively to explore their experiences of the programme and its impact[22].

Qualitative data analysis identified four thematic processes that were perceived by informants across all countries and both sports to facilitate social inclusion of athletes: (1) the personal development of athletes and partners; (2) the creation of inclusive and equal bonds; (3) the promotion of positive perceptions of athletes; and (4) building alliances within local communities. The authors concluded that the programme does provide a vehicle for promoting the social inclusion of people with intellectual disabilities, which is credible in terms of theories of social capital, particularly the concept of 'bonding'. They noted that Unified Sports provides a shared experience for both athletes and partners to develop their sporting skills along with offering both parties access to valued opportunities, such as travel to competitions. They add that this mutuality of benefit or reciprocity is often absent in other attempts to promote inclusion for people with intellectual disabilities, which are often based on altruism of the more able person as helper or supporter. Furthermore, they observed that the deliberate selection of partners as non-disabled youths with an enthusiasm for sport, but lacking the skills to advance in more competitive mainstream sports, not only reduced the discrepancies in terms of sporting competences but also introduced elements of peer mentoring. However, McConkey et al. also observed that the main beneficiaries of the programme to date have been more able athletes. While youths with more severe disabilities, who are at higher risk of social exclusion, possibly stand to gain more from participating in Unified Sports, the programme's success appears to depend on its careful matching of athletes with partners.

The pilot implementation of Project Unify (as it was called at the time) in Serbia, Italy, Romania, Austria and India was evaluated by Dowling et al. (2013). This study collected data using self-report questionnaires from athletes, partners and teachers/leaders. Data were collected close to the beginning of the programme and again after participants had been involved with the project for about 5 to 8 months. The authors concluded that there was no

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[22] These evaluations can also be accessed at http://www.science.ulster.ac.uk/unifiedsports.

clear definitive impact of taking part in Project Unify on young people's social interactions, their self-efficacy and leadership skills, but noted a general trend in a positive trajectory when comparing young people's ratings at the first and second data collection points. Furthermore, they identified some differences in responses in the two regions (European countries versus India), including a greater likelihood among European athletes to report that 'people were nice to them' at the first time point compared to Indian athletes. Encouragingly, the proportion of Indian athletes who agreed with negative statements, such as 'mostly people ignore me', declined from time point 1 to 2. In addition, improvements in attitudes towards forming friendships with peers with intellectual disabilities were larger for Indian participants compared to their European counterparts, who showed little change. Concerningly, an increase in the proportion of Indian participants who felt that people with intellectual disabilities should attend special schools (54% at point 1, to 75% at point 2) suggests a decrease in attitudes favouring inclusion. In contrast, this figure remained stable for European participants at around 33%. Overall, the results showed partners and athletes working collaboratively in sporting activities improved some but not all aspects of attitudes to intellectual disability and inclusion. The extent to which attitudes improved varied across the sites.

5.2.4.2 Impact of National Initiatives

Workfit (United Kingdom)

The WorkFit programme is designed to improve access to mainstream employment and other work activities for people with Down's Syndrome, and includes provision of training and support for employers. Only qualitative feedback is available and suggests that Workfit can have a positive effect on employers' attitudes to disability, although in the absence of formal evaluation data this should be viewed with caution[23]. One participant in Workfit is quoted in the blog as stating: *"I thought I knew a lot about Down's syndrome but it opened my eyes to the importance of work in their lives – and the extent of their aspirations. I feel that it is very positive and after initial implementation it can be very positive for employer and employee"*.

Equal in Uniform (Israel)

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[23] Down's Sydrome Association blog post. https://downssyndromeassociation.wordpress.com/2014/09/01/ workfit-growth-leads-to-more-opportunities-for-people-with-downs-syndrome/

The impact of the Equal in Uniform project (see case example, section 5.2.3.3), on the attitudes of soldiers without disabilities was independently evaluated by researchers at the Hebrew University of Jerusalem (personal communication from Dr Werner). This study included 239 soldiers without intellectual disabilities, 154 of whom reported at the beginning of the study knowing a soldier with intellectual disabilities through the project. Attitudes towards soldiers with intellectual disabilities were compared between soldiers with and without personal contact with such soldiers, using the Multidimensional Attitudes Scale. Overall soldiers with contact showed more positive attitudes than their counterparts who reported no direct contact with soldiers with intellectual disabilities; the former also showed less discomfort about social interactions and were more positive about the inclusion of soldiers with intellectual disabilities in the defense force.

Special Olympics World Games (International)

The Special Olympics World Games are an annual sporting event for athletes with intellectual disabilities. As part of the event, a large number of volunteers and communities in the host country are involved, and the host country and competitors' countries aim to achieve media coverage on a local and national level, to raise awareness of the games and consequently intellectual disabilities.

One study of the impact on attitudes resulting from the World Games has been conducted with school children in China. In May 2007, 789 young people were surveyed before the Special Olympics World Games held in Shanghai and again in November 2007 after the event [24]. Participants in the survey were from three different Chinese cities: Shanghai, Beijing and Chongquing. It was found that positive attitudes increased significantly in terms of perceived capabilities of those with intellectual disabilities, views on inclusion, and behavioural intentions towards people with intellectual disabilities. This change was greatest among youths living in Shanghai. The attitudes of youths in Beijing remained almost unchanged over time, although this may in part be due to their having shown the most positive attitudes at Time 1. In Shanghai, the greatest increases in positive attitudes were for young people who had participated in the games either as a volunteer or audience member.

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[24] Norins, J. Parker, R., & Siperstein. G. (n.d.). *Impact of the Special Olympics World Games on the Attitudes of youth in China.* University of Massachusetts, Boston; Special Olympics Global Collaborating Center. Retrieved from http://www.specialolympics.org/research_studies.aspx

5.2.4.3 Conclusions

Being able to evidence attitude change is helpful not only to affirm to those working on projects that they are creating the impact they wish; it also allows closer links to be created between policies/legislations and practical efforts so that change that the laws and policies set out to achieve can be more effectively measured. Many of the projects we identified had evidence of impact that focused on satisfaction ratings or monitoring of web traffic. Whilst useful indicators of impact, such measures tell us little about effectiveness, as high participant satisfaction or exposure to an advertising campaign cannot be assumed to equal attitude or behaviour change.

Of the 99 initiatives identified in section 5.2, we managed to identify evaluations for only 10 initiatives. It is entirely possible that some further evaluation were carried out but that we failed to identify these within our resources and timeframe. However, it seems reasonable to conclude that few initiatives that aim to raise awareness of intellectual disability and/or promote more positive attitudes are formally evaluated. Accordingly, for most initiatives conducted in this field it is impossible to reliably conclude whether their targets are indeed achieved. While initiatives may at face level appear well suited to the targets set, formal evaluation may in many instances fail to demonstrate their effectiveness, or conversely indicate that an initiative may be highly effective and that its adoption on a large scale and/or in different sites (with adaptation to the local context) should be considered. It is only through formal evaluation that we can know whether efforts to improve attitudes and promote the social inclusion of children and adults with intellectual disabilities in fact do so.

Of note, all but one of the evaluations we identified were from high income Western countries. This is likely to be due in part to the scale and scope of the respective projects, but most probably also indicates a lack of access to the resources and expertise required to conduct rigorous evaluations. As elsewhere, we note a need for increased partnership and collaboration between those in high and lower income countries and in different world regions.

Even for those initiatives for which we were able to identify evaluations, rarely was evaluation built in from the outset, for example through the collection of baseline data against which any change in awareness, attitudes or behaviour can be measured. Furthermore, several of the evaluations we identified employed measures developed for the purpose of the specific evaluation, rather than measures that have been formally tested and shown to be valid and

reliable measures of change. A further limitation concerns the fact that few evaluations have been conducted independently of those involved in delivering the initiative. Without involving evaluation personnel and processes that are independent of a given project, even with the best intentions, there is a risk that project staff's understandable vested interest to demonstrate the initiative's success may inadvertently influence both the process and outcome of any evaluation.

Chapter 6: Discussion

Overall, it seems in many countries around the globe there is a sense among the public that including people with intellectual disabilities in society is the right thing to do. Compared to the conclusions of Siperstein et al.'s (2003) *Multinational Study of Attitudes toward Individuals with Intellectual Disabilities,* in many countries attitudes appear to be becoming more positive. This can be evidenced by the gradual reduction in the use of derogatory language to talk about intellectual disabilities, particularly in some (high and middle income) countries. However, pejorative terminology, stigmatising beliefs and a desire to ostracise people with intellectual disabilities are still very much evident in many parts of Africa, Asia, Southern and Central America and the Caribbean and in Russia,. 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 dependent on the efforts of parent run organisations and NGOs.

Our project identified continued segregation in all parts of the world, while its form and extent differed across countries and regions. Segregation is detrimental because it limits a person's quality of life and potential to contribute to society, and perpetuates negative stereotypes. Segregation also deprives society of the opportunity to develop its members' capabilities to interact with people of all abilities and to develop positive values and responsibilities as citizens. Respect for diversity is being taken very seriously in many parts of the world and the rights of persons of different sexual orientations, ethnic and religious backgrounds are frequently discussed. However, in the year 2015 and despite the CRPD, children and adults with intellectual disabilities are mostly still an invisible minority.

Intellectual disability still appears to be of low priority in government actions around the world, evident in the relatively few references in States Parties reports to the CRPD Committee. Furthermore we found little evidence of governmental recognition that 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. At best, the higher proportions of unsure answers to survey questions in this domain suggest that legal protection and redress is not entirely clear in most countries.

