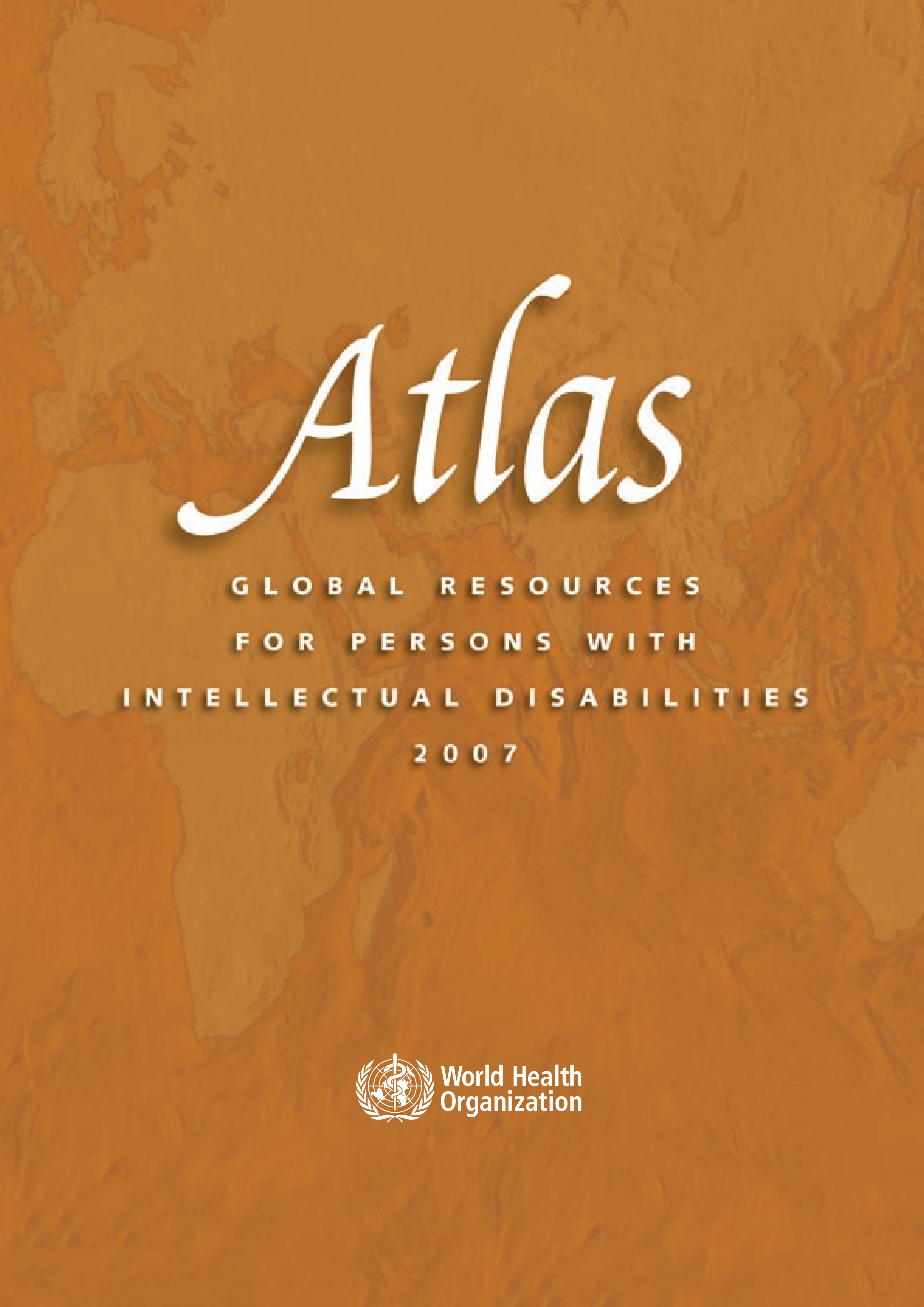
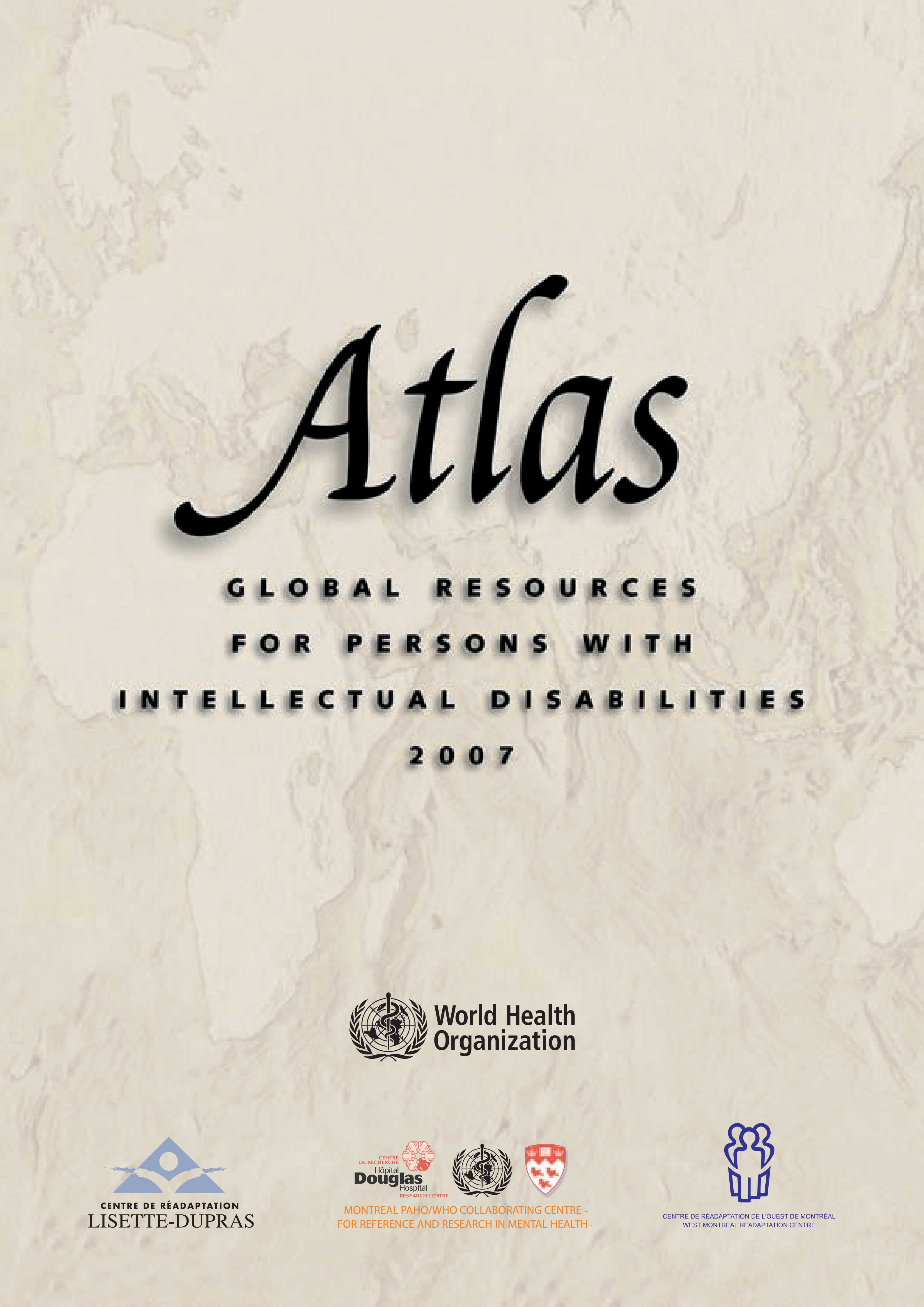


Atlas

GLOBAL RESOURCES FOR PERSONS WITH INTELLECTUAL DISABILITIES

2007

World Health Organization



Atlas

GLOBAL RESOURCES FOR PERSONS WITH INTELLECTUAL DISABILITIES

2007

World Health
Organization

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FOR REFERENCE AND RESEARCH IN MENTAL HEALTH -

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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.

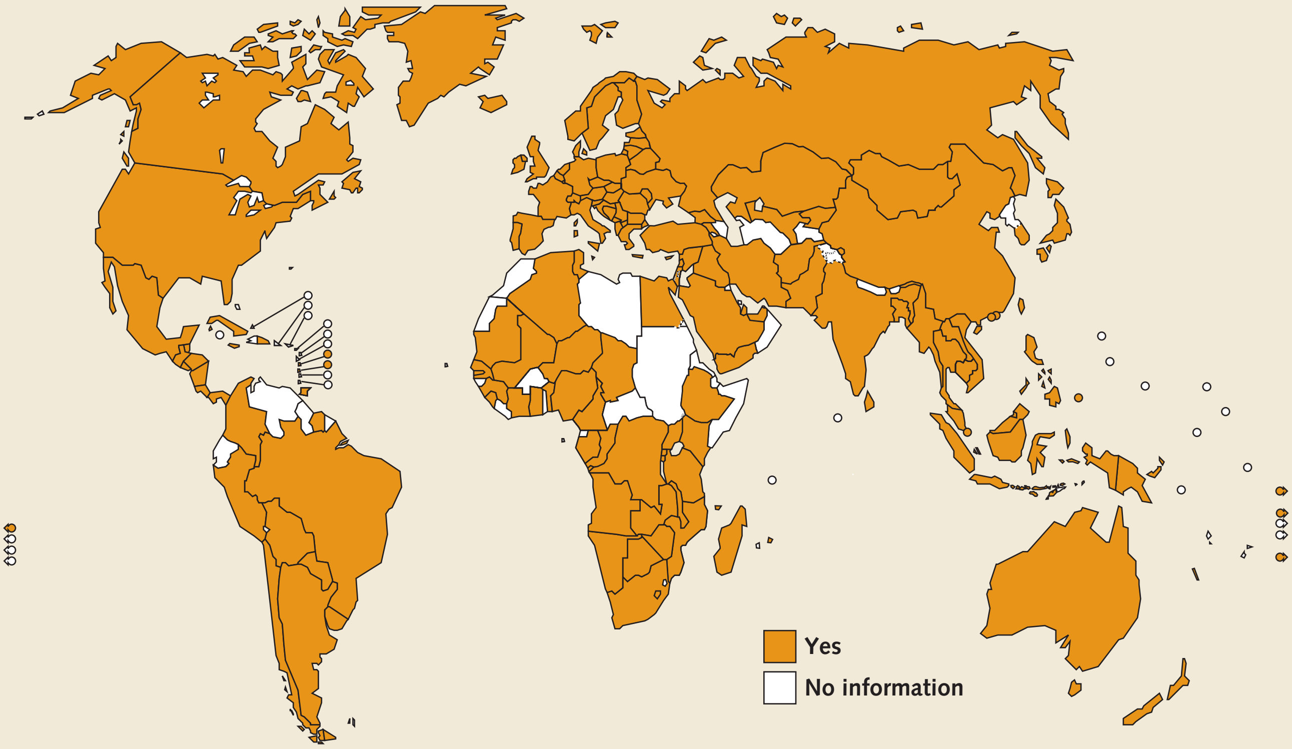
In some countries, teams of respondents from more than one, if not all three, categories of respondents cooperated through their own initiative to complete the questionnaire. In 17 instances, more than one questionnaire for the same country was received. In these cases, we gave priority according to 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%), 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%).

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

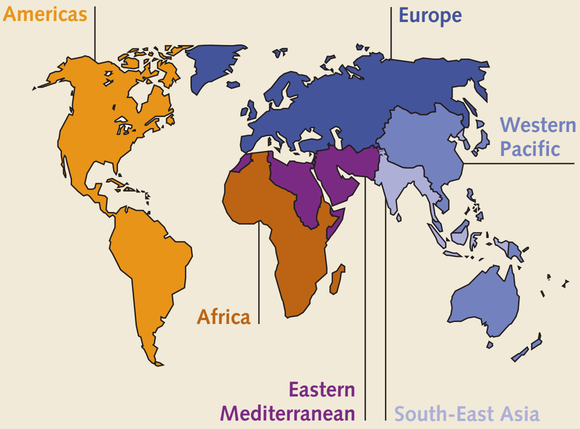


Data analysis

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)

