

The WHO Atlas on Global Resources for Persons with Intellectual Disabilities (WHO Atlas-ID)



**World Health
Organization**

The WHO Atlas on Global Resources for Persons with Intellectual Disabilities Team

Shekhar Saxena, *Coordinator, Mental Health Evidence and Research Team, Mental Health and Substance Abuse Division, WHO*

Jocelin Lecomte, *Information and Research Consultant, Gabrielle-Major, Lisette-Dupras and West Montreal Readaptation Centres for Persons with Intellectual Disabilities (Canada) and WHO Atlas-ID coordinator*

Céline Mercier, *Director, Research and Education, Gabrielle-Major, Lisette-Dupras and West Montreal Readaptation Centres for Persons with Intellectual Disabilities, and Professor, University of Montreal (Canada)*

Marco Garrido Cumbreira, *Technical Adviser, Mental Health Evidence and Research Team, Mental Health and Substance Abuse Division, WHO*

The WHO Atlas Project

- The WHO Atlas projects
- Methodology and limitations
- Salient findings



METHODOLOGY AND LIMITATIONS

- Introduction



- **Preparation and validation of questionnaire and glossary**
 - Genesis
 - Questionnaire
 - Glossary

● Atlas-ID respondents

- (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.

- **Validation of the information**
 - **Procedure**
 - **Multiple respondents**

● Results

- Based on 147 completed questionnaires (from 143 Member States of WHO, one Associate Member of WHO, and three areas or territories),
- Response rate of 74.6% of countries, and representing 94.6% of the world's population (2007).

- **Data analysis**

- **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. 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).**

● Limitations

- Terminology
- National organisation of services
- Analysis process
- Sources of biases
 - Choices of answers
 - Types of respondents
 - Epidemiological information

- Overall outlook on the data gathering process
 - Identified gaps and needs in intellectual disabilities resources and services throughout the world;
 - Developed two instruments to be used at country or regional level:
 - Glossary of terms used in intellectual disabilities
 - Atlas-ID questionnaire to map national intellectual disabilities services
 - Produced a network of country respondents in the intellectual disabilities field.

Salient Findings

How they can be used to :

- Document, demonstrate, compare
- Analyze
- Monitor
- Promote, advocate
- Make decisions about priorities



Salient Findings

- **Paucity of documentation and data**
 - **Concurrent use of terminology and systems of classification**
 - **Lack of visibility**
- 3 facts that are DOCUMENTED by the findings, including some cues on causes and consequences**

- **Paucity of documentation and data**

Presence of a reporting systems: ID, 37.9%; MH, 75.7%

Presence of epidemiological data: ID, 32.4%; MH, 60,5%

Data to COMPARE with other fields or sources



● Concurrent use of terminology

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

● Concurrent use of systems of classification

	World		Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	Western Pacific	N
	Proportion of countries	Number of countries							
ICD-10	62.3%	91	41.2%	48.0%	60.0%	89.4%	61.5%	54.5%	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
AAMR or AAIDD	15.1%	2	20.6%	16.0%	60.0%	6.4%	23.1%	9.1%	146
ICF	14.4%	21	17.6%	12.0%	20.0%	14.9%	15.4%	9.1%	146