Overall, there appears to be relatively limited action to actively combat stigma directed at children and adults with intellectual disabilities. Initiatives aimed at raising awareness of intellectual disability and combating stigma appear small in number, and mostly take place in European countries, Canada and the USA. Most respondents, even within Europe and North America, despite their specialist role or focus in the (intellectual) disability field struggled to name any specific initiatives undertaken in education settings, at local or regional level, or on a national level. Thus it seems more efforts are needed to raise awareness of intellectual disability and tackle prejudices and discrimination directed at people 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 is a slow process). 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[25]. 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. The only initiative featured in this report for which we found published randomised controlled trial (RCT), the gold standard for evaluating interventions, is the puppet show Kids on the Block. However, evaluations of this initiative did not measure changes specific to intellectual disability – it is entirely possible that the small to medium size positive changes in awareness and attitudes observed apply to disability in general but not to intellectual disability. Without robust evaluation, it is difficult to conclude reliably that any effects observed are due to the work undertaken and not to other confounding factors. Research in other fields shows that many attempts to change attitudes

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[25] Interested readers will find a more detailed discussion of the need for an evidence based approach to combating intellectual disability stigma in a forthcoming review: Scior, K. & Werner, S. (Aug. 2015). *Changing attitudes to learning disability: A review of the evidence*. London: Mencap.

and/or behaviour fail to meet their aims and at best result in increased knowledge but little attitude or behaviour change. Therefore, the impact of initiatives should be critically examined by building rigorous evaluation into new initiatives from the outset.

Our findings cast some doubt on the accuracy of the extent to which countries around the world have put campaigns or other initiatives in place to raise awareness of intellectual disability, reported in the WHO Atlas. Sixty per cent of countries that provided information for the Atlas reported conducting such national awareness raising campaigns. A similar proportion (59%) of respondents in the current survey said that national awareness raising efforts were in place in their country but only 10% were able to give any specific details of efforts that could in fact be said to raise awareness of intellectual disability. Many other awareness raising efforts named in our survey, once followed up, were either general disability awareness campaigns, that were neither specific to intellectual disability nor featured someone with intellectual disability, or aimed to raise awareness about rights, resources and services among people with intellectual disabilities and their families, but not among the wider community. Thus our findings suggest that the WHO Atlas figures may be an over-estimate of the efforts made around the world to raise awareness of intellectual disability.

Furthermore, the apparent assumption that general disability awareness campaigns are likely to raise awareness of intellectual disability needs serious questioning. In the public health arena no one would assume that running a campaign aimed at educating the public about heart disease would also increase awareness about liver disease. However, the assumption that an improved understanding of physical and sensory disabilities will translate into a better understanding of intellectual disability is commonly made. The specific needs of people with intellectual disabilities need explicit attention in awareness raising efforts, not least to ensure that governments allow for the allocation of appropriate resources in order to continue the move towards inclusion both at a theoretical and practical level.

This project's findings can serve as audit data against which progress in raising awareness of intellectual disability and combating intellectual disability can be gauged. The data presented may help individual countries and the UN to judge the extent to which more action is required to promote awareness of intellectual disability and more positive attitudes towards children and adults with intellectual disabilities.

Chapter 7: Recommendations

It is clear that adults and children with intellectual disabilities need to have greater inclusion in societies, and their fundamental rights and freedoms respected. One of the best ways to achieve this is for them to have greater voice and visibility in all areas of public life, especially with policy makers and legislators. Inclusion can only be achieved through the closure of all institutional settings around the world to provide increased opportunities for direct contact; continuing the push towards inclusive education; through work with the media to increase their voice and visibility in the public sphere and through supporting their louder voices in the disability rights movement and beyond.

In low and middle income countries, raising awareness and tackling intellectual disability stigma is likely to require collaboration between governments and NGOs, many of which are parent-led, and allocation of funding to support the activities of NGOs. Governments in collaboration with the media have an important role to play in raising the profile of people with intellectual disabilities.

Closer attention is needed in most countries globally to ensuring 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 thus recognises the aggravated nature of such crimes and provides for extended sentencing. It was not the aim of this survey to focus on legal recourse per se, rather to gain a broad picture of what, if any, recourse is available. The high level of uncertainty on this issue among respondents to the survey certainly indicates that increased awareness and education is needed to ensure that those well placed to advocate for and support people with intellectual disabilities who may be victims of hate crimes are in a good position to do so.

The UN through the CRPD and its associated reporting and monitoring system clearly has an important role to play in educating governments around the world about appropriate language to use when referring to intellectual disability, and their duty to raise awareness of intellectual disability and combat prejudice and discrimination. Certainly where government representatives use terms such as 'mental retardation' when reporting back to the CRPD

Committee, their capacity (and motivation) to promote awareness of the capabilities and contributions of persons with intellectual disabilities would appear compromised.

As there is very limited evidence as to what works in combating intellectual disability stigma in different settings and cultural contexts, evaluation should be built into future initiatives from the outset. This is likely to only be achieved through much closer collaboration of disabled people's organisations (DPOs), NGOs and other disability organisations with researchers, through increased collaboration between those seeking positive change, and increase emphasis on learning from one another. In this process it will be very important to be cognisant of the challenges many lower and middle income countries face.

Evaluation should be specific to intellectual disability and should not assume that any positive changes related to disability in general or to other types of disability will translate into increased awareness of or more positive attitudes to intellectual disability.

Finally, individual countries and the UN may wish to use the data presented in this report to judge the extent to which more action is required to promote awareness of intellectual disability and more positive attitudes towards children and adults with intellectual disabilities. The data may also prove useful as basis for any re-audit of attitudes and actions.

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Appendix 1 – Invitation Email to Contributors

English Version, also available in Arabic, French, German and Spanish

Dear all,

We are writing to seek your help. We are a team of researchers at University College London researching efforts to raise awareness and combat negative attitudes and harmful practices towards people with intellectual disabilities around the globe.

This international scoping review aims to understand current attitudes towards people with intellectual disabilities around the globe and efforts to improve these. We are keen to identify examples of good practice in this area. The project is run in partnership between a multi-national team of researchers and Leonard Cheshire Disability, Inclusion International, IASSID and with support from Special Olympics, and funded by the UCL Grand Challenge for Global Health scheme.

As a representative or expert in the (intellectual) disability field we are keen to hear your thoughts on the situation in your country. Can we ask you kindly to complete a survey that should take around 15 minutes to complete. The survey is in two parts:

(1) General questions about people with intellectual disabilities in your country;

(2) Specific questions relating to efforts to raise awareness and combat negative attitudes and harmful practices relating to people with intellectual disabilities in your country.

All questions relate to both children and adults with intellectual disabilities, unless otherwise specified.

You will have the option of completing the survey in English, Arabic, French, German or Spanish.

All responses will be summarised in a report to be published by mid-2015, and will be made available to all contributors. The findings and examples of good practice will also be reported at a free conference to be held in central London on 16 July 2014, which will be streamed via the internet.

The project has been given full ethical approval by University College London's ethics committee (Project ID 0960/001).

Thank you for taking the time to read this. We would very much appreciate you taking the time to fill out the survey.

Please follow the link to the survey: www………….. (survey link, now inactive as survey closed)

If you have any questions or comments please contact the project lead at k.scior@ucl.ac.uk.

Yours sincerely

Dr Katrina Scior   Dr Maria Kett

Senior Lecturer   Assistant Director
Clinical, Educational & Health Psychology   Leonard Cheshire Disability and
University College London   Inclusive Development Centre
                                                    University College London

Appendix 2 - Survey

English Version, also available in Arabic, French, German and Spanish

Title: Efforts to combat negative attitudes and harmful practices towards people with intellectual disabilities around the globe

Introduction

This survey focuses specifically on people who are identified as having an intellectual disability*. It seeks information about national efforts to raise awareness and combat negative and harmful practices relating to people with intellectual disabilities. Article 8 of the UN Convention on the Rights of Persons with Disabilities requires governments to work towards greater equality and non-discrimination through raising awareness throughout society and combatting prejudices and harmful practices. Whether or not there has been much attention paid to the UN Convention in your country, we are interested in hearing about efforts made towards these aims in relation to people with intellectual disabilities.

*The term intellectual disabilities (ID) refers to challenges some people face in learning and often communicating which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. Typically persons with ID experience these challenges from birth or an early age and usually require some form of lifelong support.

About you

Your country: _____

Your name: _____

Name of your organisation: _____

Position/role: _____

b. How did you hear about this survey?

- ☐ Via Inclusion International
- ☐ Via Leonard Cheshire Disability
- ☐ Via IASSID
- ☐ Direct communication from project team
- ☐ Sent to me by someone else
- ☐ Other

c. Does your work/activity relate mainly to

- ☐ People with physical and/or sensory disabilities
- ☐ People with intellectual disabilities (ID)
- ☐ Both people with ID and other disabilities
- ☐ Other (Please specify): _____

d. Are you completing this survey as a (Please select all that apply)

- ☐ Representative of an organisation focused mainly on people with ID (and their families)
- ☐ Representative of an organisation focused on people with disabilities generally
- ☐ Expert or someone with a strong interest in the ID field

- ☐ Expert or someone with a strong interest in the disability field (not specific to ID)
- ☐ None of the above (*if this option is chosen, respondent will be thanked and asked to recommend anyone in their country/region who falls into the above categories – see below*)

Thank you very much for your time. The remainder of this survey is only relevant to representatives of disability organisations or experts in this field. Do you know of any such person in your country who may be interested in taking part? If so, please forward the invitation to them or provide an email address for them below.

Part 1

This first part consists of some general questions about people with ID in your country.

1.1 What term is most commonly used among lay people and in the media in your country to refer to ID? (Please provide the term in your country's language)

_____

1.2a When developmental delay in a child/adult is apparent, to what extent is assessment offered to diagnose/establish whether ID is present?

- ☐ Never
- ☐ Rarely
- ☐ About 25% of the time
- ☐ About 50% of the time
- ☐ About 75% of the time
- ☐ Routinely
- ☐ Unsure

1.2b If assessment is recommended, for what main purpose? (Select all that apply)

- ☐ To identify needs of the individual and what support is required
- ☐ To establish eligibility for specialist support
- ☐ To establish eligibility for financial support
- ☐ To justify exclusion from mainstream activities/services

1.3 In your country, are there special schools (where children with ID are educated separately from their peers who do not have a disability)?

- ☐ Yes
- ☐ Not special schools, but special units within mainstream schools
- ☐ No special schools or units exist
- ☐ Unsure

1.4 Where do children with ID go to school in your country?

- ☐ All/most in mainstream schools
- ☐ Both in mainstream and special schools
- ☐ All/most in special schools
- ☐ Typically not sent to school at all
- ☐ Unsure

1.5a Does your country have institutional settings (<u>not</u> for the primary purpose of education) where people with ID live?

