# Atlas

## GLOBAL RESOURCES FOR PERSONS WITH INTELLECTUAL DISABILITIES

2007

World Health Organization

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World Health Organization

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## List of acronyms

| | |
|---|---|
| AAIDD | The American Association on Intellectual and Developmental Disabilities, formerly AAMR |
| DM-ID | Diagnostic Manual – Intellectual Disability |
| DSM | The Diagnostic and Statistical Manual of Mental Disorders |
| IASSID | International Association for the Scientific Study of Intellectual Disabilities |
| ICD | International Classification of Diseases |
| ICESCR | International Covenant on Economic, Social and Cultural Rights |
| ICF | International Classification of Functioning, Disability and Health |
| IDRM | International Disability Rights Monitor |
| II | Inclusion International |
| IQ | Intelligence Quotient |
| MDRI | Mental Disability Rights International |
| MSD | Department of Mental Health and Substance Abuse |
| NADD | The National Association for the Dually Diagnosed |
| NGO | Nongovernmental organization |
| OECD | Organization for Economic Co-operation and Development |
| PAHO | Pan American Health Organization |
| UNESCO | United Nations Educational, Scientific and Cultural Organization |
| WHO | World Health Organization |
| WPA | World Psychiatric Association |

# Foreword

Persons with intellectual disabilities (ID) are frequently the most vulnerable group and, on many occasions, are exposed to human rights violations and deprived of minimum services and dignity. These persons are also the most likely to be secluded in large institutions, unable to access basic health and educational services, and excluded from ordinary social relations. Although it is well known that intellectual disability is a neglected area, essential information about the presence or absence of resources and services for this population does not even exist in most of the countries of the world.

The World Health Organization (WHO) and the Montreal PAHO/WHO Collaborating Centre for Research and Training in Mental Health have worked together to develop the first 'Atlas: Global Resources for Persons with Intellectual Disabilities' (Atlas-ID). The main aim of Atlas-ID is to improve evidence-based knowledge and awareness on the global and regional disparities through essential and needed information on resources and services for persons with ID at country level. This global report includes information from 147 countries, representing 95% of the world population. The information is specifically related to terms and classification systems used for this population, policy and legislation, financing and benefits, prevention, health and social care services, human resources and training, research and information systems and roles of NGOs and international organizations. In addition, the Atlas-ID includes a complete glossary of terms with definitions of basic concepts related to the intellectual disabilities field and the questionnaire used to collect the quantitative and qualitative information.

Atlas-ID findings reveal a lack of adequate policy and legislative response and a serious deficiency of services and resources allocated to the care of persons with ID globally. The situation is especially worrisome in most low and middle income countries. The lack of consensus on basic terms and classification criteria related to the ID field do not help to improve the situation.

The evidence provided by this report is likely to be useful to professionals, NGOs, development agencies, public health and social services sector organizations, service planners, policy makers, health and social researchers, family members of people with ID, and especially to people with intellectual disabilities. This report constitutes a call for mobilization of resources and the respect of the basic individual rights of persons with ID at the international level.

We sincerely hope that Atlas-ID will be able to assist decision makers in formulation of an adequate response to the needs of persons with intellectual disabilities and their families.

Gaston P Harnois
Director, Montreal PAHO/WHO
Collaborating Centre for Research
and Reference in Mental Health

Benedetto Saraceno
Director, Department of Mental Health
and Substance Abuse
World Health Organization

*"It is my aspiration that health will finally be seen not as a blessing to be wished for, but as a human right to be fought for."*

*Kofi Annan*

# Preface

We, the editors, are pleased to present Atlas: Global Resources for Persons with Intellectual Disabilities (Atlas-ID).

The reasons behind Atlas-ID are threefold. First, the importance of intellectual disabilities for WHO, the realization that global data collection in the field of intellectual disabilities has long been neglected, and the consequent need for such a comprehensive baseline to act as a catalyst for advocacy and planning efforts. Second, the increasing emergence of disability as a human rights issue, as stated by the United Nations Convention on the Rights of Persons with Disabilities, and as the established conceptual link between health and human rights (OHCHR, 2000; WHO, 2002; Gruskin et al, 2005) and its potential implication for treaty-based obligations on countries regarding intellectual disability resources. And finally, the recent establishment of a link between WHO and the intellectual disability field, via the Montreal PAHO/WHO Collaborating Centre for Reference and Research in Mental Health and its associated partners, the Lisette-Dupras and the West Montreal Readaptation centres for persons with intellectual disabilities (PAHO/WHO, 2004; Lecomte & Mercier, 2007); this enabled the coordination of an Atlas on intellectual disability resources from an intellectual disabilities agency-based research team. WHO has previously worked in the field of ID focused in the area of health and ageing of persons with intellectual disabilities (Thorpe et al, 2000; Janicki, 2000; WHO/IASSID/II, 2001).

This project has aimed to map resources and services for intellectual disabilities in all Member States of WHO, Associate Members of WHO, and areas and territories by compiling and calculating their distribution by regions and income levels. The eventual objective is to use this information to enhance global and national awareness and support for persons with intellectual disabilities and their families. The primary target readers for Atlas-ID are planners for health and social policy and services within countries. However, the Atlas will also be useful for providers of services for intellectual disabilities, for international and national NGOs that are active in the area of intellectual disabilities, human rights advocates and activists, public health professionals and students, and for civil society in general. The value of Atlas-ID can only be judged by its readers and users, but we feel that the project has contributed to the field of intellectual disabilities in three ways. First, it has identified gaps and needs in intellectual disabilities resources and services throughout the world. Second, it has developed two instruments to be used at country or regional level: a glossary of terms used in intellectual disabilities and the Atlas-ID questionnaire to map intellectual disabilities services (see Appendix III and IV). Third, it has produced a network of country respondents in the intellectual disabilities field (see Appendix II).

We are aware of several limitations in the data presented in Atlas-ID; we welcome all suggestions to improve the quantity and quality of data, especially from countries where information on intellectual disabilities is scarce. We hope that this project, by establishing the feasibility of a worldwide research study in intellectual disabilities, can be the first step towards global empowerment of persons with intellectual disabilities and their families through awareness of the need to implement policies and programmes to fill the gap of services and resources across the globe.

Shekhar Saxena

Marco Garrido Cumbrera

Céline Mercier

Jocelin Lecomte

# The project team and partners

This project has been conceived and implemented jointly by the World Health Organization (WHO) and the Montreal PAHO/WHO Collaborating Centre for Research and Training in Mental Health at the Douglas University Institute in Mental Health. The project team consisted of Shekhar Saxena and Marco Garrido-Cumbrera from WHO, and Céline Mercier and Jocelin Lecomte (project Atlas-ID coordinator) from Montreal, who are also the editors of this report. Tarun Dua has provided technical support to the project. Benedetto Saraceno and Gaston Harnois provided vision and guidance to this project.

Financial support for this project was provided by the Lisette-Dupras and West Montreal readaptation centres, the Ministry of Health and Social Affairs of Québec, the Office des personnes handicapées du Québec, the Fédération québécoise des centres de réadaptation en déficience intellectuelle et troubles envahissants du développement, and the Government of Canada (Office of Disability Studies and Canadian Health Agency). The opinions and interpretations contained in the report do not necessarily reflect those of the Governments of Canada or of Québec.

Internal review was conducted by colleagues from the WHO Department of Mental Health and Substance Abuse as well as Regional Advisers for Mental Health and Substance Abuse: Thérèse Agossou, Regional Office for Africa; José Miguel Caldas-Almeida, Itzak Levav and Jorge Rodriguez, Regional Office for the Americas; Vijay Chandra, Regional Office for South-East Asia; Matthijs Muijen, Regional Office for Europe; Mohammad Taghi Yasamy, Regional Office for the Eastern Mediterranean, and Xiangdong Wang, Regional Office for the Western Pacific.

External review of the Atlas-ID questionnaire, glossary of terms, and of the final report was conducted by Sayyed Ali Samadi, Andrea Aznar, Giulia Balboni, Julie Beadle-Brown, David Braddock, Valerie J Bradley, Yannick Courbois, Xenia Mas De Vergara, Eric Emerson, Satish Girimaji, Diego Gonzalez, Marie-Claire Haelewyck, Abdul Hameed Al Habeeb, Michèle Isaac, Henry Kwok, Ruth Luckasson, Jayanthi Narayan, Trevor Parmenter, Brian Robertson, Luis Salvador-Carulla, Johannes Schädler, Robert L Schalock, Uma Tuli, and Michael Wehmeyer.

Appreciation must be extended to all the country respondents who worked diligently to collect and report the data contained in this report (respondents are listed in Appendix II), as well as their respective ministries, nongovernmental organizations (NGOs), universities, or research centres.

Special thanks must also be given to Geneviève Boyer, France Desjardins, Donald Foidart, Dominique Fortin, Valérie Houde, Daphné Lamontagne and Fanny Lemetayer for their assistance to this project. Rosemary Westermeyer provided assistance with the production of this report.

# Introduction

At present, information on resources and services for persons with intellectual disabilities is scarce, fragmented, and relates mainly to high-income countries. To find data about availability of services, their nature, and access to them for a given country is hard, and such data does not exist at a global level. Large differences are seen between high-income countries and countries with low or middle incomes with regard to the availability and the type of information about national services and resources. Considerable information exists for some high-income countries; detailed reports have been published, based on extensive information systems. By contrast, documentation is much more scarce and inaccurate in countries of low or middle income. Most of the time, such documentation is based on specific experiences of a given group of individuals, a type of diagnosis, or a territory. However, at all income levels, to find an overall figure that will describe the situation at the national level is difficult. Quantitative data for the contribution of families and NGOs is practically non-existent, even if their role is recognized. One of the objectives of the new Global Atlas of Resources for Persons with Intellectual Disabilities is to start filling this gap of information through key informants from different fields who are working to improve the quality of life of persons with intellectual disabilities in all Member States of WHO, Associate Members of WHO, and areas and territories.

# Methods

## Procedure

### Preparation and validation of questionnaire and glossary

A questionnaire that was initially developed to collect information on services and resources for persons with intellectual disabilities under the initiative of the International Association for Scientific Studies in Intellectual Disabilities (IASSID) was used as the starting point for the project. Areas to be covered, and the information to be gathered for each area, were established by consultation with experts in intellectual disabilities from around the world (see Project team and partners section) and review of the existing Atlas. Successive versions were submitted to the experts for assessment until a consensus was attained. Simultaneously, the same process was used to develop an accompanying glossary. The questionnaire and the glossary were developed in English and translated into the other three official languages of WHO. The English versions of the questionnaire and glossary are provided in Appendices IV and V. The definitions used in the glossary are working definitions for the purpose of the Atlas-ID project, and do not constitute official WHO definitions.

The questionnaire was organized into the following sections: (1) definitions and diagnostic classification; (2) epidemiology of intellectual disabilities; (3) policy, programmes, and legislation; (4) financing and benefits; (5) services to children, adolescents, and adults; (6) services to families; (7) human resources; (8) role of NGOs; (9) role of international organizations; and (10) data collection and research.

While trying to use terms that are as unambiguous and uncontroversial as possible, we came across many terms used for intellectual disabilities with varying levels of acceptability across disciplines, professions, and cultures. WHO's International Classification of Diseases (ICD) uses the term mental retardation, although it is recognized that many stakeholders, including groups representing persons with intellectual disabilities and their families, have serious reservations about this term. As such, in this document, the term "intellectual disabilities" (ID) has been used to improve readability since it seems to be most acceptable to the different stakeholders that collaborated to prepare this report.

### Data collection process

The data were collected through national respondents. A set of criteria was used to establish a group of respondents that was as homogeneous as possible. Thus, respondents had to be specialists in the field of intellectual disabilities and had to represent, in order of preference: (1) the government or ministry responsible for intellectual disabilities; (2) a public organization that acts as an advisory body to the government in matters of intellectual disabilities; (3) a national NGO that deals with intellectual disabilities; or (4) a reputable university or research institution that specializes in the field of intellectual disabilities.

With the aid of the glossary, the questionnaire was completed by national respondents, who could call on any other available sources of information and other contributors who might be better informed in a given area. The respondents were invited to communicate with the project coordinator in Montreal about any question that needed clarification. The respondents could complete the questionnaire either in English or one of three other languages, but the English version remained the reference version. The questionnaire could be completed electronically and respondents were asked to forward any pertinent additional documentation.

More than two thirds (67.8%) of the questionnaires were completed or approved by a member of the government or a ministry responsible for intellectual disabilities. About a quarter (23.8%) came from NGOs, and 18.4% from universities and research institutes. In low-income countries, 58.1% of respondents were from governments, whereas in lower-income countries, that proportion was 78.1%. In high-income countries, the second main sources of respondents after governments (45.7%) were universities and research institutions (34.3%). In low-income countries, national NGOs were the second most important sources of information (30.2%), after governments (58.1%). In South-East Asia and Europe, members of universities or research centres accounted for substantial proportions of informants (60.0% and 34.0%, respectively). In Africa, more than a third (37.1%) of respondents came from national NGOs, while in the Americas 72.0% came from government sources. The complete list of participating national respondents is in Appendix II.

In some countries, teams of respondents from more than one, if not all three, categories of respondents cooperated through their own initiative to complete the questionnaire. In 17 instances, more than one questionnaire for the same country was received. In these cases, we gave priority according to our preference for respondents (i.e. highest priority to government representatives). When this questionnaire contained missing data (and the respondent could not be reached), then the other questionnaires were used to complete the missing information. Missing data were taken from the questionnaire supplied by the respondent of the next highest preference.

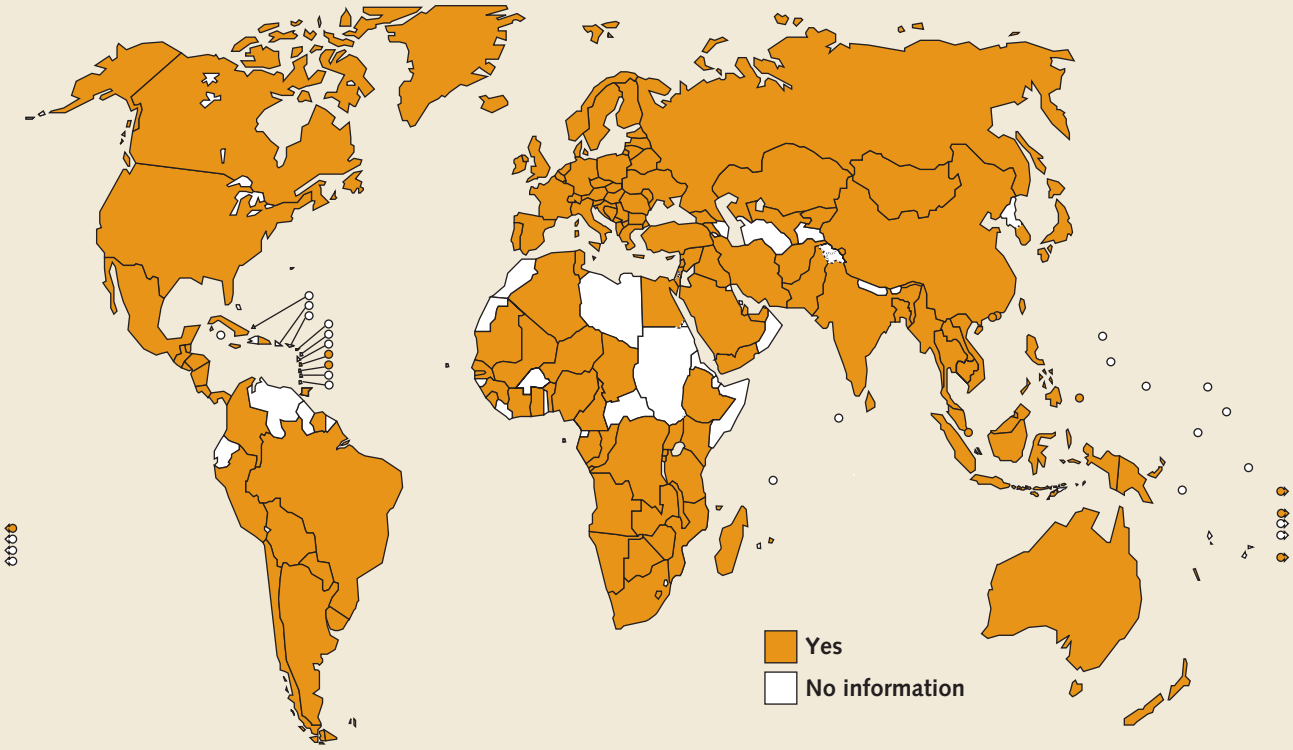
On receipt, questionnaires were verified and codified. Responses in "other" categories were redistributed in the

available categories, when justified. Some of the respondents were then contacted for further information or clarification.

Our results are based on 147 completed questionnaires (from 143 Member States of WHO, one Associate Member of WHO, and three areas or territories), corresponding toa response rate of 74.6% of countries, and representing 94.6% of the world's population (2007).

Some variations in the rate of response were seen according to WHO regions, with lower rates in South-East Asia (41.7%) and in the Eastern Mediterranean (54.2%),

**Map 1** **Participating Member States of WHO and Associate Members of WHO**



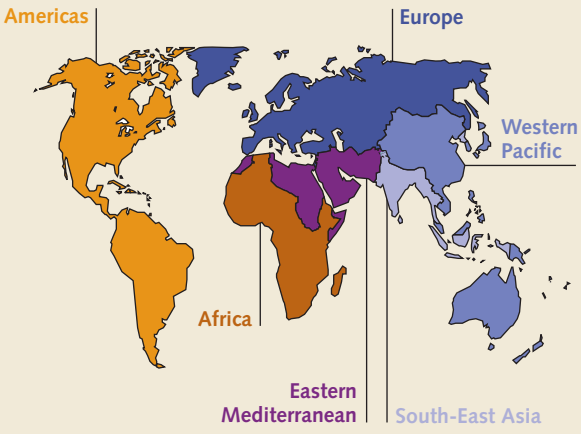

compared with higher rates in Europe (90.4%). No such variation could be seen when countries were stratified by level of income; all four income categories were close to the total median rate (74.6%) of response (range between 70.5 and 79.5%).

## Data analysis

Data were entered into a Microsoft Excel database and analysed using SPSS software. Descriptive statistical analyses were done on the data to calculate frequencies and percentages, and measures of central tendencies.

Cross-tabulations were calculated according to the six WHO regions (Africa, Americas, South-East Asia, Europe, Eastern Mediterranean, and Western Pacific) and the four country income categories established by the World Bank based on gross national income (GNI) per capita in 2003 (see Appendix I). These groups are: low income ($765 per year or less), lower middle income ($766–3035), upper middle income ($3036–9385), and high income ($9386 or more).

**Map 2** **WHO regions**



## Limitations

Global surveys such as this are subject to certain limitations. One limitation pertains to the wording of the questionnaire itself. In the absence of an international terminology and, in view of the diversity of the contexts, one cannot presume that the same term will mean the same to every respondent, or that the terms used correspond to the reality of a specific country. The fact that one cannot assume a common understanding of the terms of reference of each question, which ensures the consistency of reporting, affects the reliability of the results. We standardized the terms of reference as much as possible, to reduce the risk of ambiguity, erroneous comprehension, and divergence, by preparation of a glossary and appointment of an international coordinator in Montreal who was available to provide clarification for respondents. The verification of each questionnaire, and a contact with the respondents, allowed for correction of the most obvious inconsistencies.

A further difficulty in collecting and aggregating data was that the provision of services can be under the jurisdiction of more than one ministry and be shared between many agencies of different status – i.e. public, private, and non-profit – and by different levels of government (e.g. in federal states).

Another limitation is inherent to the process of analysis according to country-income categories or WHO regions; for example, aggregation of countries such as Canada, the USA, Mexico, Guatemala, and Brazil creates a bias towards the important economic, geographical, cultural, and regional differences between these countries.

Data could also be incomplete or partial. For example, activities in the public sector and the services offered by professional providers are usually better documented than those available in the private sector and from NGOs. Traditional resources and grassroots initiatives are under-documented, and consequently less reported in our study. The same can be said about support offered by communities, families, or traditional healers.

Many potential sources of bias can be identified. The most obvious is the absence of factual data about resources for intellectual disabilities. In such circumstances, the respondents had to rely on approximations, if not on their own experiences. Moreover, the absence of factual information is likely to occur in countries or regions that share common characteristics that could affect the findings still more.

The discrete format (i.e. answers either "yes" or "no") of most of the questions did not gather information on coverage and quality. Such a format biases the data towards an overestimation of available services or activities. Thus, the presence of a given service in the capital city of a responding country, or of a pilot project, would allow for a "yes", even if this service was accessible only to very few persons. To alleviate this bias as much as possible, the wording of the questions encouraged reference to overall trends by use of terms such as "generally" or "most of the time". One question was specifically designed to address territorial, cultural, or socioeconomic factors that might affect access to intellectual disabilities services. All in all, one should note that options were limited in many questions and the choice of the answer might not be a true reflection of the real situation in a particular country.

Due to the prioritization of types of respondents, most respondents were members of, or associated with, the government. The results were thus exposed to a risk of bias towards a government perspective, all the more so since the questionnaires were approved, and in some circumstances modified, by governments. This limitation is due to the fact that often, in countries of low or middle income, information about intellectual disabilities services is concentrated with the national government. Moreover, WHO, as the directing and coordinating authority on international health within the United Nations (UN), maintains close relations with these governments. Nevertheless, a little less than half the other respondents were representatives of NGOs or academics. Thus, in spite of a somewhat apparent bias towards government sources, the global figures were gathered from a vast array of stakeholder perspectives (see Appendix II).

Finally, current epidemiological information on intellectual disabilities is scarce, fragmented, and relates mainly to high-income countries. Prevalence and incidence rates of intellectual disabilities are based on estimates that can vary considerably (Fujiura, 2005; WHO, 2001; Leonard & Wen, 2002; Durkin, 2002). Question 2 of our questionnaire asked respondents to estimate the number of persons with intellectual disabilities in their country (per 100 000 inhabitants). However, some answers were based on rates per 100 000, while others were based on absolute country figures; this shows the diversity of comprehension of the Atlas questions, and the lack of reliability of the epidemiological data collected by this project. Accordingly, any such data has not been reported.

# Findings by themes

## Terminology and classification

Many terms and definitions are used to refer to intellectual disabilities, such as mental retardation, mental handicap, intellectual disabilities, and learning disabilities. Nevertheless, all these definitions have three criteria in common: significant limitations in intellectual functioning, significant limitations in adaptive behaviour, and manifestation of these symptoms before adulthood.

The term mental retardation was the term most used in the responses from the 147 countries covered (76.0%), followed by intellectual disabilities (56.8%), mental handicap (39.7%) and mental disability (39.0%).

**"While the conditions which give rise to mental retardation or intellectual disability are universal, how the resulting condition is conceptualized, assessed, and categorized, and the response which is made, will and does vary between countries, cultures, and economies."**

(Felce, 2006)

Mental retardation was the term most often used in countries from all income categories, as well as all six WHO regions, although it was used less in high-income countries (60.0%) than in other income categories, and less often in the Western Pacific (63.6%) than in other WHO regions. Use of the term intellectual disabilities seemed to vary with level of income: use in high-income countries (80.0%) was markedly different from that in other countries (range 44.4–54.8%).

**Figure 1** **Terminology used to refer to intellectual disabilities** (percentages of countries)

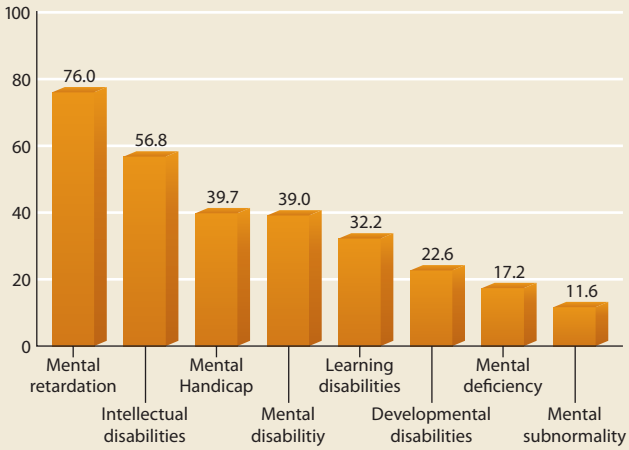


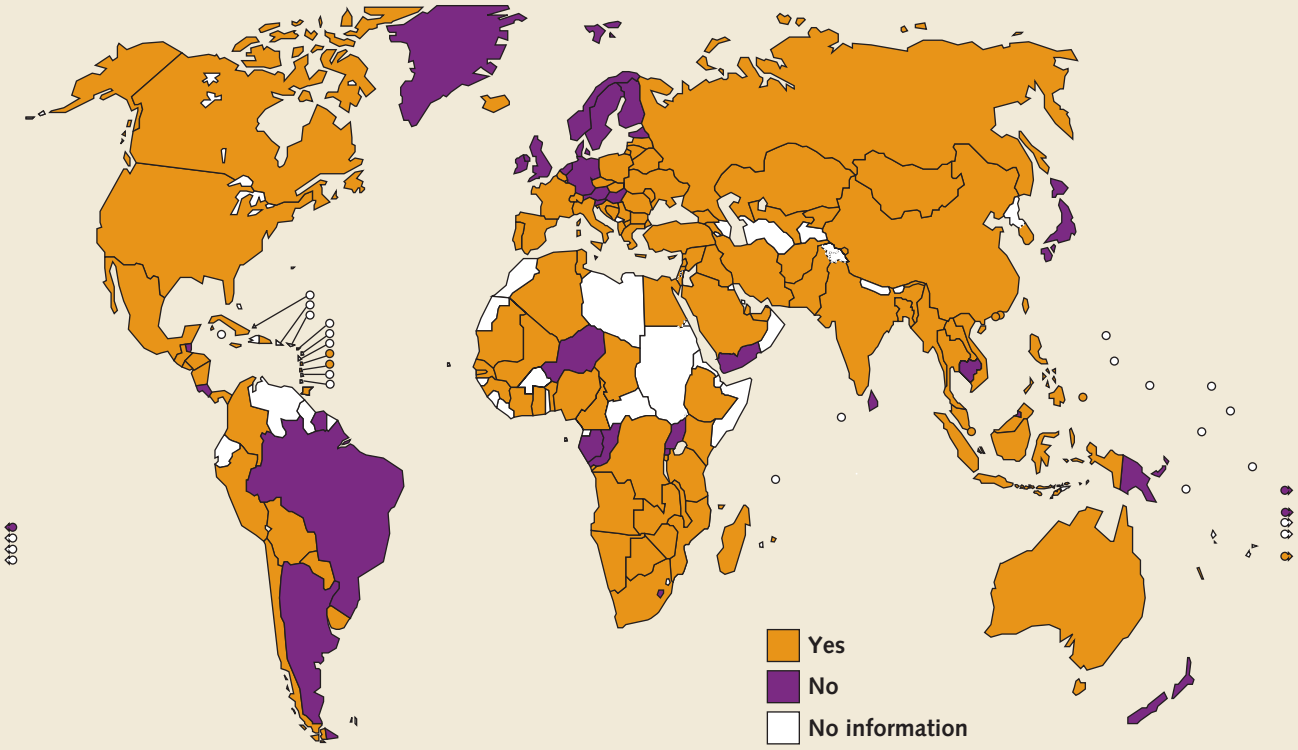

**Table 1** **Terminology used to refer to intellectual disabilities** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Developmental disabilities | 22.6% | 33 | 14.7% | 16.0% | 20.0% | 29.8% | 23.1% | 27.3% | 146 |
| Intellectual disabilities | 56.8% | 83 | 47.1% | 60.0% | 80.0% | 59.6% | 46.2% | 63.6% | 146 |
| Learning disabilities | 32.2% | 47 | 35.3% | 32.0% | 60.0% | 27.7% | 23.1% | 36.4% | 146 |
| Mental deficiency | 17.2% | 25 | 26.5% | 12.5% | 60.0% | 19.1% | 0% | 4.5% | 145 |
| Mental disability | 39.0% | 57 | 55.9% | 44.0% | 0% | 34.0% | 46.2% | 22.7% | 146 |
| Mental handicap | 39.7% | 58 | 61.8% | 16.0% | 80.0% | 34.0% | 46.2% | 31.8% | 146 |
| Mental retardation | 76.0% | 111 | 82.4% | 80.0% | 80.0% | 70.2% | 92.3% | 63.6% | 146 |
| Mental subnormality | 11.6% | 17 | 11.8% | 12.0% | 60.0% | 6.4% | 23.1% | 4.5% | 146 |

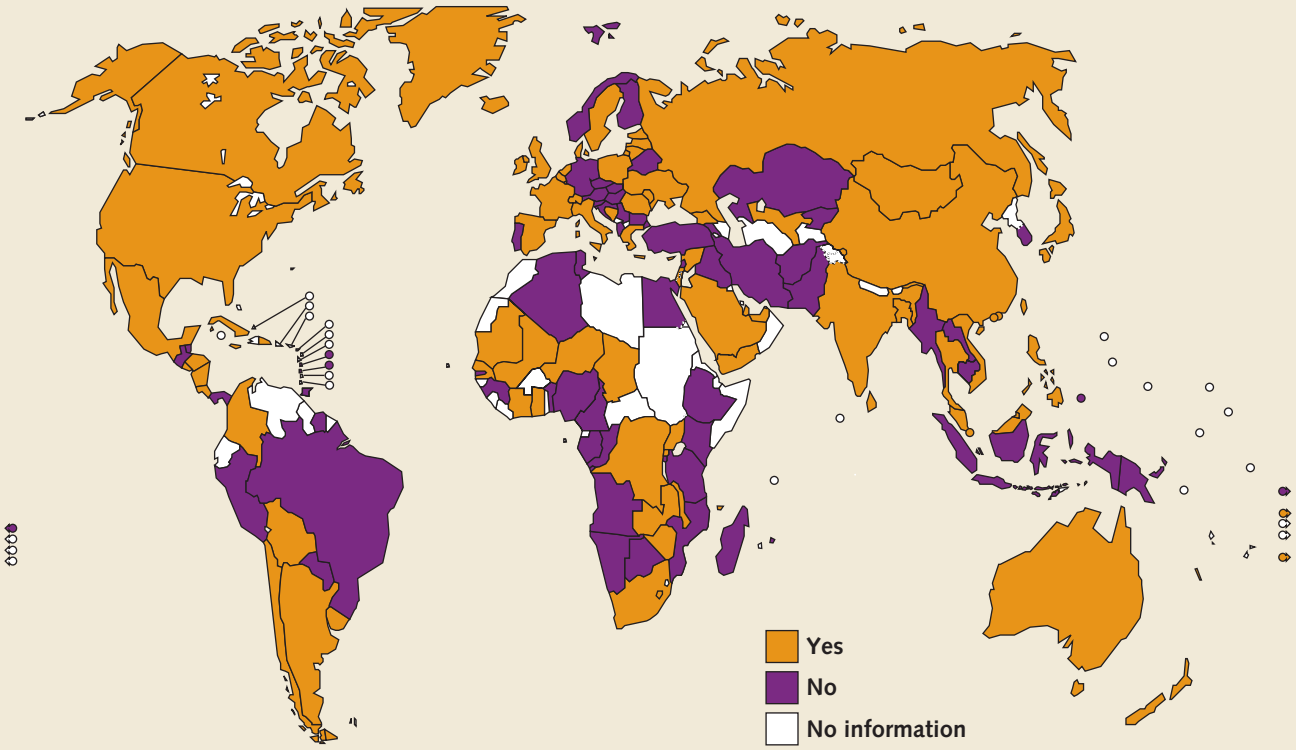
**Table 2** **Terminology used to refer to intellectual disabilities** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Developmental disabilities | 22.6% | 33 | 21.4% | 14.3% | 14.8% | 40.0% | 146 |
| Intellectual disabilities | 56.8% | 83 | 54.8% | 47.6% | 44.4% | 80.0% | 146 |
| Learning disabilities | 32.2% | 47 | 31.0% | 26.2% | 51.9% | 25.7% | 146 |
| Mental deficiency | 17.2% | 25 | 26.2% | 19.0% | 7.7% | 11.4% | 145 |
| Mental disability | 39.0% | 57 | 42.9% | 38.1% | 48.1% | 28.6% | 146 |
| Mental handicap | 39.7% | 58 | 54.8% | 31.0% | 37.0% | 34.3% | 146 |
| Mental retardation | 76.0% | 111 | 81.0% | 83.3% | 77.8% | 60.0% | 146 |
| Mental subnormality | 11.6% | 17 | 21.4% | 9.5% | 11.1% | 2.9% | 146 |

**Map 3** **Countries that used the term mental retardation**



**Map 4** **Countries that used the term intellectual disabilities**




The International Classification of Diseases (ICD) was the diagnostic instrument or classification system most often used to refer to intellectual disabilities (62.3%), followed by the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV (39.7%), and professional opinion or clinical judgment (31.5%). One should note that both the ICD and DSM-IV classification systems use the term "mental retardation" to refer to intellectual disabilities. The International Classification of Functioning, Disability, and Health (ICF) was only mentioned by 14.4% of respondents.

ICD was clearly the most popular system in Europe (89.4%), and in high-income countries (77.1%). In South-East Asia, results showed that the AAMR (now American Association on Intellectual and Developmental Disabilities; AAIDD) criteria were as popular as ICD (both 60%), whereas DSM-IV and ICD were used at much the same level in the Western Pacific (45.5% and 54.5%, respectively).

**Figure 2** **Diagnostic or classification system used in relation to intellectual disabilities** (percentages of countries)

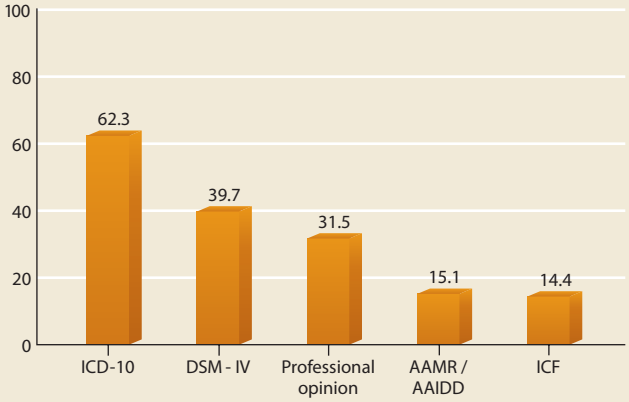


**Table 3** **Diagnostic or classification system used in relation to intellectual disabilities**
(percentages of countries by WHO regions)

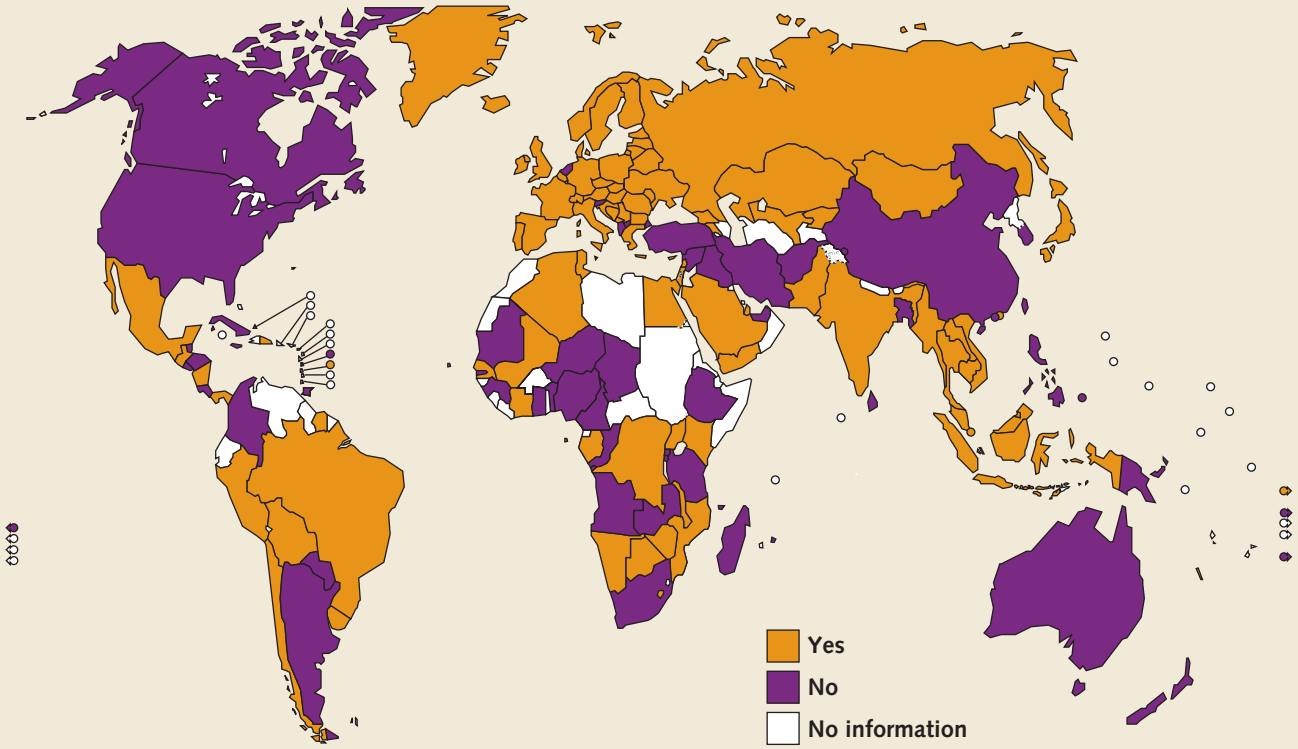
| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| AAMR or AAIDD | 15.1% | 2 | 20.6% | 16.0% | 60.0% | 6.4% | 23.1% | 9.1% | 146 |
| DSM-IV | 39.7% | 58 | 38.2% | 52.0% | 40.0% | 27.7% | 53.8% | 45.5% | 146 |
| Professional opinion | 31.5% | 46 | 50.0% | 32.0% | 20.0% | 23.4% | 46.2% | 13.6% | 146 |
| ICD-10 | 62.3% | 91 | 41.2% | 48.0% | 60.0% | 89.4% | 61.5% | 54.5% | 146 |
| ICF | 14.4% | 21 | 17.6% | 12.0% | 20.0% | 14.9% | 15.4% | 9.1% | 146 |

Use of ICD criteria varied according to country income categories; a greater proportion of countries in high-income countries used these criteria than did low-income countries (range 52.4% in low-income countries to 77.1% in high-income countries). High-income countries were less likely to rely on professional opinion (22.9%) than were low-income countries (38.1%). More high-income and upper middle-income countries used DSM-IV criteria than did countries from other income categories (48.6% and 48.1%, respectively). One should note that clinical judgment is not, per se, a diagnostic or classification system. The meaning of these data could be that professional opinion was used for clinical or administrative purposes, rather than a standardized instrument.