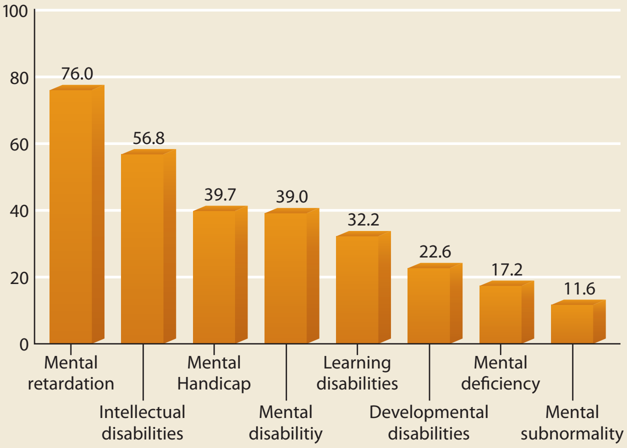


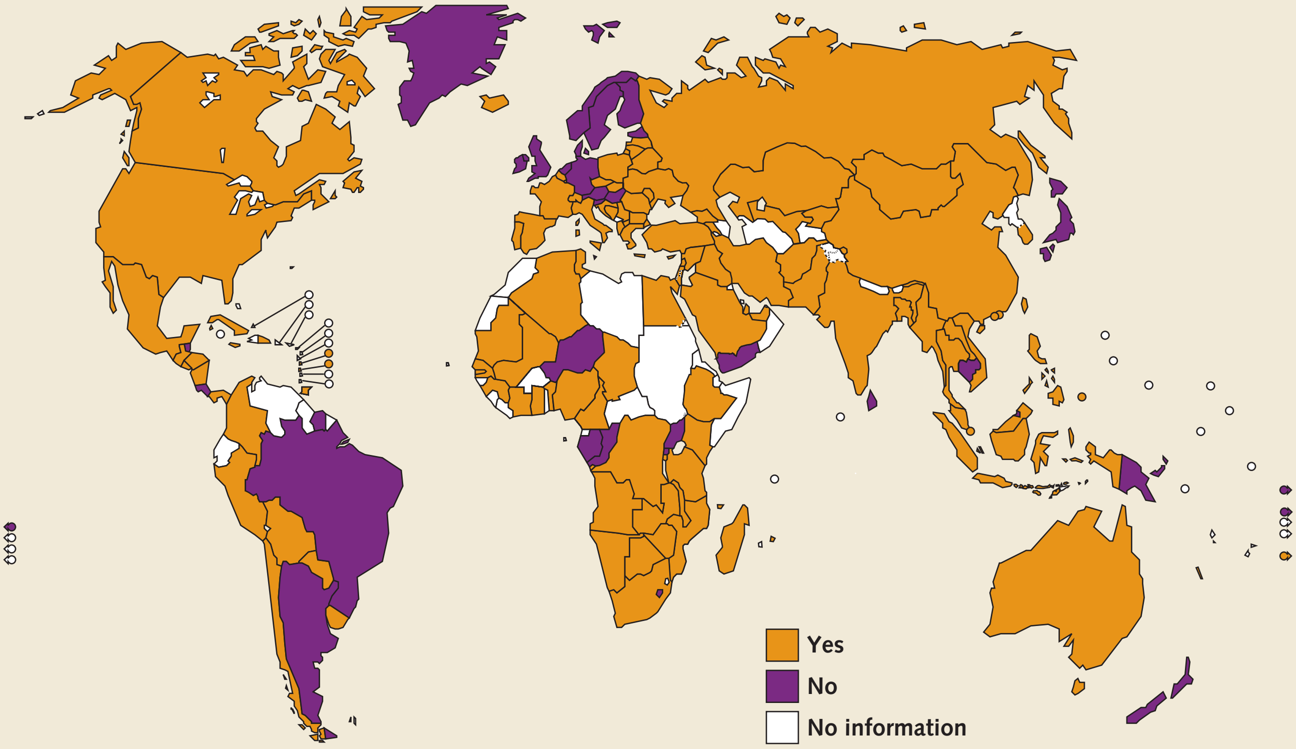
Table 1 **Terminology used to refer to intellectual disabilities** (percentages of countries by WHO regions)

	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

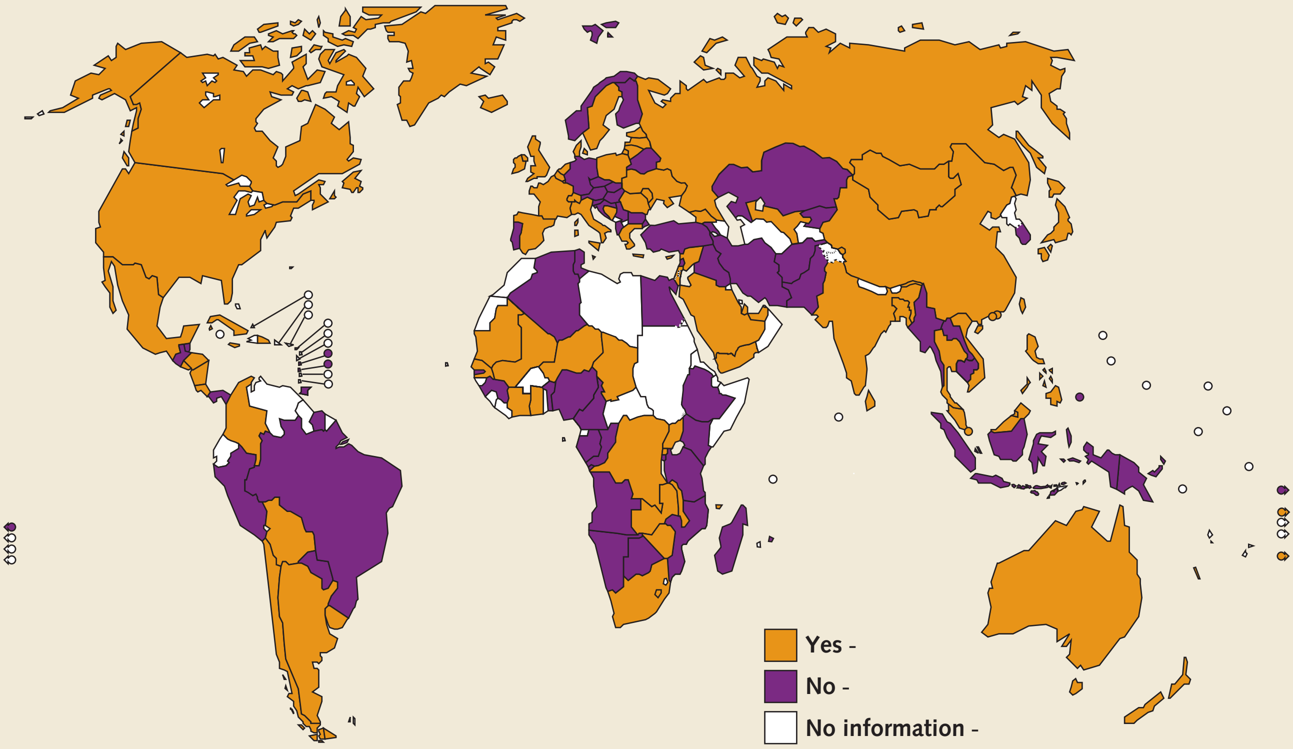
Table 2 **Terminology used to refer to intellectual disabilities** (percentages of countries by income categories)

	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)

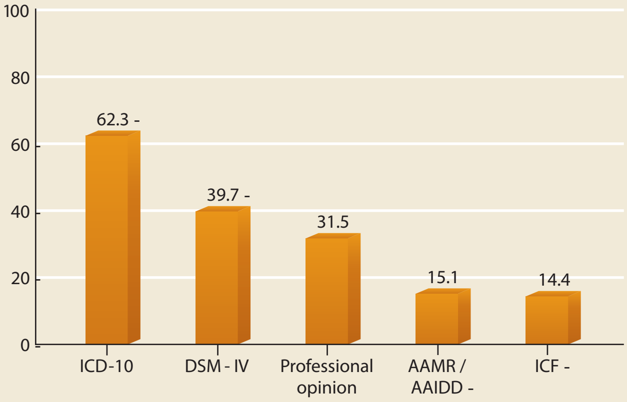


Table 3 **Diagnostic or classification system used in relation to intellectual disabilities**
(percentages of countries by WHO regions)

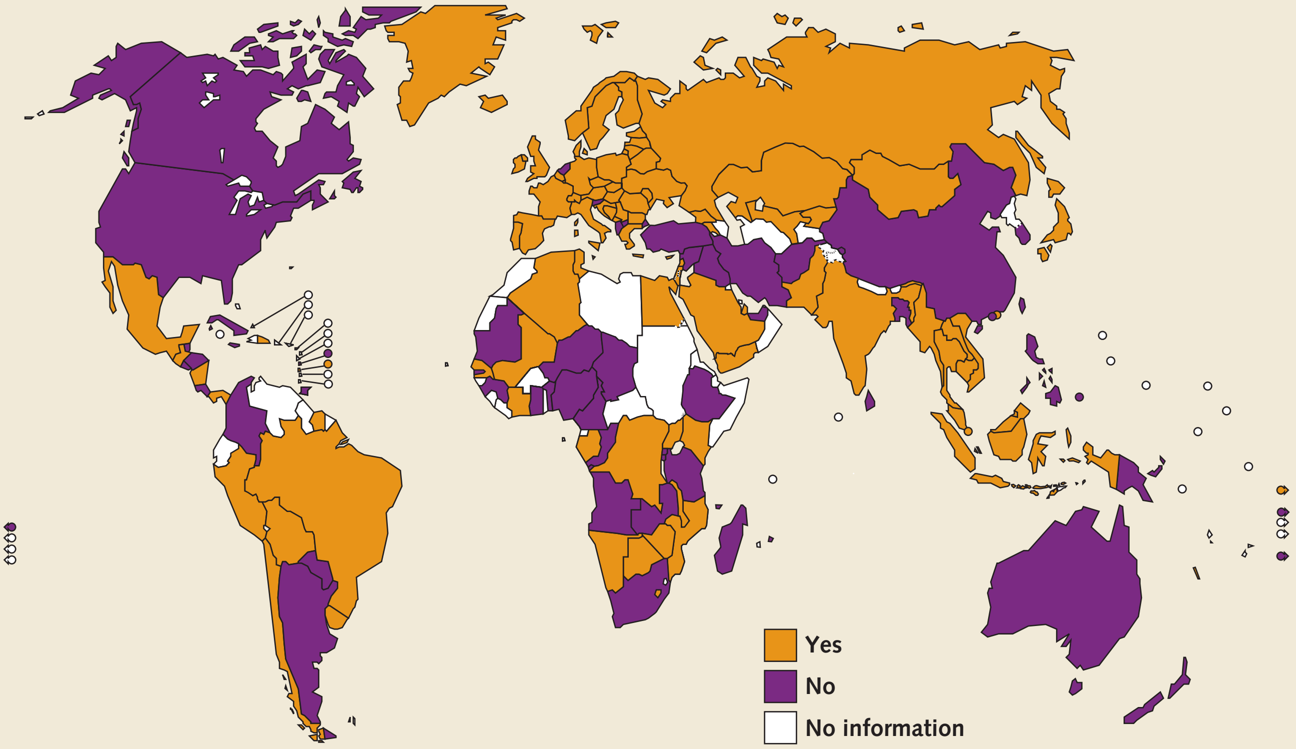
	World		Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	Western Pacific	N
	Proportion of countries	Number of countries							
AAMR or AAIDD	15.1%	2	20.6%	16.0%	60.0%	6.4%	23.1%	9.1%	146
DSM-IV	39.7%	58	38.2%	52.0%	40.0%	27.7%	53.8%	45.5%	146
Professional opinion	31.5%	46	50.0%	32.0%	20.0%	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.

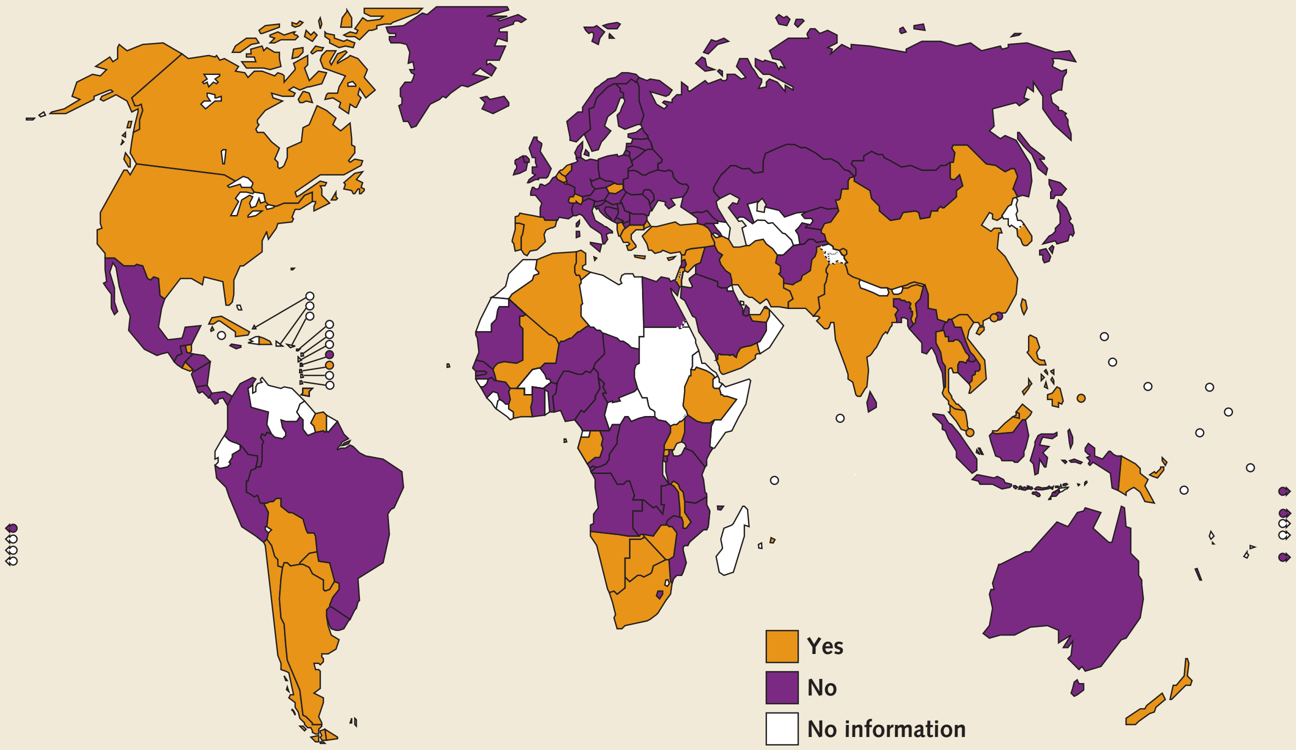
Table 4 **Diagnostic or classification system used in relation to intellectual disabilities**
(percentages of countries by income categories)

	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)