- ☐ Yes, where 100+ people live
- ☐ Yes, where 50 to 100 people live
- ☐ Yes, where 20 to 50 people live
- ☐ Yes, where 10 to 20 people live
- ☐ Yes, but only as units for short term assessment/ treatment or as secure accommodation (i.e. for offenders with ID)
- ☐ No
- ☐ Unsure

1.5b If yes, is there an active programme underway aimed at closing most such institutions?

- ☐ Yes
- ☐ No
- ☐ Unsure

1.6 Do you have any comments about beliefs people in your country commonly hold about people with intellectual disabilities, and the best place for them to be schooled and/or live?

Part 2

In the second part of this survey we ask about action at national level, but would also very much like to hear of smaller and local good practice examples in your country.

2.1a Are there any active non-governmental organisations (including charitable organisations) or networks in your country that focus on promoting and protecting the freedoms and human rights of people with ID?

- ☐ Yes
- ☐ No
- ☐ Unsure

2.1b If yes, what is/are their name(s)?

2.2 Is **disability hate crime*** recognised as a criminal offence?

- ☐ Yes
- ☐ No
- ☐ Unsure

*A 'disability hate crime' refers to any criminal offence which is motivated by hostility or prejudice based on a person's disability.

2.3 Are there active efforts to tackle disability hate crime:

	Yes	No	Unsure
by the courts or justice system?	☐	☐	☐
by the police or other law enforcement agency?	☐	☐	☐
at a community/society level?	☐	☐	☐

2.4a Are you aware of any efforts targeting children within the **education system** aimed at:

	Yes	No	Unsure
raising awareness what ID is?	☐	☐	☐
encouraging respect for the rights of people with ID?	☐	☐	☐
recognising the abilities and (potential) contribution of people with ID?	☐	☐	☐
promoting positive attitudes towards people with ID?	☐	☐	☐
encouraging more positive interactions with people with ID?	☐	☐	☐

2.4b If yes, please tell us a bit more about them (including what is being done, name of the project, and, where available, who leads the project and contact details or internet address)

_____

_____

2.4c Are you aware of any report or evaluation on these efforts? Any other information to judge the success of the project?

2.5a Are you aware of any **smaller scale, local** efforts aimed at
2.5b If yes, please tell us a bit more about them (including what is being done, name of the project,

	Yes	No	Unsure
raising awareness what ID is?	☐	☐	☐
encouraging respect for the rights of people with ID?	☐	☐	☐
recognising the abilities and (potential) contribution of people with ID?	☐	☐	☐
promoting positive attitudes towards people with ID?	☐	☐	☐
encouraging more positive interactions with people with ID?	☐	☐	☐

and, where available, who leads the project and contact details or internet address)

_____

2.5c Are you aware of any report or evaluation on these efforts? Any other information to judge the success of the project?

_____

_____

2.6a Are you aware of any **national (or regional)** efforts (e.g. campaigns) at societal level aimed at

	Yes	No	Unsure
raising awareness what ID is?	☐	☐	☐
encouraging respect for the rights of people with ID?	☐	☐	☐
recognising the abilities and (potential) contribution of people with ID?	☐	☐	☐
promoting positive attitudes towards people with ID?	☐	☐	☐
encouraging more positive interactions with people with ID?	☐	☐	☐

2.6b If yes, please tell us a bit more about them (including what is being done, name of the project, and, where available, who leads the project and contact details or internet address)

_____

2.6c Are you aware of any report or evaluation on these efforts? Any other information to judge the success of the project?

_____
_____

2.7 Are you aware of any other **good practice examples** not already mentioned? Please help us find these (names, organisations, year, contact details, internet address – anything that can help us find the project)

_____
_____
_____

Thank you for completing this survey!

Are you happy to be named as contributor in an appendix to our report?

☐ Yes, with full contact details

☐ Yes, but by name, organisation and country, but NOT my contact details

☐ No, I prefer not to be named as contributor

Appendix 3 – Survey Responses by Region and Country

Region & Country	World Bank Income Category	Number of Respondents
Sub-Saharan Africa		**37**
Botswana	Upper-Middle	1
Congo	Low	1
Ghana	Lower-Middle	1
Kenya	Low	7
Liberia	Low	1
Madagascar	Low	1
Mauritius	Upper-Middle	2
Nigeria	Lower-Middle	5
Sierra Leone	Low	1
South Africa	Upper-Middle	9
Tanzania	Low	2
Togo	Low	1
Uganda	Low	2
Zambia	Low	2
Zimbabwe	Low	1
Middle East & North Africa (MENA)		**28**
Bahrain	High	1
Egypt	Lower-Middle	1
Israel	High	17
Iraq	Upper-Middle	1
Kuwait	High	4
Lebanon	Upper-Middle	2
Qatar	High	1
Saudi Arabia	High	1
Asia (except MENA countries)		**40**
Bangladesh	Low	2
Cambodia	Low	1
China	Upper-Middle	1
Hong Kong (People's Rep. of China)	High	2
Indonesia	Lower-Middle	1
India	Lower-Middle	1
Iran	Upper-Middle	4
Japan	High	4
Malaysia	Upper-Middle	7
Myanmar	Low	1

Nepal	Low	4
Pakistan	Lower-Middle	2
Philippines	Lower-Middle	1
Singapore	High	4
South Korea	High	1
Taiwan (People's Rep. of China)	Upper-Middle	4

Europe		**217**
Albania	Upper-Middle	1
Austria	High	6
Belgium	High	12
Bulgaria	Upper-Middle	1
Croatia	High	2
Cyprus	High	2
Czech Republic	High	1
Finland	High	2
France	High	6
Germany	High	14
Hungary	Upper-Middle	2
Iceland	High	2
Ireland	High	21
Italy	High	5
Luxembourg	High	2
Malta	High	1
Netherlands	High	23
Norway	High	5
Poland	High	4
Romania	Upper-Middle	4
Russia	High	2
Slovakia	High	1
Slovenia	High	2
Spain	High	29
Sweden	High	15
Switzerland	High	6
UK	High	46

South & Central America & The Caribbean		**122**
Argentina	Upper-Middle	44
Bolivia	Lower-Middle	1
Brazil	Upper-Middle	1
Chile	High	5
Colombia	Upper-Middle	52
Costa Rica	Upper-Middle	2
Ecuador	Upper-Middle	3

El Salvador	Lower-Middle	1
Honduras C A	Lower-Middle	1
Jamaica	Upper-Middle	2
Mexico	Upper-Middle	4
Nicaragua	Lower-Middle	1
Paraguay	Lower-Middle	1
Peru	Upper-Middle	1
Rep. Dominicana	Upper-Middle	1
Venezuela	Upper-Middle	2
North America		**159**
Canada	High	55
USA	High	104
Oceania (Aus NZ Pacific)		**64**
Australia	High	48
Fiji	Upper-Middle	1
New Zealand	High	14
Papua New Guinea	Lower-Middle	1
Total		**667**

Appendix 4 – The 'R' Word

Countries where the term "retardation" is still commonly used by the public and/or media

Listed are countries where at least 10% of respondents reported that the 'r' word is still in common use; the numbers refer to respondents who stated this out of the total respondents for the country

Argentina 6/44
 Belgium 4/12
Bolivia 1/1
Chile 3/5
Colombia 16/52
Costa Rica 1/2
Croatia 2/2
Finland 1/2
France 2/6
Honduras 1/1
India 1/1
Iran 1/4
Israel 9/17
Italy 1/5
Jamaica 1/2
Kenya 1/7
Kuwait 3/4
Mauritius 1/2
Mexico 2/4
Nepal 1/4
Nicaragua 1/1
Nigeria 1/5
Norway 3/5
Pakistan 2/2
Peru 1/1
Philippines 1/1
Singapore 2/4
South Africa 3/9
Spain 3/29
Sweden 2/15
Switzerland 1/6
Taiwan 2/4
Tanzania 2/2
USA 24/104
Zambia 1/2

Appendix 5 – Legal Recognition of Disability Hate Crime by Country

Responses to the question: "Is disability hate crime recognised as a criminal offence in your country?"

Country	Yes	No	Unsure	Total
Albania	1	0	0	1
Argentina	26	11	5	42
Australia	22	10	15	47
Austria	4	0	1	5
Bahrain	1	0	0	1
Bangladesh	1	1	0	2
Belgium	6	0	6	12
Bolivia	0	1	0	1
Botswana	1	0	0	1
Brazil	0	0	1	1
Bulgaria	1	0	0	1
Cambodia	0	1	0	1
Canada	28	4	23	55
Chile	2	1	2	5
China	1	0	0	1
Colombia	15	18	16	49
Congo	1	0	0	1
Costa Rica	1	1	0	2
Croatia	1	1	0	2
Cyprus	1	0	0	1
Czech Rep.	0	1	0	1
Dominican Rep.	0	0	1	1
Ecuador	2	0	1	3
Egypt	1	0	0	1
El Salvador	1	0	0	1
Fiji	0	1	0	1
Finland	0	0	2	2
France	3	2	1	6
Germany	7	0	6	13
Ghana	1	0	0	1
Honduras C A	0	0	1	1
Hong Kong[26]	0	0	1	1
Hungary	0	0	2	2
Iceland	0	1	1	2
India	1	0	0	1
Indonesia	1	0	0	1
Iran	0	1	3	4
Iraq (Kurdistan Region)	1	0	0	1
Ireland	7	5	8	20
Israel	4	3	9	16
Israel (Arabic)	0	0	1	1
Italy	1	0	4	5
Jamaica	0	1	1	2
Japan	0	1	3	4
Kenya	6	0	1	7
Kuwait	1	1	2	4

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[26] Although governed by the People's Republic of China since 1997, Hong Kong has been listed separately in this report to reflect its status as an autonomous territory and distinct historical and cultural influences.