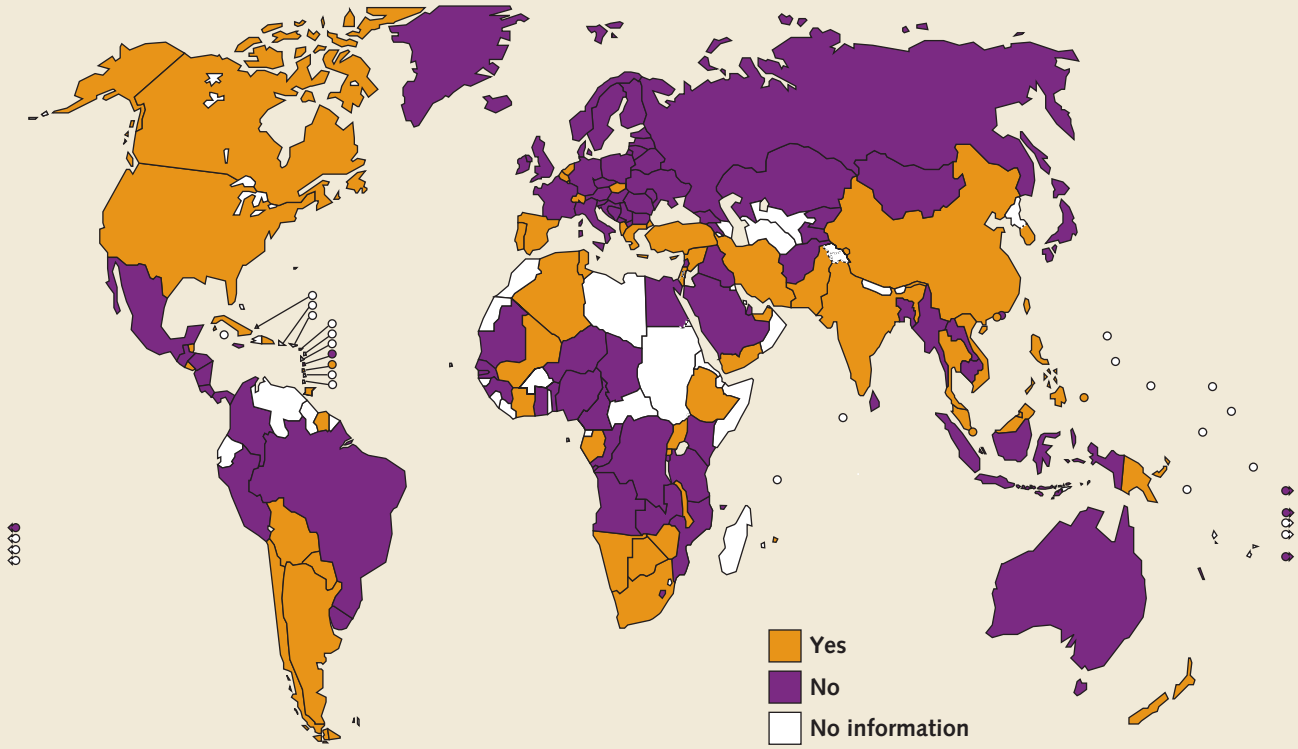
**Table 4** **Diagnostic or classification system used in relation to intellectual disabilities**
(percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| AAMR or AAIDD | 15.1% | 22 | 19.0% | 21.4% | 0% | 14.3% | 146 |
| DSM-IV | 39.7% | 58 | 28.6% | 38.1% | 48.1% | 48.6% | 146 |
| Professional opinion | 31.5% | 46 | 38.1% | 35.7% | 25.9% | 22.9% | 146 |
| ICD-10 | 62.3% | 91 | 52.4% | 57.1% | 66.7% | 77.1% | 146 |
| ICF | 14.4% | 21 | 14.3% | 9.5% | 18.5% | 17.1% | 146 |

**Map 5** Countries that used ICD as a diagnostic or classification instrument




**Map 6** Countries that used DSM-IV as a diagnostic or classification instrument



## Policies and programmes

There was a national policy or programme specifically related to intellectual disabilities in 59.2% of the countries that responded to the survey. There were few differences in these results between WHO regions, with proportions varying from 76.9% (Eastern Mediterranean) to 53.2% (Europe). Of the countries that did not have a specific national policy or programme, 22.4% (33 countries) referred to intellectual disabilities in other policies. Respondents said that intellectual disabilities were not covered by any policy or programme in 27 countries (18.4%).

**Figure 3** **Presence of a policy or programme that addressed intellectual disabilities**
(percentages of countries by WHO regions)

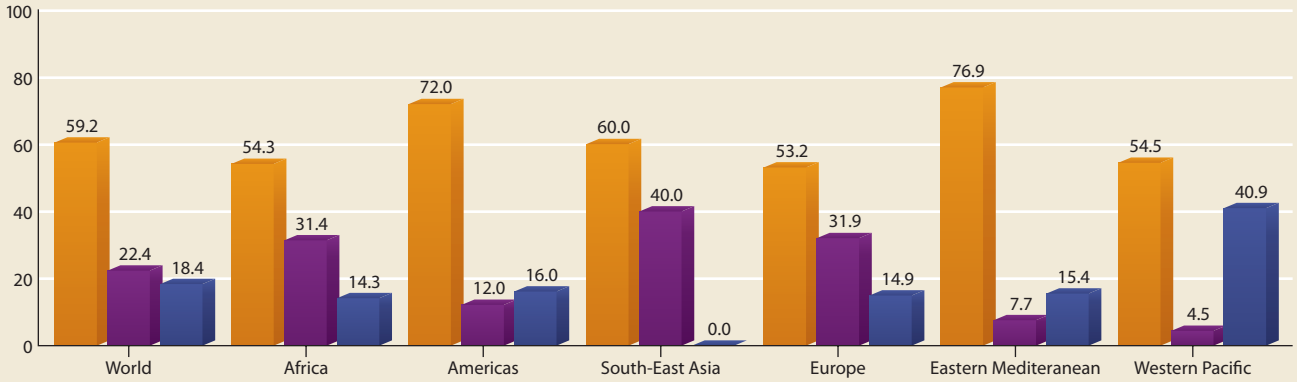
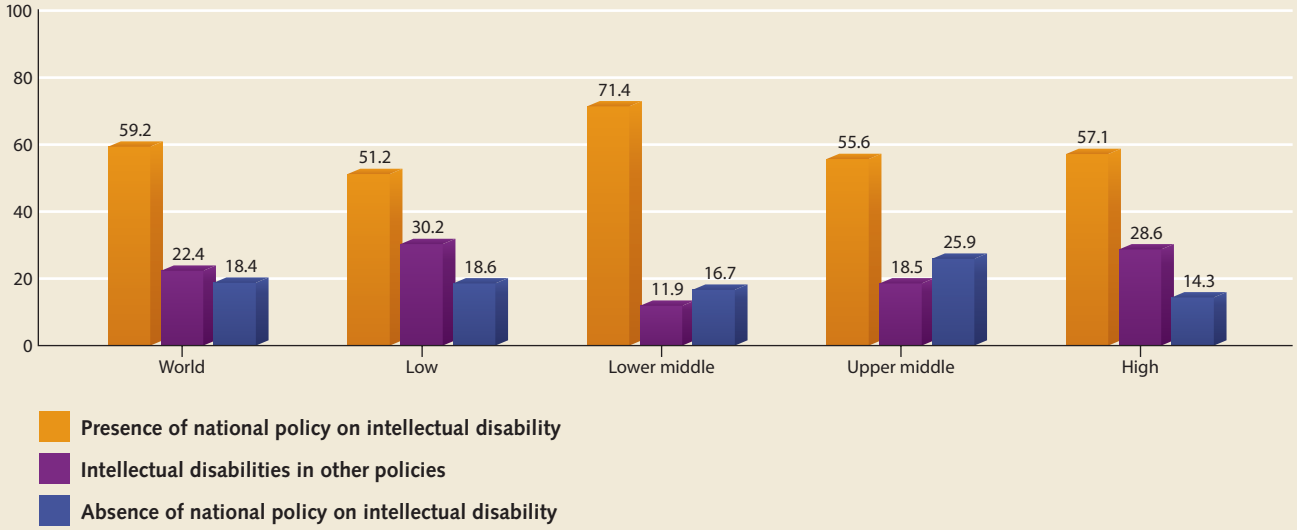



**Figure 4** **Presence of a policy or programme that addressed intellectual disabilities**
(percentages of countries by income categories)




Many governmental agencies were involved in the field of intellectual disabilities. The figure presents an overview of the national departments involved in the field of intellectual disabilities. The data indicate that different agencies have shared responsibilities for the field and that its management is scattered among many agencies. At the policy level, education (77.8%), health (71.1%), disability (67.8%), and social welfare (67.8%) were the sectors most involved in issues related to persons with intellectual disabilities.

**Map 7** Countries that had a national policy or programme

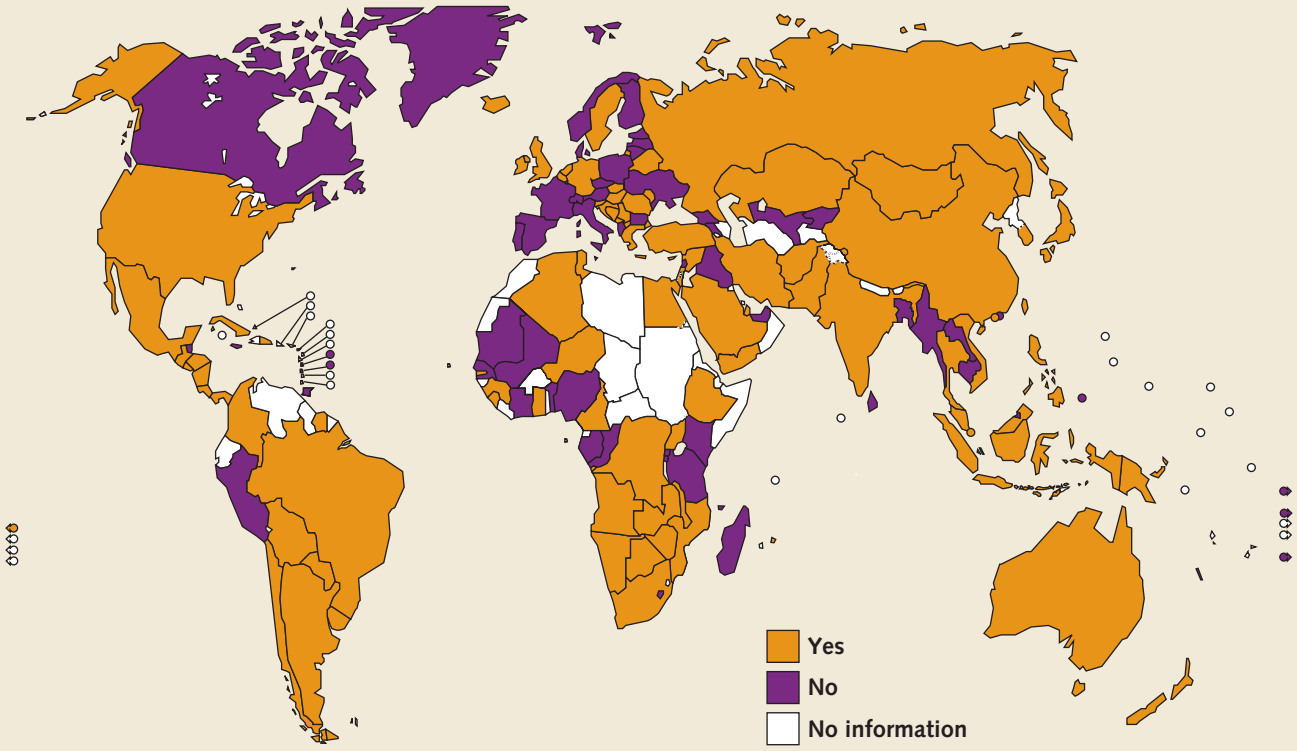



**Figure 5** Departments responsible for policies and funding or monitoring programmes (percentages of countries)

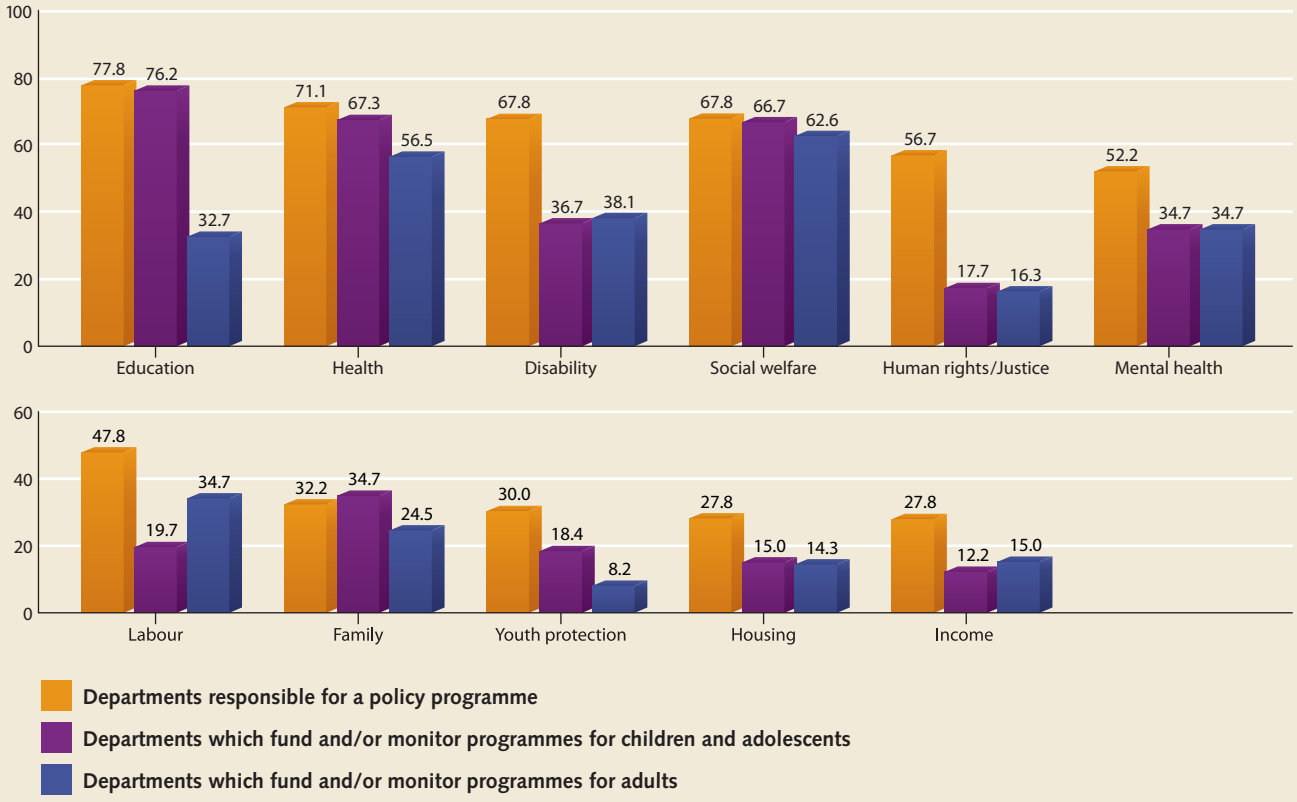


**Table 5** **Presence of a specific policy or programme in which intellectual disabilities are addressed**
(percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Disability Act | 67.8% | 61 | 60.0% | 77.8% | 66.7% | 77.8% | 60.0% | 50.0% | 90 |
| Education | 77.8% | 70 | 55.0% | 66.7% | 100% | 92.6% | 90.0% | 83.3% | 90 |
| Health | 71.1% | 64 | 55.0% | 72.2% | 66.7% | 81.5% | 80.0% | 66.7% | 90 |
| Housing | 27.8% | 25 | 5.0% | 22.2% | 0% | 59.3% | 20.0% | 16.7% | 90 |
| Human rights | 56.7% | 51 | 30.0% | 50.0% | 66.7% | 77.8% | 70.0% | 50.0% | 90 |
| Family | 32.2% | 29 | 15.0% | 22.2% | 33.3% | 51.9% | 40.0% | 25.0% | 90 |
| Income | 27.8% | 25 | 15.0% | 5.6% | 33.3% | 55.6% | 20.0% | 25.0% | 90 |
| Labour | 47.8% | 43 | 25.0% | 50.0% | 66.7% | 66.7% | 50.0% | 33.3% | 90 |
| Mental health | 52.2% | 47 | 65.0% | 50.0% | 33.3% | 48.1% | 50.0% | 50.0% | 90 |
| Social welfare | 67.8% | 61 | 65.0% | 44.4% | 100% | 81.5% | 80.0% | 58.3% | 90 |
| Youth protection | 30.0% | 27 | 25.0% | 16.7% | 33.3% | 40.7% | 30.0% | 33.3% | 90 |

**Table 6** **Presence of a specific policy or programme in which intellectual disabilities are addressed**
(percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Disability Act | 67.8% | 61 | 58.3% | 56.7% | 73.3% | 90.5% | 90 |
| Education | 77.8% | 70 | 66.7% | 73.3% | 86.7% | 90.5% | 90 |
| Health | 71.1% | 64 | 58.3% | 73.3% | 80.0% | 76.2% | 90 |
| Housing | 27.8% | 25 | 12.5% | 23.3% | 26.7% | 52.4% | 90 |
| Human rights | 56.7% | 51 | 41.7% | 56.7% | 53.3% | 76.2% | 90 |
| Family | 32.2% | 29 | 29.2% | 33.3% | 40.0% | 28.6% | 90 |
| Income | 27.8% | 25 | 25.0% | 10.0% | 20.0% | 61.9% | 90 |
| Labour | 47.8% | 43 | 16.7% | 56.7% | 53.3% | 66.7% | 90 |
| Mental health | 52.2% | 47 | 62.5% | 56.7% | 53.3% | 33.3% | 90 |
| Social welfare | 67.8% | 61 | 54.2% | 66.7% | 86.7% | 71.4% | 90 |
| Youth protection | 30.0% | 27 | 29.2% | 30.0% | 26.7% | 33.3% | 90 |

When funding and monitoring of programmes were considered, variations were seen by age group. Services for adults seemed to be much less developed than were services for children and adolescents. For children and adolescents, the following departments were, by far, the most concerned: education (76.2%), health (67.3%), and social welfare (66.7%). Programmes for adults were mainly found in social welfare (62.6%) and health (56.5%). In terms of funding or monitoring services for all age groups, sectors such as income, housing, and justice were involved in very few countries (fewer than 20%).

**Table 7** **Departments responsible for monitoring or funding services for children and adolescents**
(percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Disability | 36.7% | 54 | 31.4% | 40.0% | 0% | 48.9% | 30.8% | 27.3% | 147 |
| Education | 76.2% | 112 | 68.6% | 84.0% | 60.0% | 83.0% | 76.9% | 68.2% | 147 |
| Family welfare | 34.7% | 51 | 28.6% | 48.0% | 0% | 42.6% | 30.8% | 22.7% | 147 |
| Health | 67.3% | 99 | 60.0% | 80.0% | 60.0% | 78.7% | 61.5% | 45.5% | 147 |
| Housing | 15.0% | 22 | 11.4% | 16.0% | 0% | 23.4% | 7.7% | 9.1% | 147 |
| Justice | 17.7% | 26 | 14.3% | 16.0% | 0% | 29.8% | 7.7% | 9.1% | 147 |
| Income | 12.2% | 18 | 11.4% | 4.0% | 0% | 23.4% | 0% | 9.1% | 147 |
| Labour | 19.7% | 29 | 20.0% | 16.0% | 0% | 25.5% | 23.1% | 13.6% | 147 |
| Mental health | 34.7% | 51 | 40.0% | 28.0% | 40.0% | 36.2% | 38.5% | 27.3% | 147 |
| Social welfare | 66.7% | 98 | 68.6% | 56.0% | 100% | 76.6% | 76.9% | 40.9% | 147 |
| Youth protection | 18.4% | 27 | 20.0% | 8.0% | 20.0% | 27.7% | 0% | 18.2% | 147 |

**Table 8** **Departments responsible for monitoring or funding services for children and adolescents**
(percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Disability | 36.7% | 54 | 34.9% | 31.0% | 33.3% | 48.6% | 147 |
| Education | 76.2% | 112 | 62.8% | 69.0% | 81.5% | 97.1% | 147 |
| Family welfare | 34.7% | 51 | 34.9% | 26.2% | 44.4% | 37.1% | 147 |
| Health | 67.3% | 99 | 51.2% | 57.1% | 81.5% | 88.6% | 147 |
| Housing | 15.0% | 22 | 11.6% | 9.5% | 14.8% | 25.7% | 147 |
| Justice | 17.7% | 26 | 18.6% | 9.5% | 18.5% | 25.7% | 147 |
| Income | 12.2% | 18 | 11.6% | 2.4% | 7.4% | 28.6% | 147 |
| Labour | 19.7% | 29 | 16.3% | 16.7% | 22.2% | 25.7% | 147 |
| Mental health | 34.7% | 51 | 39.5% | 35.7% | 33.3% | 28.6% | 147 |
| Social welfare | 66.7% | 98 | 58.1% | 64.3% | 74.1% | 74.3% | 147 |
| Youth protection | 18.4% | 27 | 23.3% | 7.1% | 22.2% | 22.9% | 147 |

**Table 9** **Departments responsible for monitoring or funding services for adults** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Disability | 38.1% | 56 | 28.6% | 36.0% | 20.0% | 46.8% | 30.8% | 45.5% | 147 |
| Education | 32.7% | 48 | 31.4% | 44.0% | 0% | 36.2% | 30.8% | 22.7% | 147 |
| Family welfare | 24.5% | 26 | 17.1% | 36.0% | 0% | 29.8% | 23.1% | 18.2% | 147 |
| Health | 56.5% | 83 | 42.9% | 72.0% | 40.0% | 70.2% | 53.8% | 36.4% | 147 |
| Housing | 14.3% | 21 | 14.3% | 12.0% | 0% | 23.4% | 0% | 9.1% | 147 |
| Justice | 16.3% | 24 | 11.4% | 12.0% | 0% | 27.7% | 7.7% | 13.6% | 147 |
| Income | 15.0% | 22 | 11.4% | 8.0% | 0% | 27.7% | 0% | 13.6% | 147 |
| Labour | 34.0% | 50 | 20.0% | 28.0% | 0% | 59.6% | 38.5% | 13.6% | 147 |
| Mental health | 34.7% | 51 | 31.4% | 36.0% | 40% | 40.4% | 38.5% | 22.7% | 147 |
| Social welfare | 62.6% | 92 | 54.3% | 44.0% | 100% | 80.9% | 76.9% | 40.9% | 147 |

**Table 10** **Departments responsible for monitoring or funding services for adults** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Disability | 38.1% | 56 | 34.9% | 33.3% | 33.3% | 51.4% | 147 |
| Education | 32.7% | 48 | 30.2% | 23.8% | 40.7% | 40.0% | 147 |
| Family welfare | 24.5% | 36 | 27.9% | 16.7% | 29.6% | 25.7% | 147 |
| Health | 56.5% | 83 | 37.2% | 50.0% | 70.4% | 77.1% | 147 |
| Housing | 14.3% | 21 | 11.6% | 4.8% | 14.8% | 28.6% | 147 |
| Justice | 16.3% | 24 | 14.0% | 7.1% | 14.8% | 31.4% | 147 |
| Income | 15.0% | 22 | 11.6% | 4.8% | 11.1% | 34.3% | 147 |
| Labour | 34.0% | 50 | 16.3% | 28.6% | 37.0% | 60.0% | 147 |
| Mental health | 34.7% | 51 | 32.6% | 33.3% | 37.0% | 37.1% | 147 |
| Social welfare | 62.6% | 92 | 48.8% | 52.4% | 70.4% | 85.7% | 147 |
| Youth protection | 18.4% | 27 | 23.3% | 7.1% | 22.2% | 22.9% | 147 |

## Legislation, protection and public awareness campaigns

### Legislation and protection

Persons with intellectual disabilities are known to experience some of the most difficult living conditions in the world (Despouy, 1991; Rosenthal & Sundram, 2003; MDRI; CIR). Reasons for this situation include systemic discrimination and absence of judicial protection (Quinn & Degener, 2002).

When asked if their countries had a specific national policy or programme related to intellectual disabilities, of those that answered yes (59.2%), only 51 country respondents indicated that such a policy or programme pertained to the human rights of persons with intellectual disabilities (see page 22).

**Figure 6** **Presence of legislation to protect persons with intellectual disabilities** (percentages of countries by WHO regions)

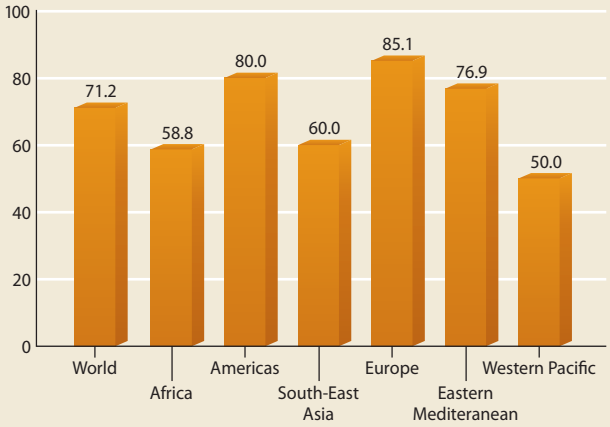
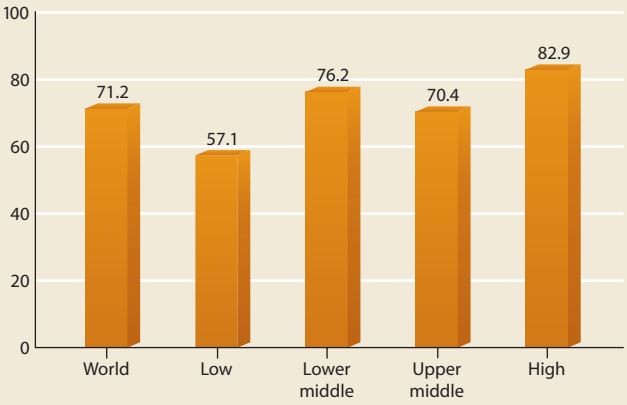


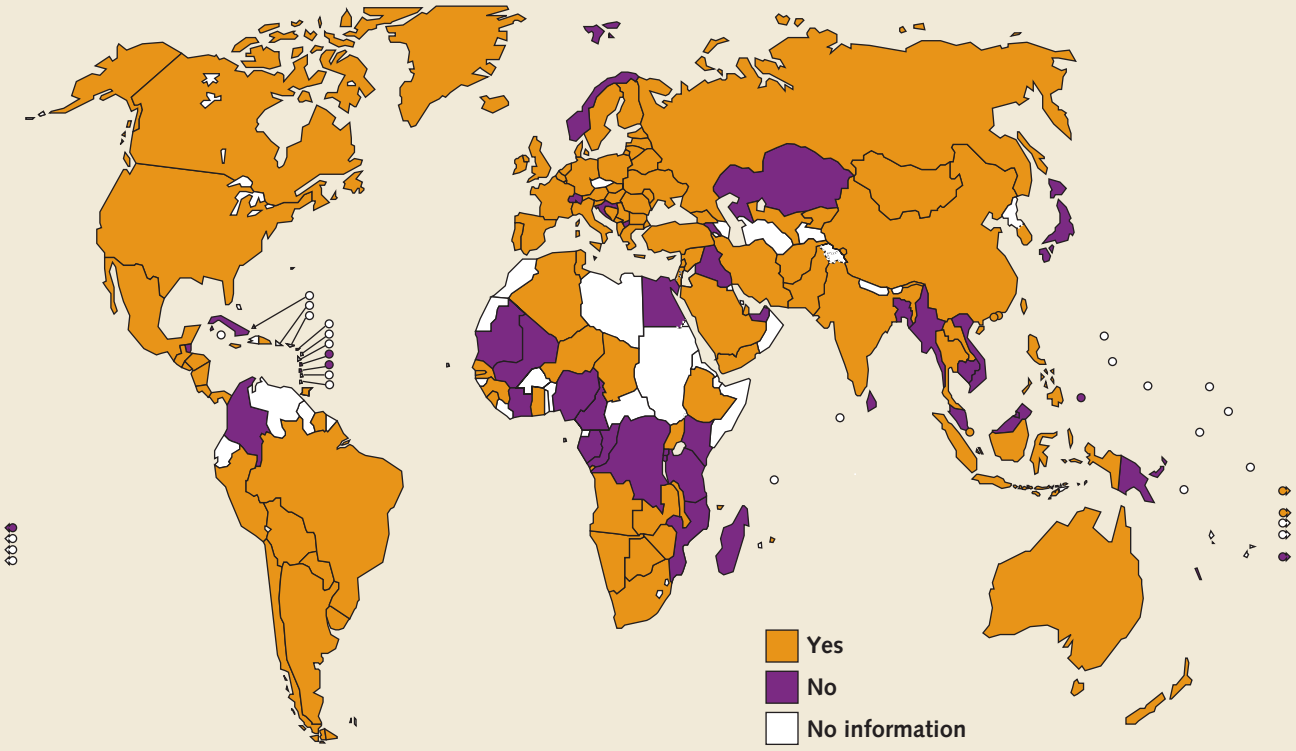

**Figure 7** **Presence of legislation to protect persons with intellectual disabilities** (percentages of countries by income categories)




**"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."**

Respondent from the Islamic Republic of Iran

**Map 8** Presence of legislation to protect persons with intellectual disabilities




71.2% of responding countries (104 of 146 countries) indicated the presence of a specific law to protect persons with intellectual disabilities. The notion of protection is one that has long been held against persons with intellectual disabilities, since guardianship laws have historically been used to deny such individuals their right to make decisions and take part in civil life. But sometimes, the civil protection of a person with intellectual disabilities and of their assets is necessary when they are unable to take care of themselves. Although the question must be dealt with case by case, the absence of legal-protection mechanisms can often lead to human right abuses of persons with intellectual disabilities. Government-based protective systems oversee the civil protection of persons with intellectual disabilities through measures that are appropriate to their condition and situation, and ensure that all decisions affecting their well-being and property reflect their best interests, respect their rights, and safeguard their autonomy (see box for recent standard on this topic). This type of protection most often involves the family and can take the form of a curatorship, a tutorship, an advisor to an adult or, most commonly, a tutorship to a minor.

**"b) […] It is only under the most extraordinary of circumstances that the legal right of persons with intellectual disabilities to make their own decisions can be lawfully interrupted. Any such interruption can only be for a limited period of time, subject to periodic review, and pertaining only to those specific decisions for which the individual has been found by an independent and competent authority to lack legal capacity;**

**c) That independent and competent authority must find by clear and convincing evidence that, even with adequate and appropriate supports, all less restrictive alternatives to the appointment of a surrogate decision-maker have been exhausted. That authority must be guided by due process, including the individual's right to: notice; be heard; present evidence; identify experts to testify on his or her behalf; be represented by one or more well-informed individuals who he or she trusts and chooses; challenge any evidence at the hearing; and appeal any adverse finding to a higher court. Any surrogate decision-maker must take account of the person's preferences and strive to make the decision that the person with an intellectual disability would make if he or she were able to do so."**

The Montreal Declaration on Intellectual Disabilities (2004), Article 6

The presence of such a law was reported less often in low-income countries (57.1%) than in countries from other income categories (from 70.4% in upper middle-income countries to 82.9% in high-income countries). In the same way, higher proportions of countries in Europe, the Americas, and the Eastern Mediterranean had such laws (85.1%, 80.0%, and 76.9%, respectively) than did the other WHO regions (South-East Asia 60.0%, Africa 58.8%, and the Western Pacific 50.0%).

**Figure 8** **Presence of a judicial protection system** (percentages of countries by WHO regions)

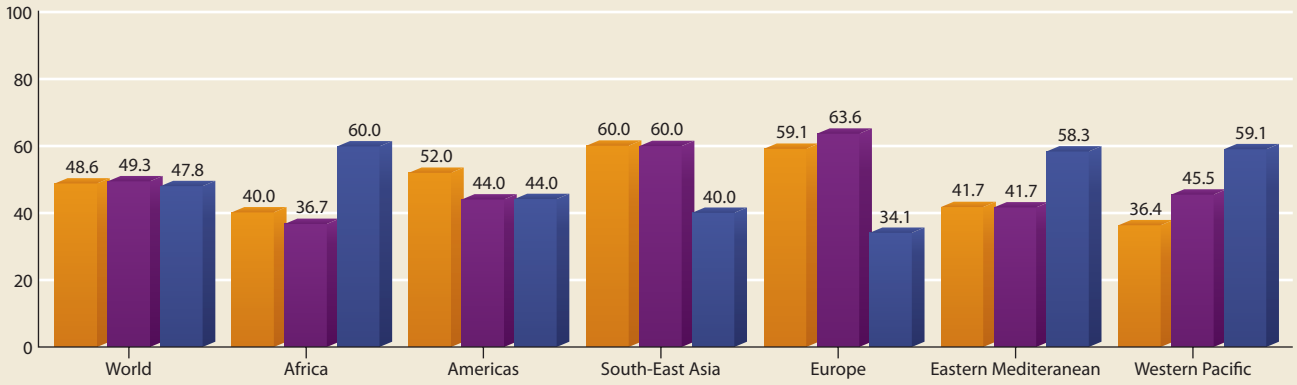
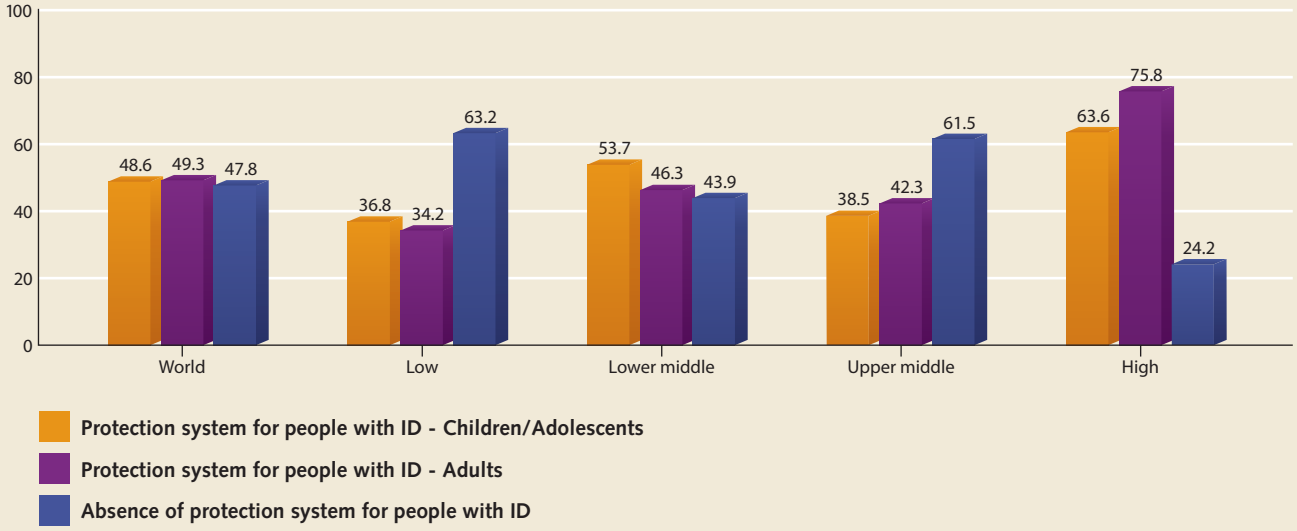



**Figure 9** **Presence of a judicial protection system** (percentages of countries by income categories)




Respondents were also asked to indicate if special provisions within the justice system existed for offenders with intellectual disabilities. This type of protection system is based on the assumption that a person with an intellectual disability who has been convicted of a crime by a court of law might be in need of specific types of support offered in detention settings. Almost half the responses indicate (48.1%) that no special provisions for offenders with intellectual disabilities existed within their national justice system. This was true for both children and adolescents (legislation absent in 44.1% of the countries) and for adults (absent in 48.9% of the countries).