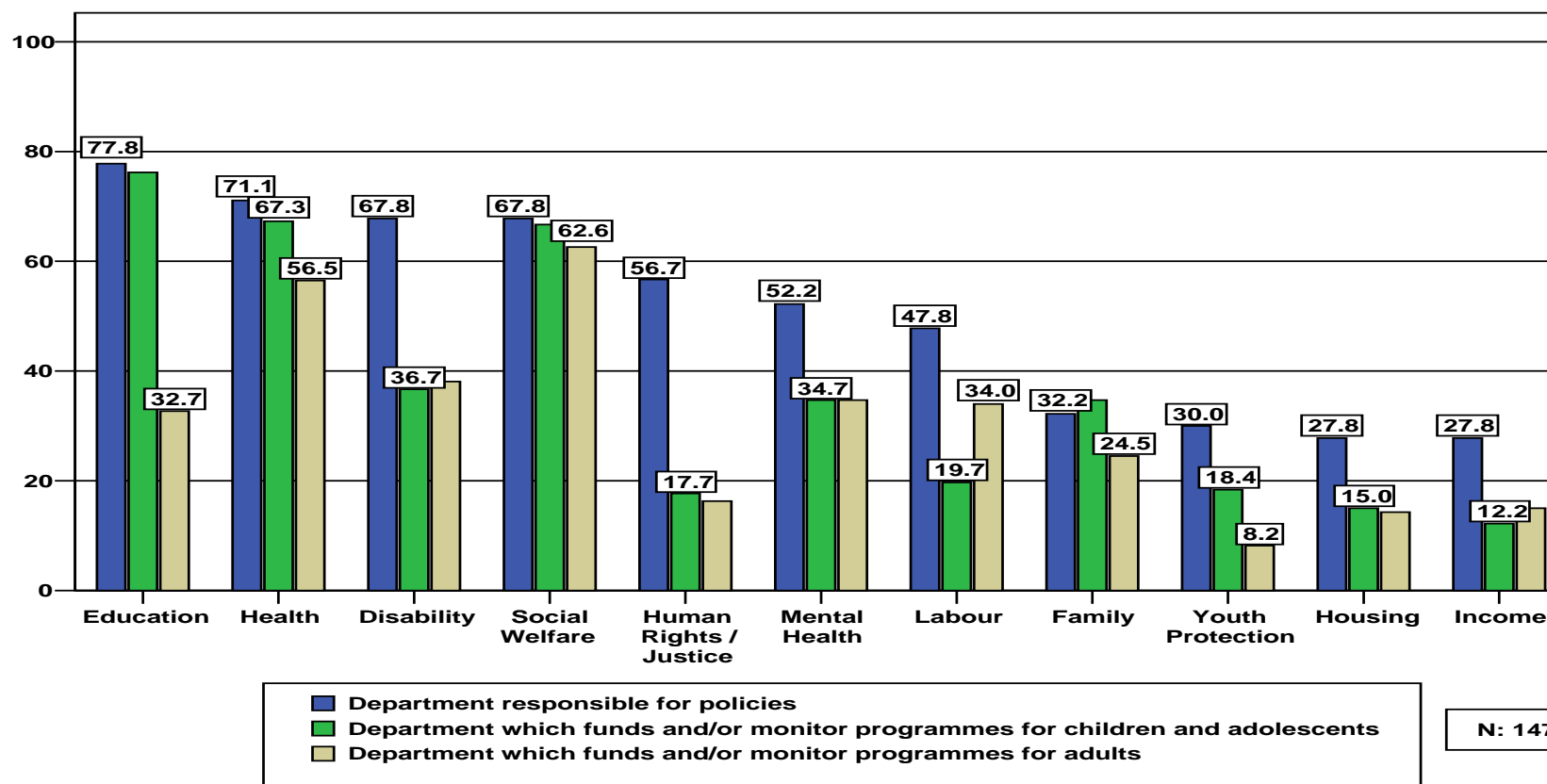
● Lack of visibility

Related data :

- Paucity of documentation and data
- Embedded with MH or/and Disabilities fields (vg. Terminology, Classification systems)
- Scattered between sectors and authorities :
 - 11 Departments have responsibilities for policies, for funding and monitoring of programmes
 - 6 Departments are mentioned by more than 50% of countries as responsible for policies

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



Salient Findings

- Sources of funding
- Access to benefits
- Barriers of access to services

3 Sets of data to DEMONSTRATE inequities



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- **Sources of funding (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

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● Access to government benefits

	Low-income	Lower-middle-income	Upper-middle-income	High-income	World	N
>10%	74.2%	46.9%	31.8%	3.0%	39.0%	46
11–25%	3.2%	9.4%	4.5%	0%	4.2%	5
26–50%	12.9%	9.4%	0%	6.1%	7.6%	9
51–74%	0%	9.4%	31.8%	6.1%	10.2%	12
>75%	9.7%	25.0%	31.8%	84.8%	39.0%	46

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● Barriers of access to services

	World		Income				N
	Proportion of countries	Number of countries	Low	Lower middle	Upper middle	High	
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

Salient Finding

- **Importance of asylum-type institutions**

Adults: 55.9% of countries

Children: 50.7% of countries

Data to SET PRIORITIES, BENCH MARK, MONITOR



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- **Asylum-type institutions**

	World		Africa	Americas	South-East Asia	Europe	Eastern Mediterranean	Western Pacific	N
	Proportion of countries	Number of countries							
Adults	55.9%	38	33.3%	64.3%	60.0%	71.4%	66.7%	20.0%	68
Children	50.7%	37	16.7%	52.9%	25.0%	71.4%	83.3%	8.3%	73