Country	Yes	No	Unsure	Total
Lebanon	0	2	0	2
Liberia	0	1	0	1
Luxembourg	1	0	1	2
Madagascar	0	0	1	1
Malaysia	1	3	3	7
Malta	0	1	0	1
Mauritius	0	1	1	2
Mexico	0	3	1	4
Myanmar	0	0	1	1
Nepal	2	1	0	3
Netherlands	10	6	7	23
New Zealand	3	3	7	13
Nicaragua	0	1	0	1
Nigeria	3	0	2	5
Norway	2	3	0	5
Pakistan	0	2	0	2
Papua New Guinea	1	0	0	1
Paraguay	0	0	1	1
Peru	1	0	0	1
Philippines	0	1	0	1
Poland	2	0	2	4
Qatar	0	1	0	1
Romania	1	1	2	4
Russia	1	1	0	2
Saudi Arabia	0	0	1	1
Sierra Leone	1	0	0	1
Singapore	0	3	1	4
Slovakia	0	0	1	1
Slovenia	1	1	0	2
South Africa	4	0	4	8
South Korea	0	1	0	1
Spain	11	2	15	28
Sweden	8	4	3	15
Switzerland	4	0	2	6
Taiwan[27]	3	1	0	4
Tanzania	1	0	1	2
Togo	0	1	0	1
Uganda	1	0	0	1
UK (unspecified)	7	0	1	8
UK (England)	20	1	1	22
UK (Jersey)[28]	0	0	1	1
UK (N Ireland)	3	0	0	3
UK (Scotland)	1	0	0	1
UK (Wales)	10	0	0	10
USA	50	11	41	102
Venezuela	2	0	0	2
Zambia	1	1	0	2
Zimbabwe	1	0	0	1
Total	**307**	**123**	**218**	**648**

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[27] The status of Taiwan is contested. Taiwan competes for recognition as an independent state with the People's Republic of China.

[28] Jersey is a self-governing territory and not part of the UK. However, as it is represented by the UK government in international affairs, Jersey has been subsumed under the UK in this report.

Appendix 6 – States Parties Reports and Article 8

The table below provides a summary of statements relevant to intellectual disability in the 16 States Parties reports that explicitly refer to intellectual disability in their reporting on Article 8 of the CRPD (see Chapter 2).

Country (Year report submitted to UN)	Article 8
Austria (2010)	"In the field of arts promotion, there are measures to promote the active participation of people of all age groups with physical, mental or intellectual disabilities. These include theatre productions by deaf people, dance projects with people with restricted mobility, cultural projects with very old people, painting and photo workshops with subsequent exhibitions by people in homes for people with disabilities, socio-cultural festivals, international integrative street theatre festivals and much more. The goals are in particular to strengthen the self-confidence of those involved and to raise public awareness for the concerns and the special abilities of people with disabilities." "In cooperation with Germany, an 'easy to read' – version of the UN Convention will be published in Austria in 2010."
Bosnia and Herzegovina (2013)	"Additionally, in cooperation and coordination with the organisations for providing for persons with disabilities, the Federal Ministry of Labour and Social Policy implemented campaigns specifically related to the occasions of significant dates, such as the 3rd of December, the International Day of People with Disability, the 21st of March, World Down Syndrome Day, etc., and persons with disabilities were involved in the activities implemented by the Ministry." "Nongovernmental organisations made accessible versions of the Convention, in Braille and 'easy to read' for persons with intellectual impairment."
Croatia (2011)	"In 2006, a documentary film "The garden of blue roses" was created, talking about the value of volunteering in the Special hospital for chronic diseases in children, Gornja Bistra, where around a hundred children with the most severe physical and psychological impairments are placed." "Aimed at raising public awareness about the right to life of persons with Down syndrome, MFVAIS in 2010 co-financed a short film, a part of regional omnibus 'Some other stories', which participated in approximately 15 film festivals and was shown in cinemas outside Croatia."
Hong Kong (2010)	"We co-organise activities every year with NGOs in support of the World Autism Awareness Day designated by the General Assembly of the United Nations, such as book report writing competitions."

Hungary (2010)	"A best practice is provided by the 'Accept it and accept me' programme of the Hand in Hand Foundation, which demonstrates the life of the mentally handicapped." "When the Convention was ratified, the ministry responsible for the promotion of equal social opportunities entrusted national interest protection organizations — those for the deaf, blind and persons with hearing and sight impairment and those for the mentally handicapped — with compiling and reproducing the sign language and Braille as well as an easily understandable version of the Convention."
Jordan (2012)	*Translated from Arabic* "Launched during the past three years, many aimed at defining the rights and the reduction of infringements by the incident awareness campaigns, such as the white stick campaign, and the campaign of the prohibition and criminalization of the compulsory hysterectomy of girls with mental disabilities, and campaign : 'Makani baynakum' (My place is among you) –to promote the integration of children with intellectual disabilities within mainstream schools."
Latvia (2014)	"Latest information regarding support measures and the rights of persons with disabilities: Ministry of Welfare (MoW) regularly provides via electronic mass media and placing the information on MoW homepage (www.lm.gov.lv), as well as by meeting with the associations that represent the interests of persons with disabilities. The home page is adapted to the needs of persons with disabilities, namely, there is a section 'Easy-to-read' where is included a concise and descriptive information in an easy-to-read language." "On November 13, 2012 the LTV Program 1 broadcasted a training video 'Accessible environment – opportunities and solutions'. The movie was made in 2011 and it includes information on implemented ERDF and CF co-funded projects regarding environmental and information accessibility measures for persons with physical, visual, hearing and mental impairments in reconstructed and renovated buildings, construction objects, reconstructed and renovated roads etc. The training video was issued also in DVD format and is available in MoW and on the internet site: http://www.youtube.com/user/LabklajibasMinistrij." "There are still prejudices, intolerant attitude and separation from people with mental impairments in the society. In everyday life the majority of people do not meet people with mental impairments therefore they have neither practical experience, nor theoretical knowledge about contact with people who have mental impairments. The lack of knowledge in the society, on the one hand, and a desire to avoid negative experience, on the other hand, create communication problems that, in turn, serves as a basis for exclusion, discrimination and social isolation of persons with mental impairments that make difficult for them to integrate in various social fields." "NGO that represent interests of persons with mental impairments have prepared various informative booklets regarding this target group. Also since 2008 on an annual basis the NGO provide information in different

Latvia contd.	articles and informative booklets about latest issues regarding specific needs of persons with mental impairments." "NGO view that insufficient attention is paid to the development of various methods of communication with persons with disabilities. State and municipal employees have not acquired necessary skills to communicate with persons with mental impairments. Wherewith persons with mental impairments have no possibility to receive information on their rights, duties and rights` protection means due to the lack of effective communication." "NGO Latvian Association 'Riga City: Child of Care' (Rūpju bērns) actively translate and issue informative booklets on differences and explain specific issues to ensure contact with people who have intellectual disability."
Luxemburg (not dated)	*Translated from French* "For 2 years awareness workshops have been organised to allow non-disabled young people aged 12-26 to understand disabilities better. In 2013, eight NGOs and 95 participants took part in workshops on the following topics: hearing impairment; visual impairment; mental handicap; physical disability; language disorders; easy language and autism."
Macedonia (2014)	"The campaigns of the civil sector for raising the public awareness are supported by the state authorities (at the national and local level) and at the same time there are efforts by the national and local authorities to ensure the sustainability and continuity of campaigns. The National Centre for Support of Persons with Intellectual Disability – PORAKA, as one of the four partner organizations, and as an organization raising an initiative relating to the Convention, was included in the programme 'Enhancing the citizens' participation in the legislative process' implemented by the National Democratic Institute (NDI) and the Institute on Parliamentary Democracy (IPD)." "Under its programme for celebrating 3rd December – the International Day of People with Disabilities, the National Centre for Support of Persons with Disabilities – PORAKA promoted a Campaign for Prevention of Abuse of Children/Persons with Intellectual Disabilities under the motto 'Life as Safe Adventure'. The campaign was intended for the |public at large, persons with intellectual disabilities, their families and the professional staff who work with persons with intellectual disabilities. The campaign's goal was to contribute to the raising of awareness about the need for developing preventive strategies regarding the ill-treatment of children/persons with intellectual disabilities. The following brochures were presented at the promotional event: 'Childhood, Disability and Violence', 'Life as Safe Adventure' and the promotional short film 'Sara's Adventure'."

Moldova (2012)	"Developed and nationally disseminated materials with the purpose to promote the rights of persons with disabilities and to combat stereotypes related to it, such as: the guide for journalists to communicate with and about people with intellectual disabilities, the book and teaching support, 'Bridge to understanding. Education for inclusion, tolerance, acceptance' intended for the primary school and approved by the Institute of Education Sciences." "During March to May 2012, were played social theater shows in 15 pilot inclusive schools in Moldova. The goal of the shows is to raise awareness in students and teachers to the needs of persons with physical and intellectual disabilities and forming non-discriminatory attitudes."
Russian Federation (2014)	*Translated from Russian* "The Government of the Russian Federation encourages and financially supports measures to create a positive image of the disabled in the mass media: television, radio, publishing. To this end, more than 40 projects have been developed in the federal and regional print media:…[including]… 'Social adaptation of a child with Down syndrome' in the magazine *Take a step'*."
Peru (2010)	"Public-awareness campaigns directed to general society, within the education system and actions undertaken through mainstream media…[including]… 'Una Sonrisa Especial' (a special smile) oral health campaign, which provides services free of charge and gives priority to children with slight or severe mental retardation and children with Down's Syndrome. In addition, 'Mentes Brillantes' (Brilliant Minds) project competitions have been held as joint public/private initiatives with support from the Special Commission on Disability."
Philippines (not dated)	"Other yearly celebrations, participated in by various GOs and NGOs, and PWD sector that aim to educate the general public are as follows: Proclamation No. 711 (January 4, 1996) Declaring the Third week of January as Autism Consciousness Week Proclamation No. 157 (February 18, 2001) Declaring the month of February as National Down Syndrome Consciousness Month Proclamation No. 1385 (February 12, 1975) Designating the Period from February 14 to 20, 1975, and Every Year Thereafter, as Retarded Children's Week. " "The Autism Society of the Philippines (ASP), a parent-support organization, has included the Convention as one of the topics in the activities they have recently conducted, namely: 11th National Conference on Autism (October 2009) 600 participants; 2nd Regional Conference on Autism (October 2010) 350 participants; 2nd Chapter Leaders Conference (August 2008) 65 participants; 3rd Chapter Leaders Conference (August 2009) 80 participants. The ASP has also conducted various sensitivity trainings in handling children with disability for tenants, and personnel of malls and airlines."