**There is in New Zealand a legal framework to divert criminal offenders who have an intellectual disability away from the mainstream criminal justice system. This legislation (the Intellectual Disability Compulsory Care and Rehabilitation Act 2003) enables care to be provided in secure forensic services co-located with mental health forensic services in the grounds of a Crown-owned Hospital.**

Respondent from New Zealand

**Figure 10** **Presence of special rules for offenders** (percentages of countries by WHO regions)

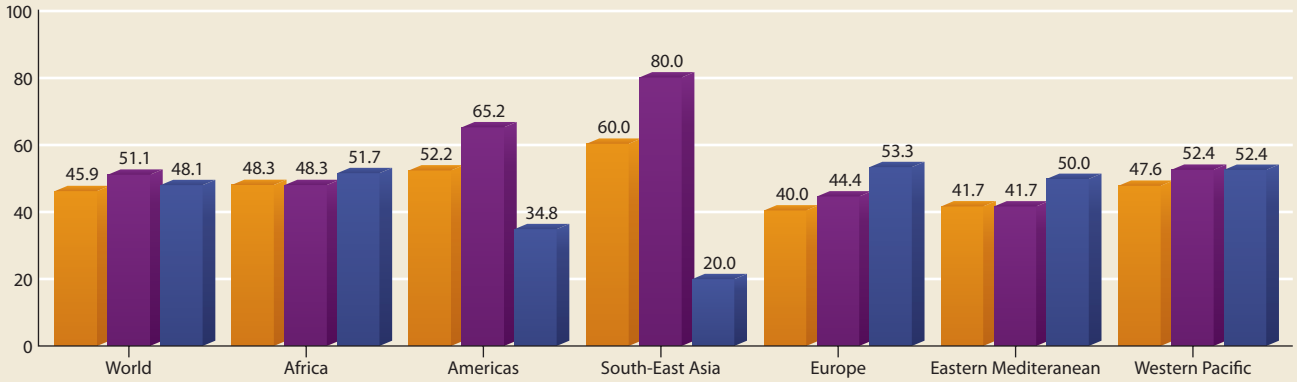
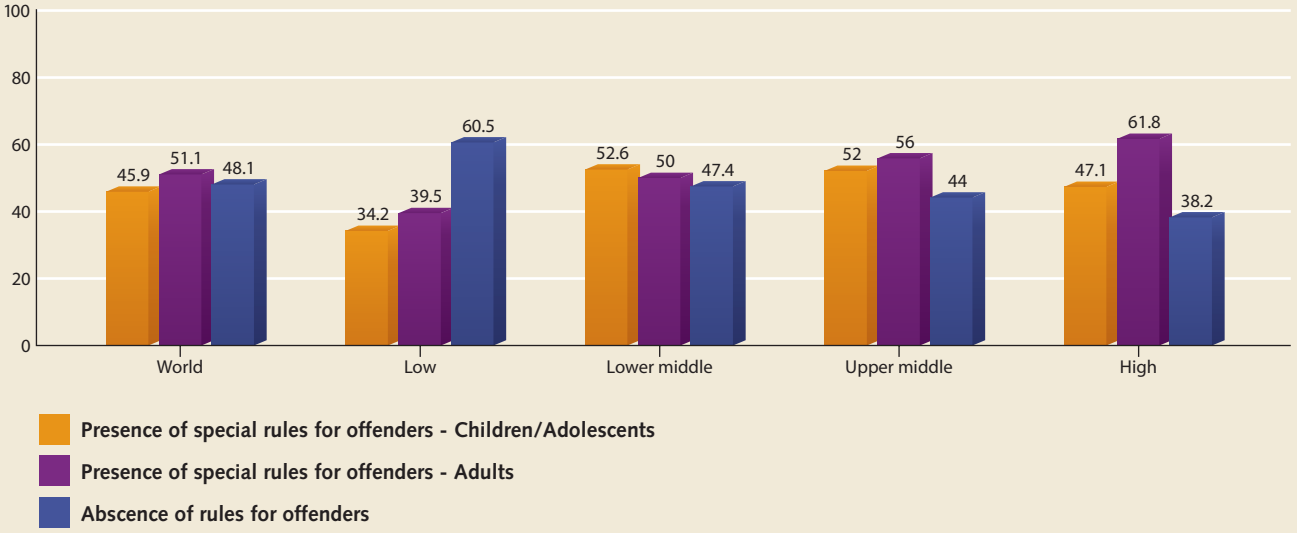



**Figure 11** **Presence of special rules for offenders** (percentages of countries by income categories)




## Public awareness campaigns

Public awareness campaigns promulgate publicity or information that supports the development of persons with intellectual disabilities, in a general or specific domain such as anti-stigma, social integration, human rights, education, access to employment, social integration, or health care. Of the participating countries, 60.3% have carried out public awareness campaigns. More countries in the high-income category (73.5%) reported that they had had such campaigns than did countries of low and middle income. Likewise, more countries in South-East Asia (80.0%) and Europe (71.7%) had done such campaigns than had countries in other WHO regions. 15% of the responding countries described these campaigns as recurring every year. Although the question pertained to specific public awareness campaigns on intellectual disabilities, these campaigns were often aggregated with general disability-awareness campaigns or with the World Mental Health Day. 70 countries provided the slogan of a recent awareness campaign (see page 31). These media campaigns range from the informative to the provocative or even poetic, and aim to inform and engage the general public on issues of importance to persons with ID and their families.

**Don't DIS my ABILITY** – Australia

**I am willing, I know, I can** – Croatia

**Everyone holds the Sun inside, only let it shine…** – Georgia

**Accept me, include me** – Hungary

**Don't let them grow without education** – Indonesia

**Do not test only your intelligence, test your humanity** – The former Yugoslav Republic of Macedonia

**Disability is not inability** – Malawi

**All different, all together** – Mauritius

**Beautiful world together with the disabled** – Republic of Korea

**We are different but not worse** – Slovakia

**Upholding the human rights of persons with intellectual disability** – South Africa

**I am like you** – Spain

**Human rights, social integration, health care, education and employment** – Syrian Arab Republic

**Simply participating** – The Netherlands

**No discrimination for intellectual disability** – Zimbabwe

## Financing

Funding for services for intellectual disabilities was provided through three main sources: (1) tax-based funding (76.0% of countries), which refers to services financed by general taxation; (2) financial support from NGOs (68.8%), which refers to support by international or national voluntary organizations, charitable groups, service-user groups, advocacy groups, or professional associations; and (3) out-of-pocket expenses (60.1%), which signifies that services were purchased by users or their families.

The proportion of countries with tax-based funding was especially low in low-income countries (54.8%), compared with countries from other income categories (range 81.0–88.9%). The proportion of countries with tax-based funding was highest in South-East Asia (100%), Europe (91.5%), and the Americas (84.0%), and the lowest in Africa (55.9%) and the Western Pacific (63.6%).

**Figure 12** Sources of funding for services
(percentages of countries)

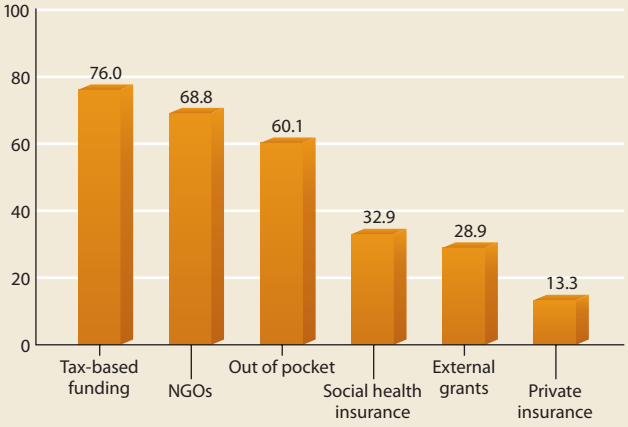


**Table 11** **Sources of funding for services** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Tax-based funding | 76.0% | 111 | 55.9% | 84.0% | 100% | 91.5% | 69.2% | 63.6% | 146 |
| Out-of-pocket | 60.1% | 87 | 70.6% | 62.5% | 100% | 45.7% | 76.9% | 52.4% | 144 |
| Social health-insurance | 32.9% | 47 | 11.8% | 52.0% | 20.0% | 48.9% | 23.1% | 19.0% | 143 |
| Private insurance | 13.3% | 19 | 8.8% | 20.8% | 0% | 17.4% | 15.4% | 4.8% | 143 |
| External grants | 28.9% | 41 | 35.3% | 29.2% | 100% | 17.4% | 23.1% | 30.0% | 142 |
| NGOs | 68.8% | 99 | 64.7% | 80.0% | 100% | 58.7% | 76.9% | 71.4% | 144 |

**Table 12** **Sources of funding for services** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Tax-based funding | 76.0% | 111 | 54.8% | 81.0% | 88.9% | 85.7% | 146 |
| Out-of-pocket | 60.1% | 87 | 66.7% | 47.6% | 60.0% | 67.6% | 143 |
| Social health-insurance | 32.9% | 47 | 11.9% | 31.0% | 50.0% | 48.5% | 143 |
| Private insurance | 13.3% | 19 | 7.1% | 11.9% | 12.0% | 23.5% | 143 |
| External grants | 28.9% | 41 | 41.5% | 31.0% | 20.0% | 17.6% | 142 |
| NGOs | 68.8% | 99 | 69.0% | 73.8% | 80.8% | 52.9% | 144 |

The proportion of funding for intellectual disability services provided by different sources may vary greatly from one group of countries to another one. Nevertheless, the median of percentages confirmed that tax-based funding was the most important source of funding for services. On this indicator, Africa had a distinct profile, with the lowest medians for tax-based funding (17.5%) and social health insurance (0.5%), and the highest for out-of-pocket expenses (40.0%) and external grants (30.0%). The role of funding from NGOs seemed especially important in the Eastern Mediterranean region (65.0%).

**Table 13** **Repartition of sources of funding for services** (median percentages by WHO regions)

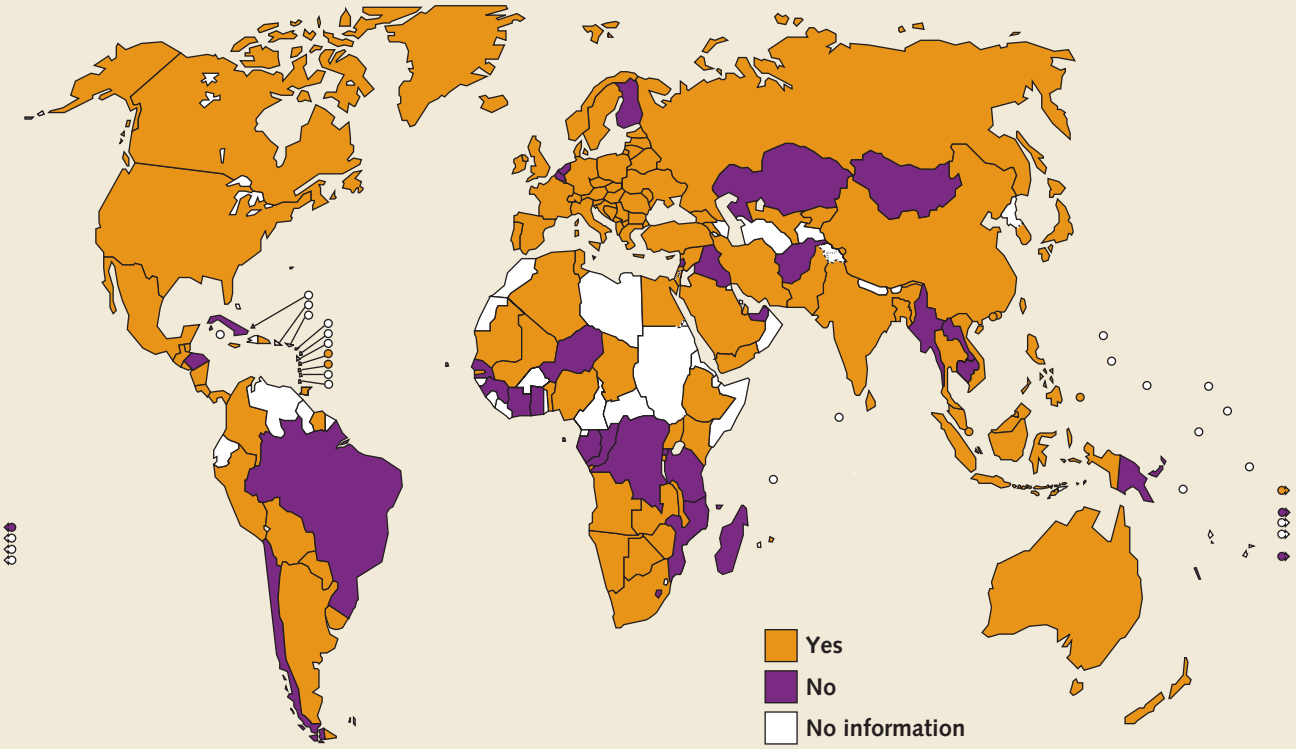
| | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | Total | N |
|---|---|---|---|---|---|---|---|---|
| Tax-based funding | 17.5% | 50.0% | 50.0% | 80.0% | 80.0% | 85.0% | 66.0% | 83 |
| Out-of-pocket | 40.0% | 17.5% | 10.0% | 10.0% | 10.0% | 30.0% | 19.4% | 66 |
| Social health-insurance | 0.5% | 20.0% | 45.0% | 20.0% | 5.0% | 35.0% | 20.0% | 34 |
| Private insurance | 2.0% | 5.0% | 0.0% | 1.3% | 2.0% | 1.0% | 2.0% | 13 |
| External grants | 30.0% | 5.0% | 3.0% | 7.0% | 15.0% | 20.0% | 10.0% | 26 |
| NGOs | 20.0% | 15.0% | 10.0% | 10.0% | 65.0% | 15.0% | 15.0% | 74 |

Note: Half of the countries are over the median percentage, and half below.

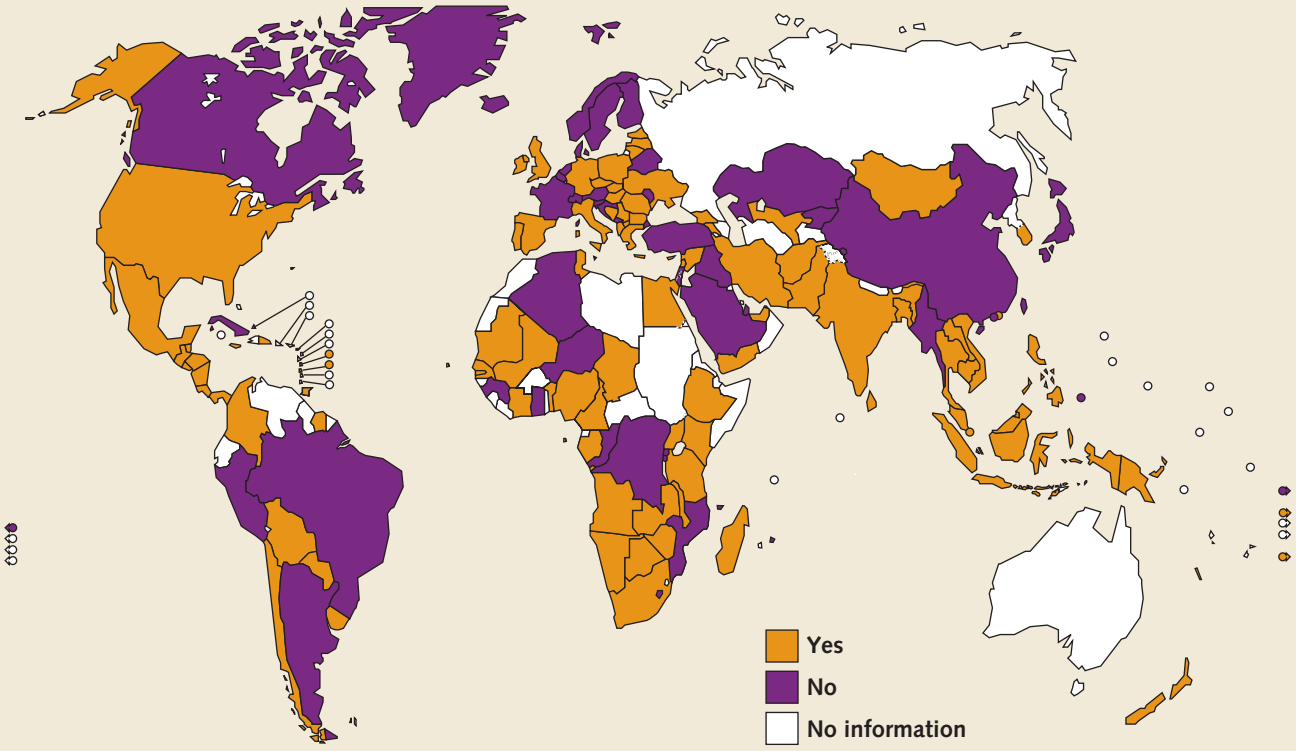
**Table 14** **Repartition of sources of funding for services** (median percentages by income categories)

| | Low-income | Lower-middle income | Upper-middle income | High income | Total | N |
|---|---|---|---|---|---|---|
| Tax-based funding | 50.0% | 55.0% | 70.0% | 90.0% | 66.0% | 83 |
| Out of pocket | 16.5% | 29.0% | 10.0% | 5.0% | 19.4% | 66 |
| Social health insurance | 1.5% | 20.0% | 15.0% | 20.0% | 20.0% | 34 |
| Private insurance | 1.0% | 2.0% | 7.5% | 1.5% | 2.0% | 13 |
| External grants | 20.0% | 7.5% | 12.5% | 5.0% | 10.0% | 26 |
| NGOs | 20.0% | 15.0% | 15.0% | 5.0% | 15.0% | 74 |

**Map 9** **Tax-based funding for services**



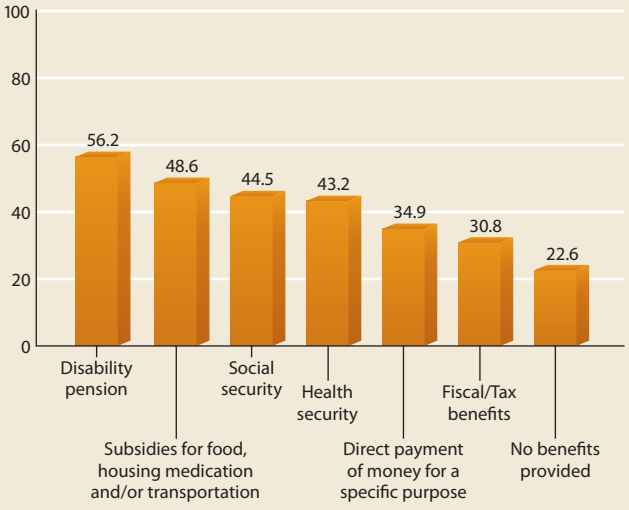
**Map 10** NGOs as a source of funding for services




## Government benefits

Most of the participating countries (77.4%) provided some form of government benefits to adults with an intellectual disability or to families with a child who had an intellectual disability. These benefits took many different forms and, as such, came from numerous sources of more or less equal importance.

**Figure 13** Presence and nature of government benefits
(percentages of countries)



52.9% 0f the 33 countries that had no government benefits whatsoever were located in the WHO African region, and almost half were low-income countries (16 countries).

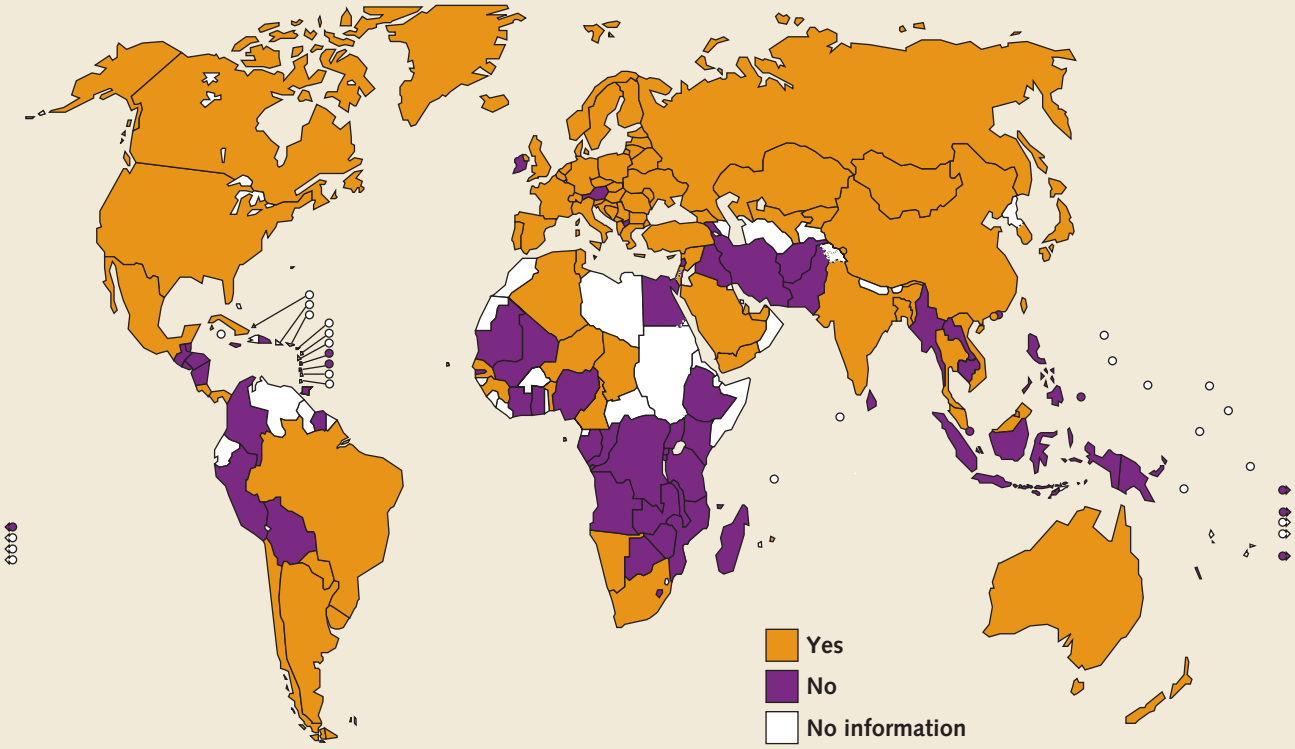
**Table 15** **Presence and nature of government benefits** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| No benefits provided | 22.6% | 33 | 52.9% | 24.0% | 0% | 0% | 23.1% | 27.3% | 146 |
| Disability pension | 56.2% | 82 | 29.4% | 44.0% | 60.0% | 91.5% | 46.2% | 40.9% | 146 |
| Health security | 43.2% | 63 | 23.5% | 24.0% | 40.0% | 74.5% | 46.2% | 27.3% | 146 |
| Social security | 44.5% | 65 | 20.6% | 44.0% | 20.0% | 70.2% | 46.2% | 31.8% | 146 |
| Subsidies for food, housing, medication, or transporta-tion | 48.6% | 71 | 26.5% | 44.0% | 60.0% | 68.1% | 53.8% | 40.9% | 146 |
| Direct payment of money for a specific purpose | 34.9% | 51 | 17.6% | 40.0% | 80.0% | 44.7% | 30.8% | 27.3% | 146 |
| Fiscal or tax benefits | 30.8% | 45 | 14.7% | 24.0% | 40.0% | 46.8% | 23.1% | 31.8% | 146 |

**Table 16** **Presence and nature of government benefits** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| No benefits provided | 22.6% | 33 | 50.0% | 21.4% | 7.4% | 2.9% | 146 |
| Disability pension | 56.2% | 82 | 33.3% | 45.2% | 70.4% | 85.7% | 146 |
| Health security | 43.2% | 63 | 19.0% | 35.7% | 44.4% | 80.0% | 146 |
| Social security | 44.5% | 65 | 11.9% | 35.7% | 55.6% | 85.7% | 146 |
| Subsidies for food, housing, medication, or transportation | 48.6% | 71 | 28.6% | 42.9% | 48.1% | 80.0% | 146 |
| Direct payment of money for a specific purpose | 34.9% | 51 | 16.7% | 26.2% | 48.1% | 57.1% | 146 |
| Fiscal or tax benefits | 30.8% | 45 | 14.3% | 26.2% | 33.3% | 54.3% | 146 |

**Map 11** Presence of disability pension




When government benefits were provided, coverage varied greatly from one country to another. 39.0% of participating countries had high access to such benefits (i.e. more than 75% of entitled individuals or families received some form of governmental benefits). However, the same proportion of countries was classed as low access (i.e. less than 10% of eligible individuals or families received any form of governmental benefits. Countries with low access were mostly located in South-East Asia (80%) and in Africa (78.3%). These countries were mainly low income (74.2%); by contrast, 84.8% of high-income countries and 75.6% of European countries had high access to benefits.

**Table 17** **Access to government benefits** (percentages of countries by WHO regions)

| | World | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|
| <10% | 39.0% | 78.3% | 57.1% | 80.0% | 2.4% | 50.0% | 33.3% | 46 |
| 11–25% | 4.2% | 4.3% | 4.8% | 0% | 2.4% | 20.0% | 0% | 5 |
| 26–50% | 7.6% | 4.3% | 9.5% | 20.0% | 2.4% | 10.0% | 16.7% | 9 |
| 51–74% | 10.2% | 8.7% | 9.5% | 0% | 17.1% | 0% | 5.6% | 12 |
| >75% | 39.0% | 4.3% | 19.0% | 0% | 75.6% | 20.0% | 44.4% | 46 |

**Table 18** **Access to government benefits** (percentages of countries by income categories)

| | World | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|
| <10% | 39.0% | 74.2% | 46.9% | 31.8% | 3.0% | 46 |
| 11–25% | 4.2% | 3.2% | 9.4% | 4.5% | 0.0% | 5 |
| 26–50% | 7.6% | 12.9% | 9.4% | 0.0% | 6.1% | 9 |
| 51–74% | 10.2% | 0.0% | 9.4% | 31.8% | 6.1% | 12 |
| >75% | 39.0% | 9.7% | 25.0% | 31.8% | 84.8% | 46 |

**Figure 14** **High access (>75%) to government benefits** (percentages of countries by WHO regions)

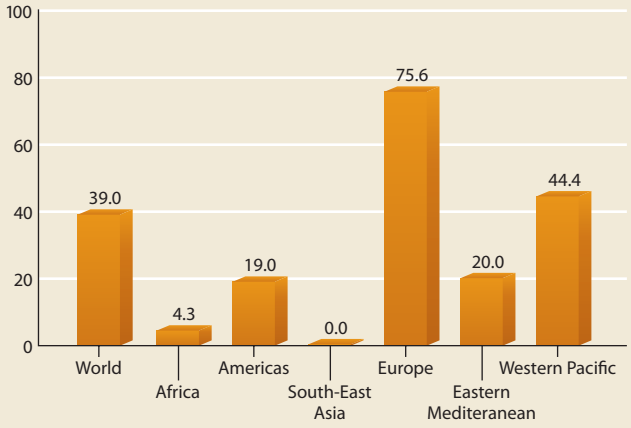
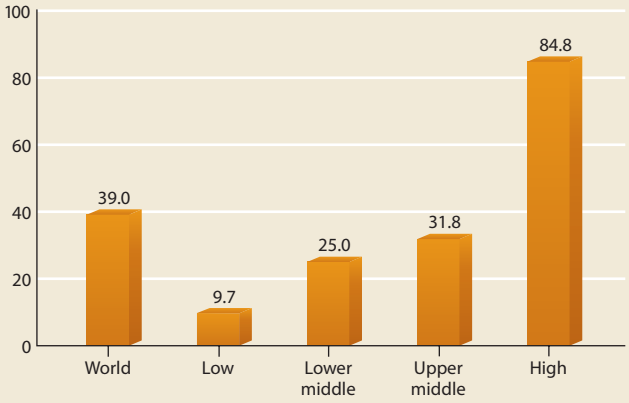



**Figure 15** **High access (>75%) to government benefits** (percentages of countries by income categories)




## Services for children, adolescents, and adults

**Human rights are indivisible, universal, interdependent and inter-connected. Therefore, the right to the highest possible level of physical and mental health and well being is inter-connected with other civil, political, economic, social, and cultural rights and fundamental freedoms. For persons with intellectual disabilities, as for other persons, the exercise of the right to health requires full social inclusion, an adequate standard of living, access to inclusive education, access to work justly compensated and access to community services.**

(Montreal Declaration on Intellectual Disabilities, 2004, article 4)

In a survey of provision of services, one must deal with the overall model of organization of services in the countries under study. The task can become very complex in terms of data collection in countries under federal jurisdictions, where services are provided by regions, states, provinces, or autonomous communities (e.g. western and northern European countries, Canada, Spain, USA), or in countries where services are greatly decentralized and administered at the municipal level (e.g. Brazil, Sweden). In these cases, the respondent for the country had to establish a sort of trend, average, or standard.

This section first summarises the organization of services in the participating countries. It is followed by a description of available services for adults, children, and adolescents. These services have been categorized in large sectors. One must remember that these results are particularly affected by bias caused by the use of discrete data. In considering these results, one must balance mere availability of services (which can be minimal) with territorial coverage and socio-cultural and economic accessibility.

## Organization of services

For most (58.4%) of the countries that responded, the responsibility for services for persons with intellectual disabilities was shared between levels of government, irrespective of country income level. In South-East Asia and the Eastern Mediterranean, the most common pattern of organization of services was at the national level (60.0% and 50.0% of countries, respectively).

The survey indicated that services for persons with intellectual disabilities were provided across at least four co-existing modalities: together with services for the general population (86.2%), with mental health services (81.3%), with disability services (84.5%), and services specific for persons with an intellectual disabilities (72.0%). This diversity was not affected by WHO region or level of income.

**Figure 16** **Level of government that was responsible for services** (percentages of countries by WHO regions)

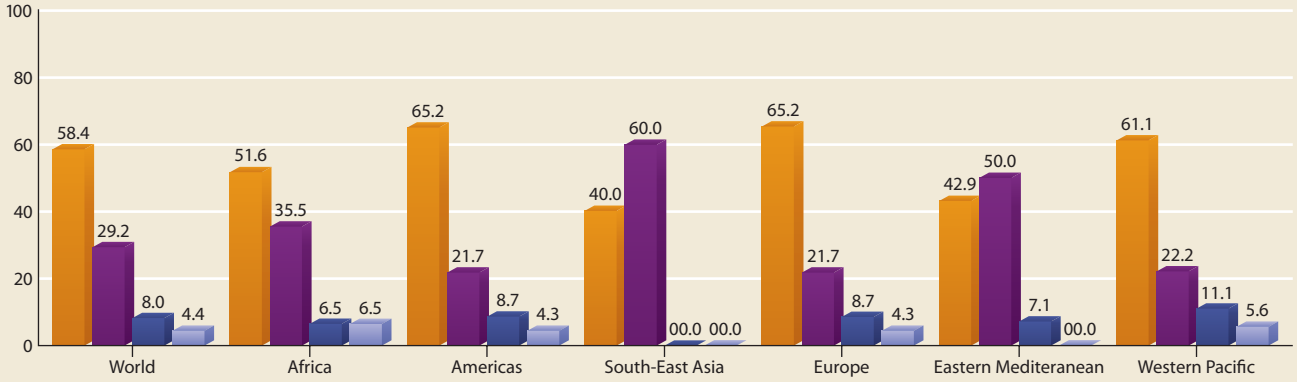
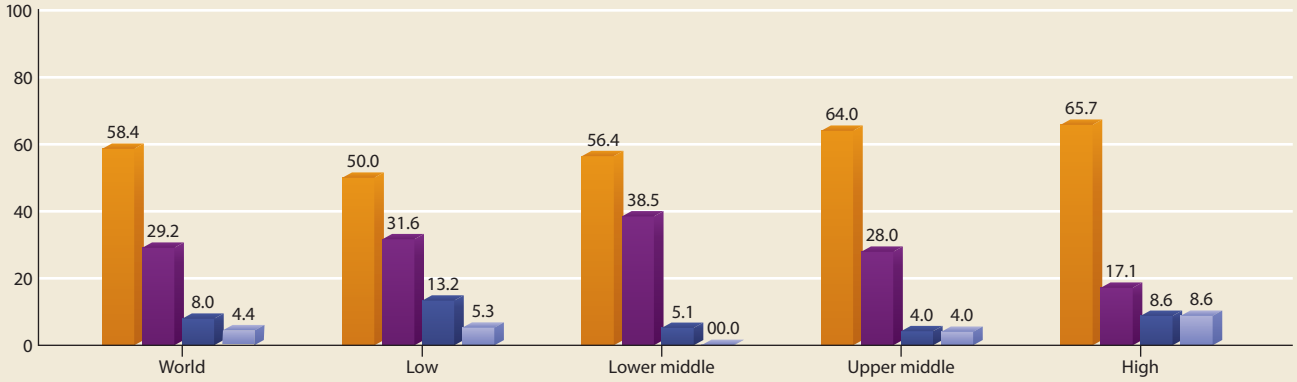



**Figure 17** **Level of government that was responsible for services** (percentages of countries by income categories)



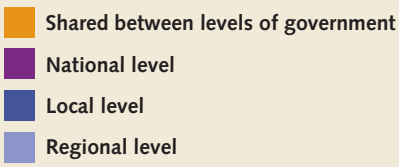



**Figure 18** **Organization of services** (percentages of countries by WHO regions)

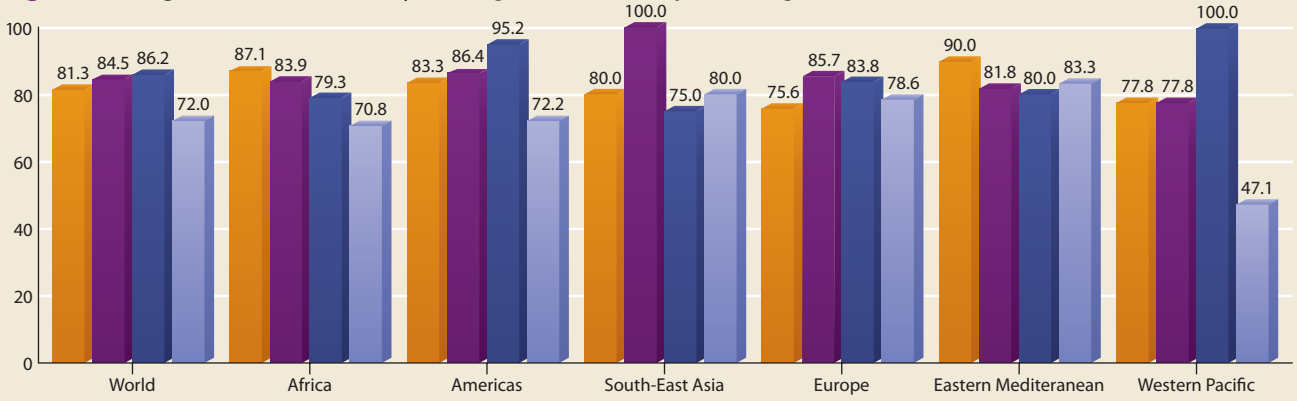
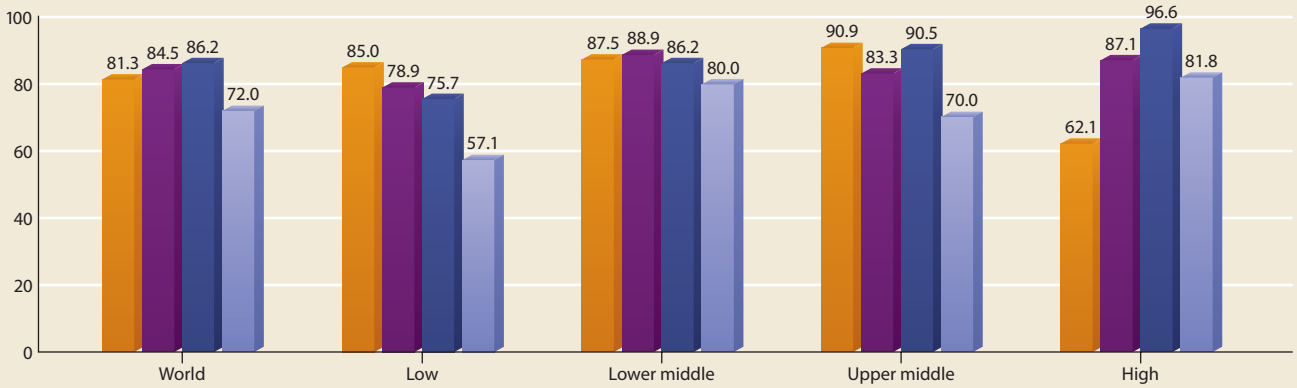



**Figure 19** **Organization of services** (percentages of countries by income categories)




**Together with services for persons with mental disorder**

**Together with services for persons with any kind of disability**

**Together with services for general population**

**Specific services for persons with intellectual disability**

## Specific services

Specific services can be offered in institutional settings or in the community. Institutions are big facilities where all services are provided within the same setting, including a place to live, work, activities during the day, and medical and psychiatric care. Community-based residential services can take many forms, from nursing homes to support for independent living. The past decades have witnessed a movement from a complete reliance on institutions to community-based services.