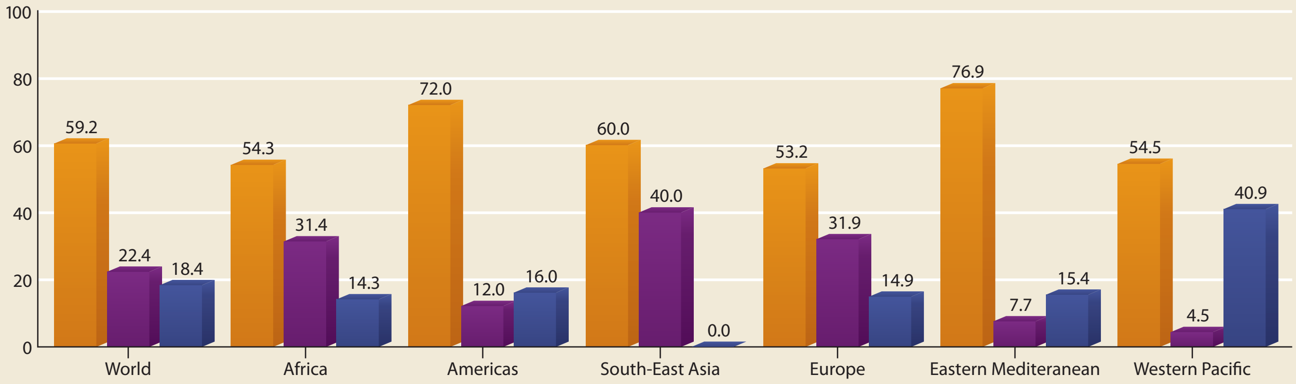
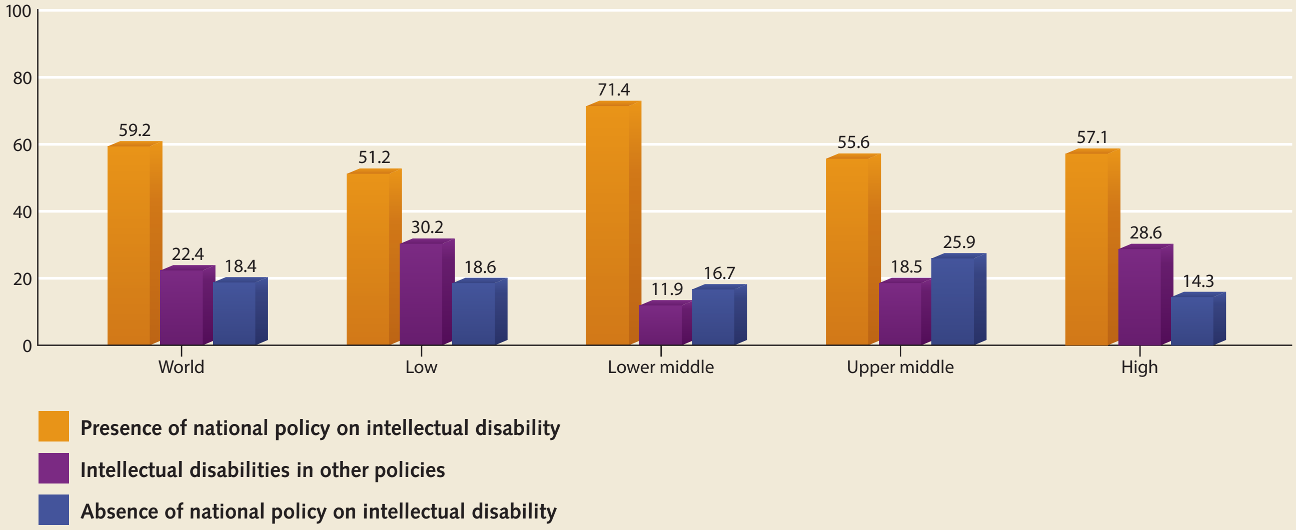


Figure 4 **Presence of a policy or programme that addressed intellectual disabilities** (percentages of countries by income categories)



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

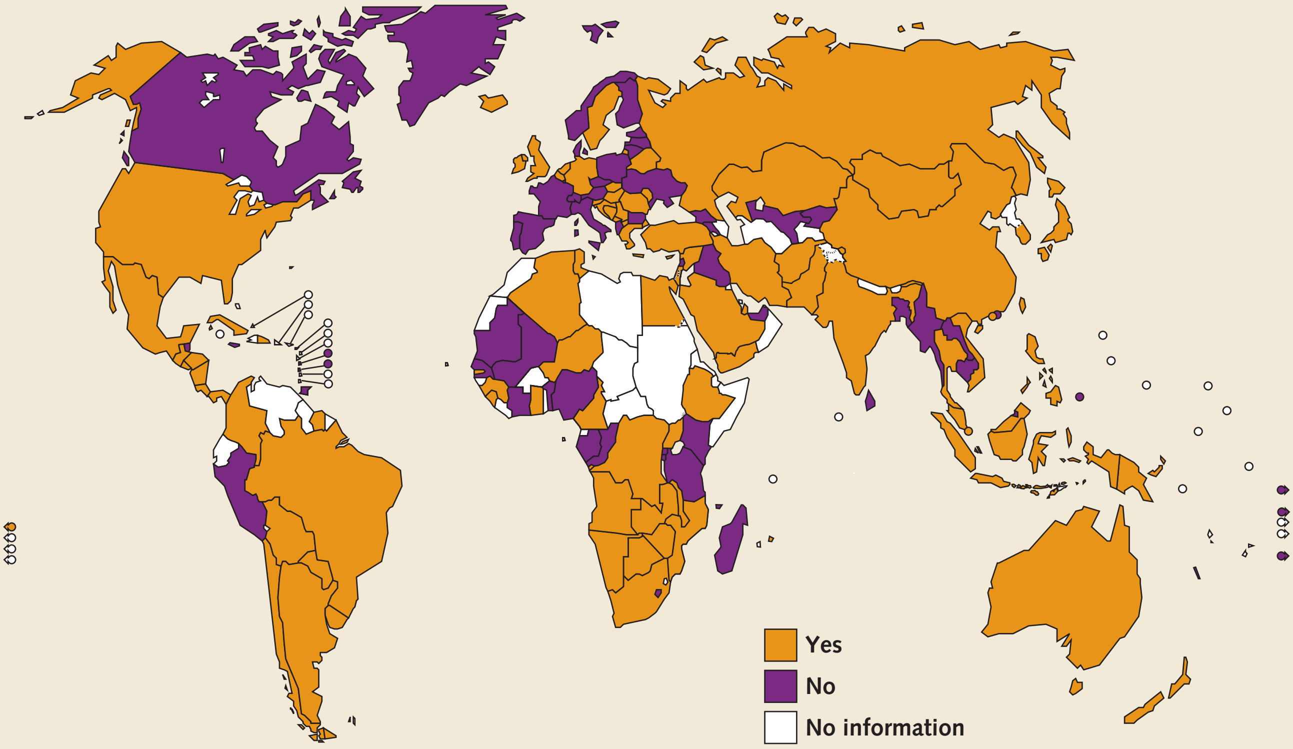


Figure 5 Departments responsible for policies and funding or monitoring programmes (percentages of countries)

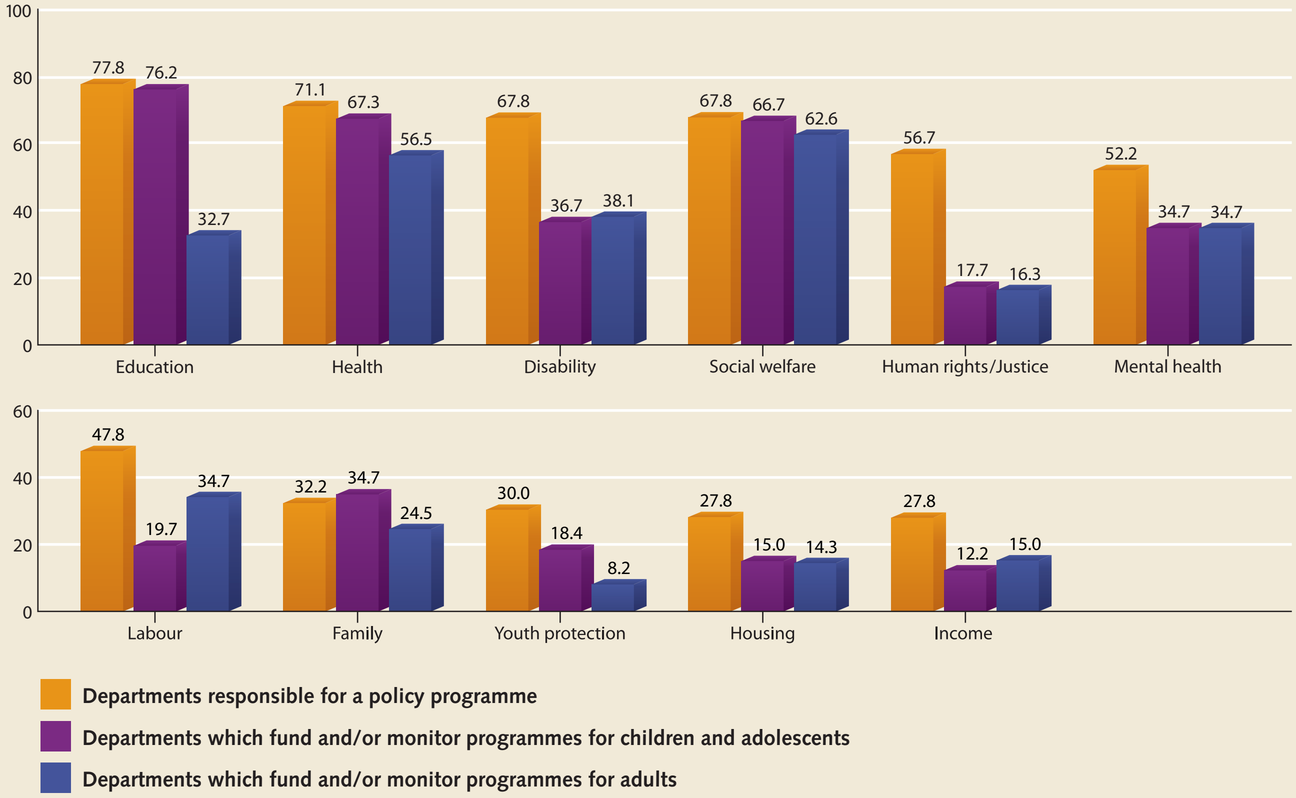


Table 5 **Presence of a specific policy or programme in which intellectual disabilities are addressed** (percentages of countries by WHO regions)

	World		Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	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 Mediterranean	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)

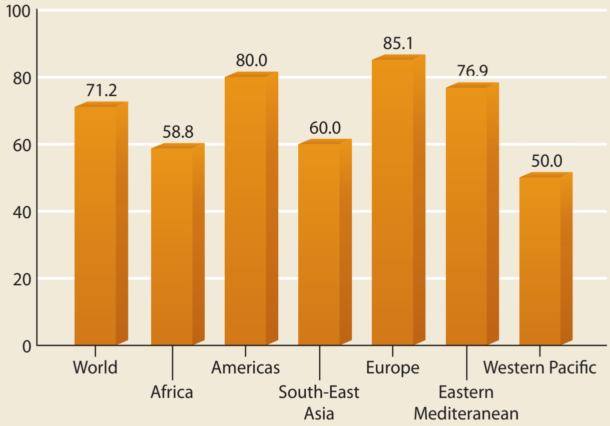
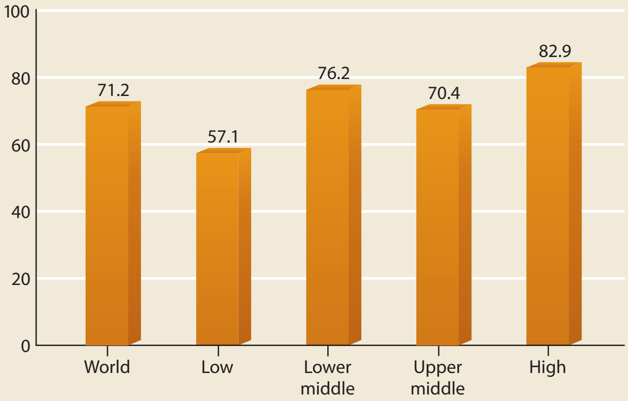
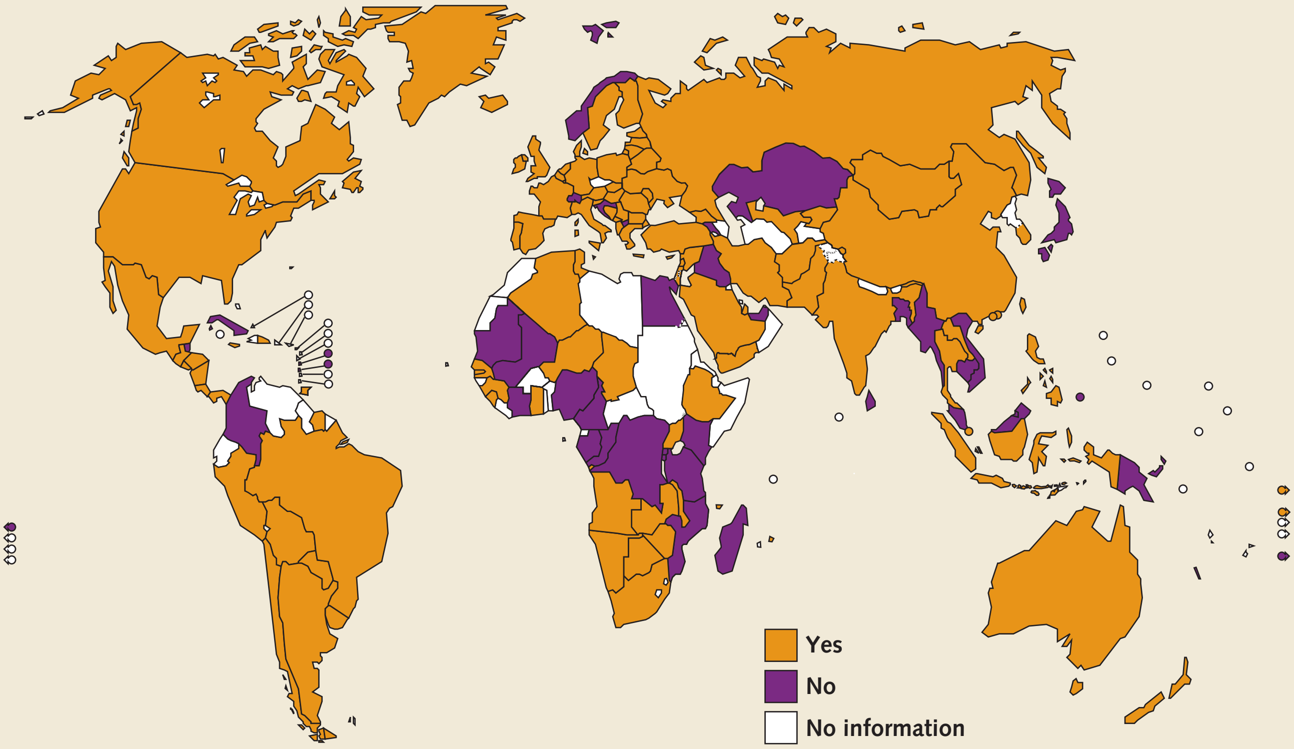