Portugal (2012)	"The Portuguese State is permanently developing information and awareness-raising activities on the rights of persons with disabilities, with a particular focus on their capacities, through the National Institute for Rehabilitation. High-impact training is undertaken for students, journalists, families and NGO leaders. Seminars and debates are held on the most problematic issues - accessibilities, sexual education, quality of life and self-representation of persons with intellectual disabilities."
Qatar (2012)	"For its part, the Shafallah Centre organized five campaigns in 2000 to raise awareness of Down syndrome and four autism awareness campaigns in 2005, 2006, 2009 and 2010."
Sweden (2011)	"A central issue for promoting equality is to increase knowledge among the general public about all forms of disability. Increased knowledge can also help to change attitudes. In 2009, the Government commissioned Handisam, in close co-operation with NSPH (National Association for Mental Health), to conduct a nationwide programme aimed at increasing knowledge about and changing attitudes towards persons with a mental illness or mental disability. Special activities targeted at employers are also planned within the assignment. A follow-up and evaluation of the effects of the assignment will be presented to the Government not later than 1 June 2012. Special activities targeted at working life are also planned within the assignment."

Appendix 7 - Contributors to the Survey

Listed are those contributors who were happy to be named in our final report.

Country	Contributor	Organisation	Role
Albania	Merita Poni	University of Tirana	Teaching staff
Argentina	Alicia Garcia	Centro de Desarrollo Infantil	Psychologist
	Amanda Catalano	AFADIM	President
	Andrea Aznar	Fundación ITINERIS	Director
	Carolina	Instituto de Artes Culinarias Inclusivas	Technical Director
	Cecilia Figari	INSSJP	Coordinator of psycho-educational workshops
	Cecilia Kligman	UNTREF	Teacher/Researcher
	Cecilia N. Centini	APPACE	Director of job training centre
	Daniel	AUPA	Director
	Daniela	Neu.De.Dis Neuquén Deporte y Discapacidad	Secretary
	Delia Carro Evangelista	Secretaría Nac. de Niñez, Adolescencia y Familia	Program Coordinator
	Dr. Omar G. Estrugo Saavedra	Universidad Nacional De Lomas De Zamora	Disability Program Coordinator
	Elena Dal Bó	Asociacion Azul	Executive Director
	Elida Mattarozzi	Familia	Parent advocate
	Eugenio Calderon	Fundación Tempo de Integrarse	Co-founder
	Fabiola Santarelli	IFDC villaregina	Teacher
	Gabriela	Cerin	Coordinator
	Horacio Angel Ali	Fundación ACCION	President / Regional Representative to the Federal Council
	Ivankow Maria Teresa	Poder Judicial	Official
	Juan Manuel	CAENCE	Collaborator
	Lidia Guintales	Taller Protegido Villa Gobernador Gálvez	Director
	Lili Ramirez Hidalgo	El Arbol de la Vida asoc. Civil	President
	Marcelo Siddig	ASDRA	Parent advocate
	Maria Alejandra	Universidad Nacional de Cuyo	Lecturer
	Maria Paz	Taller Protellido Rosario	Degree in Occupational Therapy
	Marta Mendía	Fundación DISCAR	Program Director of training and labour inclusion
	Monica	tengoSDynosoytandiferenteati	Manageress
	Monica Paccagnella	Marangeles Asoc.Padres con hijos discapacitados mentales severos	Parent advocate / Secretary
	Myrian Castillo	Defensoria General de la Ciudad	Rapporteur

Argentina Contd	Natalia Ravina	El Puente Verde	Advocate
	Patricia Fernández	Convivir Centro educativo terapeutico	Technical Director
	Patricia Moran	Comisión de Discapacidad UNSE	Member
	Patricia Ojeda	Ministerio de educación de Entre Ríos	Supervisor of special education
	Sabrina Gatti	Taller Protegido Rosario	Director
	Silvia Nudelman	Facultad de Humanidades y Ciencias Sociales- Universidad Nacional de Misiones	Teacher/Director of the Department of Special Education
	Sofia F. Long	La Casita de Emma	Partner
	Teresina Sibemhart	Educacion especial	Supervision
Australia	Agnes Sarlay	Disability ACT	Quality Safety Risk manager
	Alyce	DSC	Physiotherapist
	Andrew Pridding	Victorian Dual Disability Service	Nurse Practitioner
	Andy Calder	Uniting Church in Australia Synod of Victoria and Tasmania	Disability Inclusion
	Anne Jobling	The University of Queensland	Adjunct Researcher/ consultant
	Barbara Field	Westmead Hospital	Rehabilitation Physician
	Bob Weaver	PANDDA	Member of Executive Committee
	Brian Yates	Job Centre Australia	CEO
	Bronwen Jones	Yooralla	Community Inclusion Speech Pathologist
	C Morris	RET	Trainer
	Carol Smail	ACL Disability Services	CEO
	Caroline Ellison	Flindets university	Assoc. Professor
	Cathy Gauci	Sunshine	Practice Leader
	Daniel Leighton	Inclusion Melbourne	CEO
	Dr Angela Livingstone	Victorian Dual Disability Service	Acting Clinical Director
	Dr Ian Jackson	Catholic Education Office, Sydney	Consultant: Special School Network
	Eaine Robb	Encompass Community Services	CEO
	Greg Carey	Flinders University	Lecturer
	Gwynnyth Llewellyn	Centre for Disability Research and Policy, University of Sydney	Centre Director; Professor of Family and Disability Studies
	Ian Hopkins	Veranto	Manager IT & WHS
	Jane Tracy	Centre for Developmental Disability Health Victoria	Director
	Jeffrey Chan	Yooralla	Chief Practitioner
	Kate van Dooren	QCIDD, UQ	Postdoctoral Fellow
	Kerre Willsher	University of South Australia	Researcher
	Lesley Chenoweth	Griffith University	Professor

Australia Contd	Lorna Sullivan	International Initiative for Disability leadership	Coordinator
	Michele Wiese	University of Sydney	Researcher
	Mike Lane	Statewide Autistic Services Incorporated	Executive Manager Accommodation Services
	Paul Dolzan	Veranto	Coordinator
	Paula Firmstone	Family & Community Services	Senior Manager Access
	Peter Smith	Praxis Disability Consulting	Owner
	Rebekah Cranmer	Yooralla	Occupational Therapist
	Rhondda Vassallo	Ageing Disability & home care	Senior Project Officer & RN
	Roberta Greimel	University of Queensland	PhD Candidate
	Robyn Wallace	SHAID (specialised healthcare for adults with intellectual clinic)	Physician/Director
	Roger Stancliffe	University of Sydney	Professor of Intellectual Disability
	Stian Thoresen	Curtin University	Researcher
	Trevor R Parmenter	University of Sydney	Professor Emeritus
	Veronica Wain	Equity Works	State Coordinator
	Vicki Manton	Yooralla	Disability Nurse Consultant
Austria	Cornelia Renoldner	Verein BALANCE - Leben ohne Barrieren	Head of Employment
	Germain Weber	Universität Wien	Dean
	Guido Güntert	Lebenshilfe Salzburg gGmbH	Manager
	Heinz Tippl	University of Graz	Lecturer
Bahrain	Rima	RIA	Advisor
Bangladesh	Sarder A. Razzak	AMDA Bangladesh	Executive Director
	Sharif Al Mamun	The centre for Speech Therapy Research & Rehabiltation	Speech Pathologist
Belgium	Annick Vogels	university hospital of leuven	Child Psychiatrist
	Courtejoie Anne	COMALSO ASBL	Director / Speech Therapist / Trainer
	Fagnart	Zh Inkendaal	Neuropediatrics
	Filip Morisse	Psychiatric Centre Dr. Guislain	Coordinator
	Ghislain Magerotte	Université de Mons	Professor Emeritus
	Guy Hubert	AFrAHM asbl	Psychologist
	Haelewyck	Service d'Orthopédagogie Clinique	Professor
	Micheline van Hees	Special Olympics Belgium	European Athlete Representative and National Board Member
	Mikolajczak Olivette	ASBLle " 35 " Equipe communautaire quartir Nord	Child Psychiatrist
	Stijn Vandevelde	Ghent University	Assistant Professor
Bolivia	Marcela Morales	Centro de Investigación para el Desarrollo Socioeconómico, CEINDES	Executive Director
Botswana	Maubrey Russ Pitso	Montsamaisa Trust	Project Officer

Brazil	Daniel Nascimento	Fundação Síndrome de Down	Coordinator of Processes
Cambodia	Kong Vichetra	Komar Pikar Foundation	Executive Director
Canada	Adam Heenan	Queen's University	PhD Candidate
	Amy Betzner-Massana	Canadian Mental Health Association	Clinician, Developmental Disabilities Service
	Angela Gonzales	Surrey Place Centre	Health Care Facilitator
	Bendina Miller	CACL	Past President
	Bev Temple	University of Manitoba	Associate Professor
	Catriona Johnson	InclusionWorks!	Family Lead
	Chad Perrin	CareGivers	Program Manager
	Charmayne Dube	New Directions	Director
	Dan Verstraete	Parkland CLASS	Chief Operating Officer
	Danielle Strnad	DramaWay	Artistic Director & Founder
	Dawn LeBlanc	IWK Health Centre	Social Worker
	Donna Pettipas MSW	Government of Nova Scotia Disability Support Program	Coordinator of Audits
	Doris Power	FAIR Toronto	Chair
	Faye Matt	Special Olympics Saskatchewan	CEO
	James Holzbauer	CLT	Coordinator
	Karen Anderson	Durham College	Placement Officer
	Laura Pacheco	West Montreal Readaptation Center	Social worker, Head of parenting service
	Lisa Matsell	Disability Support Program, Department of Community Services, Nova Scotia	Trainer
	Lucie Dugas	Office des personnes handicapées du Québec	Expert Advisor Evaluation
	Mary Blinkhorn	Queen's University	Research Assistant
	Mélina Rivard	Université du Québec à Montréal	Professor
	Nancy Pilon	North Bay Regional Health Centre	Project Manager
	Rose Flaig	Independent	Advocate/Parent
	S. G. W.	NL Association for Community Living	Executive Director
	Sandra Bricker	Surrey Place Centre	Coordinator TNSC
	Shirley McMillan	Surrey Place Centre	Clinical Nurse Specialist
	Shukri	TDSB	Special Needs Teacher
	Susan Benko	Southern Network of Specialized Care	Facilitator
	Susan Doyle	IPSE Nova Scotia	Parent Advocate
	Suzanne Paradis	-	ID Education Specialist (retired)
	Tanya Whitney	Ministry of Education	Director of Schools
	Tara Brinston	Canadian Association for Community Living	National Coordinator, RWA & Strategic Policy Development
	Toinette Parisio	L'Arche	Vice Regional Coordinator
	Tricia	Springboard Services	Intake Outreach Worker
	Trisha Bower	Springboard Services	Family Support Worker