This survey revealed that asylum-type institutions were present in half the participating countries: these institutions were devoted to children and adolescents (in 50.7% of the countries) or to adults (in 55.9% of the countries). Institutions for children and adolescents were more common in the Eastern Mediterranean (83.3%), Europe (71.4%), and the Americas (52.9%) than they were in South-East Asia (25.0%), Africa (16.7%), and the Western Pacific (8.3%). Institutions for adults were present in all WHO regions (Europe, 71.4%; Eastern Mediterranean, 66.7%; the Americas, 64.3%; Africa, 33.3%; South-East Asia, 25.0%; and Western Pacific, 20.0%). Asylum-type institutions for children and adolescents were less common in low-income countries (33.3%) than in countries with an upper middle level of income (64.7%). The lowest rates of asylum-type institutions for adults with intellectual disabilities were seen in low-income countries (50%) and high-income countries (47.1%). Higher rates were seen in the upper middle income (68.8%) and the lower-middle income (57.1%) categories.

Of the community-based services, foster homes and group homes were the most common (51.4% and 50.9%, respectively) for children and adolescents. Nursing homes (53.1%), group homes (52.3%), and support for independent living (51.4%) were the most widespread for adults. All types of community-based facilities for children, adolescents, and adults were prevalent in high-income countries. The availability of these services increased with level of income.

**Table 19** **Residential services for children and adolescents** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Support to independent living * | 33.9% | 38 | 29.2% | 42.1% | 60.0% | 37.8% | 14.3% | 25.0% | 112 |
| Foster homes | 51.4% | 57 | 26.1% | 63.2% | 25.0% | 69.2% | 28.6% | 47.4% | 111 |
| Group homes | 50.9% | 54 | 40.9% | 45.0% | 60.0% | 73.5% | 14.3% | 38.9% | 106 |
| Nursing homes | 41.3% | 38 | 26.7% | 29.4% | 0% | 62.5% | 42.9% | 33.3% | 92 |
| Asylum-type institutions | 50.7% | 37 | 16.7% | 52.9% | 25.0% | 71.4% | 83.3% | 8.3% | 73 |

** Support to independent living for children and adolescents refers to children adolescent who lived with families and received support from services.*

**Table 20** **Residential services for children and adolescents** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Support to independent living * | 33.9% | 38 | 28.1% | 19.2% | 27.3% | 56.3% | 112 |
| Foster homes | 51.4% | 57 | 29.0% | 41.4% | 47.6% | 86.7% | 111 |
| Group homes | 50.9% | 54 | 36.7% | 33.3% | 42.9% | 83.9% | 106 |
| Nursing homes | 41.3% | 38 | 20.0% | 36.0% | 50.0% | 55.6% | 92 |
| Asylum-type institutions | 50.7% | 37 | 33.3% | 52.2% | 64.7% | 50.0% | 73 |

** Support to independent living for children and adolescents refers to children adolescent who lived with families and received support from services.*

**Table 21** **Residential services for adults** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Support to independent living * | 51.4% | 57 | 28.6% | 57.9% | 60.0% | 65.9% | 16.7% | 47.4% | 111 |
| Foster homes | 34.0% | 33 | 10.0% | 44.4% | 20.0% | 51.5% | 0% | 31.3% | 97 |
| Group homes | 52.3% | 57 | 19.0% | 52.6% | 60.0% | 76.9% | 25.0% | 47.1% | 109 |
| Nursing homes | 53.1% | 51 | 37.5% | 53.3% | 20.0% | 68.6% | 50.0% | 47.1% | 96 |
| Asylum-type institutions | 55.9% | 38 | 33.3% | 64.3% | 25.0% | 71.4% | 66.7% | 20.0% | 68 |

** Support to independent living for children and adolescents refers to children adolescent who lived with families and received support from services.*

**Table 22** **Residential services for adults** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Support to independent living * | 51.4% | 57 | 34.5% | 30.8% | 45.5% | 85.3% | 111 |
| Foster homes | 34.0% | 33 | 14.3% | 20.8% | 29.4% | 67.9% | 97 |
| Group homes | 52.3% | 57 | 21.4% | 40.7% | 50.0% | 88.2% | 109 |
| Nursing homes | 53.1% | 51 | 31.8% | 44.0% | 61.1% | 71.0% | 96 |
| Asylum-type institutions | 55.9% | 38 | 50.0% | 57.1% | 68.8% | 47.1% | 68 |

** Support to independent living for children and adolescents refers to children adolescent who lived with families and received support from services.*

## Health services

Health services include inpatient care, primary care, specialized services, and physical rehabilitation. From the survey data, these four types of health-care services were available for children, adolescents, and adults in most of the participating countries (range 71.4–87.9%). The percentages were greatest in high-income countries (80–90%) and lowest in low-income countries (60–70%). Primary health care was available in more than 85% of countries, except for low-income countries (75.0% for children and adolescents and 70.3% for adults). The availability of health services tended to increase with income level.

We observed some disparities between regions. Specialized services for children and adolescents were available in fewer countries in the Western Pacific (63.2%) and in Africa (65.5%) than they were in other regions. The same services were less available for adults in South-East Asia (50.0%), in the Western Pacific (61.1%), and in Africa (60.7%) than in other WHO regions. Although countries in all WHO regions offered physical rehabilitation for adults with intellectual disabilities, this service was somewhat more common in high-income countries than in low-income countries.

**Table 23** **Health services for children and adolescents** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Inpatient health services | 71.4% | 90 | 58.6% | 72.7% | 60.0% | 87.5% | 72.7% | 57.9% | 126 |
| Primary health care | 87.9% | 116 | 75.9% | 87.0% | 100% | 95.5% | 90.9% | 85.0% | 132 |
| Specialized health services | 76.4% | 97 | 65.5% | 72.7% | 80.0% | 90.7% | 77.8% | 63.2% | 127 |
| Physical Rehabilitation | 84.1% | 111 | 82.8% | 91.3% | 80.0% | 88.1% | 92.3% | 65.0% | 132 |

**Table 24** **Health services for children and adolescents** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Inpatient health services | 71.4% | 90 | 56.8% | 67.6% | 82.6% | 84.4% | 126 |
| Primary health care | 87.9% | 116 | 75.0% | 86.8% | 95.8% | 97.1% | 132 |
| Specialized health services | 76.4% | 97 | 63.9% | 76.5% | 75.0% | 90.9% | 127 |
| Physical rehabilitation | 84.1% | 111 | 73.7% | 89.7% | 87.0% | 87.5% | 132 |

**Table 25** **Health services for adults** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Inpatient health services | 75.0% | 90 | 63.0% | 86.4% | 40.0% | 89.7% | 70.0% | 58.8% | 120 |
| Primary health care | 85.5% | 112 | 70.0% | 95.5% | 80.0% | 93.2% | 80.0% | 85.0% | 131 |
| Specialized health services | 73.2% | 93 | 60.7% | 81.8% | 50.0% | 83.7% | 80.0% | 60.0% | 127 |
| Physical rehabilitation | 76.6% | 95 | 64.0% | 82.6% | 80.0% | 84.6% | 84.6% | 63.2% | 124 |

**Table 26** **Health services for adults** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Inpatient health services | 75.0% | 90 | 64.7% | 70.6% | 86.4% | 83.3% | 120 |
| Primary health care | 85.5% | 112 | 70.3% | 88.9% | 95.7% | 91.4% | 131 |
| Specialized health services | 73.2% | 93 | 60.0% | 75.8% | 70.8% | 85.7% | 127 |
| Physical rehabilitation | 76.6% | 95 | 60.6% | 75.0% | 82.6% | 90.6% | 124 |

## Services specific to intellectual disabilities

This section encompasses services offered specifically to persons with intellectual disabilities. Between 41.8% and 82.7% of respondents indicated that services related to intellectual disabilities (i.e. screening, assessment, and orientation; early intervention; individual support or case management; psychological and psychiatric interventions; psychosocial rehabilitation; and day activities) were available for children, adolescents, and adults. Services for children and adolescents that were offered in 65% of countries or fewer included: screening, assessment, and orientation in lower middle-income countries (63.6%) and Eastern Mediterranean (60.0%) countries; early intervention in low-income countries (62.5%), lower middle income countries (65.6%), and in Africa (56.0%); individual support or case management in low-income countries (65.6%), lower middle-income countries (57.1%), in Africa (61.5%), and in the Americas (65.0%); psychosocial rehabilitation in the Western Pacific (57.9%); and day activities in lower middle income countries (65.7%), the Americas (59.1%), and the Western Pacific (60.0%).

**Table 27** **Intellectual disabilities services for children and adolescents** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Screening, assessment, or orientation | 82.7% | 105 | 86.2% | 86.4% | 80.0% | 85.0% | 60.0% | 81.0% | 127 |
| Early intervention | 75.4% | 92 | 56.0% | 71.4% | 100% | 85.7% | 77.8% | 75.0% | 122 |
| Individual support or case management | 71.1% | 81 | 61.5% | 65.0% | 80.0% | 75.0% | 71.4% | 80.0% | 114 |
| Specialized psychological or psychiatric interventions | 79.2% | 99 | 73.3% | 82.6% | 75.0% | 83.8% | 83.3% | 73.7% | 125 |
| Psycho-social rehabilitation | 78.9% | 101 | 86.2% | 75.0% | 80.0% | 82.1% | 91.7% | 57.9% | 128 |
| Day centre or hospital | 72.6% | 90 | 72.0% | 59.1% | 80.0% | 80.5% | 90.9% | 60.0% | 124 |

**Table 28** **Intellectual disabilities services for children and adolescents** (percentages of countries by income categories)

| | World | | Low-income | Lower-middle income | Upper-middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Screening, assessment, or orientation | 82.7% | 105 | 83.3% | 63.6% | 91.3% | 94.3% | 127 |
| Early intervention | 75.4% | 92 | 62.5% | 65.6% | 78.3% | 94.3% | 122 |
| Individual support or case management | 71.1% | 81 | 65.6% | 57.1% | 68.2% | 90.6% | 114 |
| Specialized psychological or psychiatric interventions | 79.2% | 99 | 69.4% | 81.3% | 82.6% | 85.3% | 125 |
| Psychosocial rehabilitation | 78.9% | 101 | 83.3% | 74.4% | 72.7% | 83.9% | 128 |
| Day centre or hospital | 72.6% | 90 | 67.6% | 65.7% | 78.3% | 81.3% | 124 |

A gap was noted between high-income countries and other country income categories for all types of adult services. These services were available in more than 75% of high-income countries, but ranged from 48.4% to 83.9% in countries from other income categories. Many variations were observed in the availability of different types of services according to WHO regions; almost all types of services were offered in a lesser proportion of countries in Africa than in other regions.

**Table 29** **Intellectual disabilities services for adults** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Screening, assessment, or orientation | 69.4% | 77 | 68.0% | 80.0% | 60.0% | 70.6% | 50.0% | 68.4% | 111 |
| Individual support or case management | 68.6% | 72 | 64.0% | 72.2% | 75.0% | 67.6% | 50.0% | 77.8% | 105 |
| Specialized psychological or psychiatric interventions | 79.7% | 94 | 83.3% | 90.9% | 50.0% | 80.0% | 72.7% | 70.6% | 118 |
| Psychosocial rehabilitation | 76.4% | 97 | 63.0% | 83.3% | 80.0% | 85.4% | 75.0% | 66.7% | 127 |
| Day centre | 70.8% | 85 | 47.8% | 57.1% | 80.0% | 95.2% | 70.0% | 57.9% | 120 |

**Table 30** **Intellectual disabilities services for adults** (percentages of countries by income categories)

| | World | | Low Income | Lower middle Income | Upper middle Income | High Income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Screening, assessment, or orientation | 69.4% | 77 | 71.9% | 52.0% | 68.2% | 81.3% | 111 |
| Individual support or case management | 68.6% | 72 | 66.7% | 56.5% | 63.6% | 83.3% | 105 |
| Specialized psychological or psychiatric interventions | 79.7% | 94 | 76.7% | 83.9% | 83.3% | 75.8% | 118 |
| Psychosocial rehabilitation | 76.4% | 97 | 69.7% | 68.4% | 78.3% | 90.9% | 127 |
| Day centre | 70.8% | 85 | 48.4% | 66.7% | 72.7% | 94.1% | 120 |

## Education

Since 1994, UNESCO has promoted the principle of inclusive education for children with special needs (Salamanca statement) (UNESCO, 1994; 1996/1997; 1999). According to this approach, children and adolescents with intellectual disabilities should attend regular school classes and activities with those without intellectual disabilities However, different types of education systems for children and adolescents with intellectual disabilities now co-exist – i.e. kindergartens (segregated or inclusive), special schools, special classes in regular schools, support in regular classes, and homebound services.

**"Research indicates that facilities for early childhood education that could have served as the foundation for the implementation of [inclusive education] programmes for children with disabilities in many [developing countries] are non existent. […] Regular schools with inclusive orientation have been considered the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all."**

(Eleweke & Rodda, 2002)

The findings showed the coexistence of segregated and inclusive education worldwide: 91.3% of countries have special schools for children with intellectual disabilities; 76.3% have special classes for these children; and in 70.9% they are supported in regular classes. In all regions and groups of countries according to income levels, proportions of countries with special schools and special classes for children with intellectual disabilities were higher than those in which children were integrated in regular classes. The only exception was the Western Pacific, where integration in regular classes was available in 75% of the countries. Homebound services were available in less than 50% of countries, and mainly in South-East Asia (80.0%), Europe (68.4%), and the Americas (60.0%).

**Table 31** **Educational opportunities for children and adolescents** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Special schools | 91.3% | 126 | 87.1% | 100% | 100% | 97.8% | 100% | 68.2% | 138 |
| Special class in regular or integrated school | 76.3% | 100 | 67.9% | 85.0% | 80.0% | 84.4% | 58.3% | 71.4% | 131 |
| Support in regular class | 70.9% | 90 | 61.5% | 81.0% | 60.0% | 75.6% | 50.0% | 75.0% | 127 |
| Homebound services | 49.5% | 54 | 38.1% | 60.0% | 80.0% | 68.4% | 0% | 22.2% | 109 |
| Preschool or kindergarten | 75.0% | 90 | 56.5% | 76.5% | 100% | 88.9% | 63.6% | 65.0% | 120 |

**Table 32** **Educational opportunities for children and adolescents** (percentages of countries by income categories)

| | World | | Low Income | Lower middle Income | Upper middle Income | High Income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Special schools | 91.3% | 126 | 82.1% | 94.9% | 96.0% | 94.3% | 138 |
| Special class in regular or integrated school | 76.3% | 100 | 59.5% | 77.1% | 83.3% | 88.6% | 131 |
| Support in regular class | 70.9% | 90 | 50.0% | 69.7% | 78.3% | 88.6% | 127 |
| Homebound services | 49.5% | 54 | 38.7% | 50.0% | 55.0% | 56.7% | 109 |
| Preschool or kindergarten | 75.0% | 90 | 46.9% | 74.2% | 81.8% | 97.1% | 120 |

The data suggested that adult-education programmes and professional training were scarce. 49.5% of the participating countries provided adult-education programmes, 47.2% literacy programmes, and 66.1% professional-training programmes. Level of income affected the availability of all programmes. The proportions of low-income countries that offered adult-education programmes, literacy programmes, and professional-training programmes (29.6%, 21.4%, and 48.1%, respectively) differed widely from the proportions of high-income countries that did so (84.4%, 71.0%, and 93.9%, respectively).

**Table 33** **Educational opportunities for adults** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Literacy programme | 47.2% | 50 | 27.3% | 55.6% | 75.0% | 54.5% | 50.0% | 42.9% | 106 |
| Adult education programme | 49.5% | 53 | 33.3% | 50.0% | 50.0% | 69.4% | 37.5% | 35.0% | 107 |
| Professional training | 66.1% | 76 | 45.0% | 66.7% | 80.0% | 82.5% | 77.8% | 45.0% | 115 |

**Table 34** **Educational opportunities for adults** (percentages of countries by income categories)

| | World | | Low Income | Lower middle Income | Upper middle Income | High Income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Literacy programme | 47.2% | 50 | 21.4% | 41.4% | 55.6% | 71.0% | 106 |
| Adult education programme | 49.5% | 53 | 29.6% | 32.3% | 47.1% | 84.4% | 107 |
| Professional training | 66.1% | 76 | 48.1% | 55.9% | 61.9% | 93.9% | 115 |

## Work

Occupational, vocational, and work services include assessment and enhancement of work-related skills, attitudes and behaviours, job finding and development, and provision of job experience. Although programmes aimed at development of work skills, sheltered employment, and supported employment were available in most countries (66.1%, 66.9%, and 63% of countries, respectively), respondents indicated that work stations were less available than were other services (44.4%). Work stations are integrated enclaves within industry that allow persons with intellectual disabilities to work with crews that do not have disabilities. These work stations were scarce in the Eastern Mediterranean (33.3%) and Africa (18.2%), somewhat present in the Western Pacific (45%), Europe (55.9%), and the Americas (52.4%), and were most widespread in South-East Asia (60%). The types of available services increased with countries' levels of income.

**Table 35** **Occupational, vocational, or work services** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Sheltered employment | 66.9% | 83 | 29.2% | 81.8% | 60.0% | 86.4% | 62.5% | 57.1% | 124 |
| Work stations | 44.4% | 48 | 18.2% | 52.4% | 60.0% | 55.9% | 33.3% | 45.0% | 108 |
| Supported employment | 63.0% | 75 | 39.1% | 61.9% | 60.0% | 77.5% | 60.0% | 65.0% | 119 |
| General work skills, training, or development | 66.1% | 76 | 47.8% | 61.9% | 80.0% | 77.8% | 80.0% | 60.0% | 115 |

**Table 36** **Occupational, vocational, or work services** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Sheltered employment | 66.9% | 83 | 16.1% | 72.2% | 84.0% | 96.9% | 124 |
| Work stations | 44.4% | 48 | 19.4% | 40.7% | 36.8% | 77.4% | 108 |
| Supported employment | 63.0% | 75 | 29.0% | 56.3% | 65.2% | 100.0% | 119 |
| General work skills, training, or development | 66.1% | 76 | 35.5% | 53.3% | 76.2% | 100.0% | 115 |

## Other services

Respondents were asked about the availability of services other than those in the specified categories, such as leisure activities, transportation, assistive technology, rights and advocacy support, or supply of food and other basic necessities. The data showed that more than 70% of countries offered activities related to support for promotion of rights and advocacy for adults, children, and adolescents.

**Table 37** **Other types of services for children and adolescents** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Leisure activities | 73.4% | 91 | 72.4% | 81.0% | 60.0% | 82.1% | 66.7% | 57.1% | 124 |
| Transportation | 59.8% | 73 | 40.7% | 63.2% | 0% | 77.5% | 63.6% | 60.0% | 122 |
| Assistive technology | 54.4% | 62 | 34.8% | 55.0% | 40.0% | 73.0% | 50.0% | 47.4% | 114 |
| Rights or advocacy support | 73.3% | 88 | 70.4% | 68.2% | 80.0% | 86.8% | 80.0% | 50.0% | 120 |
| Supply of meal or food | 52.9% | 54 | 50.0% | 55.6% | 80.0% | 60.0% | 44.4% | 38.9% | 102 |

**Table 38** **Other types of services for children and adolescents** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Leisure activities | 73.4% | 91 | 55.6% | 67.7% | 68.2% | 100.0% | 124 |
| Transportation | 59.8% | 73 | 21.2% | 56.3% | 69.6% | 94.1% | 122 |
| Assistive technology | 54.4% | 62 | 25.8% | 41.4% | 52.4% | 93.9% | 114 |
| Rights or advocacy support | 73.3% | 88 | 61.8% | 66.7% | 75.0% | 93.1% | 120 |
| Supply of meal or food | 52.9% | 54 | 46.7% | 42.9% | 52.2% | 76.2% | 102 |

**Table 39** **Other types of services for adults** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Leisure activities | 68.1% | 79 | 43.5% | 81.0% | 25.0% | 78.4% | 60.0% | 76.2% | 116 |
| Transportation | 50.9% | 58 | 17.4% | 58.8% | 0% | 68.4% | 54.5% | 60.0% | 114 |
| Assistive technology | 49.6% | 56 | 22.7% | 52.4% | 40.0% | 73.0% | 40.0% | 38.9% | 113 |
| Rights or advocacy support | 74.2% | 89 | 66.7% | 73.9% | 60.0% | 84.6% | 80.0% | 63.2% | 120 |
| Supply of meal or food | 9.5% | 50 | 26.3% | 57.1% | 60.0% | 58.1% | 57.1% | 44.4% | 101 |

**Table 40** **Other types of services for adults** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Leisure activities | 68.1% | 79 | 32.3% | 60.7% | 77.3% | 100.0% | 116 |
| Transportation | 50.9% | 58 | 10.0% | 37.9% | 57.1% | 94.1% | 114 |
| Assistive technology | 49.6% | 56 | 16.7% | 25.0% | 59.1% | 93.9% | 113 |
| Rights or advocacy support | 74.2% | 89 | 59.4% | 63.6% | 78.3% | 96.9% | 120 |
| Supply of meal or food | 49.5% | 50 | 30.8% | 40.7% | 47.8% | 80.0% | 101 |

## Services to families

Families play a crucial part in support for adults, children, and adolescents with intellectual disabilities. More often that not, theirs is the only type of support available (Inclusion International, 2006). The data suggested that the services most available across regions and income levels were psychological support and counselling (in 73.5% of the participating countries), education about intellectual disabilities (66.7%), and support for rights and advocacy (57.1%). Respite care (in 29.9% of participating countries) and home aid (44.2%), provide periodic relief to family members and friends who care for persons with intellectual disabilities; these services were most commonly available only in high-income countries (in 74.3% and 85.7% of high-income countries, respectively).

**Table 41** **Services to families of persons with intellectual disabilities** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Psychological support or counselling | 73.5% | 108 | 60.0% | 72.0% | 80.0% | 87.2% | 69.2% | 68.2% | 147 |
| Education about intellectual disabilities | 66.7% | 98 | 42.9% | 68.0% | 80.0% | 80.9% | 76.9% | 63.6% | 147 |
| Respite care | 29.9% | 44 | 14.3% | 12.0% | 20.0% | 55.3% | 15.4% | 31.8% | 147 |
| Home aid | 44.2% | 65 | 31.4% | 28.0% | 40.0% | 61.7% | 38.5% | 50.0% | 147 |
| Rights or advocacy support | 57.1% | 84 | 40.0% | 56.0% | 20.0% | 72.3% | 61.5% | 59.1% | 147 |

**Table 42** **Services to families of persons with intellectual disabilities** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Psychological support or counselling | 73.5% | 108 | 60.5% | 61.9% | 81.5% | 97.1% | 147 |
| Education about intellectual disabilities | 66.7% | 98 | 46.5% | 59.5% | 74.1% | 94.3% | 147 |
| Respite care | 29.9% | 44 | 9.3% | 16.7% | 25.9% | 74.3% | 147 |
| Home aid | 44.2% | 65 | 27.9% | 28.6% | 40.7% | 85.7% | 147 |
| Rights or advocacy support | 49.5% | 50 | 30.8% | 40.7% | 47.8% | 80.0% | 147 |

## Factors that had an impact on access to services

The presence of services alone does not guarantee access to them. According to the respondents, in more than half of participating countries, three factors affected whether services could be accessed in a timely manner: location of patients in terms of urban versus rural settings (56.4%), geographical location (53.9%), and the socioeconomic status of the persons needing care (51.8%). Geographical factors (urban versus rural and territory) affected access to care in roughly the same proportion of countries, independently of their level of income (range 51.9–70.0%), with high-income countries as an exception (access was available in 32.4% of countries for both urban and rural locations and 28.6% for territories). Geographical location was especially important in South-East Asia affecting access to services in 80.0% of countries and in the Americas, where geographical location (75.0%) and the divide between urban and rural location (75.0%) were identified by the responding countries as barriers to access to services.

The effect of socioeconomic status on access to services was related to the level of income of countries. In low-income countries, respondents from 75% of countries indicated that socioeconomic status had a great effect on access to services; the situation was similar in 66.7% of lower-middle-income countries, compared with only 14.3% of high-income countries. Socioeconomic status had an effect on access to services in several countries in South-East Asia (80.0%), the Americas (79.2%), and Africa (78.1%), but on very few countries in Europe (20%).

Among other factors mentioned by respondents, ethnicity seemed to have more of an effect on access to services (in 14.3% countries) than did religion (5.8%). The countries in which ethnicity was the greatest barrier to access were generally in the Americas (25%), Africa (22.6%), and the Western Pacific (18.2%), as well as in upper middle-income countries (19.2%) and low-income countries (17.9%). Other factors that affected access to intellectual disabilities services in a timely manner were illiteracy, ignorance of the existence of services, language difficulties, sex, education of the parents, and the level of mobility of the person seeking these services, including their level of disability and the age of the person or their caregiver.

**Figure 20** **Factors that had an impact on access to services** (percentages of countries)

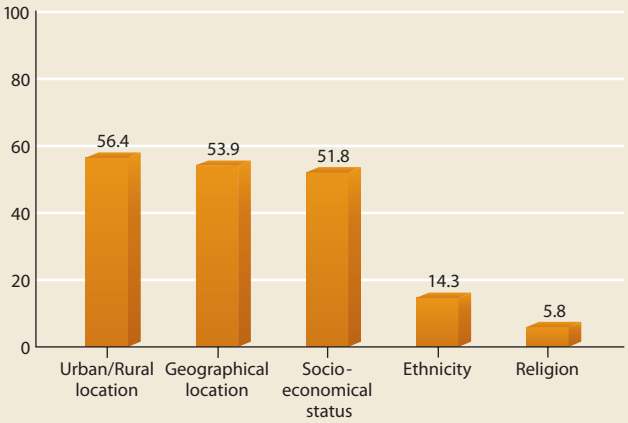


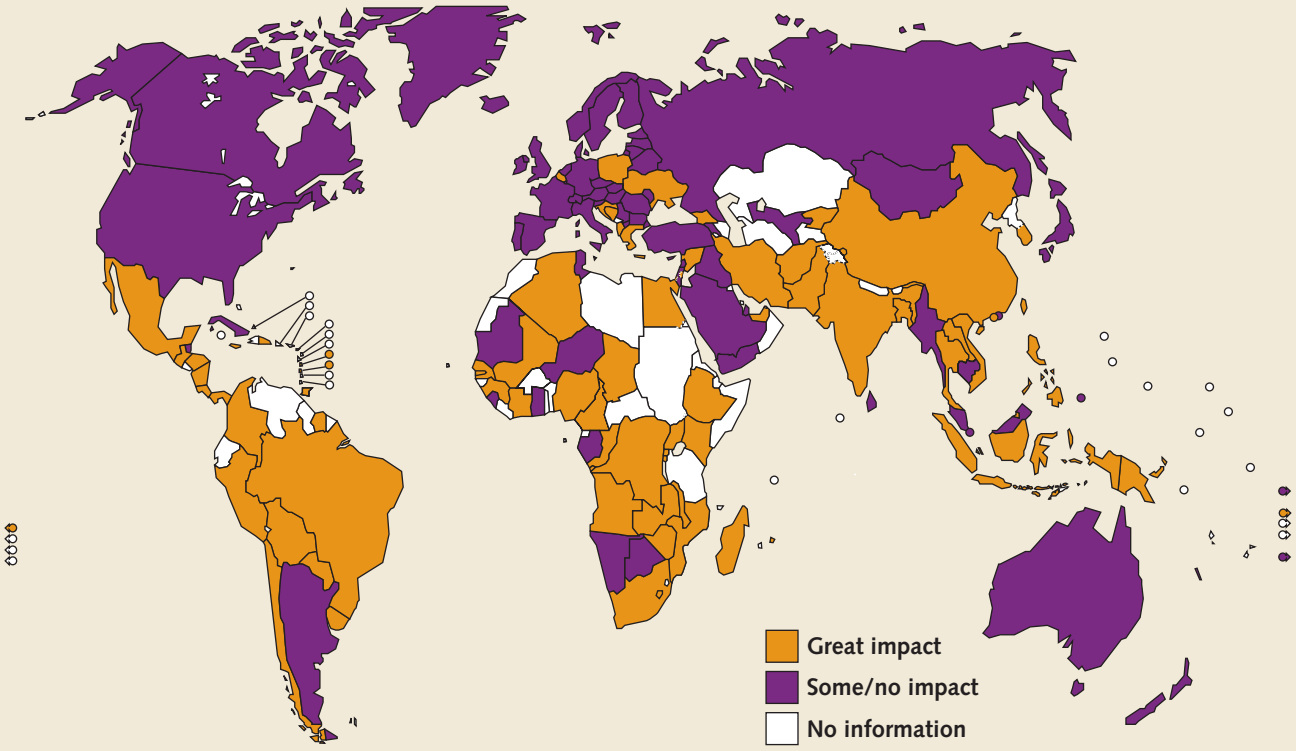
**Table 43** **Factors that had an impact on access to services** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Socioeconomic status | 51.8% | 73 | 78.1% | 79.2% | 80.0% | 20.0% | 53.8% | 40.9% | 141 |
| Geographical location | 53.9% | 76 | 64.5% | 75.0% | 80.0% | 45.7% | 46.2% | 31.8% | 141 |
| Urban or rural location | 56.4% | 79 | 65.6% | 75.0% | 60.0% | 44.4% | 61.5% | 42.9% | 140 |
| Ethnicity | 14.3% | 20 | 22.6% | 25.0% | 0% | 4.4% | 7.7% | 18.2% | 140 |
| Religion | 5.8% | 8 | 9.7% | 4.2% | 0% | 0% | 7.7% | 14.3% | 138 |

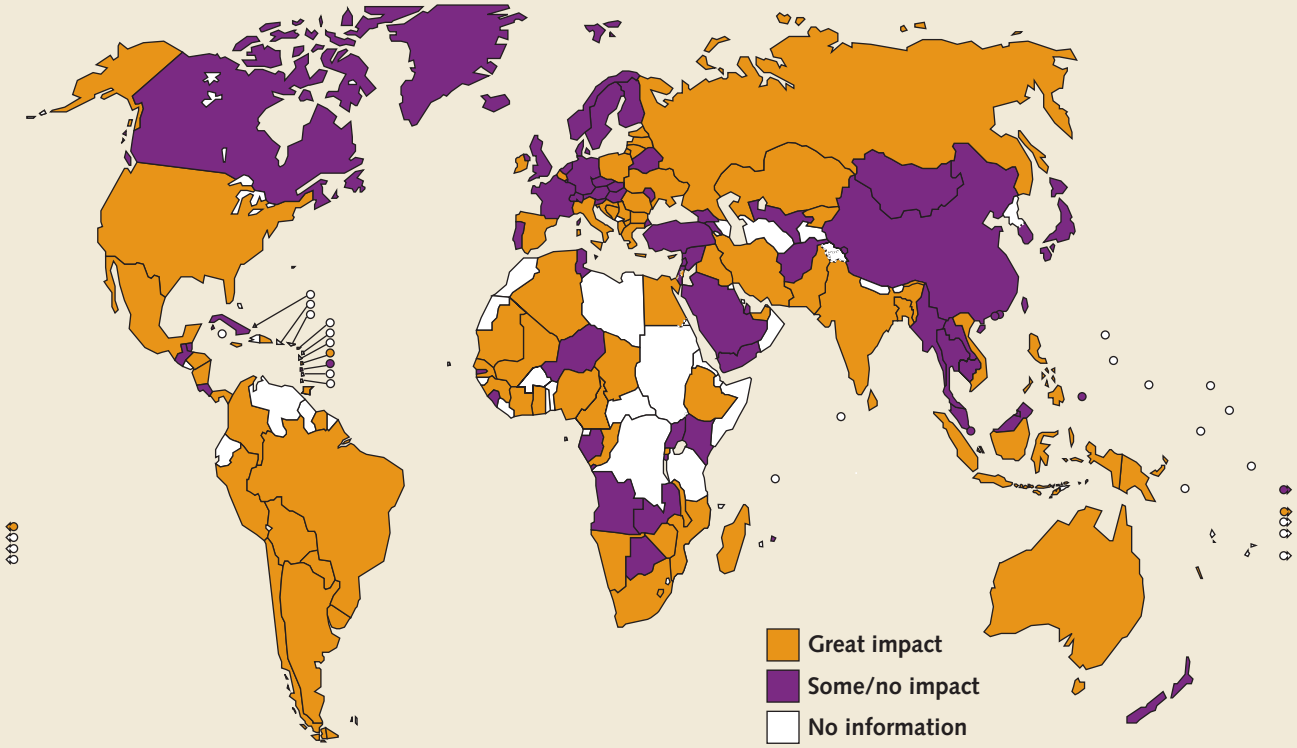
**Table 44** **Factors that had an impact on access to services** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Socioeconomic status | 51.8% | 73 | 75.0% | 66.7% | 44.4% | 14.3% | 141 |
| Geographical location | 53.9% | 76 | 61.5% | 70.0% | 51.9% | 28.6% | 141 |
| Urban or rural location | 56.4% | 79 | 65.0% | 67.5% | 57.7% | 32.4% | 140 |
| Ethnicity | 14.3% | 20 | 17.9% | 12.2% | 19.2% | 8.8% | 140 |
| Religion | 5.8% | 8 | 7.7% | 5.1% | 11.5% | 0.0% | 138 |

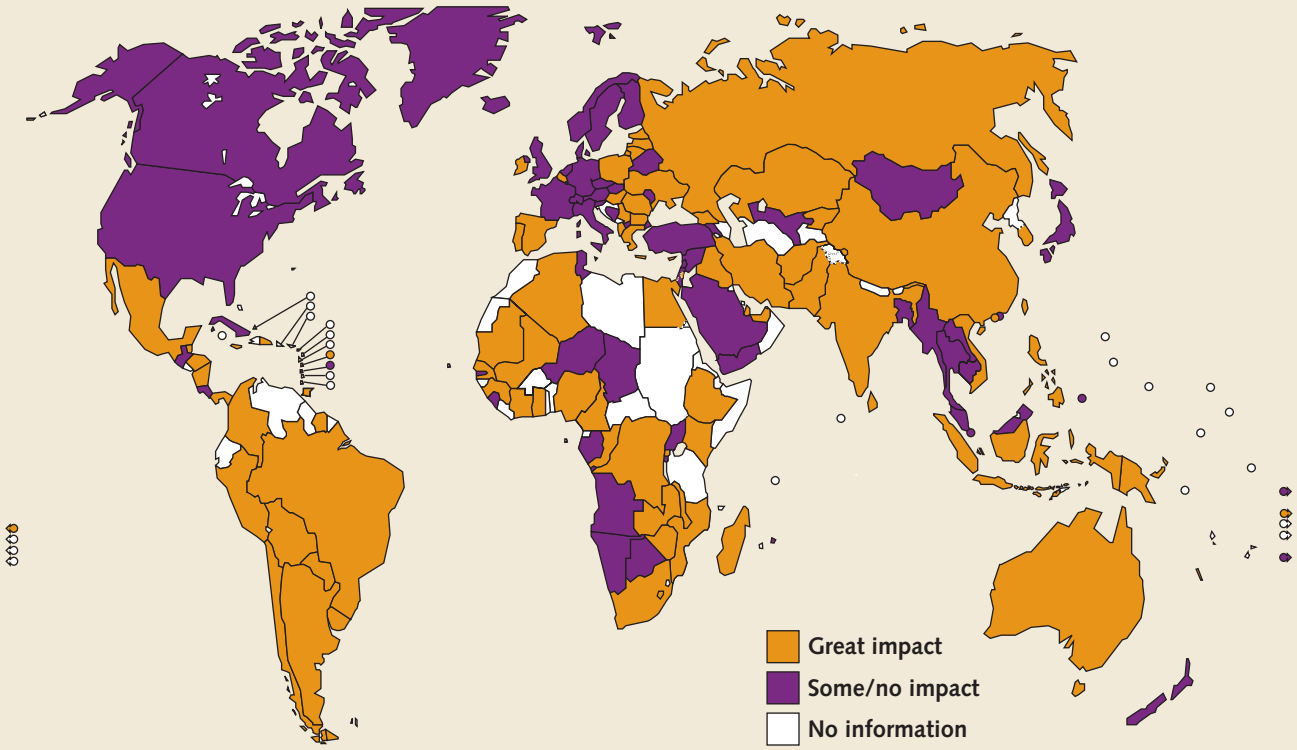
**Map 12** **Impact of socioeconomic status on access to services**



**Map 13** Impact of geographical location on access to services




**Map 14** Impact of urban or rural location on access to services



## Prevention

Although in 60% of cases of intellectual disabilities the causes are unknown, four categories of factors that can occur before, during, or after birth have been identified as etiological factors: genetic disorders, chromosomal disorders, biological and organic causes, and environmental causes. Actions can be undertaken to alleviate the effect of some of these factors. Respondents suggested that a substantial percentage of participating countries had implemented prevention strategies, across all income levels and WHO regions. These strategies included supplementation of diet by iodination of salts or folic acid in bread (in 67.1% of countries); programmes for prevention of alcohol or drug abuse during pregnancy (61.6%); genetic counselling and prenatal testing (61.0%); and tests to detect phenylketonuria, lead, or hypothyroidism (57.5%). These strategies were more common in high-income countries than in low-income countries.