Figure 7 **Presence of legislation to protect persons with intellectual disabilities** (percentages of countries by income categories)



> **"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)

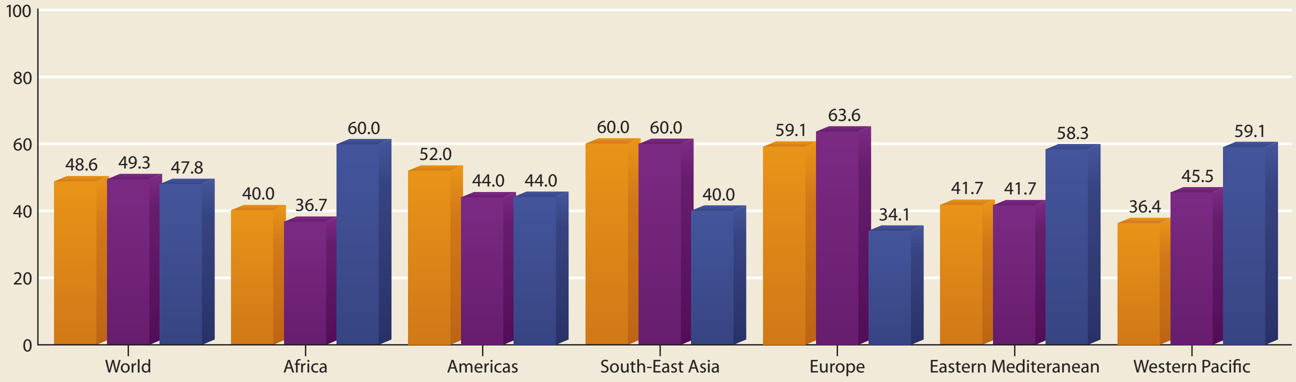
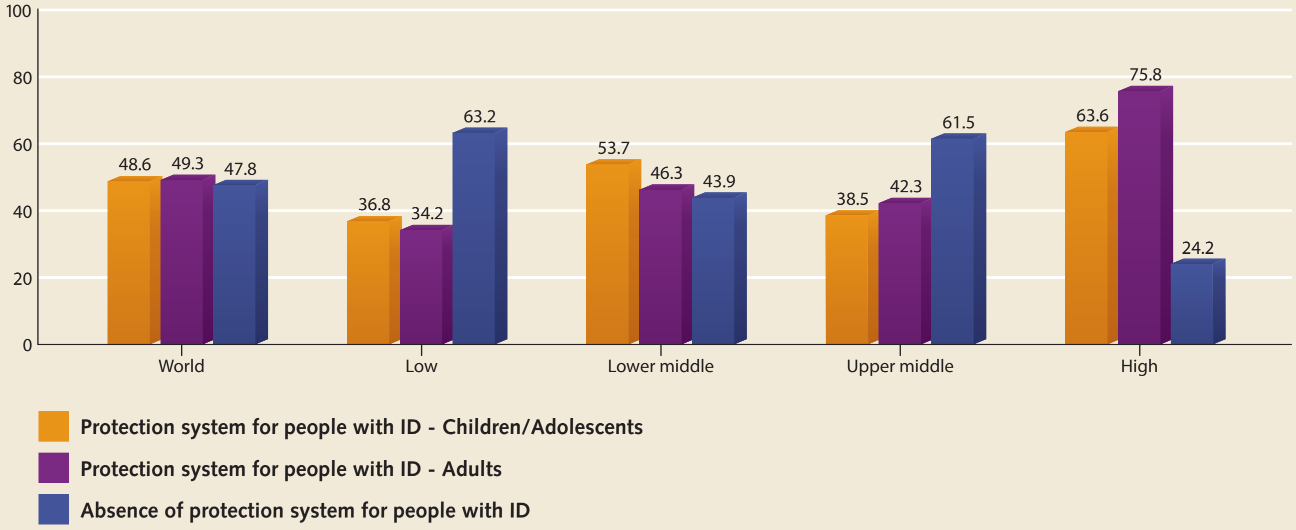


Figure 9 **Presence of a judicial protection system** (percentages of countries by income categories)



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)

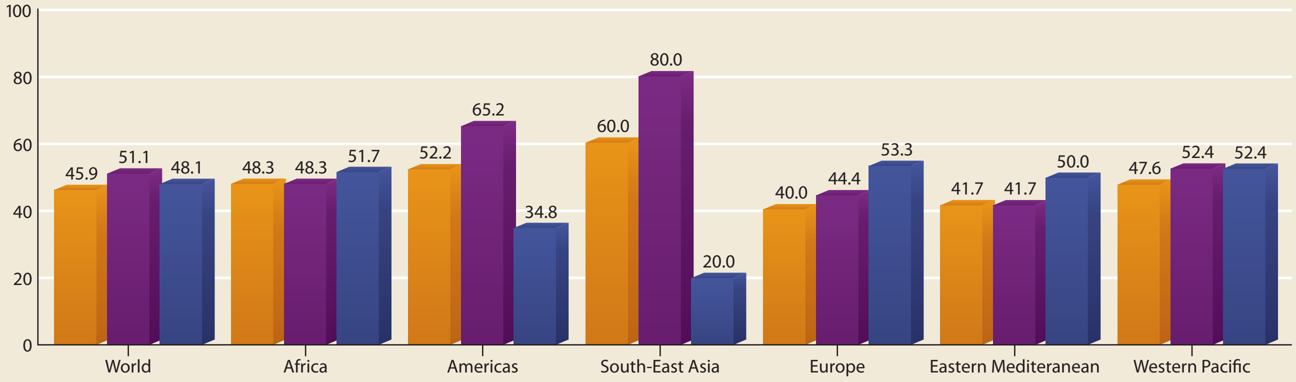
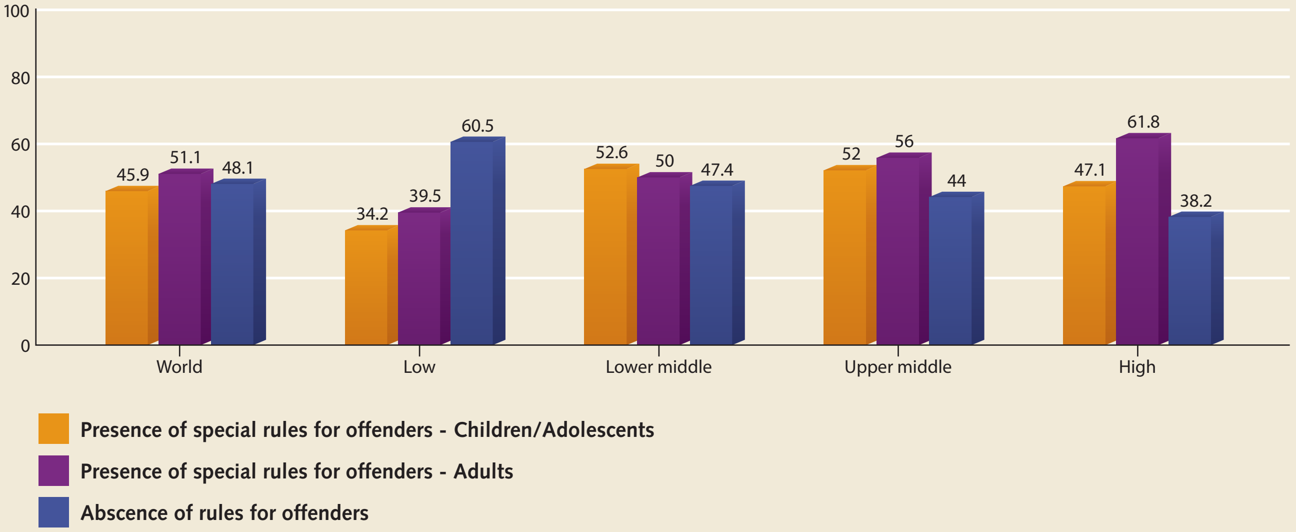


Figure 11 **Presence of special rules for offenders** (percentages of countries by income categories)



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)

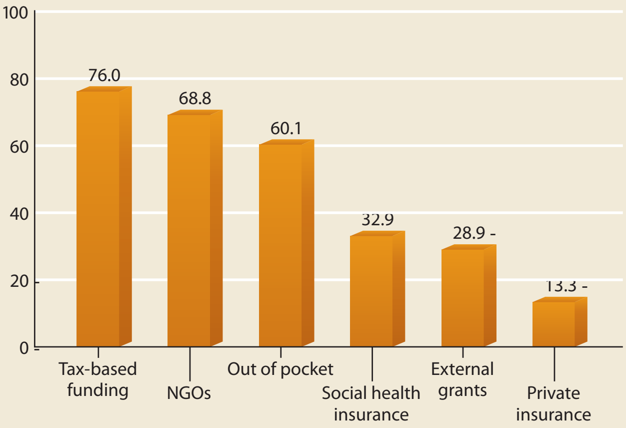


Table 11 Sources of funding for services (percentages of countries by WHO regions)

	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)

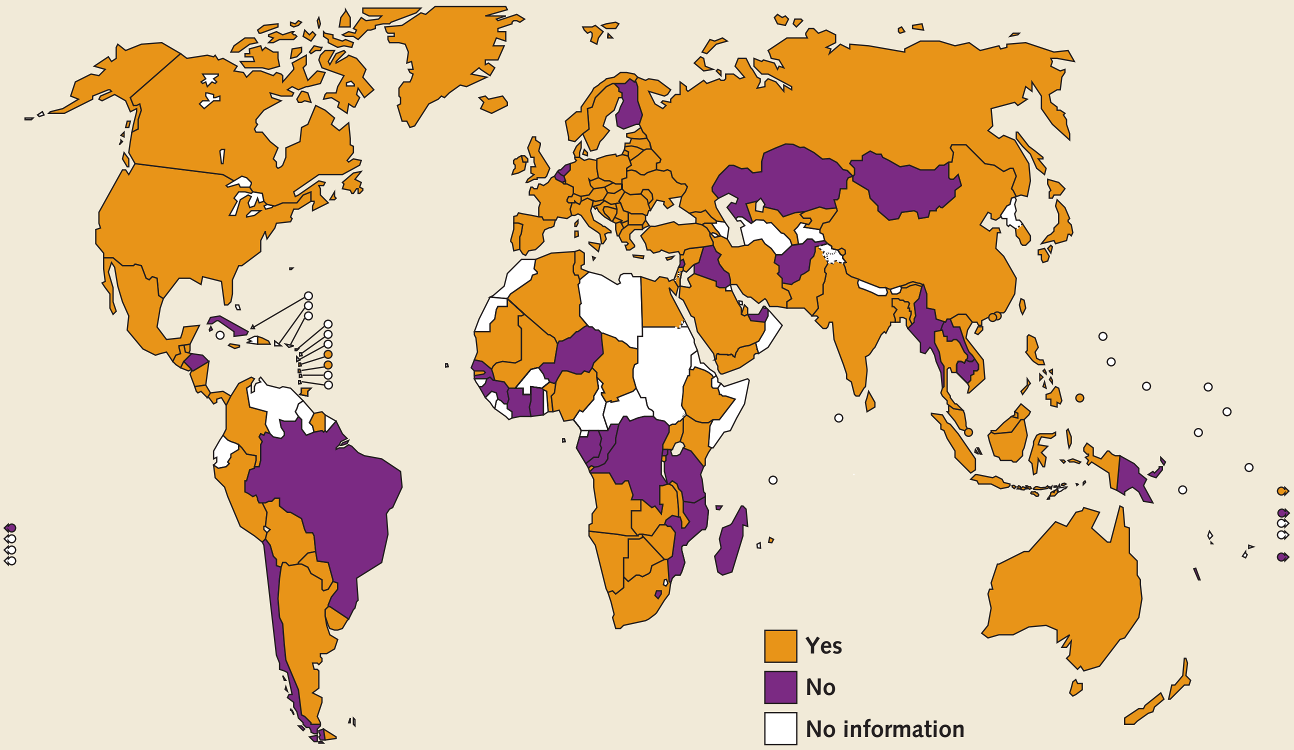
	Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	Western Pacific	Total	N
Tax-based funding	17.5%	50.0%	50.0%	80.0%	80.0%	85.0%	66.0%	83
Out-of-pocket	40.0%	17.5%	10.0%	10.0%	10.0%	30.0%	19.4%	66
Social health-insurance	0.5%	20.0%	45.0%	20.0%	5.0%	35.0%	20.0%	34
Private insurance	2.0%	5.0%	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.