Canada Contd	Wendy Arscott	A New Leaf Counselling	CEO
	Yves Lachapelle	Université du Québec à Trois-Rivières	Professor
Chile	Alexis Palá	Independiente	Research Student
	Feliciagonzalez Villarroel	UNPADE	Technical Advisory-family
	Leonardo Estrada	IP Chile	Occupational Therapist - Clinical Teaching
	Maria Alexandra Mesa Gallego	Unidad De Discapacidad Compin	Speech Therapist
	Vanessa Vega	Pontificia Universidad Católica de Valparaíso	Professor
China	Wang Xiaogeng	Rong Ai Rong Le parent organization of people with Intellectual disability	Board Chairman
Colombia	Adriana Mejía Velàsquez	COMFANDI	Support For People With Disabilities And Their Families
	Alicia Rodríguez	ASDOWN	Member
	Alvaro Hernan Macias	ASDOWN COLOMBIA	Parent advocate
	Ana Bolena Rodriguez	ASESORARTE	Director
	Ana Margarita Parra	Ministerio de Educacion	Specialized Professional
	Andrés Ramírez	Brain scholers	Neuropsychologist
	Catalina Salazar	RECA Colombia	Director
	Claudia Forero	Equipo de Apoyo Pedagógico	Professional Support - Audiology
	Consuelo Pachón Suárez	Independiente	Social Worker
	Diana L.	Grupo Sindrome de Down de Santander	Director
	Dilza Rocío	Down Odontología	Dentist (care for children with special conditions)
	Edith Betty Roncancio	Liga Colombiana de Autismo	Director
	Esperanza Angel	Sedano Angel	Clerk / Secretary
	Francisco	Music&Mind	Director
	Irma Guzmán	Asdown	Parent advocate
	Jorge Ivan Correa Alzate	Tecnológico de Antioquia	Associate Professor
	Libia Vélez	Universidad pedagógica nacional	Teaching
	Linda Patiño	ong de mujeres	Communicator
	Luisa Berrocal	Fund. Saldarriaga Concha	Leader of Social Mobilisation
	Luz Angela Gonzalez M.	Secretaria de Educacion	University Professional
	Luz Betty Cepeda	Colegio Nuevo Gimnasio	Coordinator / Teacher
	Lylo	Imagine Colombia	Volunteer Coordinator
	Maria Zuluaga Giraldo	Independiente	Parent advocate
	Maria Covadonga Fentanes	ASDOWN Colombia	Governing Board Member

Colombia Contd	Maria Del Pilar Ramos	Fundacion Gestion Apoyo Y Amor	Social Management Coordinator
	Maria Mercedes Hernández	Maria Mercedes Hernández	Parent advocate
	María Victoria Orozco	Asdown - Best Buddies	Professional Support – Voluntary
	Maritza Ferro	Hermana de adulto con DI	Occupational Therapist
	Marta Inés Cortes Giraldo	Inclusionarte Colombia	Parent advocate / Teacher
	Martha Arjona M.	Colppaz	Executive Director
	Martha C. Sepúlveda	Fundación Familia Down	Director
	Monica Cortes	Asdown Colombia	Director
	Nelly Esperanza Briceño Castro	Asdown Colombia	Associate
	Paola Goyeneche	Fundacion Internacional Maria Luisa De Moreno	Volunteer
	Patricia Morales Borja	Instituto para niños ciegos y sordos	Social Worker
	Patricia Reyes	Gathered Citizens Veedora	Community Leader
	Pillar	Fundación unicornio	Director
	Rubén Darío Martínez	AS INCLUSION	Legal Representative
	Sandra Sofía Ayala Nieto	Asdown	Parent advocate
	Sonia Judith Garcia	Corporation Sindrome de Down	Parent advocate
	Wilson Castellanos Parra	RED AUN	Chief Coordinator
	Yaneth Acero	ASDOWN	Associate
	Yasmira Romero	Fundación Saldarriga Concha	Monitoring Coordinator
Congo	Mata Matundu	CPPS	Coordinator
Costa Rica	Jose	FEREPRODIS	President
	Maria Jose Gallardo	CCSS	Medical Rehabilitation Specialist
Croatia	Marko Buljevac	Faculty of Law, Department of Social Work	PhD
	Natalija Lisak	University of Zagreb Faculty of Education and Rehabilitation Sciences	Postdoctoral
Cyprus	Constantinos Efrem	Pancyprian Parents' Ass. for People With Intellectual Disabilities (pasygoka)	President
Czech Rep.	Jan Šiška	Charles University	Professor
Dominican Rep.	Rosario Nicasio	ADOSID	Executive Director
Ecuador	Fresia Rodríguez Ochoa	FASINARM	Coordinator Resource Center
	Luis Anchatipan	APPDIC	Representative
	Marco Revelo	APROPDVIMOS	President
Egypt	Basma Ibrahim	Hope Village development and social rehabilitation for the disabled Association	Executive Director
El Salvador	Janeth Chavez	APROVIPDES	Vice President

Country	Name	Organization	Title
Fiji	Mereoni Daveta	Access to Quality Education	Disability Inclusion Coordinator
Finland	Maarit Aalto	Nordic Centre for Welfare and Social issues	Project Manager
	Riikka Juntunen	Special Olympics Finland	National Director
France	AZEMA Bernard	ONCODEFI	Psychiatrist
	Bisbrouck	Fondation Lejeune	Learning Consultant Specialised
	Denis Pelsy	Fondation des Amis de l'Atelier	Director of Emerging Programs
	Eric PLAISANCE	Université Paris Descartes	Professor Emeritus
	Sturtz	IJL	Advisor
Germany	Achim Feyhl	Lebenshilfe Offenburg-Oberkirch e. V.	Board
	Elisa Huning	Ambulant Betreutes Wohnen	Healing Education Nurse
	Gerd Sonntag	Fachschule Heilerziehungspflege	Teacher
	Jana josephowitz	awo kita	Specialist for Inclusion
	Jana Offergeld	Forschungsschwerpunkt Teilhabeforschung, KatHO NRW	Scientific Associate
	Kai Hermann	Lebenshilfe Bochum	Line Cultural Work
	Peter Leidig	Lebenshilfe Waltrop e.V.	Home Manager
	Reichelt	Lebenshilfe Duisburg	Manager
	Siems	Elbe-Werkstätten	Manager
	Sozialer Dienst	Stiftung Mensch	Social Service
	Stefanie Lehmann	PARTicipation	Project Management / Parent trainer
	Tanja Sappok	Ev. Krankenhaus Königin Elisabeth Herzberge	Physician
Ghana	Esther Quarcoe	The Disablement Foundation of Ghana	Director of Social Care
Honduras	Bertha Lidia Gomes Torres	Fenapapedish / Rocafam	Treasurer / President
Hong Kong	Kathleen Tait	Hong Kong Baptist University	Associate Professor
Iceland	Bryndís Snæbjörnsdóttir	Landssamtökin Þroskahjálp	Chairman
	James Rice	Centre for Disability Studies, U of Iceland	Assistant Professor
India	Chandrasekaran Subramaniam	EASA ECT/ Anna University	Professor
Indonesia	yohanis pakereng	ILO	Project Coordinator
Iran	Bemanali	Valeasr	Therapist
	Majid Ebrahimpour	Islamic Azad University	Faculty member
	Majid Mirkhani	Vali Asr Rehabilitation Foundation	Board of Director
Iraq (Kurdistan Region)	Noori	Rozh Society	Director
Ireland	Bernadette Flood	Trinity College Dublin & Daughters of Charity Services	Pharmacist / PhD candidate
	Emanon Teague	Walk	Director Residential Services
	Eilish Burke	IDS-TILDA	Project Manager

Ireland Contd	Fintan Sheerin	Trinity College Dublin	Lecturer in Intellectual Disabilities
	Fiona Keogh	Genio	Director of Research
	Glyza pedrosa	St peters services	Staff Nurse
	Janine Zube	St. Michael's House	Social Care Worker
	Jean Loy	National primary school	Teacher of Special Class
	Kathy O'Grady	Muiriosa Foundation	Psychologist
	Marian Murphy	Special Olympics	Director
	Mary Reidy	Waterford Institute of Technology	PhD Candidate
	Mick Teehan	WALK	New Directions Manager
	Muireann Ní Riain	Special Olympics Ireland	Health Services Coordinator
	Peter O'Brien	Special Olympics Ireland	Director Of Training and Volunteers
	Roy McConkey	University of Ulster	Emeritus Professor of Developmental Disabilities
	Ruth Connolly	Muiriosa Foundation	Clinical Psychologist
Israel	Dana Roth	Beit Issie Shapiro	Director of Research & Evaluation
	Daniel Katz	Ministry welfare	National vocational supervisor
	Dr Mike Stawski	Schneider Children's Medical Centre	Head of the Unit
	Gila Vogel	Beit Berl College	Lecturer
	Ilana Duvdevany	University of Haifa	Professor
	Ira Stern	Henrew University Jerusalem	PhD student / Research Coordinator
	Joav Merrick	Division for IDD, Ministry of Social Affairs	Medical Director
	Kirsman Natalia	Counsalting places that people with Id leave	Psychologist
	Maayan fine	Matav	Social Worker / Manager
	Noa	AKIM israel	Legal Adviser
	Shirli Werner	University	Lecturer
	Yotam tolub	Bizchut	Advocate
	Zvi Bernhardt	Shekel	Counsellor
	Mohammed Diab	Renaissance Foundation	Director
Italy	Carlotta Leonori	Associazione Italiana Persone Down Onlus	International Office
	Claudia Condoluci	IRCCS San Raffaele	Paediatrician
	Fabrizio Fea	Associazione Scuola Viva Onlus	Medical Director
	Marco Lombardi	Catholic University of the Sacred hearth of Milan	Researcher
Jamaica	Claudette Williams	University of Technology, Jamaica	Associate Dean
	Dennise Williams	Jamaica Downs Syndrome Foundation	Marketing volunteer
Japan	Keiko Sodeyama	Bamboo group	Member