**Figure 21** **Strategies to prevent intellectual disabilities** (percentages of countries by WHO regions)

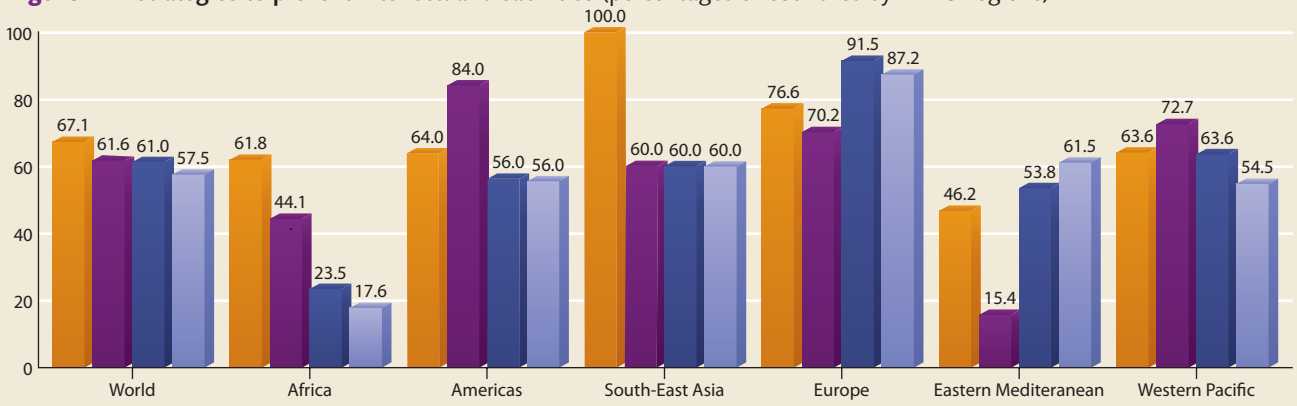
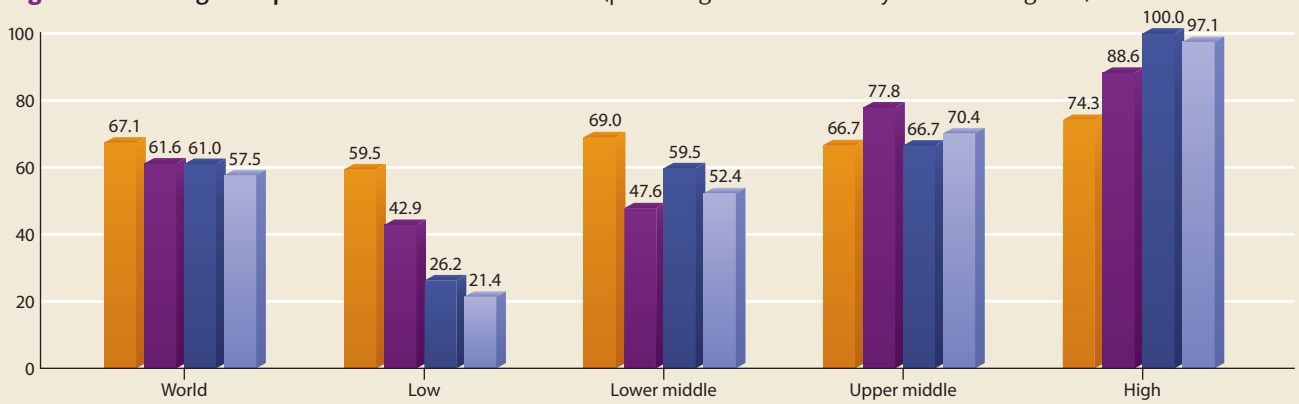



**Figure 22** **Strategies to prevent intellectual disabilities** (percentages of countries by income categories)




- Supplementation of diet
- Programmes on alcohol/drug abuse during pregnancy
- Genetic counseling and prenatal testing
- Tests to detect phenylketonuria, lead or hypothyroidism

**"Though many of the causes of developmental disabilities are understood and preventable, proven methods of prevention, such as early screening and intervention, nutritional interventions, immunization against rubella and other infections capable of causing developmental disabilities, and child safety programmes, are not being fully implemented in developing countries."**

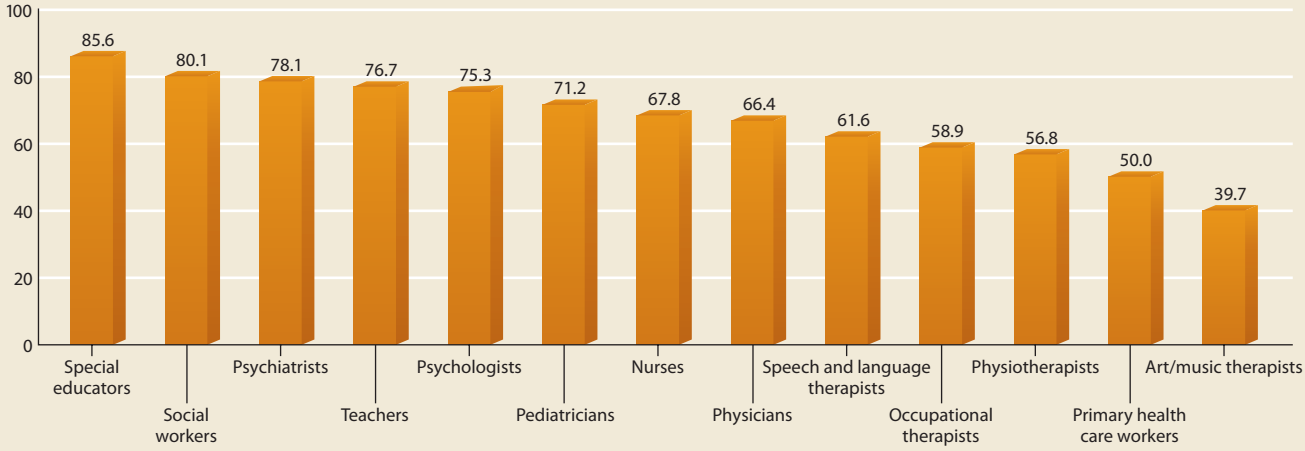
(Durkin, 2002)

## Professional service providers and standards of care

### Professional service providers

Data about professionals who were the most involved in working with persons with intellectual disabilities showed the very wide range of interventions and support that were offered to these persons. Although special educators were identified by the most respondents as the group most closely associated with persons with intellectual disabilities (85.6%), social workers (80.1%), psychiatrists (78.1%), teachers (76.7%), and psychologists (75.3%) were also mentioned, irrespective of income category or WHO region of the respondent.

**Figure 23** **Professionals involved in provision of services to persons with intellectual disabilities** (percentages of countries)




### Standards of care for professionals

Standards of care and practices are guidelines that establish minimum standards to ensure proper care and interventions for persons with intellectual disabilities. They provide a method for judging such practices and services, and improve their quality and appropriateness. 53.0% of respondents identified the presence of such standards in government organizations and 59.9% in private ones. We identified no differences between countries with different levels of income or from different WHO regions in terms of standards of care at the level of government organizations. However, the proportion of countries in which government and private organizations had standards of care varied from 36% to 76.9% in different WHO regions.

When asked how these standards were maintained, respondents indicated four principal strategies: in-service training (69.5%), use of clinical practice guidelines (61.1%), professional certification and maintenance of competency (58.9%), and clinical supervision of workers (57.9%). These results varied in different WHO regions: in-service training was the most commonly reported method of maintaining standards of care in Africa (77.3%), the Western Pacific (75.0%), Europe (73.0%), and South-East Asia (66.7%). Clinical practice guidelines were the method of choice in the Americas (85.7%), whereas clinical supervision was most often used in South-East Asia (100%). In Europe, professional certification and maintenance of competence were favoured (75.7%).

**Figure 24** **Presence of standards for professionals** (percentages of countries by WHO regions)

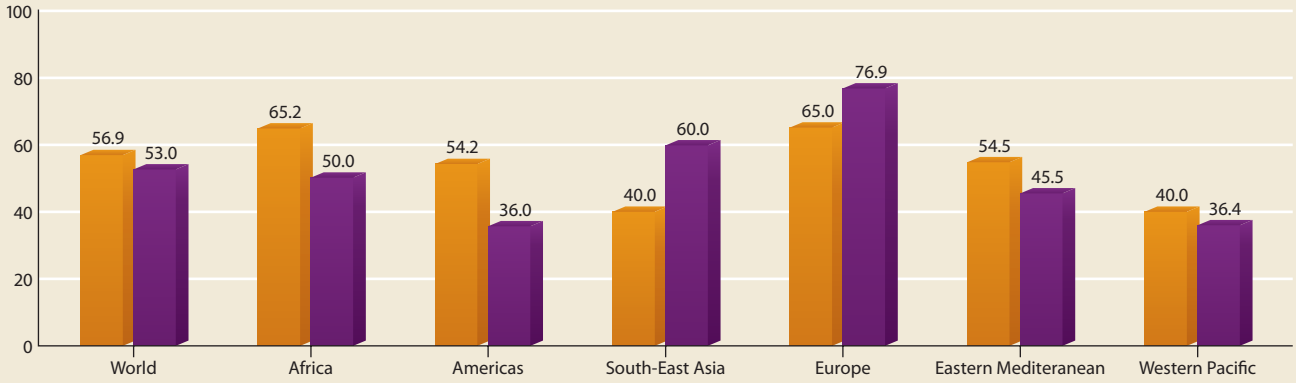



**Figure 25** **Presence of standards for professionals** (percentages of countries by income categories)

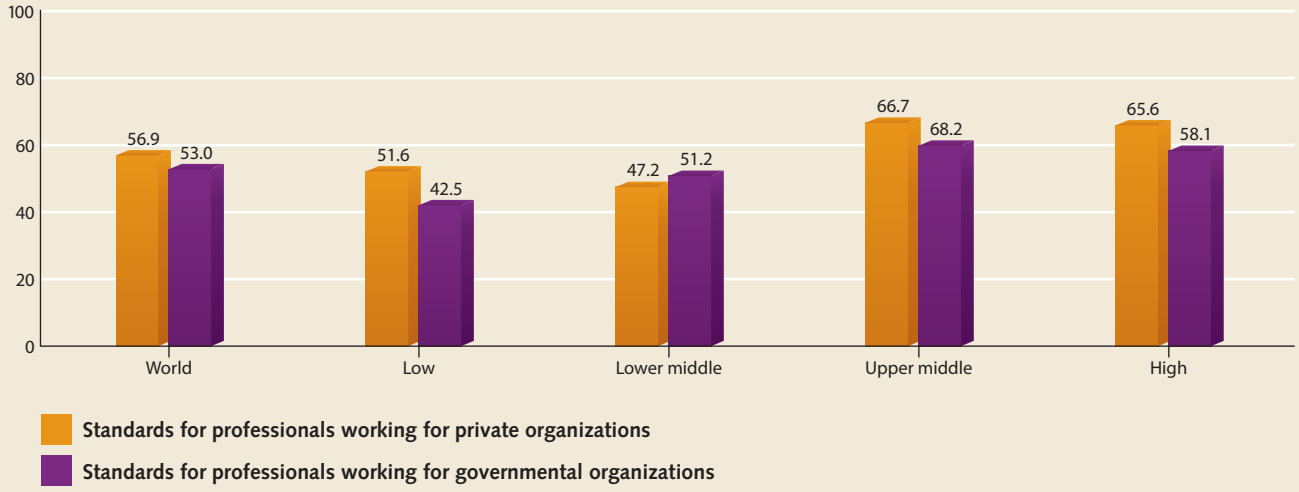



**Table 45** **Ways to maintain standards of care and practices** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Professional certification and maintenance of competency | 58.9% | 56 | 45.5% | 57.1% | 33.3% | 75.7% | 14.3% | 66.7% | 95 |
| In-service training | 69.5% | 66 | 77.3% | 64.3% | 66.7% | 73.0% | 28.6% | 75.0% | 95 |
| Clinical supervision of workers | 57.9% | 55 | 54.5% | 64.3% | 100% | 59.5% | 42.9% | 50.0% | 95 |
| Use of clinical practice guidelines | 61.1% | 58 | 50.0% | 85.7% | 66.7% | 67.6% | 28.6% | 50.0% | 95 |

**Table 46** **Ways to maintain standards of care and practices** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Professional certification and maintenance of competency | 58.9% | 56 | 52.0% | 55.6% | 66.7% | 64.0% | 95 |
| In-service training | 69.5% | 66 | 72.0% | 63.0% | 77.8% | 68.0% | 95 |
| Clinical supervision of workers | 57.9% | 55 | 60.0% | 55.6% | 50.0% | 64.0% | 95 |
| Use of clinical practice guidelines | 61.1% | 58 | 52.0% | 66.7% | 55.6% | 68.0% | 95 |

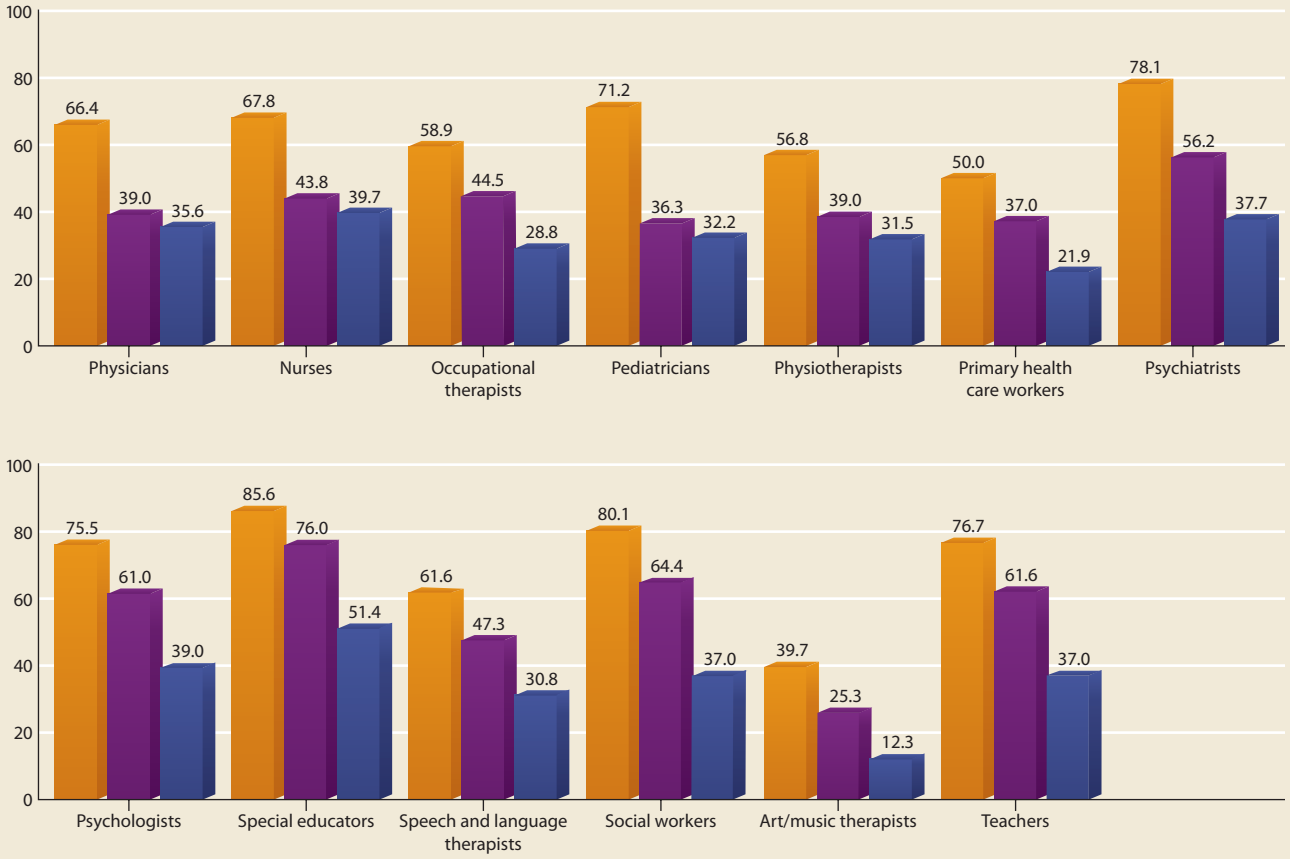
## Training

In-service training refers to services offered to professionals who work with persons with intellectual disabilities during their work hours or during paid extra-hours work. Respondents mostly identified the special educators (76%) as the professionals who had the most opportunity for in-service training, although in some regions, this status was shared with social workers (Eastern Mediterranean, South-East Asia), occupational therapists, speech therapists, psychiatrists, psychologists (Eastern Mediterranean), and teachers (South-east Asia). In more than half of countries, in-service training was offered to social workers (64.4%), teachers (61.6%), psychologists (61%), and psychiatrists (56.2%). Thus, in the greatest number of responding countries, professionals who were most involved with persons with intellectual disabilities were those most likely to be offered in-service training. However, the fact that this training was offered only in a few countries to paediatricians (36.3%), primary health-care workers (37.0%), and physicians (39.0%), might be a matter for concern.

**"Iceland has [a] university educated profession 'Developmental Therapists', who are educated to up to PhD level to provide support services for children, youths, and adults with intellectual impairment. This profession works in all spaces where one finds persons with intellectual impairment and with, if appropriate, their families. […] A new scientific field of study has recently been incorporated in one of our universities: disability studies and social models (courses available at undergraduate level at the faculty of social sciences) and graduate programs at MA and PhD levels."**

Respondent from Iceland

**Figure 26** **Training for professionals involved in providing services for persons with ID** (percentages of countries)




**Professionals most involved in working with persons with ID**

**Presence of in-service ID training**

**Presence of undergraduate training modules**

Respondents reported that few undergraduate or graduate training modules in intellectual disabilities were available or incorporated into curricula within their country. When such a curriculum did exist at the undergraduate level, it was most commonly offered to special educators (51.4%), nurses (39.7%), psychologists (39.0%), psychiatrists (37.7%), or social workers (37.0%). A graduate curriculum was offered mainly to psychiatrists (52.7% of countries), special educators (52.1%), and psychologists (46.6%).

**Table 47** **In-service training for professionals** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Physicians | 39.0% | 57 | 32.4% | 40.0% | 40.0% | 44.7% | 46.2% | 31.8% | 146 |
| Nurses | 43.8% | 64 | 41.2% | 44.0% | 40.0% | 48.9% | 38.5% | 40.9% | 146 |
| Occupational therapists | 44.5% | 65 | 26.5% | 48.0% | 60.0% | 46.8% | 69.2% | 45.5% | 146 |
| Pediatricians | 36.3% | 53 | 29.4% | 32.0% | 40.0% | 38.3% | 38.5% | 45.5% | 146 |
| Physiotherapists | 39.0% | 57 | 26.5% | 48.0% | 40.0% | 40.4% | 53.8% | 36.4% | 146 |
| Primary health-care workers | 37.0% | 54 | 35.3% | 28.0% | 60.0% | 34.0% | 46.2% | 45.5% | 146 |
| Psychiatrists | 56.2% | 82 | 50.0% | 60.0% | 40.0% | 59.6% | 76.9% | 45.5% | 146 |
| Psychologists | 61.0% | 89 | 50.0% | 68.0% | 40.0% | 70.2% | 76.9% | 45.5% | 146 |
| Special educators | 76.0% | 111 | 73.5% | 84.0% | 100.0% | 80.9% | 61.5% | 63.6% | 146 |
| Speech and language therapists | 47.3% | 69 | 23.5% | 40.0% | 60.0% | 66.0% | 69.2% | 36.4% | 146 |
| Social workers | 64.4% | 94 | 64.7% | 56.0% | 100% | 63.8% | 76.9% | 59.1% | 146 |
| Art or music therapists | 25.3% | 37 | 17.6% | 16.0% | 60.0% | 38.3% | 15.4% | 18.2% | 146 |
| Teachers | 61.6% | 90 | 55.9% | 64.0% | 100% | 59.6% | 61.5% | 63.6% | 146 |

**Table 48** **In-service training for professionals** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Physicians | 39.0% | 57 | 42.9% | 28.6% | 25.9% | 57.1% | 146 |
| Nurses | 43.8% | 64 | 45.2% | 35.7% | 29.6% | 62.9% | 146 |
| Occupational therapists | 44.5% | 65 | 26.2% | 33.3% | 48.1% | 77.1% | 146 |
| Pediatricians | 36.3% | 53 | 45.2% | 19.0% | 29.6% | 51.4% | 146 |
| Physiotherapists | 39.0% | 57 | 31.0% | 33.3% | 37.0% | 57.1% | 146 |
| Primary health-care workers | 37.0% | 54 | 42.9% | 31.0% | 33.3% | 40.0% | 146 |
| Psychiatrists | 56.2% | 82 | 59.5% | 57.1% | 44.4% | 60.0% | 146 |
| Psychologists | 61.0% | 89 | 52.4% | 57.1% | 55.6% | 80.0% | 146 |
| Special educators | 76.0% | 111 | 69.0% | 69.0% | 92.6% | 80.0% | 146 |
| Speech and language therapists | 47.3% | 69 | 26.2% | 45.2% | 48.1% | 74.3% | 146 |
| Social workers | 64.4% | 49 | 61.9% | 57.1% | 70.4% | 71.4% | 146 |
| Art or music therapists | 25.3% | 37 | 21.4% | 11.9% | 22.2% | 48.6% | 146 |
| Teachers | 61.6% | 90 | 61.9% | 66.7% | 40.7% | 71.4% | 146 |

**Table 49** **Undergraduate training** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Physicians | 35.6% | 52 | 32.4% | 32.0% | 80.0% | 34.0% | 46.2% | 31.8% | 146 |
| Nurses | 39.7% | 58 | 35.3% | 36.0% | 80.0% | 36.2% | 61.5% | 36.4% | 146 |
| Occupational therapists | 28.8% | 42 | 11.8% | 36.0% | 60.0% | 34.0% | 38.5% | 22.7% | 146 |
| Pediatricians | 32.2% | 47 | 29.4% | 24.0% | 60.0% | 38.3% | 30.8% | 27.3% | 146 |
| Physiotherapists | 31.5% | 46 | 23.5% | 32.0% | 40.0% | 38.3% | 46.2% | 18.2% | 146 |
| Primary health-care workers | 21.9% | 32 | 23.5% | 8.0% | 40.0% | 25.5% | 23.1% | 22.7% | 146 |
| Psychiatrists | 37.7% | 55 | 32.4% | 32.0% | 40.0% | 46.8% | 46.2% | 27.3% | 146 |
| Psychologists | 39.0% | 57 | 26.5% | 56.0% | 60.0% | 34.0% | 61.5% | 31.8% | 146 |
| Special educators | 51.4% | 75 | 50.0% | 56.0% | 80.0% | 51.1% | 46.2% | 45.5% | 146 |
| Speech and language therapists | 30.8% | 45 | 8.8% | 28.0% | 60.0% | 46.8% | 38.5% | 22.7% | 146 |
| Social workers | 37.0% | 54 | 38.2% | 28.0% | 100% | 34.0% | 61.5% | 22.7% | 146 |
| Art or music therapists | 12.3% | 18 | 11.8% | 12.0% | 0% | 17.0% | 0% | 13.6% | 146 |
| Teachers | 37.0% | 54 | 38.2% | 40.0% | 100% | 31.9% | 23.1% | 36.4% | 146 |

**Table 50** **Undergraduate training** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Physicians | 35.6% | 52 | 35.7% | 40.5% | 29.6% | 34.3% | 146 |
| Nurses | 39.7% | 58 | 38.1% | 40.5% | 29.6% | 48.6% | 146 |
| Occupational therapists | 28.8% | 42 | 16.7% | 23.8% | 37.0% | 42.9% | 146 |
| Pediatricians | 32.2% | 47 | 31.0% | 38.1% | 18.5% | 37.1% | 146 |
| Physiotherapists | 31.5% | 46 | 23.8% | 38.1% | 29.6% | 34.3% | 146 |
| Primary health-care workers | 21.9% | 32 | 21.4% | 21.4% | 18.5% | 25.7% | 146 |
| Psychiatrists | 37.7% | 55 | 40.5% | 42.9% | 25.9% | 37.1% | 146 |
| Psychologists | 39.0% | 57 | 35.7% | 45.2% | 40.7% | 34.3% | 146 |
| Special educators | 51.4% | 75 | 40.5% | 50.0% | 59.3% | 60.0% | 146 |
| Speech and language therapists | 30.8% | 45 | 14.3% | 31.0% | 33.3% | 48.6% | 146 |
| Social workers | 37.0% | 54 | 28.6% | 35.7% | 37.0% | 48.6% | 146 |
| Art or music therapists | 12.3% | 18 | 7.1% | 2.4% | 11.1% | 31.4% | 146 |
| Teachers | 37.0% | 54 | 38.1% | 31.0% | 29.6% | 48.6% | 146 |

**Table 51** **Graduate training** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediter-ranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Physicians | 29.5% | 43 | 35.3% | 28.0% | 40.0% | 17.0% | 38.5% | 40.9% | 146 |
| Nurses | 24.7% | 36 | 20.6% | 20.0% | 60.0% | 17.0% | 46.2% | 31.8% | 146 |
| Occupational therapists | 20.5% | 30 | 11.8% | 20.0% | 40.0% | 12.8% | 38.5% | 36.4% | 146 |
| Pediatricians | 31.5% | 46 | 32.4% | 32.0% | 60.0% | 21.3% | 38.5% | 40.9% | 146 |
| Physiotherapists | 21.2% | 31 | 20.6% | 28.0% | 40.0% | 10.6% | 30.8% | 27.3% | 146 |
| Primary health-care workers | 15.1% | 22 | 20.6% | 12.0% | 40.0% | 8.5% | 15.4% | 18.2% | 146 |
| Psychiatrists | 52.7% | 77 | 50.0% | 56.0% | 60.0% | 46.8% | 76.9% | 50.0% | 146 |
| Psychologists | 46.6% | 68 | 38.2% | 56.0% | 60.0% | 38.3% | 69.2% | 50.0% | 146 |
| Special educators | 52.1% | 76 | 35.3% | 52.0% | 80.0% | 59.6% | 53.8% | 54.5% | 146 |
| Speech and language therapists | 32.9% | 48 | 17.6% | 20.0% | 40.0% | 44.7% | 53.8% | 31.8% | 146 |
| Social workers | 34.2% | 50 | 35.3% | 36.0% | 60.0% | 25.5% | 53.8% | 31.8% | 146 |
| Art or music therapists | 11.0% | 16 | 5.9% | 16.0% | 0% | 12.8% | 0% | 18.2% | 146 |
| Teachers | 32.9% | 48 | 23.5% | 28.0% | 80.0% | 29.8% | 23.1% | 54.5% | 146 |

**Table 52** **Graduate training** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Physicians | 29.5% | 43 | 40.5% | 21.4% | 29.6% | 25.7% | 146 |
| Nurses | 24.7% | 36 | 26.2% | 31.0% | 18.5% | 20.0% | 146 |
| Occupational therapists | 20.5% | 30 | 14.3% | 26.2% | 18.5% | 22.9% | 146 |
| Pediatricians | 31.5% | 46 | 38.1% | 31.0% | 2220.0% | 31.4% | 146 |
| Physiotherapists | 21.2% | 31 | 21.4% | 26.2% | 14.8% | 20.0% | 146 |
| Primary health-care workers | 15.1% | 22 | 31.0% | 14.3% | 7.4% | 2.9% | 146 |
| Psychiatrists | 52.7% | 77 | 54.8% | 64.3% | 40.7% | 45.7% | 146 |
| Psychologists | 46.6% | 68 | 47.6% | 57.1% | 33.3% | 42.9% | 146 |
| Special educators | 52.1% | 76 | 45.2% | 59.5% | 48.1% | 54.3% | 146 |
| Speech and language therapists | 32.9% | 48 | 26.2% | 38.1% | 40.7% | 28.6% | 146 |
| Social workers | 34.2% | 50 | 35.7% | 33.3% | 33.3% | 34.3% | 146 |
| Art or music therapists | 11.0% | 16 | 7.1% | 9.5% | 11.1% | 17.1% | 146 |
| Teachers | 32.9% | 48 | 31.0% | 35.7% | 22.2% | 40.0% | 146 |

## The role of NGOs and international organizations

NGOs are national or local grassroot organizations of a voluntary nature (e.g. charitable groups, service-user groups, parent groups, advocacy groups, and professional associations); although they are sometimes attached to international NGOs. International organizations are international agencies, such as UNESCO or WHO, or federations or associations of national organizations.

According to the data, NGOs were active in 88.2% of countries and international organizations in 62.2%.

The percentages do not vary much according to level of income or WHO region. International organizations were in fewer high-income countries (47.1%) than in countries of other income levels (61.5–69.4%). International organizations were more active in the Eastern Mediterranean (92.3%) and South-East Asia (80%) than in Europe (60.5%), the Western Pacific (50%), and the Americas (48.0%).

**Figure 27** **Presence of NGOs and international organizations active in the field of ID**
(percentages of countries by WHO regions)

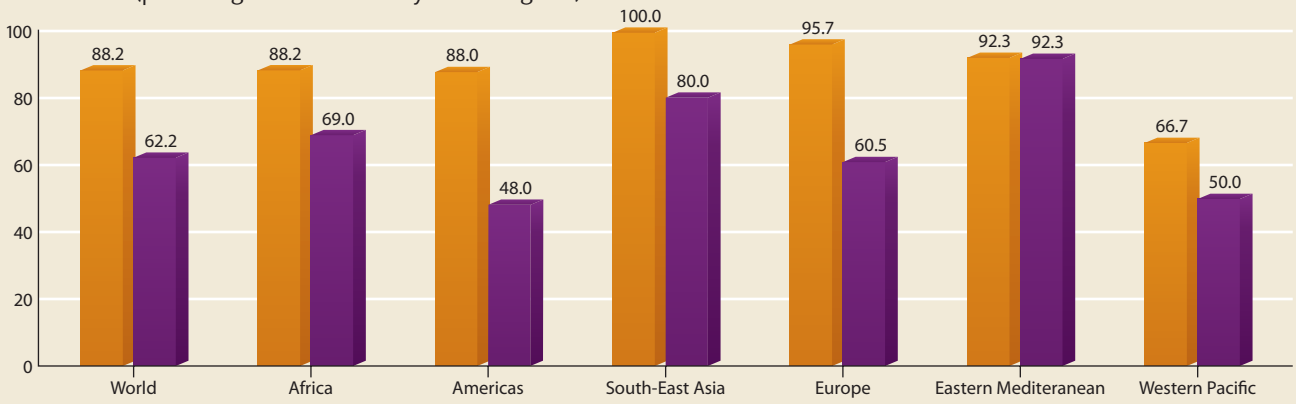
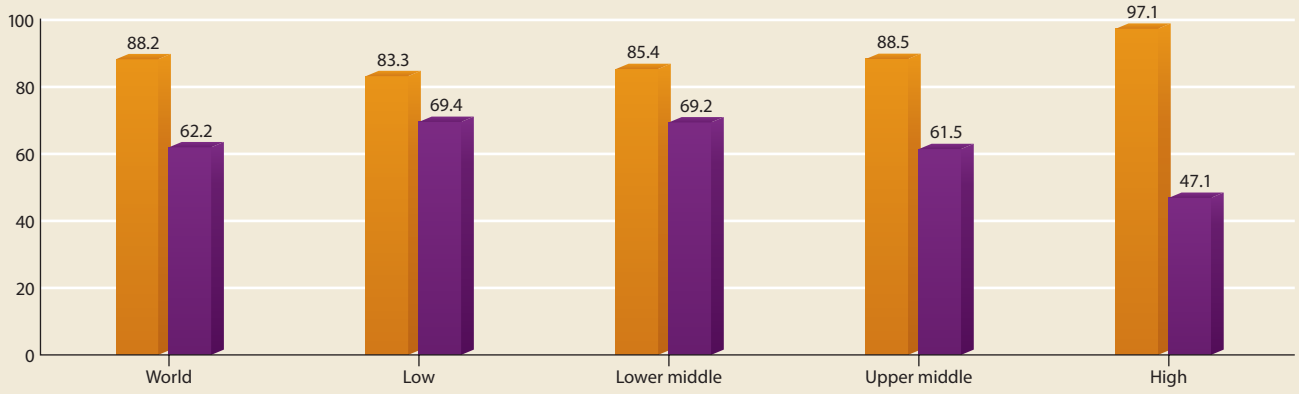



**Figure 28** **Presence of NGOs and international organizations active in the field of ID**
(percentages of countries by income categories)




NGOs active in the field of intellectual disabilities

International organizations active on the field of intellectual disabilities

The six main domains of NGOs' activities were: education (80.2%); support, self-help, and empowerment (76.2%); advocacy (73.8%); rehabilitation (73.8%); family (69.8%); and direct services (65.1%). Education was the main sector of NGO activity in Africa (83.3%), the Americas (95.5%), the Eastern Mediterranean (90.9%), and South-East Asia (100%). However, education was followed, sometimes very closely, by support, self-help, and empowerment (Africa, the Americas), rehabilitation (Africa, the Americas, South-East Asia), work and employment (South-East Asia), and family (the Americas, South-East Asia). We noted that in Europe and in the Western Pacific, education (67.4% and 73.3%, respectively) was lower than advocacy (81.4% and 80.0%, respectively).

**Table 53** **Domains of NGOs' activities** (percentages of countries by WHO regions)

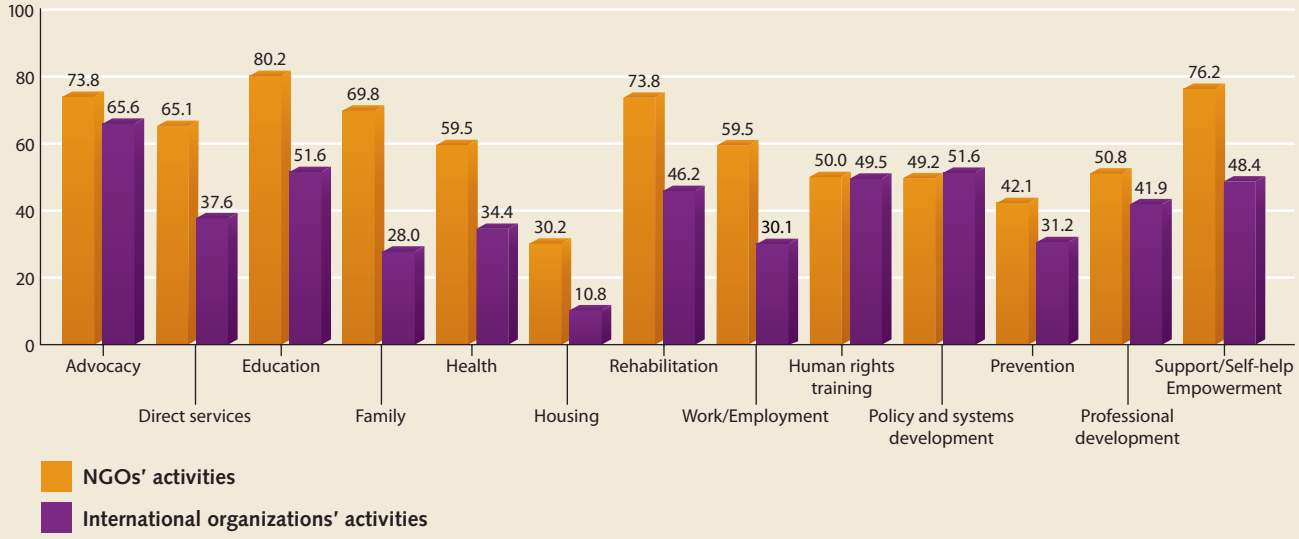
| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Advocacy | 73.8% | 93 | 66.7% | 68.2% | 40.0% | 81.4% | 81.8% | 80.0% | 126 |
| Direct services | 65.1% | 82 | 36.7% | 77.3% | 80.0% | 74.4% | 72.7% | 66.7% | 126 |
| Education | 80.2% | 101 | 83.3% | 95.5% | 100% | 67.4% | 90.9% | 73.3% | 126 |
| Family | 69.8% | 88 | 60.0% | 81.8% | 80.0% | 74.4% | 54.5% | 66.7% | 126 |
| Health | 59.5% | 75 | 60.0% | 77.3% | 40.0% | 48.8% | 81.8% | 53.3% | 126 |
| Housing | 30.2% | 38 | 13.3% | 22.7% | 0% | 58.1% | 9.1% | 20.0% | 126 |
| Rehabilitation | 73.8% | 93 | 73.3% | 81.8% | 100% | 69.8% | 72.7% | 66.7% | 126 |
| Work/ employment | 59.5% | 75 | 40.0% | 68.2% | 80.0% | 65.1% | 54.5% | 66.7% | 126 |
| Human rights training | 50.0% | 63 | 46.7% | 40.9% | 0% | 65.1% | 27.3% | 60.0% | 126 |
| Policy and systems development | 49.2% | 62 | 43.3% | 40.9% | 0% | 72.1% | 9.1% | 53.3% | 126 |
| Prevention | 42.1% | 53 | 43.3% | 50.0% | 20.0% | 39.5% | 54.5% | 33.3% | 126 |
| Professional development | 50.8% | 64 | 43.3% | 45.5% | 60.0% | 65.1% | 54.5% | 26.7% | 126 |
| Support/self-help/ empowerment | 76.2% | 96 | 73.3% | 81.8% | 80.0% | 81.4% | 63.6% | 66.7% | 126 |

Education represented the main sector of activity for NGOs that were active in low-income (79.4%), lower-middle income (83.3%), and upper middle income (91.3%) countries. Rehabilitation was equally important to education in upper middle-income countries. Support, self-help, and empowerment and advocacy were ranked second in low-income countries (both 73.5%), and rehabilitation was ranked second in lower-middle-income countries (80.6%). In high-income countries, advocacy was the main recipient of the endeavours of NGOs (93.9%), followed by policy and systems development, and support, self-help, and empowerment (81.8%).