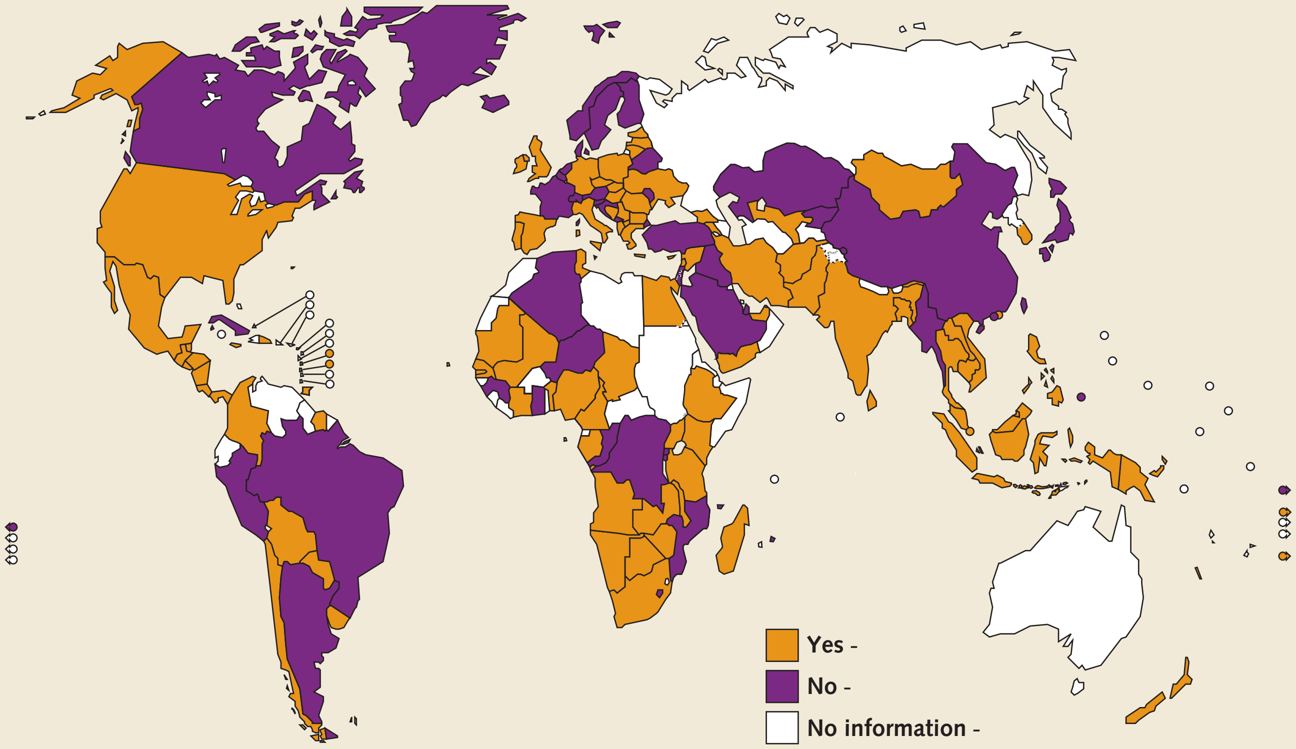
Table 14 **Repartition of sources of funding for services** (median percentages by income categories)

	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**



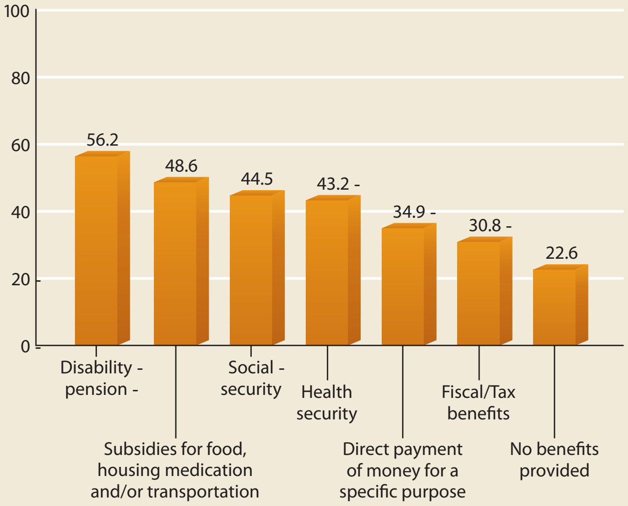
Map 10 NGOs as a source of funding for services



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% Of 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).

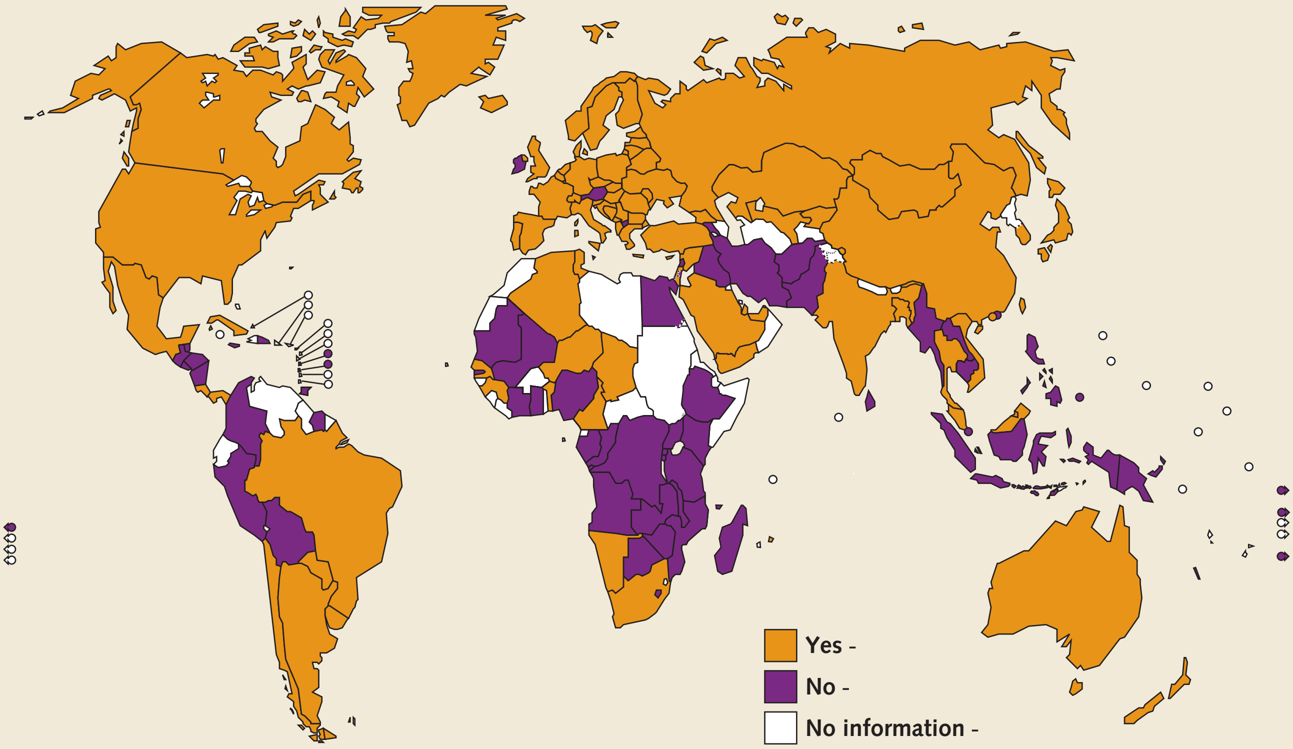
Table 15 **Presence and nature of government benefits** (percentages of countries by WHO regions)

	World		Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	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 transportation	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 Mediter ranean	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)

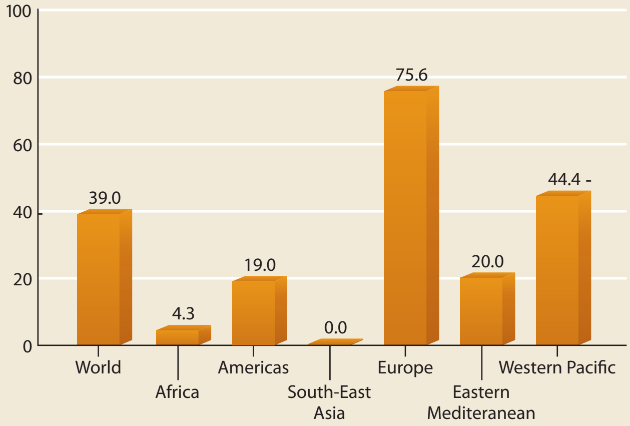
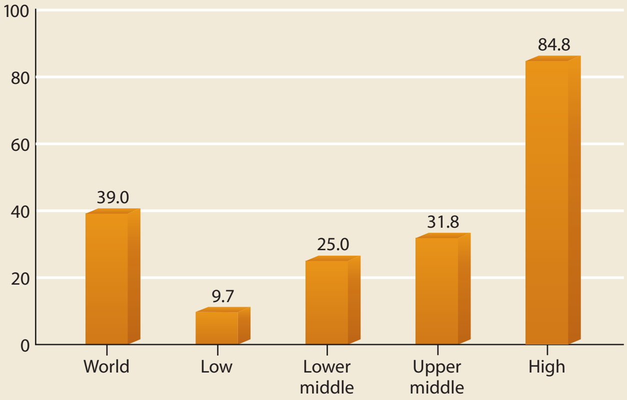


Figure 15 **High access (>75%) to government benefits** (percentages of countries by income categories)



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)

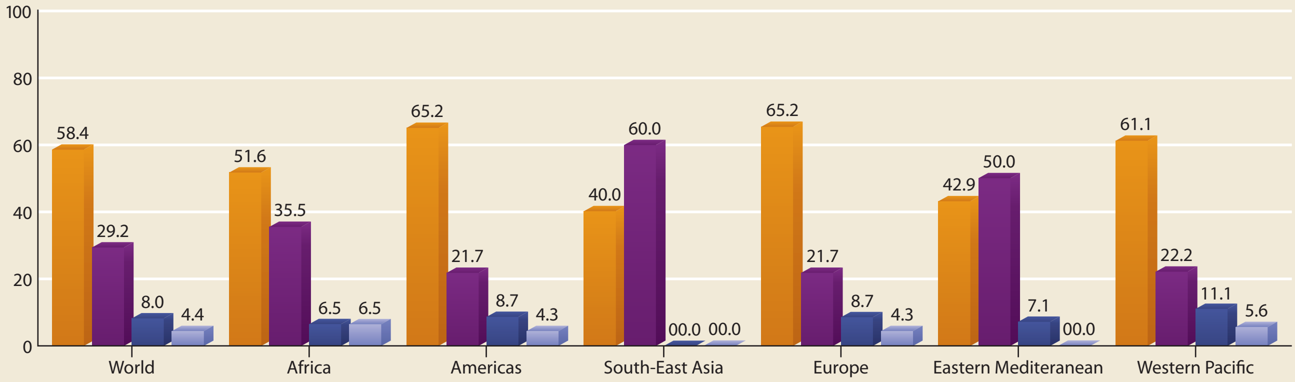


Figure 17 **Level of government that was responsible for services** (percentages of countries by income categories)

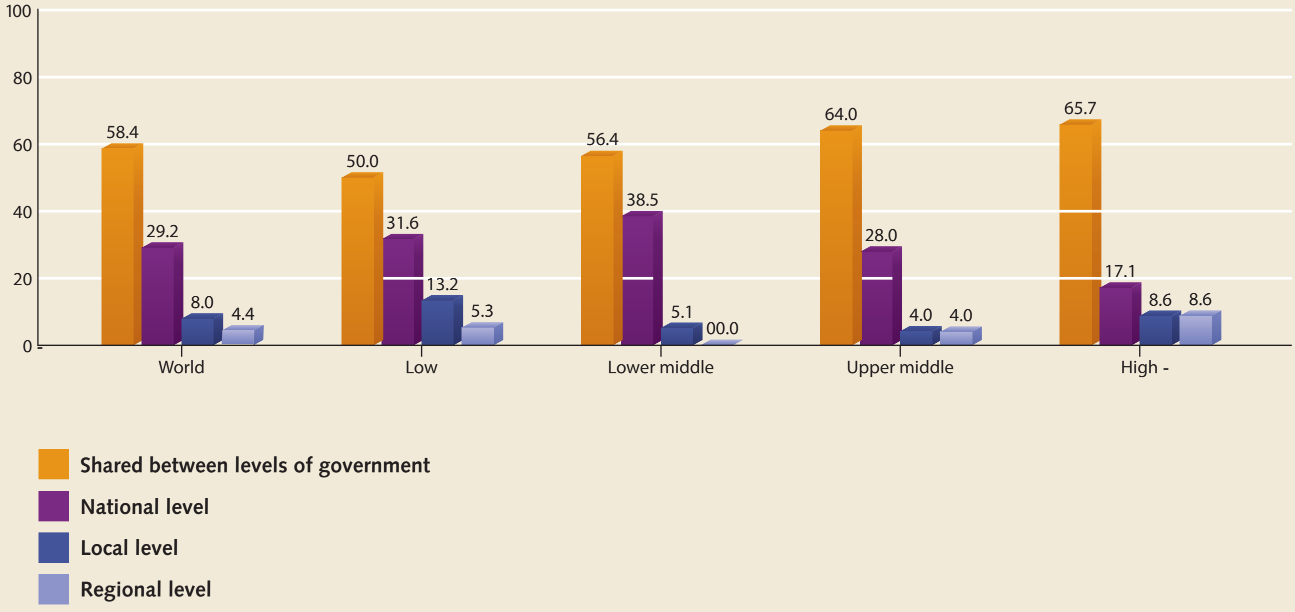


Figure 18 **Organization of services** (percentages of countries by WHO regions)