Country	Name	Organization	Role
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	Yutaka Tone	Okayama HIgashi school for	Teacher
Jersey	Martin McMahon	Health & Social Services	Clinical Practitioner/ Practice Education Facilitator
Kenya	Dennis Kebori	Macmedia Africa	Managing Consultant
	Fatma Wangare	Kenya Association of the Intellectually Handicapped (KAIH)	Executive Director/Parent
	Geoffrey Atieli	Sense International	Consultant
	Hesbon Achola	World Friends	Project Manager
	James Ndwiga	National Council for Persons with Disabilities	Deputy Director
	Margaret Kamau	Kccl _ Kenya community centre for learning	Patent / Board Member
	Martin Osangiri	ICEVI; www.icevi.org	Region Coordinator (Africa)
Kuwait	Abdessatar Mahfoudhi	Center for Child Evaluation & Teaching	Consultant
	Rehab Mohammed Boresly	Kuwait Society for parents of disabled	Chairman of Board of Directors
Lebanon	Fadia Farah	LASA	President
	Nizar Salam	Friends of the Disabled Association	Director
Liberia	Lovetie Major	My Heart's Appeal, Inc.	Founder & CEO
Luxembourg	Marc Feltgen	Special Olympics Luxembourg	National Director
	Rol Anen	APEMH	President
Madagascar	Rafanomezantsoa	Tànana Mirana	Coordinator
Malaysia	Amar-Singh HSS	National Early Childhood Intervention Council (NECIC)	President
	Chan Shiu Sum	Hua Ming Autism Society	Principal
	Chew Siok Cheng	Methodist Care Centre	Director
	Dr Toh Teck Hock	Sibu Hospital	Paediatrician
	Jun Woo	Sunway University	Senior Lecturer
	Yeong	United Voice	Coordinator
Malta	Marica Gatt	Education Department	Head of Department
Mauritius	Amelie E. Noel	Reve & Espoir	Manager
	Jocelyne Beesoon	Inclusion Mauritius	Member of Committee / Support Person
Mexico	Fabiana Romero	Subsecretaría de Educación Básica	Special Education Advisory
	María Elena de los Dolores Márquez-Caraveo	Hospital Psiquiátrico Infantil "Dr. Juan N. Navarro"	Head of Research Division
	Martha Zanabria Salcedo	Universidad Autónoma Metropolitana	Professor
	Verónica P. Barrón	Hospital Psiquiátrico Infantil "Dr. Juan N. Navarro"	Researcher
Myanmar	Salai Vanni Bawi	Future Stars Self Advocacy of IDs	Consultant

Nepal	Birendra Raj pokharel	Action on Disability Rights And Development (ADRAD)	Chairperson
	Dr Lalita Joshi	Down Syndrome Association of Nepal (DSAN)	President
	Suraj Sigdel	Mental Health and Participatory Research Center	Research Director
	Tikaram Sapkota	Guardian Federation of Persons with Intellectual Disabilities (GFPD)	Secretary
Netherlands	Brenda Frederiks	Vu médical Centre Amsterdam	Assistant Professor Health Law
	Frans Ewals	Erasmus MC	Head Training Department / IDD Physician
	Gerda de Kuijper	Centre for Intellectual disability and mental health	ID Physician / Researcher
	Hans van Wouwe	ASVZ	Manager of Treatment
	Henny van Schrojenstein Lantman- de Valk	Radboudumc Nijmegen	Professor
	HJM GRimbel du Bois	Regional Center OPSY	Program Manager: Care / Psychologist
	J.C. Smits	Inclusion Netherlands	Board Member
	Johan de Koning	Markant	Editor
	Marjolein Herps	Vilans/Maastricht university	Senior Researcher/PhD-candidate
	Martin Schuurman	Kalliope Consult	Director / Researcher
	Mathilde Mastebroek	Primary and Community Care- section ID medicine	PhD candidate
	Monique Boon	Esdégé-Reigersdaal	Psychologist
	P Nouwens	Prisma	CEO
	Theo Verhappen	Koraal Groep	Psychologist
New Zealand	Brigit Mirfin-Veitch	Donald Beasley Institute	Director / Researcher
	Cindy Johns	People First New Zealand Nga Tangata Tuatahi	National Manager
	David Corner	IHC New Zealand	National Self Advocate Adviser
	Fiona Pettit	IDEA Services (IHC)	Health Advisor
	Geraldine Whatnell	MidCentral Health District Health Board	Clinical Nurse Specialist Lead Developmental Disabilities
	Ingrid Jones	University of Waikato	PhD candidate
	Leigh Hale	University of Otago	Deputy Dean, School of Physiotherapy
	Louisa Medlicott	Private Practice	Clinical Psychologist
	Lyn Burns	IDEA Services - Hawkes Bay / Gisborne	Health Advisor
	Tanya Breen	Private Practice	Consultant Clinical Psychologist
	Trish Grant	IHC	Director of Advocacy
New Zealand Contd	Yanny Webb-Walker	Enrich Community Chaplaincy Trust	Chaplain and Counsellor
Nicaragua	Indiana Fonseca Salgado	ASNIC	Director
Nigeria	Dr. Olayinka Akindayomi	Children's Developmental Centre	Service Director

Nigeria Contd	Hildegard Ebigbo	Therapeutic Schools	Directress
	Joanne Umolu	Open Doors for Special Learners	Director
	Paul Ajuwon	IASSIDD	Representative of IASSIDD Special Interest group on Family Quality of Life for Africa
	Rose Mordi	Down Syndrome Foundation Nigeria	National President
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	Erik Søndenaa	St. Olavs Hospital	Researcher
	Jeanette Engeland	Norwegian Centre for Research, Education and Service Development	Project Manager
	Trude Stenhammer	The SOR Foundation	Senior Advisor
Pakistan	Ghulam Nabi Nizamani	All Sanghar Handicaps' Association (ASHA)	Coordinator
	Haq Nawaz	Special Education Department punjab	Low Vision Counsellor
Papua New Guinea	Dr. Betty Etami Koka	Divine Word University	Head of Department/Senior Lecturer, Department of Rural Health
Peru	Vilma Galarza	Lozano Asociacion De Especialistas En Rehabilitacion Profesional	Board Member
Philippines	Alce Sentones	La salle Green Hills	Faculty Member
Poland	Ewa Maria Kulesza	The Maria Grzegorzewska Academy of Special Education in Warsaw	Professor
	Grzegorz Szumski	Academy of Special Education	Professor
	Joanna Styczen-Lasocka	Special Olympics Poland	Director
	Pawe	Jan Kochanowski University	Lecturer
Romania	Maria Vislan	Asociatia Langdon Down Oltenia Centrul Educational Teodora	President
	Mercea Anca	The Association for the Protection and Help for Intellectually Disabled People	Day Care Centre's Coordinator
	Raluca Cetatean	Professional Association of Social NGOs ASSOC Baia Mare	Social Worker
Russia	Zoya Talitskaya	Downside Up Charity Fund	GR Director
Saudi Arabia	Daniah Ghandour	Help Center	Head of Psychology/ Educational Consultant
Sierra Leone	Osman Mohamed Bah	Leonard Cheshire Disability	Pegional Programme Manager
Singapore	Daphna	West East Pte Ltd	Director / Expressive Therapist
	Ding Liqin	Institute of Mental Health	Staff Nurse
	Joanne Cheng	Institute of Mental Health	Senior Med. Social Worker
Slovenia	Katja Vadnal	Zveza SOŽITJE	President

South Africa	Ancella Ramjas	Down Syndrome South Africa	National Director
	Callista	University of Cape Town	Student
	Elna Welman	Pietermaritzburg Mental Health Society	Executive Director
	Felicity Dreyer	Western Cape Forum for Intellectual Disability	Administrator
	John Cruickshank	Retired from Cluny Farm Centre	Retired Executive Director
	Juan Bornman	Centre for Augmentative and Alternative Communication	Director
	Judith McKenzie	University of Cape Town	Senior Lecturer
	Ockert Coetzee	Department of Health Western Cape	Clinical Psychologist
	Sihle Kraai	PMB Mental Health Society	Social Work Manager
Spain	Ana Gonzalez Sanchez	APROSUBA-13	Psychology
	Berta	FEAPS	Lead for Quality of Life
	Daniel Paredes	Centro Ocupacional Aprosuba-4	Psychologist
	Elena	DINCAT	Labor Integration
	Elena Gómez	Feaps Cantabria	Expert
	Gema	FEAPS Madrid	Expert in Family arena
	Joaquim Serrahima	Grup Catalonia	Managing Director
	Jose Maria Jimenez	FEAPS Madrid	Project Coordinator
	Juan Endara Rosales	Dincat	Expert on Citizenship
	Lourdes Cuesta	ANFAS	Area Lead
	Luis	Dincat	Social Worker
	Maria José Montesinos Moreno	ASINDI	Director / Psychologist
	Maite	ATAM	Lead
	Marc Badia	Fundació Catalonia	Psychologist
	Maria-Leticia Meseguer-Santamaria	Universidad de Castilla-La Mancha	Professor / Doctor
	Moisés Lamigueiro	FADEMGA FEAPS GALICIA	Area Technical Manager of Family and Social Area
	Óscar Tena García	APROSUBA-9	Graduate In Social Work / Responsible For Quality
	Pako Mendizabal	ULIAZPI	Psychology Coordinator
	Patricia	University of Zaragoza	Assistant Professor
	Sara	FEAPS Madrid	Project Coordinator
	Víctor Franco	Social Think	Director
Sweden	Anna-Lena Oesterberg	Swedish Down Organisation	Board Member
	Bengt Weidow	Swedish National Agency for Education	Director of Education
	Eva Flygare Wallén	Karolinska Institutet	PhD candidate
	Gunnel janeslätt	SUF resource center	Researcher