**Table 54** **Domains of NGOs' activities** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Advocacy | 73.8% | 93 | 73.5% | 58.3% | 69.6% | 93.9% | 126 |
| Direct services | 65.1% | 82 | 50.0% | 69.4% | 69.6% | 72.7% | 126 |
| Education | 80.2% | 101 | 79.4% | 83.3% | 91.3% | 69.7% | 126 |
| Family | 69.8% | 88 | 70.6% | 66.7% | 73.9% | 69.7% | 126 |
| Health | 59.5% | 75 | 61.8% | 69.4% | 52.2% | 51.5% | 126 |
| Housing | 30.2% | 38 | 8.8% | 19.4% | 34.8% | 60.6% | 126 |
| Rehabilitation | 73.8% | 93 | 67.6% | 80.6% | 91.3% | 60.6% | 126 |
| Work/ employment | 59.5% | 75 | 38.2% | 50.0% | 78.3% | 78.8% | 126 |
| Human rights training | 50.0% | 63 | 41.2% | 33.3% | 60.9% | 69.7% | 126 |
| Policy and systems development | 49.2% | 62 | 38.2% | 33.3% | 43.5% | 81.8% | 126 |
| Prevention | 42.1% | 53 | 38.2% | 38.9% | 43.5% | 48.5% | 126 |
| Professional development | 50.8% | 64 | 41.2% | 41.7% | 52.2% | 69.7% | 126 |
| Support/self-help/ empowerment | 76.2% | 96 | 73.5% | 66.7% | 87.0% | 81.8% | 126 |

**Figure 29** **Domains of NGOs' and international organizations' activities** (percentages of countries)



Advocacy represented the major sector of activities by international organization for the WHO regions of Africa (68.0%), the Americas (75.0% ex-aquo with policy and systems development), and Europe (62.1%). In the Eastern Mediterranean, international organizations were heavily involved in health-related activities for persons with intellectual disability (75.0%), whereas in South-East Asia, education and rehabilitation were the two main activities (75.0%). In the Western Pacific, advocacy and human rights training (both 63.6%) were second to support, self-help, and empowerment (72.7%). Advocacy and development of policy and systems were the main sectors of activity for international organizations that were active in high-income countries (both 70.6%). In lower-middle-income countries, support, self-help, and empowerment (62.1%) was the main sector of international organization activities.

**Table 55 Domains of international organizations' activities** (percentages by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Advocacy | 65.6% | 61 | 68.0% | 75.0% | 50.0% | 62.1% | 66.7% | 63.6% | 93 |
| Direct services | 37.6% | 35 | 16.0% | 41.7% | 25.0% | 48.3% | 66.7% | 27.3% | 93 |
| Education | 51.6% | 48 | 40.0% | 50.0% | 75.0% | 51.7% | 66.7% | 54.5% | 93 |
| Family | 28.0% | 26 | 32.0% | 25.0% | 25.0% | 24.1% | 33.3% | 27.3% | 93 |
| Health | 34.4% | 32 | 32.0% | 50.0% | 25.0% | 17.2% | 75.0% | 27.3% | 93 |
| Housing | 10.8% | 10 | 8.0% | 0% | 0% | 20.7% | 0% | 18.2% | 93 |
| Rehabilitation | 46.2% | 43 | 40.0% | 25.0% | 75.0% | 51.7% | 58.3% | 45.5% | 93 |
| Work/employment | 30.1% | 28 | 12.0% | 25.0% | 25.0% | 44.8% | 25.0% | 45.5% | 93 |
| Human rights training | 49.5% | 46 | 48.0% | 58.3% | 0% | 51.7% | 41.7% | 63.6% | 93 |
| Policy and systems development | 51.6% | 48 | 44.0% | 75.0% | 25.0% | 51.7% | 50.0% | 54.5% | 93 |
| Prevention | 31.2% | 29 | 36.0% | 41.7% | 25.0% | 20.7% | 50.0% | 18.2% | 93 |
| Professional development | 41.9% | 39 | 40.0% | 58.3% | 50.0% | 34.5% | 33.3% | 54.5% | 93 |
| Support/self-help/ empowerment | 48.4% | 45 | 44.0% | 50.0% | 25.0% | 51.7% | 33.3% | 72.7% | 93 |

**Table 56** **Domains of international organizations' activities** (percentages by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Advocacy | 65.6% | 61 | 63.3% | 55.2% | 82.4% | 70.6% | 93 |
| Direct services | 37.6% | 35 | 23.3% | 44.8% | 58.8% | 29.4% | 93 |
| Education | 51.6% | 48 | 43.3% | 51.7% | 58.8% | 58.8% | 93 |
| Family | 28.0% | 26 | 30.0% | 27.6% | 35.3% | 17.6% | 93 |
| Health | 34.4% | 32 | 40.0% | 27.6% | 41.2% | 29.4% | 93 |
| Housing | 10.8% | 10 | 3.3% | 3.4% | 29.4% | 17.6% | 93 |
| Rehabilitation | 46.2% | 43 | 36.7% | 55.2% | 47.1% | 47.1% | 93 |
| Work/ employment | 30.1% | 28 | 10.0% | 27.6% | 41.2% | 58.8% | 93 |
| Human rights training | 49.5% | 46 | 46.7% | 37.9% | 70.6% | 52.9% | 93 |
| Policy and systems development | 51.6% | 48 | 40.0% | 44.8% | 64.7% | 70.6% | 93 |
| Prevention | 31.2% | 29 | 36.7% | 24.1% | 23.5% | 41.2% | 93 |
| Professional development | 41.9% | 39 | 36.7% | 44.8% | 35.3% | 52.9% | 93 |
| Support/self-help/ empowerment | 48.4% | 45 | 33.3% | 62.1% | 47.1% | 52.9% | 93 |

Nine respondents indicated activities in the "other" category. These activities included infrastructure projects (construction or renovation of schools, houses, hospitals, day and day-care centres), mobilization training, parent-to-parent support training, and provision of meals and basic necessities such as clothing.

## Documentation and research

The data obtained from project respondents showed that 41.0% of countries did not seem to have any publications on services for intellectual disabilities; the percentage of countries in this situation was highest in low-income (61.5%) and African (67.7%) countries.

**Table 57** **Availability of publications on services for intellectual disabilities** (percentages of countries by WHO regions)

| | World | | Africa | Americas | South-East Asia | Europe | Eastern Mediterranean | Western Pacific | N |
|---|---|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | | | |
| Presence of publications on intellectual disabilities services | 59.0% | 79 | 32.3% | 45.8% | 80.0% | 78.0% | 72.7% | 63.6% | 134 |

**Table 58** **Availability of publications on services for intellectual disabilities** (percentages of countries by income categories)

| | World | | Low income | Lower middle income | Upper middle income | High income | N |
|---|---|---|---|---|---|---|---|
| | Proportion of countries | Number of countries | | | | | |
| Presence of publications on intellectual disabilities services | 59.0% | 79 | 38.5% | 60.0% | 50.0% | 90.3% | 134 |

We noted that less than 50% of participating countries reported some data every year about intellectual disabilities (48.6%), and only a third of countries collected epidemiological information (32.4%). Only 32.4% of countries could rely on epidemiological trends or on information systems to obtain data about services.

**Figure 30** **Research and data on ID** (percentages of countries by WHO regions)

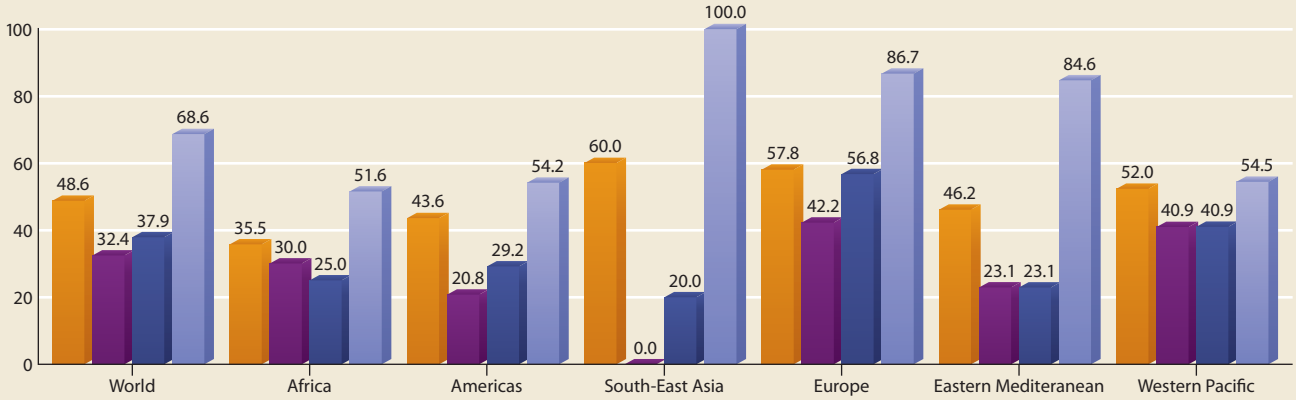
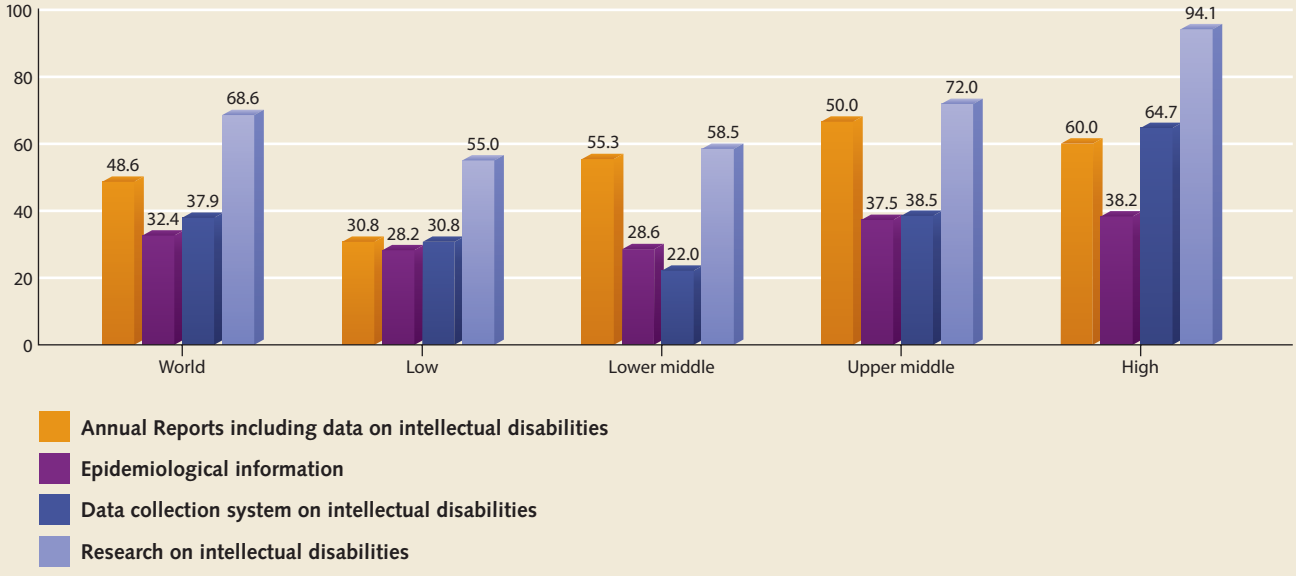


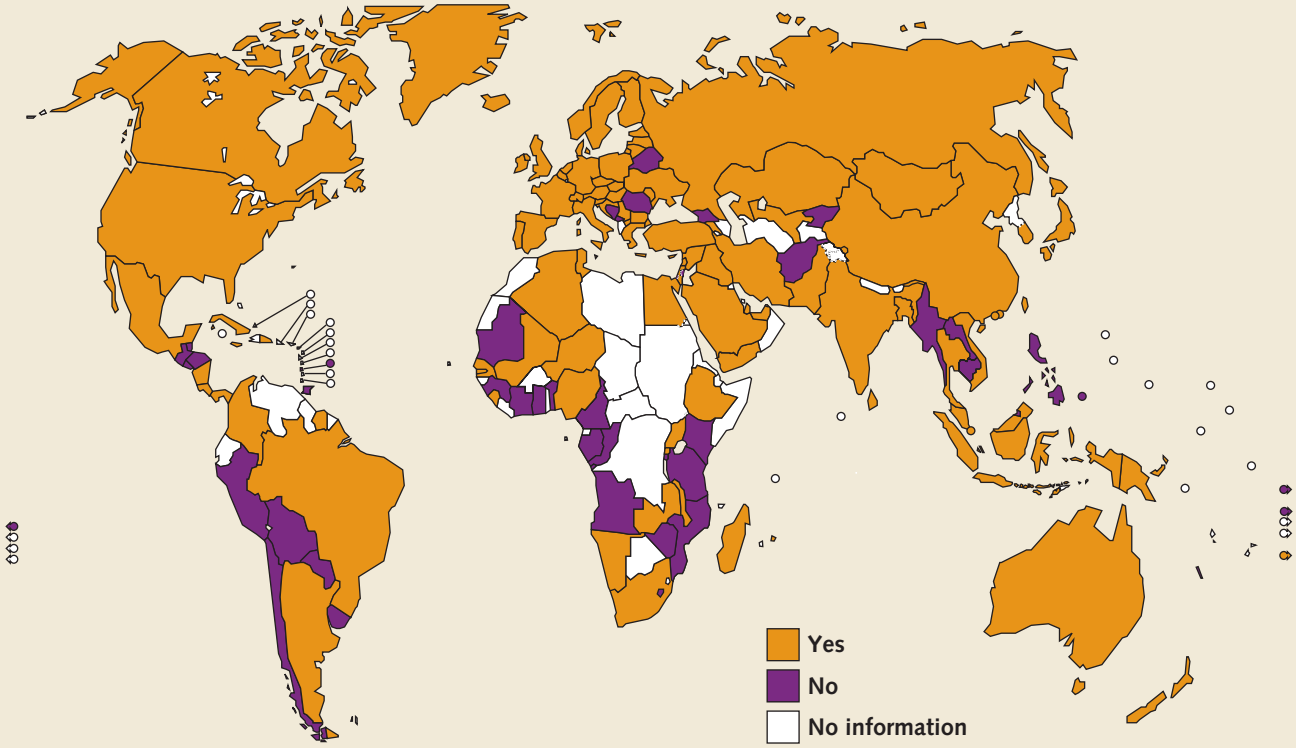

**Figure 31** **Research and data on ID** (percentages of countries by income categories)




- Annual Reports including data on intellectual disabilities
- Epidemiological information
- Data collection system on intellectual disabilities
- Research on intellectual disabilities

68.6% of respondents indicated that research on intellectual disabilities was done in their respective countries. Research activities occurred mainly in high-income countries (94.1%), South-East Asia (100%), Europe (86.7%), and the Eastern Mediterranean (84.6%). Only 28 countries reported having at least one research centre on intellectual disabilities. The research was mainly done with the support of the universities (65.0%), NGOs (58.3%), and governments (50.5%)

**Map 15** Presence of research on ID




## Open-ended comments

The last item in the questionnaire was open-ended; respondents were asked if they had any comments on the questionnaire or other information that they wanted to add. Here we present a selection of these qualitative comments, as a complement to the quantitative data. They provide some insights into specific political, social, economic, and historical circumstances that are relevant to resources for people with intellectual disabilities. They offer the advantage of emphasizing the situation in the respondents' own words. They are presented according to different categories of country income. These comments have been slightly edited, and some have been translated into English.

### Low-income countries

#### Afghanistan

Afghanistan has been at war for more than two decades. Here you cannot find health facilities, even for the general population. […] Very little has been done for intellectual disability. Neither governmental nor nongovernmental organizations have any specific programme to care for persons with intellectual disability. Only some NGOs are offering services for children with special needs.

#### Cambodia

Families have to take care of their own […], because they have some belief that mental disability is the karma for everything they have done in their past life. [They] still believe that only the monk or the traditional healer can treat and help them. […] Cambodia still lacks a system for supporting persons with mental disabilities. Many parents who have children […] complain about poverty more than they do about the way of [taking] care of their children. Some lock the child in the house and go out to run their businesses.

#### Republic of the Congo

[There is a] very important lack of human resources, together with the absence of national policies for training, as well as retirement of trained staff who are not being replaced, little public funding, little participation of national NGOs

with regard to funding (mainly outside funding), low participation rate from families, [and an] absence of associations for families and users.

**Ethiopia**

Intellectual disability is the least addressed area in the country. Basic research to find out the extent of the problem should be an urgent task while special programmes for [persons with intellectual] disabilities are established. WHO should urge and encourage its member countries, especially those affected by natural disasters and disasters created by human activity, to focus on childhood developmental disorders including intellectual disability. Sharing of resources and expertise is what is demanded by the poor countries of the world.

**Gambia**

[…] there is no current or fixed institution that specializes in mental retardation studies. Rather, we are engaged in treatment and prevention, […] Specific vaccines to avoid outbreak of certain diseases that […] bring about disabilities […] before or after pregnancies or before or after birth. That's why there is no specific analysis [or] accurate data system. Since Gambia is a small country […], it doesn't or can't take up any research institutions […]. But we do [offer] rehabilitation methods while counselling on intellectual disabilities in education, health and leisure […], sports, education, work, and employment, as for normal citizens.

**Kenya**

There is a paucity of information and few databases at a national level for intellectual disabilities. Hopefully, we will develop a national policy, legislation, and programmes for intellectual disabilities. This process [should involve] multidisciplinary and intersectoral collaboration. However, we lack the resources, especially funding and technical assistance.

**Nicaragua**

Efforts made by NGOs, international organizations, and the state are minimal when compared with the huge number of persons with intellectual disabilities that lack services in [areas] such as health, education, housing, social welfare, social security, work, etc. Intellectual disability is part of the group of disabilities that is least prioritized, the one that is the least taken into account, and the one that does not raise its voice to defend itself and fight back for its own good. […] Another problem is the fact that in Nicaragua, intellectual disability is regarded as a health problem, without a transversal approach, which limits actions and policies that should be elaborated on to obtain fundamental claims for this category of the population.

**Nigeria**

There is very little information available about intellectual disabilities. For now, the focus is more on physical disabilities. There is no coordinated or concerted effort to look into the area of intellectual disabilities at present.

**Pakistan**

In Pakistan there is not any mechanism of networking, collaboration, and information sharing in the area of disability. […] the disability field is ignored vigorously by all stakeholders […]. Therefore, it is […] time we all join together to improve the livelihood of persons with disabilities, including those with intellectual disabilities.

**Papua New Guinea**

[…] Papua New Guinea is making progress in regard to services for persons with disabilities in general. In 1993, the Government adopted a policy of inclusive education which covers all children. […] Community-based rehabilitation is the declared direction for the future […] and has been for the past 15 years. In this context, although intellectual disabilities has not received any specific focus in Papua New Guinea, the outlook of the Government and organized society for persons with disabilities is generally positive. Services in inclusive education and community-based rehabilitation […] have multiplied steadily in the past 10 years […].

**Senegal**

Specific vocational training does not exist in Senegal, for example for psychologists, occupational therapists, physiotherapists, or speech therapists. Therefore, we do not know about their pregraduate training. One of the major problems that we have is [a] lack of a database in the health sector. The data [are] scattered and fragmented and are […] not national. It is possible that international NGOs are active in mental disability but if they are, we have not noticed.

**United Republic of Tanzania**

In Tanzania these disabilities, to millions of peasants and workers, are a bad omen to the clan concerned and a curse to the parents. And as the African woman occupies a legal position in the traditional social ladder, the mother is always the inevitable victim of speculation and disregard. As such, intermarriages with clans who have children with mental disabilities are classified, socially, as being taboo […] Concealment of information about the prevalence of disability in individual traditional families gives rise to a lack of knowledge about extent and magnitude of disability problems and, therefore, stifles initiatives and efforts for relevant data collection methods to get started and developed. […] By-and-by, however, [there] was growing awareness among the general public, Government, and religious leaders. The UN, above all, resorted to much critical discussion about

the plight of marginalized groupings (children and adolescents); a matter which helped to establish standard rules to deal with the problem of mental disability more effectively. Private and religious NGOs have been established with the support of donors all over the world.

**Zambia**

There is no specific policy or research that has been done in Zambia specifically for persons with intellectual disabilities. […] [Therefore], it is imperative to mobilize resources for comprehensive data collection programmes and to set up a data collection system, if proper and timely planning is to be enhanced on issues of persons with intellectual disabilities.

## Lower middle-income countries

**Bolivia**

[…] Despite the existence of laws […], their implementation is minimal because of the lack of knowledge on this subject and the lack of human and economic resources. The majority of these centres deliver services up to persons aged 18 years. From there on, they go back home or to begging.

**Bosnia and Herzegovina**

Before the war (1992–95), Bosnia and Herzegovina as constituent parts of Yugoslavia, [had] institutions for children with mental disorders. These institutions still exist. However these persons are no longer children or youths. They have become adults, but yet they still reside in the very same institutions. […] Today […] even healthy and young persons are unemployed, [so there are no funds available for] sheltered workshops, educational programmes, self-help, literacy programmes, rehabilitation, prevention, caring for healthy life styles, advocacy support, or other manners of support for mentally disabled.

**Colombia**

In Colombia some advances […] can be found in Bogotá, whereas in the rest of the country, there are isolated efforts at the ground level and always from the private sector or from the NGOs.

**Cook Islands**

There is no specific service for persons with intellectual disability, although there is an NGO group that is working for all persons with disabilities […].

**Guatemala**

It is necessary to support research, which must be systematized. We must manage to improve the communication of the information with regard to these aspects of intellectual disabilities. International organizations should provide information from studies and results […] in other countries.

**Islamic Republic of Iran**

[…] It must be pointed out that [not] all the intellectually disabled children in Iran […] go to school, the comparison between the prevalence rate and the number of the intellectually disabled students […] shows that only 3.18% of this population get the opportunity to receive the special education […]. All the Iranian students including the students with intellectual disability have the right of receiving free and mandatory education for 8 years […]. The maximum age of registration for a student with intellectual disability in the first grade of the primary school is 13 years.

**Romania**

Most of the data we can find are general presentations of all disabilities and there are just a few referrals to persons with intellectual disability.

**Russian Federation**

It is necessary to consider that conditions of rendering assistance to persons with intellectual disability in various regions [depends] on economic development of the region and the degree of development of its infrastructure.

**Tonga**

As a [professional] staff [with] persons with disabilities, I have been serving these persons since 1977 and […] there hasn't been any help from anywhere, and disabled persons are [more numerous that ever] but [there still is] very limited support, and very little funding from anywhere.

**Ukraine**

There is no centralized source which collects information about the number of persons with intellectual disability who use services for intellectual disability in Ukraine. The Ministry of Health is responsible for intellectual disability and for persons with mental disorders who address their problems to the medical doctors. The Ministry of Social Affairs is responsible for [persons with intellectual disability] in social internats. The Ministry of Education is responsible for [persons with intellectual disability] in schools. Yet, even the statistics in each of the Ministries is not available.

## Upper middle-income countries

**Barbados**

[In Barbados], although there are some services for persons with intellectual disabilities, service users have found the services to be sparse or sadly lacking. All parties agree that there is an urgent need for research and a need to collate the existing information. Funding is also needed to support both research as well as services for persons with intellectual difficulties.

**Chile**

In Chile, although there are initiatives in diverse sectors with respect to [intellectual disabilities], these initiatives are not coordinated by any institution, either in the public or private sectors.

**Lithuania**

There were difficulties in answering some of the questions, mainly because the topic of intellectual disabilities is governed by very different agencies and sectors.

**Mauritius**

In Mauritius, […] the local associations (NGOs) […] are responsible for intellectual disability and all services provided. […] They give direct pension to disabled persons and free public transport, for all types of disabilities […] but nothing particular [for persons with] intellectual disability. NGOs are very active and lobby strongly for the rights, provision of services, development of education policies, and implementation of resources.

**Poland**

Persons with intellectual disability in Poland are still very marginalized. Governmental policy is focused on segregated education and provision of asylum type institutions. The integration and inclusion movement is in its initial stages. New ideas such as early intervention, day-care centres, occupational therapy workshops, vocational training, group homes, supported employment and sheltered employment, and individual support for persons with intellectual disability and their families are introduced by NGOs.

## High-income countries

**Canada**

In Canada, services to persons with intellectual disabilities are completed on a provincial level. The federal government makes health transfer payments to the provinces in the yearly budget, but these are administered and prioritized on a provincial level. Hence, there is no national federal policy for the care of individuals with intellectual disabilities in Canada. […] As such, there are no set curricula for professionals working in the area of intellectual disability across Canada. Instead, we have "pockets" of interests within university settings that offer courses in disciplines in the intellectual disability field. […] However, these are not mandated by either a provincial or federal training mandates.

**Greece**

No specific epidemiological data [are] available for persons with intellectual disabilities in Greece […]. At present, information derived from clinical experience, relevant studies of persons with disabilities, and indicative statistical data are [all that is] available.

**Iceland**

Health services are largely inexpensive to all Icelanders, and for persons with intellectual impairment such services are almost always free of charge and provided in local and national health services that serve the general public. Disabled persons rank among the poorest persons in Iceland […]. Preschools for children from 1–6 years are free for those with disabilities […]. One of the biggest problems for adults with intellectual impairment is the lack of opportunities to join the world of work. Sheltered workshops are not always available and potential workers spend their adult life either at home (mostly in group homes) or in rehabilitation centres, from which very few graduate.

**Switzerland**

Switzerland is a federated state composed of 26 cantons, each with its own autonomy. Hence, there is a lot of diversity in the terminology employed, the laws applied, the types of services offered, as well as the attribution of individual and collective training in intellectual disabilities.

**United Kingdom of Great Britain and Northern Ireland**

Almost all professional input to persons with learning disabilities (e.g. doctors, nurses, social workers, therapists, etc.) is funded by the public sector. […] Similarly, employment or day occupation services are publicly funded. Historically, the majority were also publicly provided. However, the trend is towards employment support and provision of new forms of day activities to be commissioned from independent sector providers.

**United States of America**

In the USA, the services to persons with intellectual and other disabilities are managed at the state level. These services vary greatly in quantity and quality from state to state. The national government plays a major part in financing services provided to persons with intellectual disabilities (especially adults with intellectual disabilities), but it has a fairly modest role in specifying the nature and quality of the services actually provided by the states.

# Salient findings

This survey was designed to investigate resources and services for intellectual disabilities in WHO Member States, Associate Members of WHO, and areas and territories. Some findings pertain to almost all countries; whereas others apply to specific subgroups, according to their region or level of income. We will now discuss the most salient findings from a global perspective. However, since lack of information was our first finding, some of these results should be interpreted with caution. Many experts who reviewed the results expressed concern that some of the findings could be misleading, over-positive, and perhaps not applicable to people's everyday experiences. With this in mind, we have formulated the salient findings in broad terms to emphasize general trends. The tables and figures can be used to facilitate comparison of similarities and differences between the six WHO regions and the four income categories and thus shed light on commonalities and differences between countries in resources and services for intellectual disabilities.

## Availability of information

Respondents from 147 countries collaborated to supplement the data. With an overall response rate of 74.6%, covering countries with 94.6% of the world population, this survey provides a unique source of information. Unfortunately, in the absence of comprehensive official data, most respondents had to answer survey questions on the basis of their personal knowledge and experience. As such, one finding is the paucity of documentation about intellectual disabilities, such as publications or references in national reports, epidemiological data, or data on services provision and delivery. The poor reliability of the epidemiological data we collected seems, with hindsight, to reinforce this finding. However, respondents from more than two thirds of countries reported that some type of research had been done in their countries, although very few had a research centre that was specifically dedicated to intellectual disabilities.

## Use of terminology and systems of classification

Intellectual disabilities were referred to as illnesses, disabilities, or both, and no consensus about these terms existed. The survey showed that mental retardation is the most widely used term, although many persons also referred to intellectual disabilities. One incentive for implementation of standard use of a term that refers to disability, rather than to intellectual or mental retardation, is the fight against stigmatisation of persons with intellectual disabilities and their families. Apart from this concern, a common term of reference would aid parallel use of international systems of diagnosis and classification, such as ICD and DSM-IV.

## Visibility of the issue

Identification of a suitable respondent in each country to whom a request for information about intellectual disabilities could be addressed was a long and difficult process. We noted that resources and services for intellectual disabilities seemed to be embedded within other fields, and scattered between sectors and authorities. Partly for this reason, information specific to intellectual disabilities was difficult to access in almost all countries. Because persons with intellectual disabilities such as vision, hearing, or locomotor impairments do not have conspicuous disabilities, they might also be difficult to identify as a target group.

Other indicators that intellectual disabilities have low visibility in some countries, and low priority on national political, economic, and social agendas, included the number of countries without any specific national policy, protection law, government benefits, or public funding for intellectual disabilities. In some circumstances coverage of intellectual disabilities in generic policies, laws, or programmes can remain largely theoretical.

## Sources of funding

The findings indicated that funding for services originated mainly from public funds, out-of-pocket expenses, and NGO contributions. The public sector had the greatest responsibility for financing services for intellectual disabilities throughout the world; however, in low-income countries, especially in Africa, NGOs and international organizations were more involved in delivery of services for intellectual disabilities. In countries across the four different income categories, respondents reported a high proportion of out-of-pocket payment for services. However, this finding might be indicative of general access to any type of health and welfare services, in most of the countries of the world.

## Provision of services

Data about provision of services could have been affected by the discrete format used in the questionnaire (with only "yes" and "no" options), since even a single occurrence of a service could elicit a "yes" response. The finding that more than 75% of countries offered some form of services for intellectual disabilities could have been affected by this limitation. The services available in more than 75% of countries included health care (primary health care, inpatient health-care services, specialized services, and physical rehabilitation) and were tailored to children, adolescents, and adults. More than 75% of countries we surveyed also offered services for children and adolescents within the education sector (whether mainstream or special schools). More than 65% of countries provided services that were specifically related to intellectual disabilities, such as screening, assessment, or orientation, early intervention, individual support, psychological and psychiatric interventions, psychosocial rehabilitation, and day centres. About the same proportion of countries (60–65%) had professional training, work-skills training or development, and sheltered or supported employment for persons with intellectual disabili-

ties). Other services that were available in most countries (across all age groups), included support for protection of rights and advocacy; leisure activities; transportation; so-called assistive technology; and supply of food. However, by contrast, fewer than half the countries we surveyed offered residential services (foster homes, group homes, nursing homes, or support for independent living); literacy programmes; and adult education programmes. Services for intellectual disabilities that involve asylums remained very important: 56.5% of participating countries had this type of facility for adults, and 49.2% for children and adolescents.

Availability of different types of services for families varied widely; for example, psychological counselling was offered to families in almost 75% of countries; education on intellectual disabilities in two thirds; and support for the defence of rights and advocacy in almost 60%. However, only a few countries provided home aid and respite care (44% and 30%, respectively).

## Access to services

Despite the finding that many countries provided some level of services, the available services were not necessarily sufficient to meet need. Access – both to government benefits and to services – was critical. In 39% of countries, fewer than 10% of persons with intellectual disabilities received government benefits to which they were legally entitled; in 38% of countries more than 75% did so. Socioeconomic status and geographical location were the main barriers to access to services; they had a major effect in more than half of countries surveyed.

## Prevention efforts

Some known causes of intellectual disabilities are preventable. More than half the countries that participated in the survey, across all country-income categories and WHO regions, had programmes designed to prevent intellectual disabilities. Implementation tended to be proportional to income. These strategies targeted all categories of risk factors, from environmental factors (e.g. iodine supplementation) to behavioural factors (e.g. maternal alcohol consumption). However, we did not cover wide-spectrum initiatives, such as maternal care, child care, and poverty alleviation, that are known to affect the incidence of intellectual disabilities.

## Human resources and training

The five main groups of professionals who provided services for persons with intellectual disabilities were special educators, social workers, psychiatrists, psychologists, and teachers. These professionals were reported to benefit the most from training programmes in services for intellectual disabilities. In-service training was the most common form of training, whereas graduate training was rare, and concentrated in high-income countries.

Although primary care services were important to persons with intellectual disabilities, few respondents mentioned primary health care workers among the professionals who worked with such persons, and few countries seemed to offer training to these workers. However, we note that the questionnaire did not mention traditional healers or non-professionals in the list of resources that could offer support to persons with intellectual disabilities and their families.

## Role of NGOs and international organizations

NGOs were present in 88.2% of responding countries, and international organizations in 62.2% of them. Although both NGOs and international organizations focused their activities on advocacy and education, international organizations were also involved with policy and system development and human rights training, whereas NGOs concentrated on support, self-help, empowerment, and rehabilitation services.

The roles of NGOs and international organizations tended to differ according to the income levels of the countries in which they operated. In high-income countries, NGOs focused on advocacy and development of policies and systems; whereas in other countries they devoted more effort to education, rehabilitation, support, self-help, empowerment, and provision of direct services. In low-income countries the contribution of NGOs to financing services for persons with intellectual disabilities was highest.

## Gaps in resources between countries

The survey showed that although countries in all WHO regions had some resources for persons with intellectual disabilities, they were proportional to income. The number, type, and comprehensiveness of available resources also increased according to income. Services available to adults or children and adolescents with intellectual disability in high-income countries tended to be community-based, and specific or exclusive to intellectual disabilities; whereas low-income countries showed unmet needs across the whole range of services. We also noted inadequate research capacities, especially in low-income and middle-income countries. Since research from high-income countries cannot be applied directly to situations in other countries, local efforts will be required to solve local problems through development and dissemination of knowledge.

**"Although more than 90% of children and families affected by developmental disabilities are likely to live in developing countries, it appears that more than 90% of research, preventive efforts and services related to developmental disabilities is directed toward the populations of the world's wealthier countries.**

**(Durkin, 2002)**

# The way forward

The following paragraphs present implications for further actions based both on the findings from the Atlas-ID survey and on the comments and criticisms of the experts who were consulted.

## Change priorities of governments and civil society

The issue of intellectual disabilities has had a low position in many related fields, such as mental health, rehabilitation, public health, and primary care. In some countries, the reality of intellectual disabilities has been almost overshadowed by other concerns. Indicators of the priority accorded to intellectual disabilities include national policies on intellectual disabilities, national protection laws for persons with intellectual disabilities, government benefits for such persons and the proportion of persons who received such benefits, public funding for the delivery of services, epidemiological data, and national documentation and reporting of this issue. Most countries we surveyed received low scores for all of these indicators. The absence of standard terminology, or of a system of classification, seemed to contribute to this low position. The intersection of intellectual disabilities with at least three other fields (education, psychiatry, and rehabilitation) could exacerbate its low status.

One clear implication is that advocacy initiatives should be organized and supported at the international and national levels to prioritise intellectual disabilities on government agendas and to increase civil-society awareness of intellectual disabilities. Technical assistance to countries is also needed, to facilitate formulation of policies and laws, implementation and monitoring of programmes, database development, and research.

Resources should also be allocated to development and promotion of tools that will support capacity building for relevant professionals, non-professionals, and community members.

## Clearly identify accountable authorities

Responsibilities for intellectual disabilities were scattered between many constituencies, government departments, and agencies, with the consequence that none of these authorities had overall accountability at the national level. We encountered this situation in many countries when we attempted to identify relevant contacts; those whom we did survey also reported difficulty in obtaining information to answer questions related to policies and programmes, financing, organization of services, and delivery.

Sharing of responsibilities between many constituencies and departments could be regarded as a strength, since it ensures that support will be provided to persons with intellectual disabilities and their families by the most appropriate government entity, and that these persons will have access to programmes designed for the general population. However, potential for benefit from shared accountability depends on at least three conditions. First, each country must develop a national action plan for intellectual disabilities, which can be implemented to support consultation between different stakeholders in the field and coordination of actions by different entities. Second, existing policies, and especially those related to disability, will need to be framed to clearly include intellectual disabilities, so that intellectual disabilities gain parity with other disabilities. Third, these policies and action plans must be enforced at the national and local levels through accountability mechanisms.

## Close gap between needs and financial resources

Survey respondents emphasized the paucity of financial resources in their countries to meet the needs of persons with intellectual disabilities and their families. This situation was worsened by the low priority of this issue and its low visibility. In many countries, especially in Africa and low-income countries, international organizations and NGOs have a crucial and unique role in support for persons with intellectual disabilities and their families.

Any planning effort geared to scale up resources must recognize and mobilize all existing resources in the community, whether from public, private, or third sector sources, and develop shoe-string strategies to maximize the efficiency of their use, without duplication of services. When new financial resources are available for services development, they should be allocated in a way that prioritizes efficiency and coverage.

## Recognize the role of families

Respondents reported that families were crucial to support for persons with intellectual disabilities, whether they were adults, children, or adolescents. For more than half the countries family support was the only form of support available. Care of children with intellectual disabilities by productive adults represents a substantial burden to society.

The cost of this burden must be taken into account when drafting plans, development strategies, and initiatives for persons with intellectual disabilities. Governments must coordinate national support plans for families with children with intellectual disabilities that offer some form of respite care and home-aid, and thus allow these individuals to remain as productive members of society.

## Distribute resources between and within countries

These findings showed that resources and services for intellectual disabilities varied in different contexts and between countries according to differences in income levels and regions. The data also showed that geographical locations and socioeconomic factors hindered access to services in more than half the countries in the world.