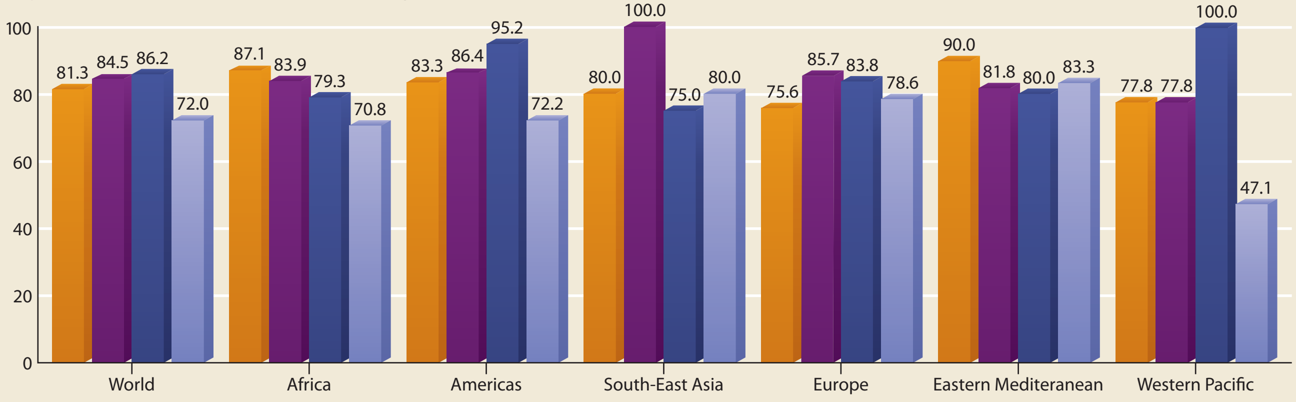
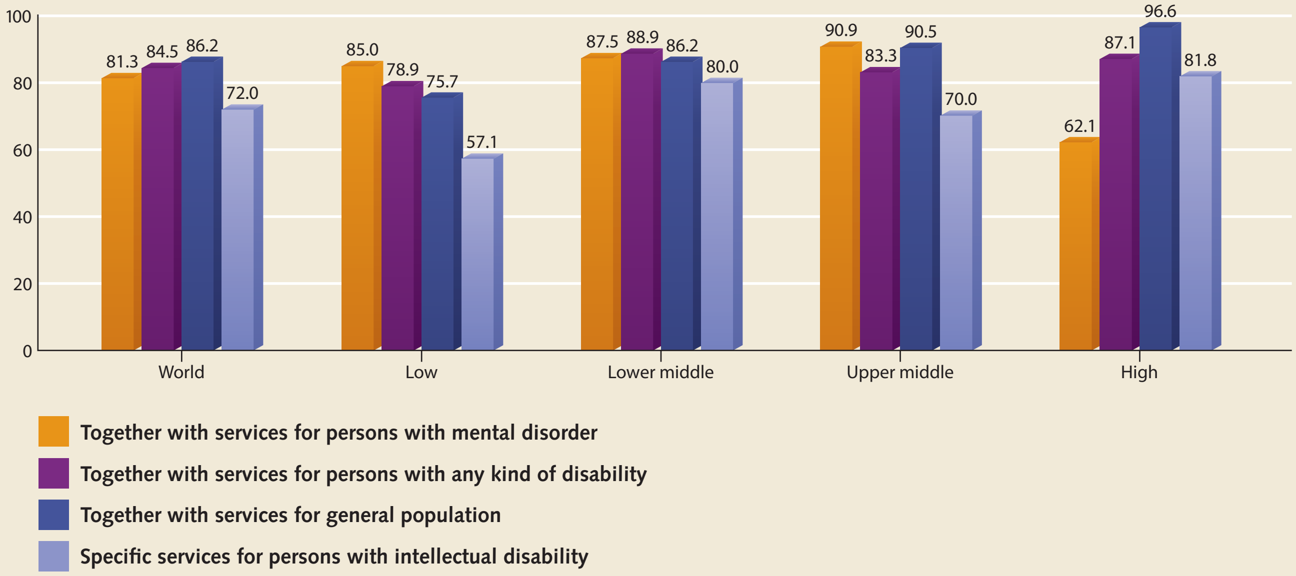


Figure 19 **Organization of services** (percentages of countries by income categories)



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 Mediter ranean	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 Mediterranean	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 Mediterranean	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)

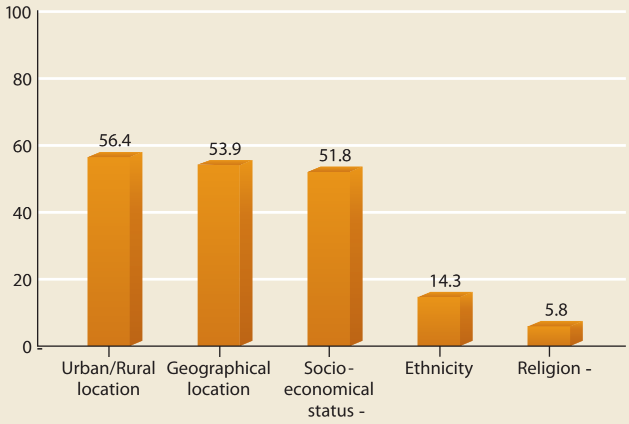


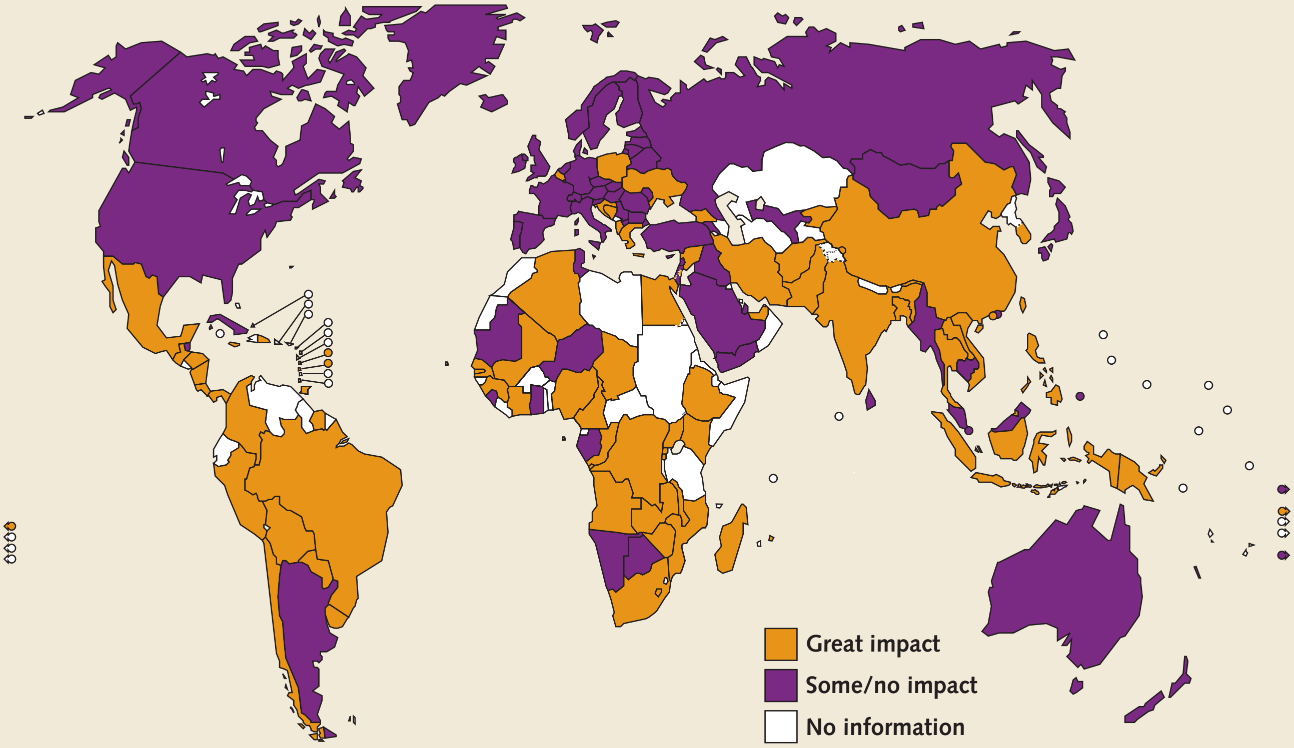
Table 43 **Factors that had an impact on access to services** (percentages of countries by WHO regions)

	World		Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	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

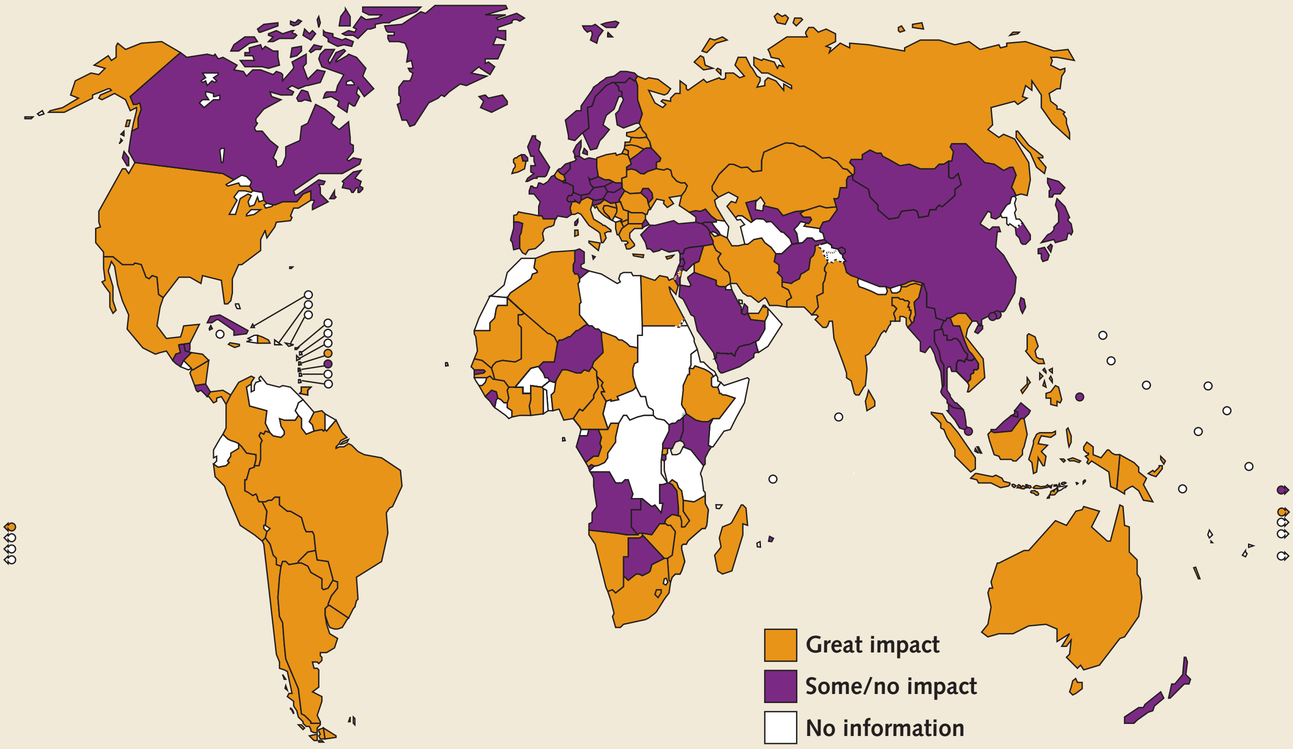
Table 44 **Factors that had an impact on access to services** (percentages of countries by income categories)

	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

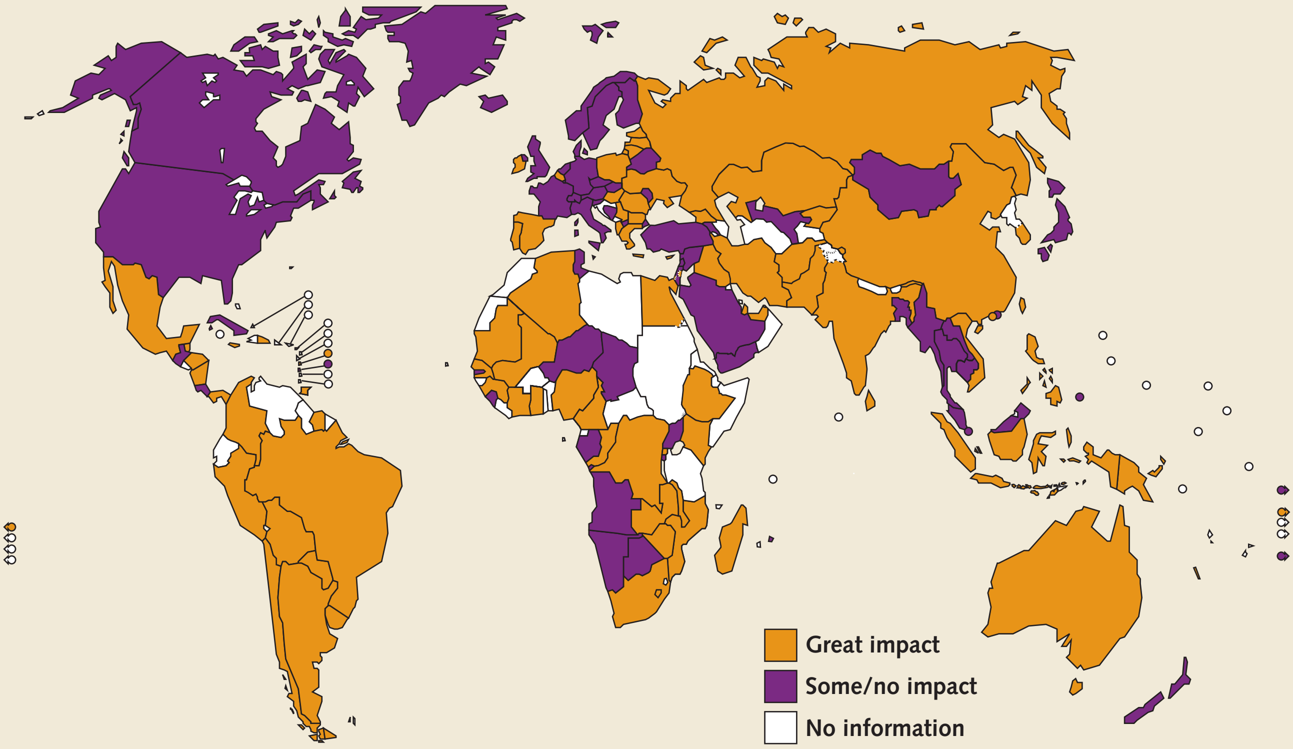
Map 12 **Impact of socioeconomic status on access to services**



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)