Sweden Contd	Iren Åhlund	FUB	Chairman of Local Group / Former Researcher
	Judith Timoney	FUB/The Swedish National Organisation for Persons with Intellectual Disability	International Co-ordinator
	Lennart Sauer	Dept of Social Work, Umeå Univ. y	Lecturer / PhD candidate
	Lottie Gietz	Linneaus University	Senior Lecturer
	Lydia Springer	SUF Kunskapscenter	Psychologist
	Magnus Tideman	Halmstad University	Professor
	Mariella Niemi	University West	Head of Section, Social Pedagogics & Sociology
	Pehr Granqvist	Stockholm University	Professor
	Petra Boström	University of Gothenburg	Lecturer / Researcher
Switzerland	Juliane Dind	Univ. de Fribourg	Graduate Assistant
	Korpes Jean-Louis	HETS.FR	Retired Teacher
	Markus Kosel	Hôpitaux Universitaires de Genève	Lead Medic for ID Unit
	Petitpierre	Université de Fribourg	Professor
	Simon Christian Meier	Hochschule für Heilpädagogik	Scientific Assistant
	Straccia	Updm, hug	Psychologist
Taiwan	Ching-Chi, Yang	Kaohsiung Medical University	Student
	Heng-hao Chang	Dept. of Sociology, National Taipei University	Assoc. Professor
	Wang Kuo-yu	National chung cheng University	Professor
	Yueh-Ching Chou	National Yang-Ming University	Professor
Tanzania	Hamisi Pazi	Tanzania Association For Mentally Handicapped	Chair Person (retired)
	Suleiman Suleiman	Zanzibar Association for People with Developmental Disabilities	Executive Director
Togo	ALIPUI NANA Yawovi Victor	Ass. des Parents et Amis des Personnes Encéphalopathes (APAPE)	Program Director
Uganda	Kakeeto Gerald	Abilities Talent Foundation	Chairman
	Michael Okiro – Emadit	The Uganda Down Syndrome Association	Director / Overall Planning Coordination
UK	Ailis Hardy	Mencap	Staff Development Coordinator
	David Towell	Centre for Inclusive Futures	Director
	Karen Wallin	Special Olympics	CEO
	Sarah Barnes	NHS	Speech & Language Therapist
	Barry Ingham	Northumberland Tyne & Wear NHS	Professional Lead
	Christopher Garrod	NHS Humber Foundation Trust	Clinical Psychologist
	David Cox	Cornwall Foundation Trust	Consultant psychiatrist
	Dr David Charnock	Univ. of Nottingham	Assistant Professor
	Dr Pat Frankish	PFP&PC	Director /Clin. Psychologist

UK Contd	Dr William Howie	South West London & St George's Mental Health NHS Trust	Consultant Psychiatrist in Intellectual Disabilities
	Gemma Unwin	Univ. of Birmingham	Research Fellow
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	Jeanne Carlin	None	Family Carer
	Jim Foyle	Kent & Medway Care NHS Trust	Clinical Psychologist
	Lisa Richardson	Tizard Centre, University of Kent	Researcher
	Martin Bollard	Coventry University	Academic/Practitioner
	Martin Stevens	Social Care Workforce Research Unit, King's College London	Senior Research Fellow
	Paul Swift	National Family Carer Network	Associate
	Peter Mittler	Univ. of Manchester	Hon. Research Fellow
	Salim Razak	Sirona	Consultant Psychiatrist
	Silvana Mengoni	University of Hertfordshire	Research Fellow
	Simon Whitaker	South West Yorks NHS Trust	Clinical Psychologist
	Tina Seed	Northern Lincolnshire and Goole NHS Hospital Trust	Principal speech & Language Therapist
UK (N Ireland)	Laurence Taggart	Ulster University	Reader
	Maureen Piggot	Inclusion international/Europe	Council Member / European President
	Sandra Dowling	Queen's University Belfast	Research Fellow
UK (Scotland)	Audrey Espie	NHS	Consultant Clinical Psychologist
	Janet Finlayson	Glasgow Caledonian University	Senior Research Fellow
UK (Wales)	Andrea Meek	Cardiff University	Researcher
	Angela Jones	ABMU Health Board	Principal Speech and Language Therapist
	Celia Lewis	N.E.W.S.A. LTD	Development Officer
	Edwin Jones	ABMUHB	Service Development Consultant
	Julian Hallett	Down Syndrome Association	Director Wales
	Sara Pickard	Inclusion International	Europe Representative
	Tracey Lloyd	Hywel Dda UHB	Macmillan Nurse LD
USA	Alexandra Bonardi	Human Services Research Institute	Senior Policy Associate
	Alice	University of Kentucky	Researcher
	Alida Howard	Disability Attorney	Attorney
	Amanda L Cade	Evergreen Life Services	Executive Director
	Amy	Opportunity Project	Development Director
	Amy Hewitt	Center on Community Living, Univ. of Minnesota	Director of Research and Training
	Ann Hudson	Special Olympics Arkansas	Staff / Field Representative
	Anne Desnoyers Hurley	Univ. of New Hampshire	Associate Professor
	Ashley	New Jersey Self-Advocacy Project	Training and Technical Assistance Specialist

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	Bill Gaventa	Summer Institute on Theology and Disability	Director
	Bob Schalock	Hastings College	Professor Emeritus
	Cassandra Bailey	West Virginia University Research Corp	Parent Network Specialist
	Clarissa Kripke	Office of Developmental Primay Care	Clinical Professor
	Cory Nourie	Nemours AI duPont Hospital for Children	Transition Social Work Coordinator
	D. McComb	Delmarva Foundation	Quality Improvement
	Dana Henning	Dana Henning Training Programs	Director
	David A. Ervin	The Resource Exchange, Inc.	CEO
	Diana Boltz	Arc of Camden County	Vocational Rehabilitation Coordinator
	Donald Silberberg	University of Pennsylvania	Emeritus Professor
	Donna Morey	Special Olympics Arkansas	Board of Directors
	Dr. Krysti DeZonia	TERI, Inc.	Executive
	Dr. Tim Thompson	Pacific University	Associate Prof of English & Disability Studies
	Drew Boshell	Special Olympics Inc.	Snr Director Global Health
	Elizabeth W. Bauer	Macomb-Oakland Regional Center (MORC, Inc.)	Governing Board Member
	Name withheld	Institute on Disabilities at Temple University	Publications Specialist
	Gabrielle Kowalski	Cardinal Stritch University	Professor Emeritus
	Ilka Riddle	Center for Excellence in Dev. Disabilities, Univ. of Cincinnati	Director
	Ira Frazier	Palmer Seminary	Faculty
	Janet Mason	Special Olympics Arkansas	Area Director / Coach / Volunteer
	Jerry Bridges	Special Olympics Arkansas	Board Member
	John Foley	State University of New York	Professor
	John Maltby	WIHD	Director Community Services
	Josh Wall	Camp Spearhead	Therapeutic Recreation Coordinator
	Julia Scherba de Valenzuela	Univ. of New Mexico	Associate Professor
	Julie Christensen	Strong Center for Dev. Disabilities, Univ. of Rochester	Director of Employment Programs
	Kathleen Fisher	Drexel University	Professor
	Kathy Carter	University of Louisville	Assistant Professor
	Laura Stough	Center on Disability and Development	Interdisciplinary Training Director
	Lauren Agoratus	Family Voices NJ	Parent/State Coordinator
	Linda Barton	PennRose Management	SSC
	Lynne Tamor	Center for Accessible Information	Executive Director

USA Contd	Lynnette Richardson	The Arc of Spokane (Washington)	Director of Supported Living
	Maggie Kolk	The Arc Kent County	Advocate
	Margaret McGee	Lesley University	Doctoral student/ Private practice
	Margaret Reed	The Point, Arc of N. KY	Outreach Director
	Mark Smith	University of Nebraska Medical Center	Resource / Family Support Project Coordinator
	Matt Holder	AADMD	President
	Michael Wehmeyer	University of Kansas	Professor / Director
	Nadyne Guzman	JFK Partners	Spiritual Care Fellow
	Nancy Haydt	Law Offices of Nancy Haydt	Attorney at Law
	Nancy Jakubczyk	Hillside Lions	Treasurer
	Olivia Raynor	Tarjan Center at UCLA	Director
	Peter Berns	The Arc	Chief Executive Officer
	Philip McCallion	University at Albany	Distinguished Professor & Director
	Rebecca Dixon	Bernalillo Public Schools	Educational Diagnostician
	Renata Ticha	University of Minnesota	Research Associate
	Santa Perez	People First of Nevada	President
	Sara Wolfson	Univ of Nebraska medical Center	Nurse practitioner
	Scott Sleeman	Alternative Services-Oregon, Inc.	Clinical Director
	Shari White	The Arc Middlesex County	Assistant Executive Director
	Silva Bey	Community Living Alternatives	Executive Director
	Stephen Coston	Special Olympics of New Jersey	Special Olympics Athletes Congress
	Tierra	Special Olympics	Co-director
	Travis Chisom	Special Olympics Arkansas	Area IX Director
	Vonnie Greer	Special Olympics Arkansas	Area Director
	William Kiernan	Institute for Community Inclusion	Director
	William Ted Brown	Institute for Basic Research in DD	Director
Venezuela	Maria Grasso	Asoc. Venezolana para el Sindrome de Down AVESID	President
	Nilka Calderón	Fundadiscapacidad	Director
Zambia	Agnes Rego	Zambia Ass. on Employment for Persons with disabilities	Director
	Masauso Chirwa	University of Zambia	Researcher/Lecturer
Zimbabwe	Sibonisiwe	Zimbabwe Down Syndrome Association	Coordinator