Access must be considered in every plan or development strategy. Action plans must take into account differences in financial and human resources and acknowledge the social and cultural contexts. Development of services based on a biomedical approach has tended to result in facilities that are clustered in urban areas, near to health officials. These services, when available, were reported to be expensive and integrated with other health services that did not necessarily align with the needs and preoccupations of persons with intellectual disabilities and their families. Every action plan must be flexible enough to adjust to national circumstances, since more than one model for provision of services exists. The current consensus is that services should be planned on the basis of promising approaches such as the life-cycle model, the support model, and community-based rehabilitation.

## Address custodial care institutions

The findings indicated that asylum-type institutions were still important in many countries, in an era of downsizing or closing down such institutions in favour of community-based resources.

Future plans, development strategies, and initiatives for persons with intellectual disabilities must involve downsizing of asylum-type facilities and establishment of services that are community-based and integrated into the national networks of services. However, this process must incorporate solutions to specific challenges associated with persons who have lived in such institutions, such as severely limited basic skills, co-occurrence of psychiatric disorders and challenging behaviours, and lack of social support.

## Build capacity

Capacity building for intellectual disabilities must be prioritized within primary care, since respondents reported that, primary care was an important resource for these persons in most countries. However, a large gap exists between the importance of these services for persons with intellectual disabilities and their families and training opportunities for primary-care workers.

The capacity of primary care workers to deliver services for persons with intellectual disabilities must be improved via on-site training programmes or other didactic approaches. Professionals should be trained to support families, informal caregivers, and community leaders, and to provide consultations to primary health care workers. Distance-education programmes that have been developed in both high-income and low-income countries offer interesting opportunities for such training. Such initiatives should aim to enhance community capacity and social capital so that more natural solutions can be provided within communities, in conjunction with government supports.

## Make intellectual disabilities a public health issue

Public health agencies need to include persons with intellectual disabilities as part of their concerns. Many countries have targeted specific risk factors associated with intellectual disabilities, and implemented preventive strategies. Such strategies can be developed at every life-stage and can target environmental factors, prenatal and postnatal circumstances, early childhood, and behaviours in adolescence and adult age. Progress in the implementation of some of these strategies has been recorded over the past 10 years (Durkin, 2002).

Specific actions can alleviate some causes of intellectual disabilities. Public health programmes that target environmental factors (e.g. iodine, mercury, and lead), living conditions (poverty), behaviours (tobacco, alcohol, and drug abuse), provision of services (mother and child care and vaccination) could reduce the incidence of intellectual disabilities. Perinatal health care needs to be emphasized, since it is the most important cause of intellectual disabilities in low-income countries. General practitioners (physicians), primary-health workers, midwives, and skilled birth attendants should get training and guidance in prevention and identification of intellectual disabilities, and in early intervention for such disabilities.

## Enforce human rights and right to health

Existing state-based resources for intellectual disabilities derive from treaty-based rights. Such rights are set out in binding international instruments, such as the International Covenant on Economic, Social and Cultural Rights (OHCHR, 2000), the International Covenant on Civil and Political Rights (UNCHR, 1994), and the Convention on the Rights of Persons with Disabilities (UNGA, 2007); non-binding instruments, such as the Universal Declaration on Human Rights (UNGA, 1948), the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UNGA, 1993), and ICESCR General Comments 5 and 14 (OHCHR, 2000); and civil-society instruments, such as the Caracas Declaration (PAHO & WHO, 1990) and the Montreal Declaration on Intellectual Disabilities (PAHO & WHO, 2004). One challenge will be to ensure that recent attention on human rights issues can be translated into policies, programmes, and actions that will improve underlying conditions necessary for health and especially for intellectual disabilities.

Issues related to intellectual disabilities need to be incorporated into a right-based approach to disability resources and services. Governments should therefore guarantee the presence, availability, access to, and enjoyment of adequate health and social services based on the needs of persons with intellectual disabilities and their free and informed consent, in line with article 25 of the UN Convention on the Rights of Persons with Disabilities (UNGA, 2007). Accordingly, persons with intellectual disability should always be actively involved in a rights-based approach, whose outcomes should promote the organization of community-based services that guarantee the enforcement of these rights.

**Table 59** The way forward: a summary of issues and actions

| Issues | Actions |
|---|---|
| Intellectual disabilities (ID) are a low priority for both governments and civil society | ■ Advocacy<br>■ Technical assistance for development of policies and programmes, planning, and operational research |
| Lack of well identified accountable authorities | ■ National action plans<br>■ Revision of existing laws to encompass ID<br>■ Accountability mechanisms for implementation |
| Gap between needs and funding for ID | ■ Recognition and mobilization of existing resources<br>■ Cost effective strategies for efficient use of resources with potential for large coverage |
| Critical role of families | ■ Inclusion of families in any policy, plan, or initiative<br>■ Development of respite and home-aid |
| Discrepancies in access to services between countries and within each country | ■ Flexibility and adaptability to local circumstances in action plans<br>■ Diversification of approaches with more emphasis on the life-cycle, support model, and community-based rehabilitation approaches |
| Persistence of asylum-type institutions | ■ Downsizing of these facilities in favour of community-based care |
| Importance of primary care services to persons with ID, and need for capacity building, mainly at the primary care level | ■ Build capacity in primary care by diffusion and adaptation of existing educational resources<br>■ Develop approaches such as consultation-liaison and supervision at distance |
| Intellectual disabilities as a public health issue | ■ Presence in public health strategies and campaigns that target risk factors<br>■ Special emphasis on perinatal care |
| Enforcement of human rights and right to health for persons with ID | ■ Adoption of a right-based approach to disability |

# References


CIR. International disability rights monitor (IDRM) project. Chicago, IL, USA: Centre for International Rehabilitation. http://www.ideanet.org. (accessed July 2007).

Durkin M. The epidemiology of developmental disabilities in low-income countries, *Mental Retardation and Developmental Disabilities Research Reviews*, 2002; 8; 206–211.

Despouy L. *Human Rights and Disability. Final Report of the Special Rapporteur*, 3. UN Doc E/C4/Sub2/1991/31 (July 1991).

Eleweke CJ & Rodda M. The challenge of enhancing inclusive education in developing countries. *International Journal of Inclusive Education*, 2002; 6 (2): 113–126.

Felce D. What is Mental Retardation? In: Switzky HN & Greenspan S (eds). *What is Mental Retardation? Ideas for an Evolving Disability in the 21st Century*. Washington, DC, USA: American Association on Mental Retardation, 2006: xiii–xiv.

Fujiura GT, Park HJ, Rutkowski-Kmitta V. Disability statistics in the developing world: a reflection on the meanings in our numbers. *Journal of Applied Research in Intellectual Disabilities*, 2005; 18, 295–304, 297.

Gruskin S, et al (eds). *Perspectives in health and human rights. New York*, NY, USA: Taylor & Francis (Routledge), 2005.

Inclusion International. *World Report on Poverty and Disability: 'Hear Our Voices: Persons with an Intellectual disability and their families speak out on Poverty and Exclusion'*. London, UK: Inclusion International, 2006: 47 http://www.inclusion-international.org (accessed July 2007).

Janicki MP. IASSID/WHO Healthy Ageing reports: an update from the IASSID Ageing Special Interest Research Group. *Journal of Intellectual Disability Research*, 2000: 44 (2), 185–88.

Leonard H & Wen X. The Epidemiology of Mental Retardation: Challenges and Opportunities in the New Millennium. *Mental Retardation and Developmental Disabilities Research Review*, 2002; 8, 117–134.

Lecomte J & Mercier C. The Montreal declaration on intellectual disabilities of 2004: an important first step. *Journal of Policy and Practice in Intellectual Disabilities*, March 2007; 4: 66–69.

MDRI. Reports and publications. Washington, DC, USA: Mental Disability Rights International. http://www.mdri.org/publications/index.htm (accessed July 2007).

PAHO & WHO. *Caracas declaration on intellectual disabilities. Conference on Intellectual Disability*. Caracas, Venezuela: Pan-American Health Organization & World Health Organization, 1990.

PAHO & WHO. *Montreal declaration on intellectual disabilities*. Conference on Intellectual Disability. Montreal, Canada: Pan-American Health Organization & World Health Organization, October 2004. http://www.montrealdeclaration.com/docs/declaration_eng.pdf (accessed July 2007).

OHCHR. *International covenant on economic, social and cultural rights (ICESCR) General Comment 14* (22nd session, 2000). Geneva, Switzerland: The Office of the High Commissioner for Human Rights, 2000.

OHCHR. *International covenant on civil and political rights*. New York, NY, USA: 1966.

Quinn G & Degener T. *Human Rights are for all: a study on the current use and future potential of the United Nations Human Rights instruments in the context of disability*. Geneva, Switzerland: Office of the UN High Commissioner for Human Rights, February 2002.

Rosenthal E & Sundram CJ. *Recommendations for developing nations. In: Herr S, Gostin L, Koh HH (eds). The human rights of persons with intellectual disabilities: different but equal*. New York, NY, USA: Oxford Press, 2003: 486, 551.

Thorpe L, Davidson P, Janicki MP. *Healthy ageing – adults with intellectual disabilities: biobehavioural issues*. Geneva, Switzerland: World Health Organization, 2000.

UNESCO. *Inclusive Schooling and Community Support Programs*. Paris, France: UNESCO, 1996/97.

UNESCO. *Salamanca Statement and Framework for Action*. World Conference on Special Needs Education: Access and equality. Salamanca, Spain, 7–10 June, 1994.

UNESCO. *Welcoming Schools: Students with Disabilities in Regular Classroom*. Paris, France: UNESCO, 1999.

UNGA. *Convention on the Rights of Persons with Disabilities*. New York, NY, USA: UN General Assembly, 2007.

UNGA. *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. New York, NY, USA: UN General Assembly, 1993.

UNGA. *Universal Declaration on Human Rights*. New York, NY, USA: UN General Assembly, 1948.

WHO. *25 questions and answers on health and human rights*. Health & Human Rights Publication Series, 1. Geneva, Switzerland: World Health Organization, July 2002.

WHO. *The World Health Report 2001. Mental health: new understanding, new hope*. Geneva, Switzerland: World Health Organization, 2001: 33.

World Bank. Country classification. Washington DC, USA: World Bank Group, 2003. http://www.worldbank.org. (accessed March 2006).

WHO/ IASSID/Inclusion International. Healthy ageing – adults with intellectual disabilities: summative report. *Journal of Applied Research in Intellectual Disabilities*, 2001, 14: 256–75.

# Appendix 1

## List of participating Members States of WHO, Associate Members of WHO, and areas or territories

| MEMBER STATES OF WHO AND ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | WHO REGION | WORLD BANK INCOME CATEGORY |
|---|---|---|
| **Afghanistan** | Eastern Mediterranean | Low |
| **Albania** | Europe | Lower middle |
| **Algeria** | Africa | Lower middle |
| **Angola** | Africa | Lower middle |
| **Argentina** | Americas | Upper middle |
| **Armenia** | Europe | Lower middle |
| **Australia** | Western Pacific | High |
| **Austria** | Europe | High |
| **Bangladesh** | South-East Asia | Low |
| **Barbados** | Americas | Upper middle |
| **Belarus** | Europe | Lower middle |
| **Belgium** | Europe | High |
| **Belize** | Americas | Upper middle |
| **Benin** | Africa | Low |
| **Bolivia** | Americas | Lower middle |
| **Bosnia and Herzegovina** | Europe | Lower middle |
| **Botswana** | Africa | Upper middle |
| **Brazil** | Americas | Lower middle |
| **Brunei Darussalam** | Western Pacific | High |
| **Bulgaria** | Europe | Lower middle |
| **Burundi** | Africa | Low |
| **Cambodia** | Western Pacific | Low |
| **Cameroon** | Africa | Low |
| **Canada** | Americas | High |
| **Chad** | Africa | Low |
| **Chile** | Americas | Upper middle |
| **China** | Western Pacific | Lower middle |
| **China - Hong Kong Special Administrative Region (1)** | Western Pacific | High |
| **Colombia** | Americas | Lower middle |
| **Comoros** | Africa | Low |
| **Republic of the Congo** | Africa | Low |

| MEMBER STATES OF WHO AND ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | WHO REGION | WORLD BANK INCOME CATEGORY |
|---|---|---|
| **Cook Islands** | Western Pacific | Lower middle |
| **Costa Rica** | Americas | Upper middle |
| **Côte d'Ivoire** | Africa | Low |
| **Croatia** | Europe | Upper middle |
| **Cuba** | Americas | Lower middle |
| **Cyprus** | Europe | High |
| **Czech Republic** | Europe | Upper middle |
| **Democratic Republic of the Congo** | Africa | Low |
| **Denmark** | Europe | High |
| **Dominican Republic** | Americas | Lower middle |
| **Egypt** | Eastern Mediterranean | Lower middle |
| **El Salvador** | Americas | Lower middle |
| **Estonia** | Europe | Upper middle |
| **Ethiopia** | Africa | Low |
| **Finland** | Europe | High |
| **France** | Europe | High |
| **Gabon** | Africa | Upper middle |
| **Gambia** | Africa | Low |
| **Georgia** | Europe | Lower middle |
| **Germany** | Europe | High |
| **Ghana** | Africa | Low |
| **Greece** | Europe | High |
| **Guatemala** | Americas | Lower middle |
| **Guinea** | Africa | Low |
| **Honduras** | Americas | Lower middle |
| **Hungary** | Europe | Upper middle |
| **Iceland** | Europe | High |
| **India** | South-East Asia | Low |
| **Indonesia** | South-East Asia | Lower middle |
| **Iran (Islamic Republic of)** | Eastern Mediterranean | Lower middle |
| **Iraq** | Eastern Mediterranean | Lower middle |
| **Ireland** | Europe | High |
| **Israel** | Europe | High |
| **Italy** | Europe | High |
| **Jamaica** | Americas | Lower middle |

| MEMBER STATES OF WHO AND ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | WHO REGION | WORLD BANK INCOME CATEGORY |
|---|---|---|
| **Japan** | Western Pacific | High |
| **Kazakhstan** | Europe | Lower middle |
| **Kenya** | Africa | Low |
| **Kyrgyzstan** | Europe | Low |
| **Lao People's Democratic Republic** | Western Pacific | Low |
| **Latvia** | Europe | Upper middle |
| **Lebanon** | Eastern Mediterranean | Upper middle |
| **Lesotho** | Africa | Low |
| **Lithuania** | Europe | Upper middle |
| **Luxembourg** | Europe | High |
| **Madagascar** | Africa | Low |
| **Malawi** | Africa | Low |
| **Malaysia** | Western Pacific | Upper middle |
| **Mali** | Africa | Low |
| **Malta** | Europe | High |
| **Mauritania** | Africa | Low |
| **Mauritius** | Africa | Upper middle |
| **Mexico** | Americas | Upper middle |
| **Mongolia** | Western Pacific | Low |
| **Montenegro** | Europe | Lower middle |
| **Mozambique** | Africa | Low |
| **Myanmar** | Western Pacific | Low |
| **Namibia** | Africa | Lower middle |
| **Netherlands** | Europe | High |
| **New Caledonia (1)** | Western Pacific | High |
| **New Zealand** | Western Pacific | High |
| **Nicaragua** | Americas | Low |
| **Niger** | Africa | Low |
| **Nigeria** | Africa | Low |
| **Norway** | Europe | High |
| **Pakistan** | Eastern Mediterranean | Low |
| **Palau** | Western Pacific | Upper middle |
| **Panama** | Americas | Upper middle |
| **Papua New Guinea** | Western Pacific | Low |
| **Paraguay** | Americas | Lower middle |

| MEMBER STATES OF WHO AND ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | WHO REGION | WORLD BANK INCOME CATEGORY |
|---|---|---|
| **Peru** | Americas | Lower middle |
| **Philippines** | Western Pacific | Lower middle |
| **Poland** | Europe | Upper middle |
| **Portugal** | Europe | High |
| **Qatar** | Eastern Mediterranean | High |
| **Republic of Korea** | Western Pacific | High |
| **Republic of Moldova** | Europe | Low |
| **Romania** | Europe | Lower middle |
| **Russian Federation** | Europe | Upper middle |
| **Rwanda** | Africa | Low |
| **Saint Lucia** | Americas | Upper middle |
| **Samoa** | Western Pacific | Lower middle |
| **Saudi Arabia** | Eastern Mediterranean | High |
| **Senegal** | Africa | Low |
| **Serbia** | Europe | Lower middle |
| **Sierra Leone** | Africa | Low |
| **Singapore** | Western Pacific | High |
| **Slovakia** | Europe | Upper middle |
| **Slovenia** | Europe | High |
| **South Africa** | Africa | Upper middle |
| **Spain** | Europe | High |
| **Sri Lanka** | South-East Asia | Lower middle |
| **Suriname** | Americas | Lower middle |
| **Sweden** | Europe | High |
| **Switzerland** | Europe | High |
| **Syrian Arab Republic** | Eastern Mediterranean | Lower middle |
| **Thailand** | South-East Asia | Lower middle |
| **The former Yugoslav Republic of Macedonia** | Europe | Lower middle |
| **Tokelau (2)** | Western Pacific | Lower middle |
| **Tonga** | Western Pacific | Lower middle |
| **Trinidad and Tobago** | Americas | Upper middle |
| **Tunisia** | Eastern Mediterranean | Lower middle |
| **Turkey** | Europe | Upper middle |
| **Uganda** | Africa | Low |

| MEMBER STATES OF WHO AND ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | WHO REGION | WORLD BANK INCOME CATEGORY |
|---|---|---|
| **Ukraine** | Europe | Lower middle |
| **United Arab Emirates** | Eastern Mediterranean | High |
| **United Kingdom of Great Britain and Northern Ireland** | Europe | High |
| **United Republic of Tanzania** | Americas | Low |
| **United States of America** | Americas | High |
| **Uruguay** | Americas | Upper middle |
| **Uzbekistan** | Europe | Low |
| **Viet Nam** | Western Pacific | Low |
| **West Bank and Gaza Strip (1)** | Eastern Mediterranean | Lower middle |
| **Yemen** | Eastern Mediterranean | Low |
| **Zambia** | Africa | Low |
| **Zimbabwe** | Africa | Low |

| COUNTRY INCOME CATEGORIES | GNI PER CAPITA IN US$ (ATLAS METHODOLOGY) 2003 |
|---|---|
| **Low income** | <= 765 |
| **Lower middle income** | 766–3,035 |
| **Upper middle income** | 3,036–9,385 |
| **High income** | > 9,386 |

1 Areas or territories that are not Member States of WHO.

2 Associate Member of WHO.

# Appendix 2

## List of respondents

| MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | NAME OF THE RESPONDENT(S) | ORGANIZATION, ASSOCIATION, OR NGO |
|---|---|---|
| **Afghanistan** | Haji Omara Khan Muneeb | Afghan Disabled Union (ADU) |
| | Ruhullah Nassery | Ministry of Health |
| **Albania** | Viktor Lami | Association Internationale de Recherche scientifique en faveur des personnes Handicapées Mentales (AIRHM) |
| **Algeria** | Aïcha Berriche | Handicap international - Mission Algérie |
| | Aïda Hakimi Osmanbégovic | |
| **Angola** | Silva Lopes Etiambulo Agostinho | Associacao Nacional dos Deficientes de Angola (ANDA) |
| **Armenia** | Khachatur Gasparyan | Association of Child Psychiatrists and Psychologists (ACPP) |
| | Maruke Yeghiyan | |
| | Armen Soghoyan | M. Heratsi State Medical University |
| **Argentina** | Hilda M. De Aubert | Federation Argentina de Entidades pro Atenci_n a las Personas con Discapacidad Intelectual y a sus Familias (FENDIM) |
| **Australia** | Tim Beard | Australian Institute of Health and Welfare |
| | Xingyan Wen | |
| | Susan Hayes | University of Sydney |
| | Lisa Mitchell | Community Services and Indigenous Affairs |
| **Austria** | Ernst Berger | Neurologisches Zentrum Rosenhuegel |
| **Bangladesh** | Anika Rahman Lipy | Centre for Disability and Development (CDD) |
| **Barbados** | Boneta Phillips | Barbados Council for the Disabled |
| | Goldwin Wdwards | Children's Development Centre |
| **Belarus** | Pavel Rynkov | Ministry of Health |
| **Belgium** | Pol Gerits | Ministère des Affaires sociales de la Santé publique et de l'Environnement |
| **Belize** | Peter A. August | Belizean Assembly of & for Persons with Disabilities (BAPD) |
| | Michael Pitts | |
| **Benin** | Emilie Fiossi-Kpadonou | Université d'Abomey Calavi |
| **Bolivia** | Gonzalo Rivero Chavez | Centro de Rehabilitación Fisíca y Educación Especial (CEREFE) |
| | Ricardo Quiroga | |
| | Rodolfo López Hartman | Ministry of Health |
| **Bosnia and Herzegovina** | Joka Simic Blagovcanin | Ministry of Health and Social Protection |
| **Botswana** | Virginia S. Chakalisa | Ministry of Health |
| | Buzwani Ngada | |
| **Brazil** | Francisco B. Assumpção | Instituto de Psicologia da Universidade de São Paulo |
| | Flavia Cintra | Instituto Paradigma |
| | Renato Laurenti | |
| | Naira Rodrigues | |
| | Romeu Kazumi Sassak | |
| | Heloisa Brunow Ventura Di Nubila | WHO Collaborating Centre for the Family of International Classifications in Portuguese |
| | Antonio Carlos Sestaro | Federação Brasileira das Associações de Sindrome de Down |

| MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | NAME OF THE RESPONDENT(S) | ORGANIZATION, ASSOCIATION, OR NGO |
|---|---|---|
| **Brunei Darrusalam** | Abang Bennet Taha | Raja Isteri Pengiran Anak Saleha (RIPAS) Hospital |
| **Bulgaria** | Nadezhda Harizanova | Ministry of Labour and Social Policy |
| | Slavka Nikolova Kukova | Bulgarian Association for Persons with Intellectual Disabilities (BAPID) |
| **Burundi** | Polycarpe Nduwayo | Ministère de la Santé Publique |
| **Cambodia** | Sody Ang | Ministry of Health |
| **Cameroon** | Bakang Bitep Bitep Andre | Aide et Assistance aux Invalides et Handicapés |
| | Dieudonné Bignomo Mengela | Fonds des Invalides du Cameroun |
| **Canada** | Nathalie Garcin | Miriam Home and Services & l'Intégrale; Queen's University; Université du Québec à Montréal (UQAM) |
| **Chad** | Hassan Terab | Ministère de l'action sociale et de la famille |
| | Saklah Djimadoungar | Réinsertion des personnes handicapées |
| **Chile** | Alberto Minoletti | Ministerio de Salud |
| | Andrea Poblete | |
| **China** | Minjie Wang | Nanjing Brain Hospital |
| **China - Hong Kong Special Administrative Region (1)** | Henry Wai Ming Kwok | Kwai Chung Hospital |
| **Colombia** | Miguel Sabogal Garcia | La Asociación Colombiana Para la Salud Mental |
| | José Posada | Fundación Saldarriaga Concha y Experto en Salud Mental en Colombia |
| | Maria Vilma Restrepo | Universidad de Antioquia |
| | Jenny Garcia Valencia | |
| **Comoros** | Said Hassan Sitti Hadidja | Ministère de la Santé, de la Condition Féminine et des Affaires Sociales |
| **Republic of the Congo** | Gilbert Boumba | L'École spéciale de Brazzaville et son Association "Mille soucis, 2000 Sourires" |
| | Alain Maxime Mouanga | Centre Hospitalier et Universitaire de Brazzaville |
| **Cook Islands** | Tearoa Iorangi | Ministry of Health |
| | Daniel Roro | |
| | Donna Smith | |
| **Costa Rica** | Carmen Macanche Baltodano | Ministerio de Salud |
| | José Alberto Blanco Mendoza | Consejo Nacional de Rehabilitación y Educación Especial |
| **Côte d'Ivoire** | Marguerite Te Bonle Diawar | Institut national de Santé publique |
| **Croatia** | Sandra Cirkinagic | Association for Promoting Inclusion |
| **Cuba** | Tatiana Chkout | Ministerio de Trabaho y Seguridad Social |
| | Yusimi Campos Suarez | |
| | Mario Pichardo Diaz | Organización Panamericana de la Salud – Cuba |
| | Marcia Cobaz Ruiz | Ministerio de Salud Publica |
| **Cyprus** | Evangelos Anastassiou | Athalassa Hospital |
| | Marina Payiatsov | Committee for the Protection of the Rights of Persons with a Mental Handicap (CPRPMH) |
| | Stella Playbell | |
| **Czech Republic** | Jitka Bartonova | Prague Psychiatric Centre |
| | Eva Dragomirecka | |

| MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | NAME OF THE RESPONDENT(S) | ORGANIZATION, ASSOCIATION, OR NGO |
|---|---|---|
| **Democratic Republic of the Congo** | Nza'kay Lende Kipupila | Association d'Entraide Médico-Sociale (AEMS-ASBL) |
| **Denmark** | Mogens Wiederholt | Center for Ligebehandling af Handicappede |
| **Dominican Republic** | José Mieses | Ministry of Health |
| | Franklin J.Gómez Montero | Secretaria de Estado de Salud Publica y Asistencia Social |
| | Ivonne Soto | |
| | Escarle Peña | Consejo Nacional de Discapacidad (CONADIS) |
| **Egypt** | Nasser Loza | Ministry of Health & Population |
| **El Salvador** | Eva Mateu de Mayorga | Ministerio de Salud |
| **Estonia** | Agne Raudmees | Estonian Mentally Disabled Persons Support Organization (EVPIT) |
| **Ethiopia** | Ato Asfa Ashengo Agago | Ministry of Labor and Social Affairs |
| | Mesfin Araya | Addis Ababa University |
| **Finland** | Sari Kauppinen | STAKES National Research and Development Agency for Welfare and Health |
| | Kristian Wahlbeck | |
| **France** | Martine Barres | Direction générale de l'action sociale |
| | Laurent Cocquebert | Union Nationale des Associations de Parents et Amis de Personnes Handicapées Mentales (UNAPEI) |
| | Julie Laubard | |
| **Gabon** | Frédéric Mbungu Mabiala | Centre National de Santé Mentale |
| **Gambia** | Musa M. Jagne | Gambia Future Hands on Disabled Persons |
| | Assan Sinyan | Department of Social Welfare |
| **Georgia** | Manana Sharashidze | Georgian Association for Mental Health |
| **Germany** | Gerhard Hegendörfer | Bundesministerium für Gesundheit und Soziale Sicherung |
| | Thomas Stracke | |
| | Johannes Schaedler | Zentrum für Planung und Evaluation Sozialer Dienste; University of Siegen |
| **Ghana** | Salome François | New Horizon School Association |
| **Greece** | H. Assimopoulos | Athens University Medical School |
| | S. Diareme | |
| | G. Kolaitis | |
| | E. Soumaki | |
| | John Tsiantis | |
| | D. Giannak Opoulou | Association for the Psychosocial Health of Children and Adolescents (APHCA) |
| **Guatemala** | Juan Fernando Guzman Coronado | Ministerio de Salud Pública y Asistencia Social |
| | Elena Alejandra Ortiz Flores | |
| | Maria Alejandra Flores | |
| | Mario Gudiel Lemus | |
| | Edna G. Palomo | |
| | Carlos Layle Romero | |

| MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | NAME OF THE RESPONDENT(S) | ORGANIZATION, ASSOCIATION, OR NGO |
|---|---|---|
| **Guinea** | Mariama Barry | Federation guineenne pour la promotion des associations de et pour personnes handicapées (FEGUIPAH) |
| | Mohamed Camara | |
| | Aboubacar Kamballah Koulibaly | Ministère des Affaires Sociales, Promotion Feminine et de l'Enfance |
| **Honduras** | Gladys E. Gonzàlez | Instituto Juana Leclerc |
| | Esmeralda Moncada | |
| | Yolany Montes | |
| | Maribel Chacòn de Reinoso | |
| **Hungary** | Istvan Bitter | Semmelweis University |
| | Zsuzsa Csato | Federation of NGOs of persons with Chronic Illnesses |
| **Iceland** | Dóra S. Bjarnason | Iceland University of Education |
| **India** | Manju Mehta | All India Institute of Medical Sciences |
| | Suman Sinha | WHO Office India |
| **Indonesia** | Natalingrum Sukmarini | External consultant to the WHO Indonesia Office |
| **Iran (Islamic Republic of)** | Sayyed Ali Samadi | Valiasr Rehabilitation Foundation for Mentally Retarded Children |
| **Iraq** | Salih Al Hasnawi | National Mental Health Council |
| **Ireland** | Suzanne Quinn | University College Dublin |
| | Patricia Noonan Walsh | |
| **Israel** | Joav Merrick | Ministry of Social Affairs |
| **Italy** | Teresa di Fiandra | Ministry of Health |
| | Giampalo La Malfa | Italian Society for Mental retardation (SIRM),/University of Florence |
| **Jamaica** | Grace Duncan | Jamaican Association on Mental Retardation |
| **Japan** | Keiko Sodeyama | Japan League on Intellectual Disabilites |
| **Kazakhstan** | Aigul Tastanova | Ministry of Health |
| **Kenya** | David Musau Kiima | Ministry of Health |
| **Kyrgyzstan** | Janyl Alymkulova | Ministry of Health |
| | Sabira Musabayev | |
| | Abjalal Begmatov | Republican Center for Mental Health (RCMH) |
| | Tamilla Kadyrova | Kyrgyz State Medical Academy (CGMA) |
| **Lao People's Democratic Republic** | Chantharavady Choulamany | Mahosot Hospital |
| | Sichanh Sitthiphonh | Handicap International |
| **Latvia** | Maris Taube | State Mental Health Agency |
| **Lebanon** | Radwan Saleh Abdullah | Palestinian Social Youth Association |
| | Samia Ghazzaoui | Ministry of Health |
| | Mohamed Ali Kanaan | |
| | Rita Saba | Ministère des affaires sociales |
| | Gaby Saliba | Institut des Sciences Sociales |
| **Lesotho** | K. Motsamai | Lesotho Society of Mentally Handicapped Persons, Parents & Families (LSMHP) |

| MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | NAME OF THE RESPONDENT(S) | ORGANIZATION, ASSOCIATION, OR NGO |
|---|---|---|
| **Lithuania** | Ona Davidoniene | State Mental Health Centre |
| | Lina Malisauskaite | Lithuanian welfare society for persons with mental disability (Viltis) |
| | Dainius Puras | Vilnius University |
| **Luxembourg** | Carole Warnier | Ministère de la Famille et de l'Intégration |
| **Madagascar** | Sonia Andrianabela | Ministère de la Santé et du Planning Familial |
| **Malaysia** | Mettilda John | Dignity and Services (D&S) |
| | Aminah Bee Mohd Kassim | Ministry of Health |
| | Mangama A/P Murugesu | Society for the Severely Mentally Handicapped |
| | Wong Nam Sang | Disabled Personss' International (DPI) Asia-Pacific Region |
| **Malawi** | Immaculate Chamangwana | Zomba Mental Health Hospital |
| **Mali** | Souleymane Coulibaly | Hôpital du point G Bamako |
| **Malta** | Jean Karl Soler | Malta College of Family Doctors |
| **Mauritania** | Houssein Dia | Centre Neuro-Psychiatrique |
| **Mauritius** | Irene Alessandri | Association de Parents d'Enfants Inadaptés de l'Ile Maurice (APEIM) |
| | Azize Bankur | Ministry of Social Security |
| **Mexico** | Lauro Suarez Alcocer | Ministerio de la Salud |
| | Virginia Gonzalez Torres | |
| | Maria Elena Marquez Caraveo | Hospital Psiquiatrico Juan N. Navarro |
| **Mongolia** | Ayushjav Bayankhuu | Mental Health and Narcology Center |
| | Tsetsegdary Gombodorj | Ministry of Health |
| **Montenegro** | Zorica Otasevic Barac | Clinical Centre of Montenegro Klinika za mentalno zdravlje |
| **Mozambique** | Lidia Gouveia | Ministério da Saude |
| | Victor Igreja | Associação Esperança Para Todos |
| **Myanmar** | Hla Htay | Ministry of Health |
| **Namibia** | A. Barandonga | Ministry of Health and Social Service |
| **Netherlands** | Will Buntinx | University of Maastricht |
| **New Caledonia (1)** | Sylvie Barny | Direction des Affaires Sanitaires et Sociales de Nouvelle-Calédonie (DASS) |
| | Chantal Donnet | |
| | Patrick Devivies | |
| | Alain Grabias | |
| | Marie-Claire Tramoni | |
| **New Zealand** | Rob Gill | Ministry of Health |
| **Nicaragua** | Gerardo Mejìa Baltodano | Asociación Nicaraguense para la Integración Comunitaria (ASNIC) / Hospital "Manuel de Jesus Rivera" |
| | Héctor Collado | Ministerio de Salud |
| | Carlos Fletes Gonzalez | |
| | Wilber Torrez Morales | Organización de Revolucionarios Discapacitados (ORD) |
| **Niger** | Diofo Beido | Fédération Nigerienne des Personnes Handicapées (FNPH) |

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|---|---|---|
| **Nigeria** | Bukola Ruth Akinbola | University of Ibadan |
| | Stella Kanu | |
| | Olayinka Omigbodun | University College Hospital |
| **Norway** | Freja Ulvestad Kärki | Directorate for Health and Social Affairs |
| **Pakistan** | Ghulam Nabi Nizamani | All Sanghar Handicapped Association (ASHA) |
| | Khalid Saeed | WHO Office Pakistan |
| **Palau** | Annabel Lyman | Ministry of Health |
| **Panama** | Elena Castro | Oficina Nacional de Salud Integral para la Población con Discapacidad (ONSIP - MINSA) |
| | Laura de Díaz | Instituto Nacional de Salud Mental de Panamá |
| | Eira González | |
| | Juana del C. Herrera | |
| | Antonio De León | |
| | Carmita de Lima | |
| | Bethania B. de Lin | |
| | Lisbeth Morales | |
| | Elmer L. Rodríguez | |
| | Itzel Fernández | Instituto Nacional de Habilitación Especial |
| | Eneida Ferrer F | Secretaria Nacional para la Integración Social de las Personas con Discapacidad (SENADIS) |
| | Luis A. Daniel H. | Federación Nacional de Padres y Amigos de Personas con Discapacidad (FENAPADEDI-REPA) |
| | Fanía de Roach | Salud Mental Ministerio |
| | Ana Lorena Ruí | Ministerio de Vivienda |
| **Papua New Guinea** | Graeme Leach | Callan Services for persons with a disability in Papua New Guinea |
| **Paraguay** | Ruth Irala de Kurz | Ministerio de Salud Publica y Bienestar Social |
| | Javier Espíndola | Ministry of Health |
| **Peru** | Tulio Quevedo Linares | Ministerio de Salud |
| | Beatríz Seclén Santisteban | |
| **Philippines** | Rhodora Andrea M. Concepcion | World Association for Psychosocial Rehabilitation-Philiippines |
| | Yolanda E. Oliveros | Department of Health |
| **Poland** | Jan Czeslaw Czabala | Institute of Psychiatry and Neurology |
| | Grazyna Herczynska | |
| | Anna Firkowska | Academy of Special Education |
| | Joanna Glodkowsa | |
| | Krystyna Mrugalska | Polish Association of Persons with Mental Handicap |
| **Portugal** | Maria João Heitor Dos Santos | Direcção Geral da Saude |
| **Qatar** | Eddie M. Denning | Shafallah Center for Children with Special Needs |
| **Republic of Korea** | Myoung-Gyun Ko | Korean Association for the Mentally Disabled |
| | Tae-Yeon Hwang | Yongin Mental Hospital |
| **Republic of Moldova** | Anatol Nacu | Ministry of Health and Social Protection |

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|---|---|---|
| **Republic of Viet Nam** | Frederique F. Berger | Family Medical Practice (FMP) center |
| | Ly Ngoc Kinh | Ministry of Health |
| | Do Thuy Lan | National Psychiatric Hospital |
| | Cao Va Tuan | |
| | Nghiem Xuan Tue | National coordinating council on disability |
| **Romania** | Alexandra Carmen Câra | Family physician |
| **Russian Federation** | Zurab Ilyich Kekelidze | Serbsky National Research Center for Social and Forensic Psychiatry |
| **Rwanda** | Yvonne Kayiteshonga | Handicap international - Rwanda |
| | Augustin Nziguheba | |
| | Patona Mulisanze | Ministère de la Santé |
| **Samoa** | La-Toya Lee | Ministry of Health |
| | Ian Parkin | |
| | Fuatino Utumapu | |
| **Saudi Arabia** | Abdul Hameed Al Habeeb | Mental Health and Social Sciences |
| | Naseem A. Qureshi | |
| **Senegal** | Mamadou Habib Thiam | Ministère de santé et de la Prévention Médicale |
| **Serbia** | Aleksandra Milicevic Kalasic | City Institute of Gerontology, Home Treatment and Care |
| | Sladjana Markovic | Ministry of Labour, Employment and Social Policy |
| **Sierra Leone** | Edward A. Nahim | Ministry of Health and Sanitation |
| **Singapore** | Hsin Chuan Alex Su | Ministry of Health |
| | Khaw Boon Wan | |
| **Slovakia** | Mišová Iveta | Association for Help to the Mentally Handicapped Persons in Slovakia |
| | Róbert Lezo | Spolocnosti Downovho syndromu na Slovensku |
| | Piatková Magdaléna | Ministry of Labour, Social Affairs and Family |
| | Mária Orgonášová | Alliance of Organizations of Disabled Persons in Slovakia |
| | Eva Palova | Ministry of Health |
| **Slovenia** | Nadja Cobal | Ministry of Health |
| | Janja Cotic Pajntar | |
| | Tomaz Jereb | National Association for Mentally Handicapped Persons of Slovenia (Sozitje) |
| | Andrej Marusic | Institute of Public Health of the Republic of Slovenia |
| **South Africa** | Pam McClaren | South Africa Federation for Mental Health |
| | Corrie Ras | |
| **Spain** | Juana Zarzuela Domínguez | Down´s Syndrome Association (ASPANIDO) |
| | Rafael Martínez-Leal | Spanish Association of Professionals in Intellectual Disabilities (AEECMR) |
| | Ramón Novell Alsina | |
| | Luis Salvador-Carulla | World Psychiatric Association – Intellectual Disability section |
| **Sri Lanka** | Raja S. Marasinghe | Central Council of Disabled Persons |

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|---|---|---|
| **Sweden** | Kent O. Ericsson | Uppsala University |
| | Helena Silfverhielm | National Board of Health and Welfare |
| **Switzerland** | Markus Buri | Office fédéral des assurances sociales |
| | Galli Carminati Giuliane | World Psychiatric Association |
| | Viviane Guerdan | Association Internationale de Recherche Scientifique en faveur des personnes Handicapées Mentales (AIRHM) |
| | Heidi Lauper | Institutions sociales suisses pour personnes handicapées (INSOS) |
| | Josée Martin | |
| **Syrian Arab Republic** | Diala El-Haj Aref | Ministry of Labour, Health and Social Affairs |
| | Ferial Hamid | Vocational Rehabilitation Institutes for the Disabled |
| | Pier Sheniara | Ministry of Health |
| **Saint Lucia** | Caroline Archibald | The National council of and for persons with disabilities |
| | Lancia Isidore | |
| **Suriname** | M. Algoe | Ministry of Health |
| **Thailand** | Panpimol Lotrakul | Rajanukul Intellectual Disability Institute |
| **The former Yugoslav Republic of Macedonia** | Vasilka Dimoska | Republic centre for support of persons with intellectual disability (PORAKA) |
| **Tonga** | Lavinia Satini | Petesaita & Alonga Disabled Centre |
| **Tokelau (1)** | Tekie T Iosefa | Ministry of Health |
| **Trinidad and Tobago** | Ian Hypolite | Ministry of Health |
| **Tunisia** | Lotfi Ben Lellahom | Ministère des Affaires Sociales, de la Solidarité des Tunisiens à l'Etranger |
| **Turkey** | Nihal Ildes | Ministry of Health |
| **Uganda** | Richard Mugisha | Persons with Disabilities Uganda |
| | Sheila Z. NDyanabangi | Ministry of Health |
| **Ukraine** | Raisa Kravchenko | Charity Association of Help to Disabled Persons with Intellectual Dissabilities (Dzherela) |
| | Igor A. Martsenkovsky | Ukrainian Institute of Social and Forensic Psychiatry and Narkology |
| | Olga Petrichenko | Ministry of Health |
| | Irina Pinchuk | Ukrainian Health Care Ministry |
| | Yuliya Zinova | WHO Office Ukraine |
| **United Arab Emirates** | Noura Ibrahim Almarri | Sharjah City for Humanitarian Services |
| **United Kingdom of Great Britain and Northern Ireland** | David Felce | International Association for the Scientific Study of Intellectual Disability (IASSID) |
| | Marion Thompson | Department of Health (Scotland) |
| | Alana Wolf | Department of Health (England) |
| **United Republic of Tanzania** | Josephine Bakhita | Amani Centre for Persons with Mental Disabilities |
| **United States of America** | Valerie Bradley | Human Services Research Institute |
| | Christopher J. Hickey | Department of Health and Human Services |
| | Charlie Lakin | University Minnesota |

| MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES | NAME OF THE RESPONDENT(S) | ORGANIZATION, ASSOCIATION, OR NGO |
|---|---|---|
| **Uruguay** | Nilda Rama Vieytes | Asociación Nacional de padres de personas con discapacidad intelectual (ANR) |
| | Alberto Della Gatta | Ministerio de Salud Publica |
| | Guillermo Manito | |
| | Gabriela Martoy | |
| **Uzbekistan** | Nargiza Khodjaeva | Ministry of Health |
| | Kharabara Grigoriy | |
| | Sunatulla SuleyManov | |
| **West Bank and Gaza Strip (1)** | Othman Karameh | Ministry of Health |
| | Ayesh M. Samour | |
| **Yemen** | Raja Abdulah Ahmed Almasabi | Arab Human Rights Foundation |
| **Zambia** | James Mung'omba | Zambia Association for Children with Learning Disabilities (ZACALD) |
| | Kalunga Mahone Eunice | |
| **Zimbabwe** | Alice B. Chatindo | L'Arche Zimbabwe |
| | Munyaradzi B. T. Nyanhongo | |
| | Christine Tawengwa | |
| | Tawengwa Chinyowa | |
| | Dorcas Shirley Sithole | Ministry of Health and Child Welfare |
| | Elizabeth Matare | Dominican Convent Fundayi House |

**(1) Associate Members of WHO, Areas and Territories**

# Appendix 3

## Atlas-ID questionnaire

Terms with * are defined in the glossary of terms.