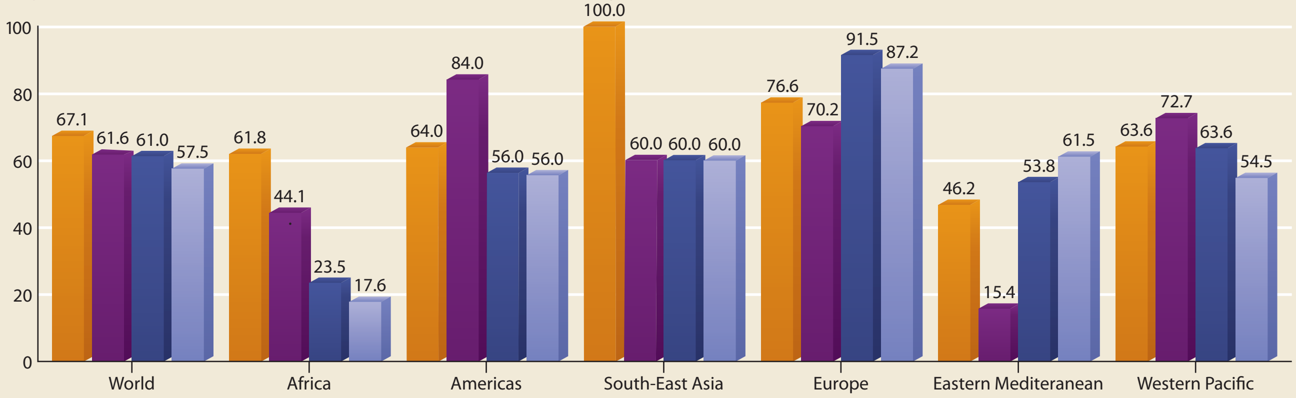
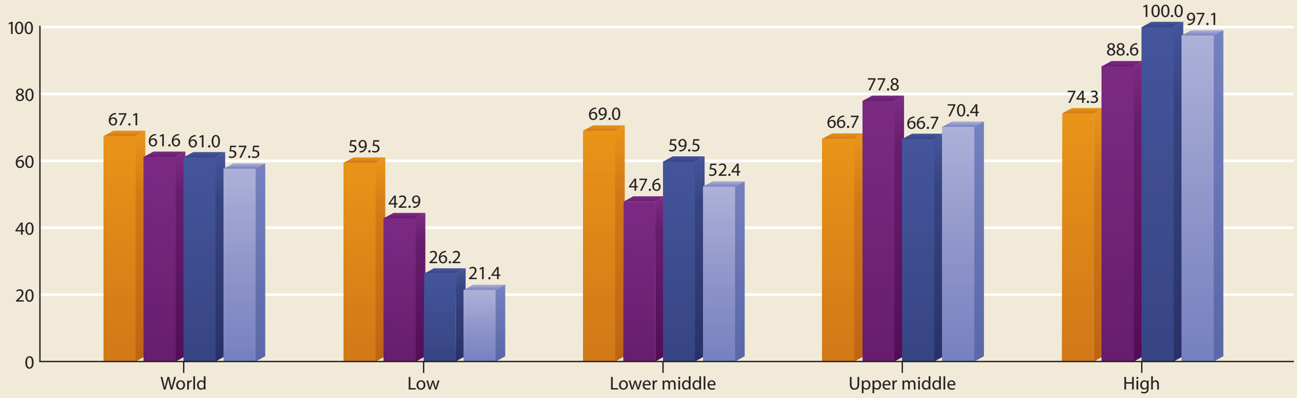


Figure 22 **Strategies to prevent intellectual disabilities** (percentages of countries by income categories)



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

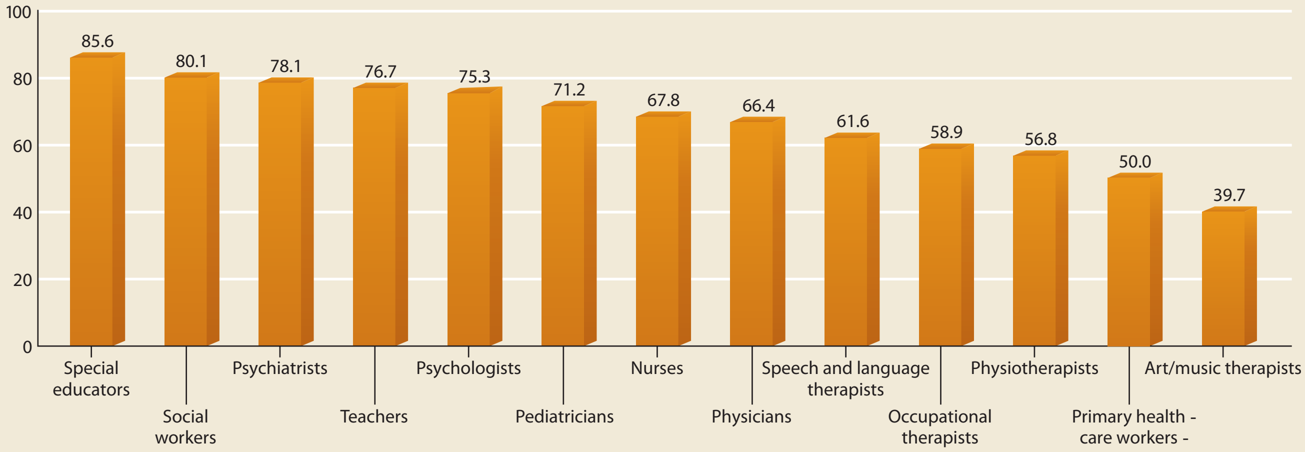
> **"Though many of the causes of developmental disabilities are understood and preventable, proven methods of prevention, such as early screening and intervention, nutritional interventions, immunization against rubella and other infections capable of causing developmental disabilities, and child safety 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)

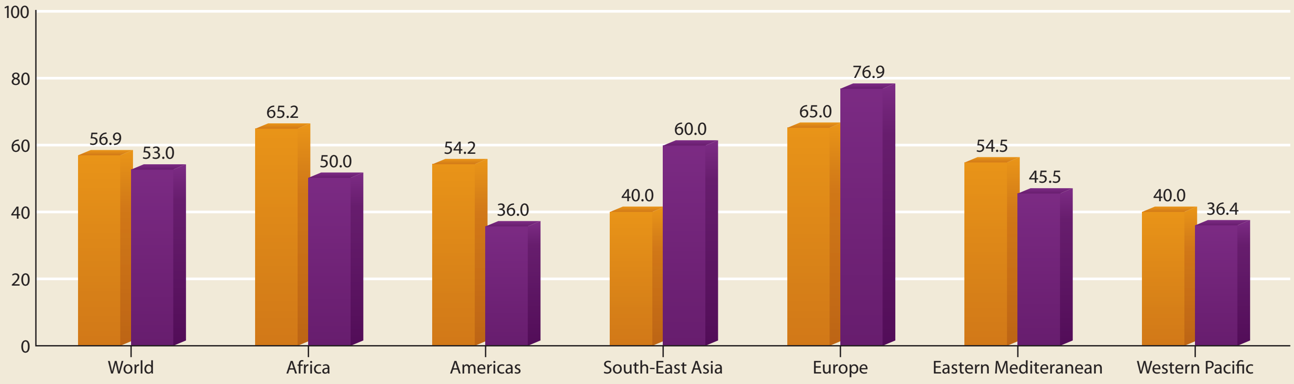


Figure 25 **Presence of standards for professionals** (percentages of countries by income categories)

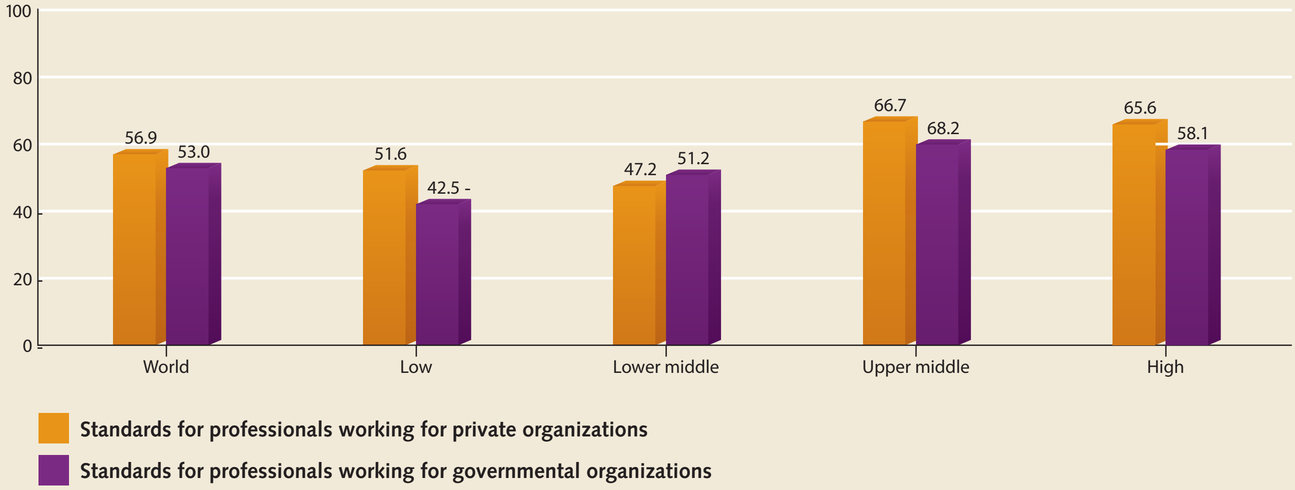


Table 45 **Ways to maintain standards of care and practices** (percentages of countries by WHO regions)

	World		Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	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)

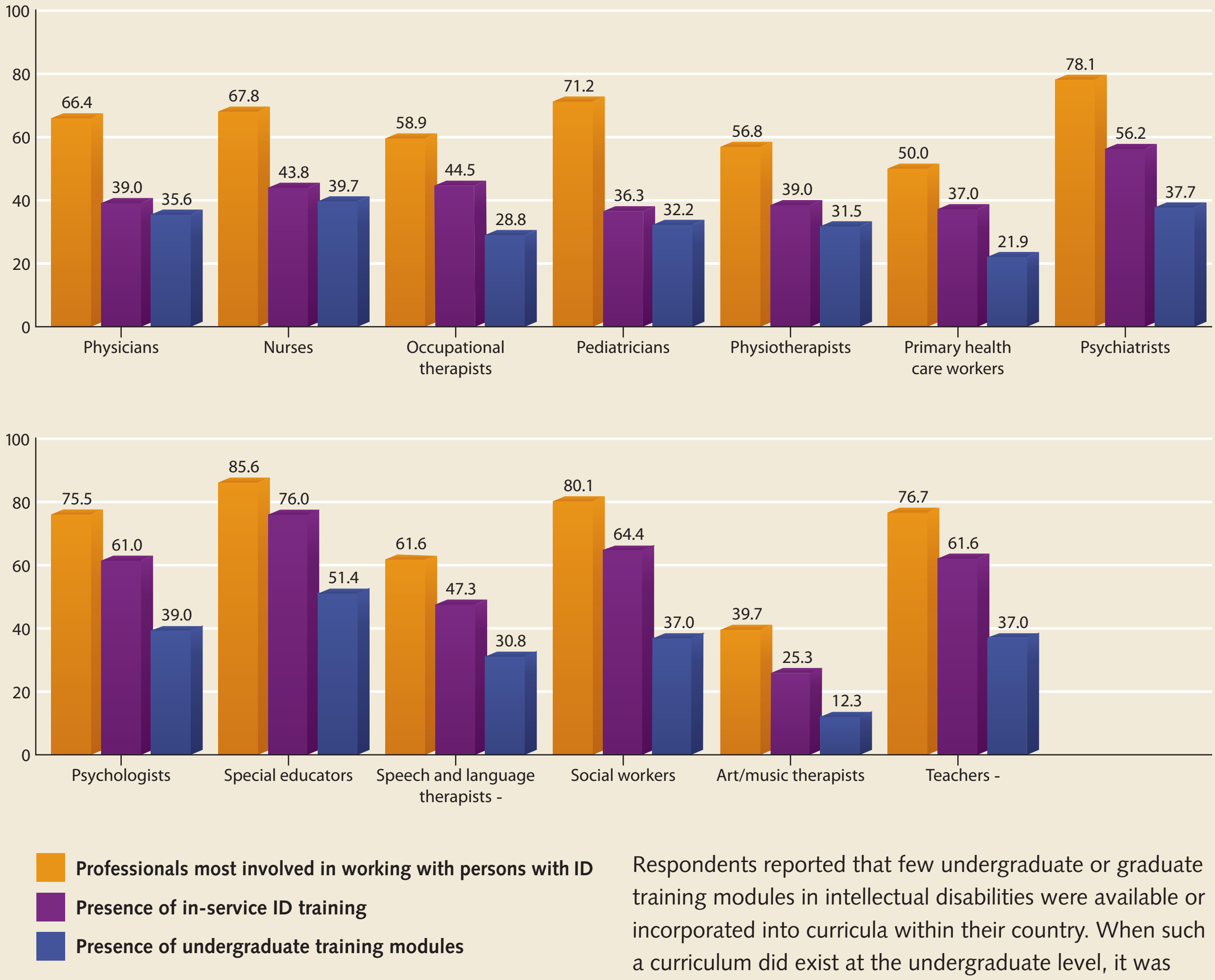
	World		Low income	Lower middle income	Upper middle income	High income	N
	Proportion of countries	Number of countries					
Professional certification and maintenance of competency	58.9%	56	52.0%	55.6%	66.7%	64.0%	95
In-service training	69.5%	66	72.0%	63.0%	77.8%	68.0%	95
Clinical supervision of workers	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)



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 Mediterranean	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 Mediterranean	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 Mediterranean	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)

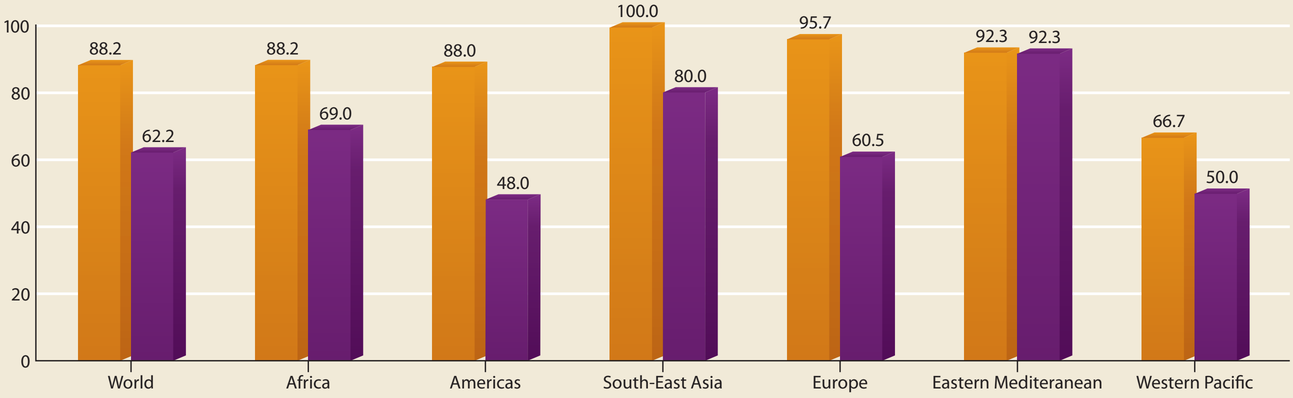
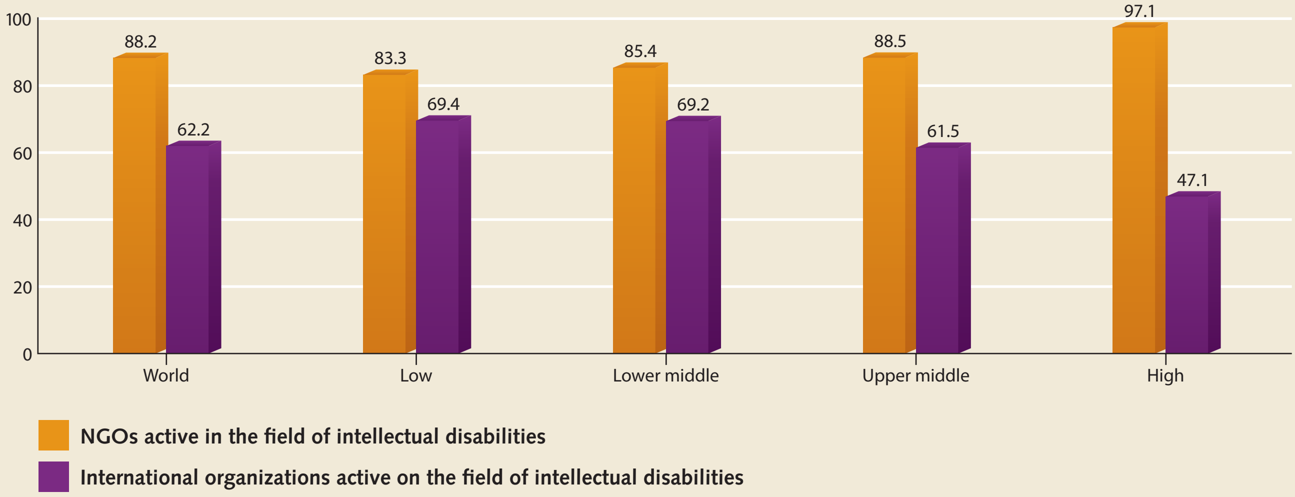


Figure 28 Presence of NGOs and international organizations active in the field of ID (percentages of countries by income categories)



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)

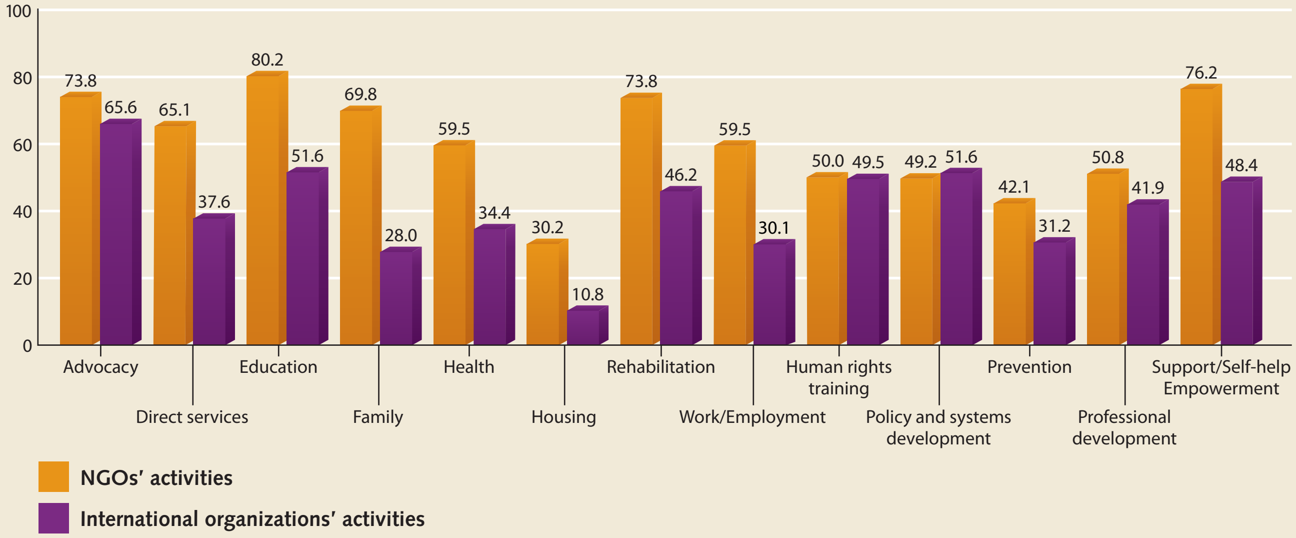
	World		Africa	Americas	South-East Asia	Europe	Eastern Mediter ranean	Western Pacific	N
	Proportion of countries	Number of countries							
Advocacy	73.8%	93	66.7%	68.2%	40.0%	81.4%	81.8%	80.0%	126
Direct services	65.1%	82	36.7%	77.3%	80.0%	74.4%	72.7%	66.7%	126
Education	80.2%	101	83.3%	95.5%	100%	67.4%	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)

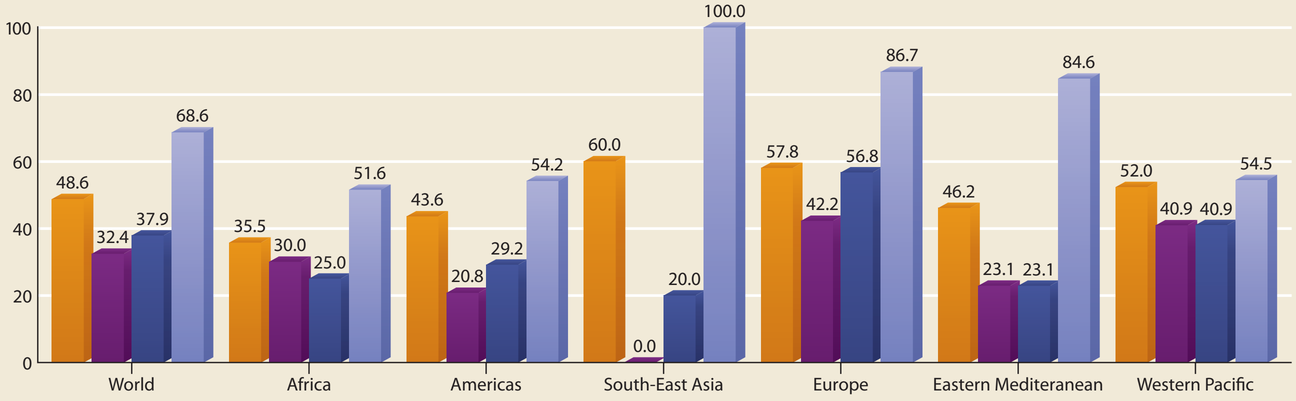
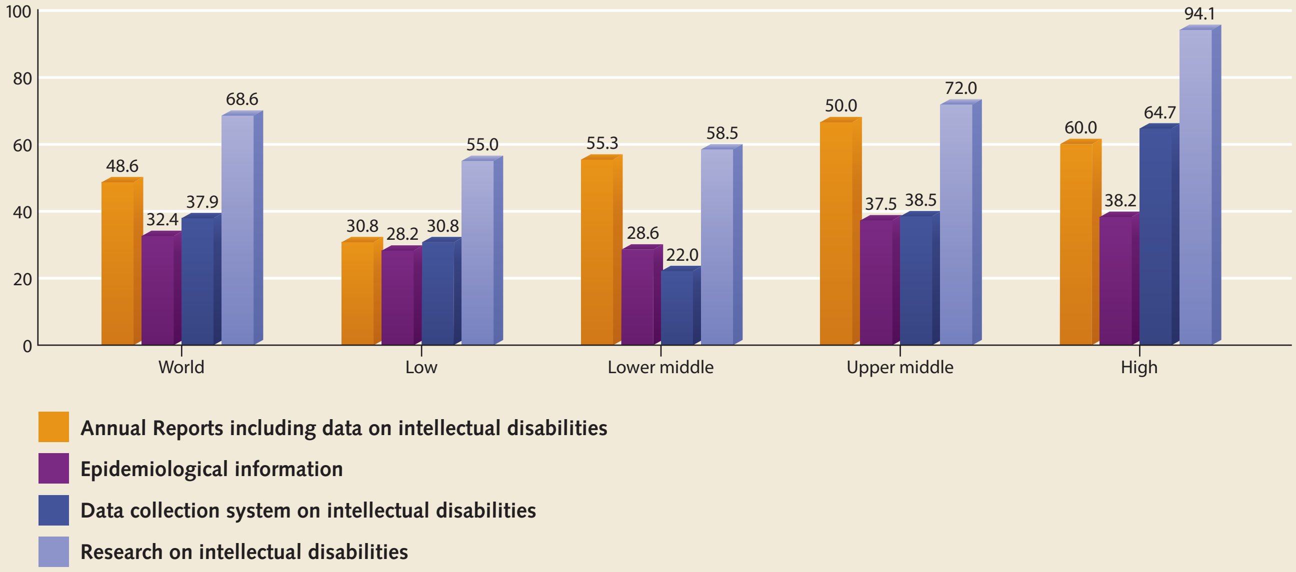
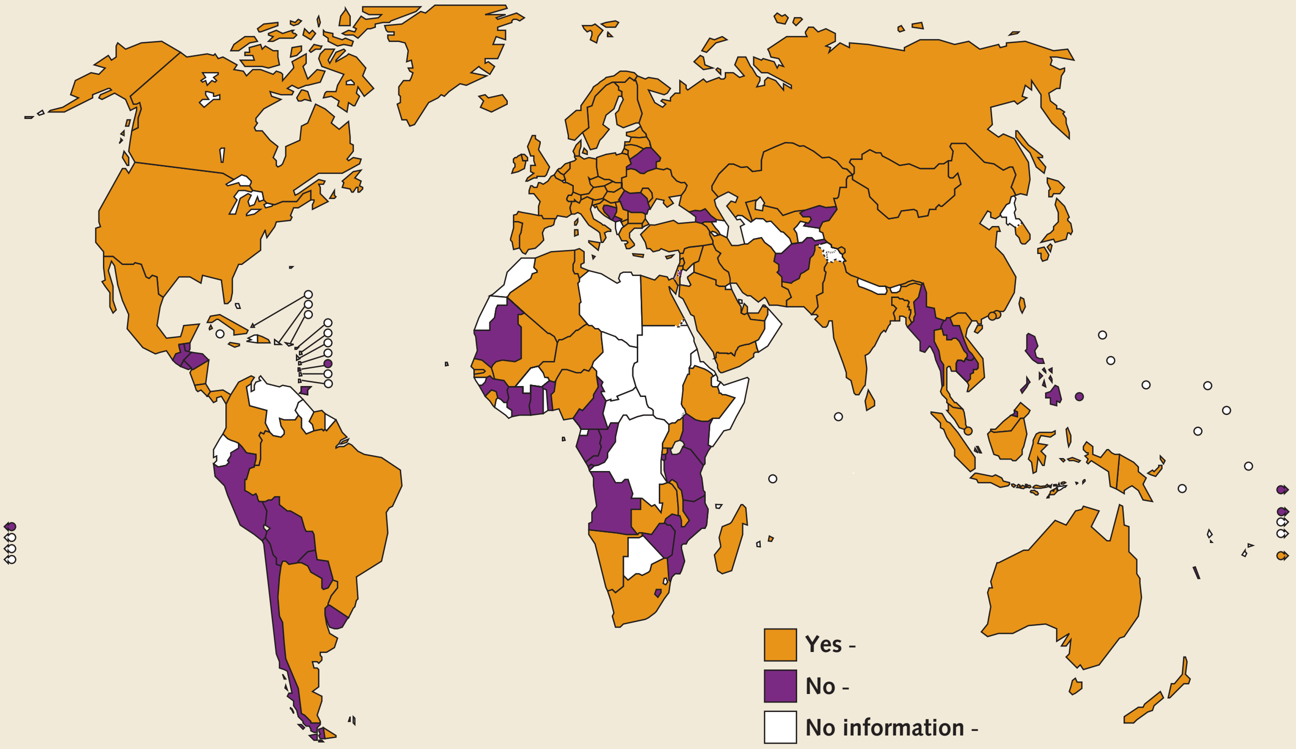


Figure 31 **Research and data on ID** (percentages of countries by income categories)



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 disabilities). 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 ■ Technical assistance for development of policies and programmes, planning, and operational research
Lack of well identified accountable authorities	■ National action plans ■ Revision of existing laws to encompass ID ■ Accountability mechanisms for implementation
Gap between needs and funding for ID	■ Recognition and mobilization of existing resources ■ 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 ■ 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 ■ 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 ■ 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 ■ 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

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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 Física 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)

MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES	NAME OF THE RESPONDENT(S)	ORGANIZATION, ASSOCIATION, OR NGO
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

MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES	NAME OF THE RESPONDENT(S)	ORGANIZATION, ASSOCIATION, OR NGO
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

MEMBER STATES OF WHO, ASSOCIATE MEMBERS OF WHO, AREAS OR TERRITORIES	NAME OF THE RESPONDENT(S)	ORGANIZATION, ASSOCIATION, OR NGO
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
☐ DSM-IV
☐ Professional opinion
☐ ICD-10
☐ ICF
☐ 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
☐ Education
☐ Health
☐ Housing
☐ Human Rights
☐ Family
☐ Income
☐ Labour
☐ Mental Health
☐ Social Welfare
☐ Youth Protection
☐ 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.

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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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