### 1. Definition

1.1 What term is more frequently used to describe intellectual disabilities* in your country? (If more than one, rank the most commonly used terms with 1 being the most common term. Choose the most similar equivalent in English)

| | | |
|---|---|---|
| | Developmental disabilities | Mental disability |
| | Intellectual disabilities | Mental handicap |
| | Learning disabilities | Mental retardation |
| | Mental deficiency | Mental subnormality |
| | Other (Please specify): | |

1.2 What diagnostic and/or classification* is most often used in your country to determine the presence of intellectual disabilities?

☐ AAMR criteria ☐ ICD-10

☐ DSM-IV ☐ ICF

☐ Professional opinion ☐ Other (Please specify) _____

### 2. Epidemiology of intellectual disabilities

2.1 Could you estimate the number of persons with intellectual disability in your country (per 100,000 inhabitants)? _____

2.1.1 What is the information source and year for this figure? _____

2.2 In the last year, how many persons with intellectual disability were in touch with intellectual disabilities services (per 100,000 inhabitants)? _____

2.2.1 What is the information source and year for this figure? _____

### 3. Policies, programmes and legislation

3.1 Does your country have a specific national policy/programme* related to the intellectual disabilities field?

☐ Yes, for adults only

☐ Yes, for children, adolescents and adults

☐ Yes, for children and adolescents only

☐ No

3.1.1 If yes, in which type of policy is it addressed? (Check all that apply)

☐ Disability Act ☐ Income

☐ Education ☐ Labour

☐ Health ☐ Mental Health

☐ Housing ☐ Social Welfare

☐ Human Right s ☐ Youth Protection

☐ Family ☐ Other (Please specify): _____

3.1.2 If no, are intellectual disabilities specifically addressed in any official national policy?

☐ Yes ☐ No If yes, please specify : _____

3.2 What level of government is primarily responsible for services to persons with intellectual disability?

☐ National level* ☐ Shared between levels of government

☐ Regional level*

☐ Local level* ☐ Other (Please specify): _____

3.3 Which Department funds and/or monitors programmes for adults or children/adolescents with intellectual disability? (Please rank the following, with 1 being the most responsible)

| | Children/Adolescents | Adults |
|---|---|---|
| Disability | | |
| Education | | |
| Family Welfare | | |
| Health | | |
| Housing | | |
| Justice | | |
| Income | | |
| Labour | | |
| Mental Health | | |
| Social Welfare | | |
| Youth Protection | | |
| Other: (Please specify) | | |

3.4 Does any law strive to protect persons with intellectual disability?

☐ Yes ☐ No

3.4.1 If yes, please specify the name of this/these law(s): _____

3.5 Is there or has there been any public awareness campaign* on intellectual disabilities carried out within your country (stigma, human rights, social integration, health care, education, employment)?

☐ Yes ☐ No

3.5.1 If yes, please specify the year, topic and slogan of the latest campaign: _____

## 4. Financing and benefits

4.1 How are intellectual disabilities services in your country funded*? Please rank the following, with 1 being the most important, and attribute to each one a percentage.

☐ Tax-based funding (National/Federal government)* _____ %

☐ Out of pocket (Consumer/Patient/Family)* _____ %

☐ Social health insurance * _____ %

☐ Private insurance* _____ %

☐ External Grants* _____ %

☐ NGOs*/non-profit organizations _____ %

☐ Other (Please specify): _____ %

4.2 What percentage of all intellectual disabilities services are provided in:

(Total should equal 100%)

Public sector _____ %

Private sector _____ %

NGOs/non-profits organizations _____ %

Other (Please specify): _____ %

4.3 What government benefits* are provided (free or subsidized) to an adult with intellectual disability or a family who has a child with intellectual disability?

(Check all that apply)

- ☐ No benefits are provided
- ☐ Disability pension
- ☐ Health security
- ☐ Social security
- ☐ Subsidies for food, housing, medication and/or transportation
- ☐ Direct payment of money for a specific purpose
- ☐ Fiscal/Tax benefits
- ☐ Other (Please specify) : _____

4.4 What is the percentage of persons with intellectual disability or families of persons with intellectual disability that are actually receiving the government benefits to which they are legally entitled?

- ☐ <10%
- ☐ 11% - 25%
- ☐ 26% - 50%
- ☐ 51%-74%
- ☐ >75%

## 5. Services to children, adolescents and adults

5.1 How are social and health care services for persons with intellectual disability organized in your country (please check more than one if appropriate)

| | Yes | No |
|---|---|---|
| a) Specific services for persons with intellectual disability | ☐ | ☐ |
| b) Together with services for persons with any kind of disabilities | ☐ | ☐ |
| c) Together with services for persons with mental disorder | ☐ | ☐ |
| d) Together with services for general population | ☐ | ☐ |

e) Other (Please specify): _____

5.2 Please indicate the services that are available to adults or children/adolescents with intellectual disability:

5.2.1 **Inpatient – Residential services***

| | Children/Adolescents | | Adults | |
|---|---|---|---|---|
| | Yes | No | Yes | No |
| Short term (< 1 month) | ☐ | ☐ | ☐ | ☐ |
| Inpatient health service | ☐ | ☐ | ☐ | ☐ |
| Long term (> 1 month) | ☐ | ☐ | ☐ | ☐ |
| Support to independent living* | ☐ | ☐ | ☐ | ☐ |

| | Children/Adolescents | | Adults | |
|---|---|---|---|---|
| | Yes | No | Yes | No |
| Foster homes* | ☐ | ☐ | ☐ | ☐ |
| Group homes* | ☐ | ☐ | ☐ | ☐ |
| Nursing homes* | ☐ | ☐ | ☐ | ☐ |
| Asylum-type institutions* | ☐ | ☐ | ☐ | ☐ |
| ID exclusive | ☐ | ☐ | ☐ | ☐ |
| Mixed Mental Disability | ☐ | ☐ | ☐ | ☐ |
| General Health | ☐ | ☐ | ☐ | ☐ |
| Specific for persons with ID | ☐ | ☐ | ☐ | ☐ |
| Psychiatric* | ☐ | ☐ | ☐ | ☐ |
| Forensic* | ☐ | ☐ | ☐ | ☐ |
| Specialized in-patient psychiatric institution* | ☐ | ☐ | ☐ | ☐ |

Other (Please specify): _____

5.2.2 **Out patient care***

| | Children/Adolescents | | Adults | |
|---|---|---|---|---|
| | Yes | No | Yes | No |
| Primary health services* | ☐ | ☐ | ☐ | ☐ |
| Specialized health services* | ☐ | ☐ | ☐ | ☐ |
| Screening/Assessment/Orientation* | ☐ | ☐ | ☐ | ☐ |
| Early intervention* | ☐ | ☐ | ☐ | ☐ |
| Individual support/Case management* | ☐ | ☐ | ☐ | ☐ |
| Specialized psychological/psychiatric interventions | ☐ | ☐ | ☐ | ☐ |

Other (Please specify): _____

5.2.3 **Rehabilitation/Day care ***

| | Children/Adolescents | | Adults | |
|---|---|---|---|---|
| | Yes | No | Yes | No |
| Psycho-social Rehabilitation* | ☐ | ☐ | ☐ | ☐ |
| Physical Rehabilitation* | ☐ | ☐ | ☐ | ☐ |
| Day centre/hospital | ☐ | ☐ | ☐ | ☐ |

Other (Please specify): _____

5.2.4 **Education**

| | Children/Adolescents | | Adults | |
|---|---|---|---|---|
| | Yes | No | Yes | No |
| Special Schools* | ☐ | ☐ | | |
| Special class in regular/integrated school* | ☐ | ☐ | | |
| Support in regular class* | ☐ | ☐ | | |
| Homebound services* | ☐ | ☐ | | |
| Pre-school/Kindergarten | ☐ | ☐ | | |

| | Children/Adolescents | | Adults | |
|---|---|---|---|---|
| | Yes | No | Yes | No |
| Literacy programme* | ☐ | ☐ | ☐ | ☐ |
| Adult education programme* | ☐ | ☐ | ☐ | ☐ |
| Professional training* | ☐ | ☐ | ☐ | ☐ |
| Other (Please specify): _____ | ☐ | ☐ | ☐ | ☐ |

5.2.5 **Occupational/Vocational/Work services***

| | Adults | |
|---|---|---|
| | Yes | No |
| Sheltered employment* | ☐ | ☐ |
| Work stations* | ☐ | ☐ |
| Supported employment* | ☐ | ☐ |
| General work skills, training or development* | ☐ | ☐ |
| Other (Please specify): _____ | ☐ | ☐ |

5.2.6 **Other services**

| | Children/Adolescents | | Adults | |
|---|---|---|---|---|
| | Yes | No | Yes | No |
| Leisure activities* | ☐ | ☐ | ☐ | ☐ |
| Transportation* | ☐ | ☐ | ☐ | ☐ |
| Assistive technology* | ☐ | ☐ | ☐ | ☐ |
| Rights/advocacy support* | ☐ | ☐ | ☐ | ☐ |
| Supply of meal/food | ☐ | ☐ | ☐ | ☐ |
| 5.2.7. **Other** (Please specify): _____ | ☐ | ☐ | ☐ | ☐ |

5.3 Please indicate the preventive intellectual disabilities services* available in your country.

☐ Supplementation of diet, e.g. iodination of salts, folic acid in bread

☐ Tests to detect phenylketonuria, lead, hypothyroidism etc.

☐ Genetic counselling and prenatal testing

☐ Programmes related to prevention of alcohol/drug abuse during pregnancy

☐ Other (Please specify): _____

5.4 Are there special provisions within the justice system for offenders with intellectual disability*?

☐ Children/Adolescents ☐ Adults ☐ None

5.5 Is there a governmental intellectual disabilities protection system* for:

☐ Children/Adolescents ☐ Adults ☐ None

5.6 Do the following issues have an impact on access to intellectual disabilities services in a timely manner?

5.6.1 Socio-economical status

☐ Great impact ☐ Some impact ☐ No impact

5.6.2 Geographical location (Territory)

☐ Great impact ☐ Some impact ☐ No impact

5.6.3 Urban / Rural location

☐ Great impact ☐ Some impact ☐ No impact

5.6.4 Ethnicity

☐ Great impact ☐ Some impact ☐ No impact

5.6.5 Religion

☐ Great impact ☐ Some impact ☐ No impact

5.6.6. Other (Please specify):

☐ Great impact ☐ Some impact ☐ No impact

5.7 Is there a publication or reference that refers to intellectual disabilities services in your country?

☐ Yes ☐ No

If yes, please give the reference and/or attach a copy of the publication(s). _____

## 6. Services to families

6.1 Please indicate the services available in most of the regions of your country to families of persons with intellectual disability (check all that are available):

☐ Psychological support/counselling

☐ Education on intellectual disabilities

☐ Respite care*

☐ Home aid*

☐ Rights/advocacy support*

☐ Other (Please specify): _____

## 7. Human resources

7.1. Which professionals are more involved in working with persons with intellectual disability? (Please rank all that apply, with 1 being the highest)

| | | | |
|---|---|---|---|
| | Physicians | | Psychologists |
| | Nurses | | Special educators |
| | Occupational therapists | | Speech and language therapists |
| | Paediatricians | | Social workers |
| | Physiotherapists | | Art/music therapists |
| | Primary health careworkers | | Teachers |
| | Psychiatrists | | Other (Please specify): |

7.2 Which professionals have the opportunity for in-service training* in the support of persons with intellectual disability?

☐ Physicians ☐ Psychologists

☐ Nurses ☐ Special educators

☐ Occupational therapists ☐ Speech and language therapists

☐ Paediatricians ☐ Social workers

- ☐ Physiotherapists
- ☐ Primary health care workers
- ☐ Psychiatrists
- ☐ Art/music therapists
- ☐ Teachers
- ☐ Other (Please specify): _____

7.3 Is there a training module in intellectual disabilities incorporated into the under-graduate* or graduate* curriculum within the country? (Check all that apply)

| | Under-graduate | Graduate | No training offered |
|---|---|---|---|
| Physicians | ☐ | ☐ | ☐ |
| Nurses | ☐ | ☐ | ☐ |
| Occupational therapists | ☐ | ☐ | ☐ |
| Paediatricians | ☐ | ☐ | ☐ |
| Physiotherapists | ☐ | ☐ | ☐ |
| Primary health care workers | ☐ | ☐ | ☐ |
| Psychiatrists | ☐ | ☐ | ☐ |
| Psychologists | ☐ | ☐ | ☐ |
| Special educators | ☐ | ☐ | ☐ |
| Speech and language therapists | ☐ | ☐ | ☐ |
| Social workers | ☐ | ☐ | ☐ |
| Art/music therapists | ☐ | ☐ | ☐ |
| Teachers | ☐ | ☐ | ☐ |
| Other (please specify): _____ | ☐ | ☐ | ☐ |

7.4 Are there national minimal standards of care* expected from professionals working in the field of intellectual disabilities?

7.4.1 Only for governmental organizations

☐ Yes ☐ No

7.4.2 Amongst private organizations

☐ Yes ☐ No

7.4.3 If yes, how are standards maintained? (Check all that apply).

- ☐ Professional certification and maintenance of competency
- ☐ In-service training
- ☐ Clinical supervision of workers
- ☐ Usage of clinical practice guidelines
- ☐ Just the initial habilitation
- ☐ Other (Please specify): _____

## 8. Nongovernmental Organizations (NGOs)

8.1 Are there any active national NGOs* in your country which focus mainly on intellectual disabilities?

☐ Yes ☐ No

8.1.1 If yes, please list three of these NGOs (mainly those active at the national level): _____

8.1.2 With which intellectual disabilities activities have this/these NGO/s been involved? (Check all that apply)

- ☐ Advocacy
- ☐ Direct services
- ☐ Education
- ☐ Family
- ☐ Health
- ☐ Housing
- ☐ Rehabilitation
- ☐ Work/Employment
- ☐ Human rights training
- ☐ Policy and systems development
- ☐ Prevention
- ☐ Professional development
- ☐ Support/Self-help/Empowerment*
- ☐ Other (Please specify): _____

## 9. International organizations

9.1 Are international organizations (directly or through their regional or country offices) involved in providing any assistance in the development and/or maintenance of intellectual disabilities services in your country?

☐ Yes ☐ No

9.1.1 If yes, please list three: _____

9.1.2 With which intellectual disabilities activities have this/these international organization(s) been involved? (Check all that apply)

- ☐ Advocacy
- ☐ Direct services
- ☐ Education
- ☐ Family
- ☐ Health
- ☐ Housing
- ☐ Rehabilitation
- ☐ Work/Employment
- ☐ Human rights training
- ☐ Policy and systems development
- ☐ Prevention
- ☐ Professional development
- ☐ Support/Self-help/Empowerment
- ☐ Other (Please specify): _____

## 10. Data collection and research

If different from previously stated on page 1, please indicate the contact details of the person who completed the following section:

10.1 Are specific data about intellectual disabilities included in any of your country's Annual Reports*?

☐ Yes ☐ No

10.1.1 If yes, please give the reference and/or attach a copy of the publication(s). _____

10.2 Is there any epidemiological data* collection system for intellectual disabilities?

☐ Yes ☐ No

10.2.1 If yes, please give the reference and/or attach a copy of the publication(s). _____

10.3 Is there any services delivery data collection system* for intellectual disabilities?

☐ Yes ☐ No

10.3.1 If yes, please give the reference and/or attach a copy of the publication(s). _____

10.4 Which are the best sources to obtain epidemiological data on persons with intellectual disability in your country? (Please specify):

_____

10.5 Is there any research on intellectual disabilities done in your country?

☐ Yes ☐ No

10.5.1 If yes, which types of organizations are carrying out research on intellectual disabilities in your country? (Check all that apply)

☐ Government
☐ International organization or supranational
☐ Universities
☐ NGOs
☐ Pharmaceutical industry
☐ Foundations
☐ Other (Please specify): _____

10.5.2 If yes, what are the sources of funding of this/these research on intellectual disabilities in your country? (Check all that apply)

☐ Public
☐ Private
☐ Joint public/private sector ventures
☐ International organization or supranational
☐ NGOs
☐ Other (Please specify): _____

10.5.3 Is there a national research centre* which does research in intellectual disabilities in your country?

☐ Yes ☐ No

If yes, please list contact details (head of research, address, website, etc.) _____

10.5.4 Name three common areas of research in intellectual disabilities being carried out in your country:

_____

_____

_____

## 11. Comments

11.1 Do you have any comments on this questionnaire or other information that you want to include? If so, please use the box below to give us your feedback.

# Appendix 4

## Glossary of terms used in the Atlas-ID questionnaire

The definitions used in this glossary are simply working definitions for the purpose of this project and are not official WHO definitions. In case of discrepancies between glossary translations, the English version should prevail.

**Adult education programme:**
Programme that provides a full range of educational services from basic literacy through the primary diploma and college courses.

**Annual reports:**
Information covering health or social services utilization, available resources (services, human resources), programmes and allocation of funds for each year by the government.

**Assistive technology:**
Any item or product system that is used to increase, maintain, or improve functional capabilities of individuals with disability.

**Asylum-type institutions:**
Large facility which is not community integrated and which offers general care for residents including a place to live, work, activities during the day, medical and psychiatric care. As some asylums are exclusively for the housing of persons with intellectual disability, others have specific settings for persons with ID, to elderly persons or are destined to receive persons with intellectual disability as well as persons with mental disabilities.

**Data collection system:**
An organized information system for gathering information about service utilization.

**Diagnostic/Classification:**
There are numerous diagnostic and/or classifications of intellectual disabilities. The four most commonly used ones are the AAMR definition, the DSM-IV, the ICD, and ICF.

**a)** *American Association for Mental Retardation (AAMR) classification (2002):* "Mental retardation is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18."

**b)** *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV):* definition "Significantly sub average general intellectual functioning that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, work, leisure, health, and safety. The onset must occur before age 18 years." According to the association, there are five degrees of mental retardation: mild, moderate, severe, profound, and severity unspecified.

**c)** *International Statistical Classification of Disease and Related Health Problems (ICD):* "Mental retardation is a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, skills which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities. Degrees of mental retardation are conventionally estimated by standardized intelligence tests. These measures provide an approximate indication of the degree of mental retardation [mild mental retardation, moderate mental retardation, severe mental retardation, profound mental retardation, other mental retardation, and unspecified mental retardation]." (WHO, 1992).

**d)** *The International Classification of Functioning, Disability and Health (ICF):* The ICF proposed that the conception of intellectual disability no longer be regarded as a disease or even the simple physical or psychological consequence of disease, but rather as a problem of functioning of the whole person. In this model, functioning is considered as interaction of the person with his environment and is the result of interactions between a person who is experiencing health problems and environmental factors. The picture produced by this combination of factors and dimensions is of "the person in his or her world" (WHO, 2001).

**Early intervention services:**
Services to children and their families for the purpose of lessening the effects of the intellectual disability condition. Early intervention may begin at any time between birth and school age.

**Empowerment:**
Mechanism whereby individuals, organizations, and communities gain strength and mastery in the management of their affairs.

**Epidemiological data:**
Epidemiological data focuses on the extent and nature of intellectual disabilities as this information is used to plan and evaluate strategies to prevent intellectual disabilities and as a guide to the management of services for those who have intellectual disabilities. It usually incorporates incidence, prevalence and frequency rates.

**Forensic residential services:**
Provision of care to persons with intellectual disability in a specialized hospital for criminal offenders.

**Foster home:**
Provision of a living arrangement in a household rather than with the family of the person with intellectual disability.

**Funding of intellectual disability services:**
Health and social services to persons with intellectual disability can be funded by one or many of the following methods:

- Tax-based funding: Way of financing services raised by general taxation.
- Out-of-pocket – Way of financing services by payments made by the user or his / her family as the need arises.
- Social insurance: Way of financing services by a fixed percentage of income that everyone above a certain level of income is required to pay to the government-administered health insurance fund which, in return, pays for part or all of consumers' services. Within those systems, persons receive care even if they don't contribute to the system due to their low-income level.
- Private insurance: Way of financing by a premium that social/health-care consumers pay voluntarily to a private insurance company which, in return, pays for part or all of their care.
- External grants: Way of financing by money provided by other countries or international organizations for direct or indirect services to persons, or a family member, with intellectual disability.

**General work skills, training or development:**
Any training for which an employee would normally be expected to undertake in order to be able to carry out the core duties associated with his / her employment.

**Government benefits:**
Benefits that are provided by the government as part of the legal rights of persons with intellectual disabilities. These benefits could be provided in different ways as monetary, access to services, personal staff care, etc.

**Governmental intellectual disabilities protective system:**
A government based protective supervision system for the protection of persons with intellectual disability and their assets. This system oversees the protection of persons with intellectual disability unable to take care of themselves, through appropriated measures to their condition and situation, while ensuring that all decisions affecting their well-being and property reflect their best interests, respect their rights and safeguard their autonomy. This type of protective supervision can take the form of a curatorship, of a tutorship, of an advisor to a person of full age or of a tutorship to a minor.

**Graduate curriculum:**
Mainstream or continuing education beyond a bachelor's degree, offered by a University or any recognized educational institution.

**Group homes:**
Community situated living facility where more than one person with intellectual disability resides.

**Home aid:**
Help at home provided to the family of a person with intellectual disabilities. Examples include parent training, counselling, and working with family members to identify, find, or provide other necessary help. The goal is to prevent the person with intellectual disability from being placed outside of the home. (Alternate term: in-home supports)

**Homebound services:**
Schooling done at home by tutors or special educators for persons with intellectual disability.

**In-service training:**
Training services offered to the personnel working with persons with intellectual disabilities during their work hours or paid extra-hours.

**Individual support/Case management services:**
Process of follow up individually to persons with intellectual disabilities, including assessment, service planning and review or process for co-ordinating services and inputs from different agencies and sectors around individual needs.

**Inpatient – residential services:**
Services where a person with intellectual disability resides.

**Intellectual disability:**
Refers to a condition of arrested or incomplete development of the mind that can occur with or without any other physical or mental disorders and is characterized by impairment of skills and overall intelligence in areas such as cognition, language, and motor and social abilities. This includes children, adolescents, adults and the elderly population.

**Leisure activities:**
Service for persons with intellectual disability, often in a facility that provides activities and support, focusing on relaxation, amusement and social interaction.

**Literacy programme:**
Refers to a programme that aims at the acquisition of the ability to read and write by persons with intellectual disability.

**Local level:**
Refers to municipal authorities.

**Minimal standards of care:**
Guidelines establishing a minimal standard to ensure proper care for the persons with intellectual disability. The professionals working in the intellectual disabilities field are expected to achieve compliance with each standard. While the standards are qualitative, they provide a tool for judging the quality of life of consumers and improve the quality and appropriateness of care and other services

**National level:**
Refers to national or federal authorities.

**National policy:**
An organized set of values, principles, objectives and areas of action to improve the situation of persons with intellectual disability in the country, the priorities among those goals and the main directions for attaining them.

**National programme:**
A national plan of action that includes the lines of action required to give effect to a policy. It describes and organizes actions aimed at the achievement of the objectives.

**National research centre:**
National centre that aims at supporting research, policy, and programme development nationwide.

**Nongovernmental organizations (NGOs):**
Voluntary organizations, charitable groups, service-user, advocacy groups or professional associations.

**Nursing homes:**
A facility for the care of individuals who do not require hospitalization and who cannot be cared at home. Usually staffed 24 hours per day.

**Occupational/Vocational/Work services:**
Broad range of services designed to address skills necessary for participation in job-related activities. Services that include job finding/development, assessment and enhancement of work-related training and skills, attitudes, and behaviours as well as provision of job experience to persons with intellectual disability.

**Offenders with intellectual disability:**
A person with intellectual disability who has been convicted of a crime by a court of law.

**Out patient care:**
The provision of care to persons with intellectual disability outside of a hospital setting.

**Physical Rehabilitation:**
Improvement of the independence and quality of life of the person with intellectual disability through physical therapy.

**Preventive intellectual disability services:**
All organized activities in the community to prevent the occurrence as well as the evolution of intellectual disability, including the timely application of means to provide information and education on the known causes of intellectual disability, or etiology.

**Primary health care services:**
The first level of care and the initial point of contact that a patient has with the health system. Often, primary health care begins with the family physician or community health nurse. Primary health care is meant to be the first step in obtaining care, emphasizing health promotion and illness prevention, and providing a link to more specialized care, such as that provided in hospitals.

**Professional training:**
Education with specific reference to develop specific skills to getting or retaining a job.

**Psycho-social rehabilitation:**
Process of facilitating an individual's rehabilitation and social training to an optimal level of independent functioning in everyday activities in the community.

**Psychiatric residential services:**
The provision of care to persons with intellectual disability in a hospital that provides mental health services in at least one separate psychiatric unit with specially allocated staff and space for the treatment of persons with mental illness.

**Public awareness campaign:**
Publicity and/or information campaign to support the development of persons with intellectual disabilities, in a general or, specific domain as anti-stigma, social integration, human rights, education, employment access, social integration and health care.

**Regional level:**
Refers to state, departmental authorities or province.

**Rehabilitation/Day care:**
Services given to persons with intellectual disability in the form of knowledge, skills and training to help them achieve their optimum level of social and psychological functioning and development. These services can take the form of psycho-social rehabilitation, medical and/or physical rehabilitation, as well as individual support on individual needs.

**Respite care:**
Provision of periodic relief to the usual family members and friends who care for the person with intellectual disability. Trained parents or counsellors take care of the person with intellectual disability for

a brief period of time to give families relief from the strain of caring for the person with intellectual disability. This type of care can be provided in the home or in another location.

**Rights/Advocacy support:**
A combination of individual and social actions designed to raise awareness and to gain political commitment, policy support, human rights promotion, social acceptance and health systems support for intellectual disabilities goals.

**Screening/Assessment/Orientation services:**
Services designed to briefly assess the condition of persons with intellectual disability to advice about which services are needed and to link him/her to the most appropriate. Services may include interviews, psychological testing, physical examinations including speech/hearing, and laboratory studies.

**Sheltered employment:**
Work facility for persons with intellectual disability that, for several reasons, are not able to take part in the regular labour market. Persons do not receive a normal salary and the aim is to train persons in skills that prepare them for regular or supported employment.

**Special class in regular school:**
Separate classes for persons with intellectual disability in a regular school composed of persons both with and without intellectual disability.

**Special school**:
Separate and exclusive school for persons with intellectual disability.

**Specialized health services:**
Provision of mainstream specialized health services such as angioplasty procedures, dialysis, surgery, trauma services, mental health, cancer treatment, dental care, and speech therapy (etc.) to persons with intellectual disability.

**Specialized in-patient psychiatric institution**:
Provision of care to persons with intellectual disability in a specialized and separate psychiatric institution.

**Supported employment:**
Supportive services that include assisting individuals in finding work; assessing individuals' skills, attitudes, behaviours, and interests relevant to work; providing vocational rehabilitation and/or other training; and providing work opportunities. Includes transitional and supported employment services.

**Support in regular class:**
Support of persons with intellectual disability who are in regular school classes in which children and adolescents both with and without intellectual disability, attend lessons and school activities together, with assistance provided by special education destined to those with intellectual disability.

**Support to independent living:**
The person has his own home, by renting or by purchase, and receives support from services. Services assist how to handle financial, medical, housing, transportation, and other daily living needs.

**Under-graduate curriculum:**
Mainstream or continuing education leading to a bachelor's degree, offered by a University or any recognized educational institution.

**Transportation:**
A service provided to persons with intellectual disability making it possible for them to travel out of their residence to take part in any social activity.

**Work stations:**
An enclave within the industry allowing a person(s) with an intellectual disability to work. Usually, but not always, integrated in a normal working environment with work crews that do not have an intellectual disability.

## Sources of information for the glossary


Braddock D, Hemp R, Rizzolo MC, Coulter D, Haffer L, Thompson M. The state of the states in developmental disabilities (6th edition). Washington, DC, USA; American Association on Mental Retardation, 2005.

Crosse C, Hocking B. Discussion Paper. Social Rehabilitation: What are the Issues?. Paper presented at DVA National Rehabilitation Conference; SANE Australia, 2004.

Garcin N. Les définitions et les systèmes de classification. In M.J. Tassé et D. Morin (Éds). La déficience intellectuelle. Montréal: Éditions Gaëtan Morin, 2003 :9–21.

Lachapelle Y. What is intellectual disability? Paper presented at the Montreal PAHO/WHO Conference on Intellectual Disability, 2004. www.montrealdeclaration.com/docs/intellectual_disability.pdf. (accessed on July 2007)

Luckasson R, Borthwick-Duffy S, Buntinx WHE, Coulter DL, Craig EM, Reeve A, et al. Mental retardation: definition, classification, and systems of support. 10th American Association on Mental Retardation. 10th edn.; Washington, DC, USA, 2002.

Martin JF. La déficience intellectuelle: Concepts de base. Montréal: Éditions Saint-Martin, 2002.

Tassé MJ, Morin D. La déficience intellectuelle, Montréal: Éditions Gaëtan Morin, 2003.

WHO.The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines. Geneva, Switzerland: WHO, 1992

WHO. The International Classification of Functioning, Disability and Health (ICF). Geneva, Switzerland: WHO, 2001.

WHO. Mental Health Atlas. Geneva, Switzerland: WHO, 2005.

WHO. Mental Health Policy and Service Guidance Package: Advocacy for mental health. Geneva, Switzerland: WHO, 2003.

WHO. World Health Report. Geneva, Switzerland: WHO, 2001.

# Reviewers' comments on the Intellectual Disabilities Atlas

**In medicine, it is difficult to find a case similar to intellectual disability. It is a frequent and lifelong condition, which is related to preventable etiologies in many cases. It is associated to multiple disabilities and other medical conditions and it has consequences all along the life-span, imposing a considerable burden on families and caregivers. However, intellectual disabilities were largely disregarded by national and international organizations. The Atlas is a cornerstone to understanding intellectual disabilities from a global perspective. Given the scarcity of information on intellectual disabilities and the traditional overshadowing of this health condition in any relevant global health report published to date, WHO should be praised for putting intellectual disabilities onto the health policy agenda, and for doing so, not through a declaration, but by producing a full and comprehensive report on the resources and care situation in 147 countries around the world. From the general health care perspective, it may be hard to understand the effort carried forward by WHO`s Department of Mental Health and Substance Abuse and the WHO Montreal Collaborating Centre for Research and Training in Mental Health in completing this task. The report provides information that may be generally available in other health areas but which was completely missing in intellectual disabilities. This document goes far beyond a service or an epidemiological atlas. This is the first study to provide world information on critical issues related to intellectual disabilities, such as the terminology, use of classification systems, funding, care patterns, legislation, public awareness campaigns and training; as well as role of NGOs and international organizations and sources of information and research.**

Luis Salvador-Carulla
Chair Section "Psychiatry of Intellectual Disability"
World Psychiatric Association

**For the first time we have a comprehensive view of this small but significant population. It will provide policy planners, advocacy groups, and researchers a base from which to investigate issues more intensively. Hopefully, it will provide countries alike with some impetus to improve supports to these persons and their families. Hopefully too, it might lead to greater cooperation among nations for a common purpose. Reaching out by developed economies to the less developed, in a true spirit of cooperation, rather than self-interest, which is the hallmark of some international aid agencies, will help to alleviate some of the more gross injustices experienced by this often neglected section of the population. The "otherness" and lack of "personhood" of persons who experience a cognitive impairment (including mental illness) in society is well documented in the literature. This leads to discriminating practices both overt and covert.**

Trevor Parmenter
Director of Centre for Developmental Disability Studies
University of Sydney

The results of Atlas Global Resources for Persons with Intellectual Disabilities (Atlas-ID) reveal a lack of adequate policy and legislative response and a serious deficiency of services and resources allocated to the care of persons with intellectual disabilities globally. The situation is especially worrisome in most low- and middle-income countries. Persons with intellectual disabilities are frequently the most vulnerable group and, on many occasions, are exposed to human rights violations and deprived of minimum services and dignity.

This joint report by the World Health Organization and the Montreal PAHO/WHO Collaborating Centre for Research and Training in Mental Health, Douglas University Institute in Mental Health, includes information from 147 countries, representing 95% of the world population.

It is hoped that this Atlas will enhance knowledge and awareness on the global and regional disparities on resources and services for persons with intellectual disability at country level and will help in the development of policies and programmes for this group of persons.

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