Salient Findings

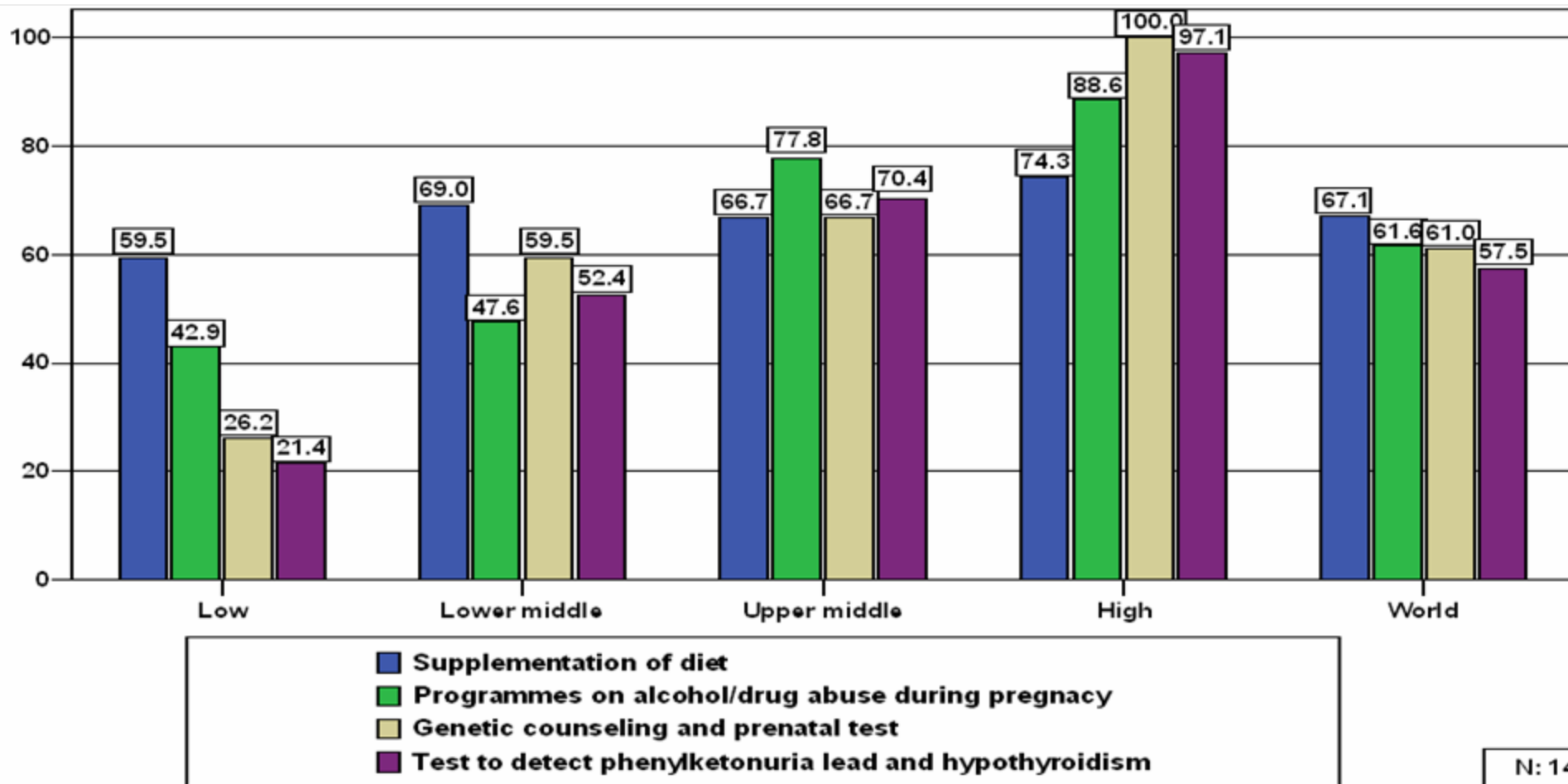
- Preventive efforts
- Provision of services by primary health care workers *(the most available health care service (more than 75% of countries, except for low-income countries (70.3%))*
- In-service training of primary health care workers

Facts to PROMOTE a public health approach

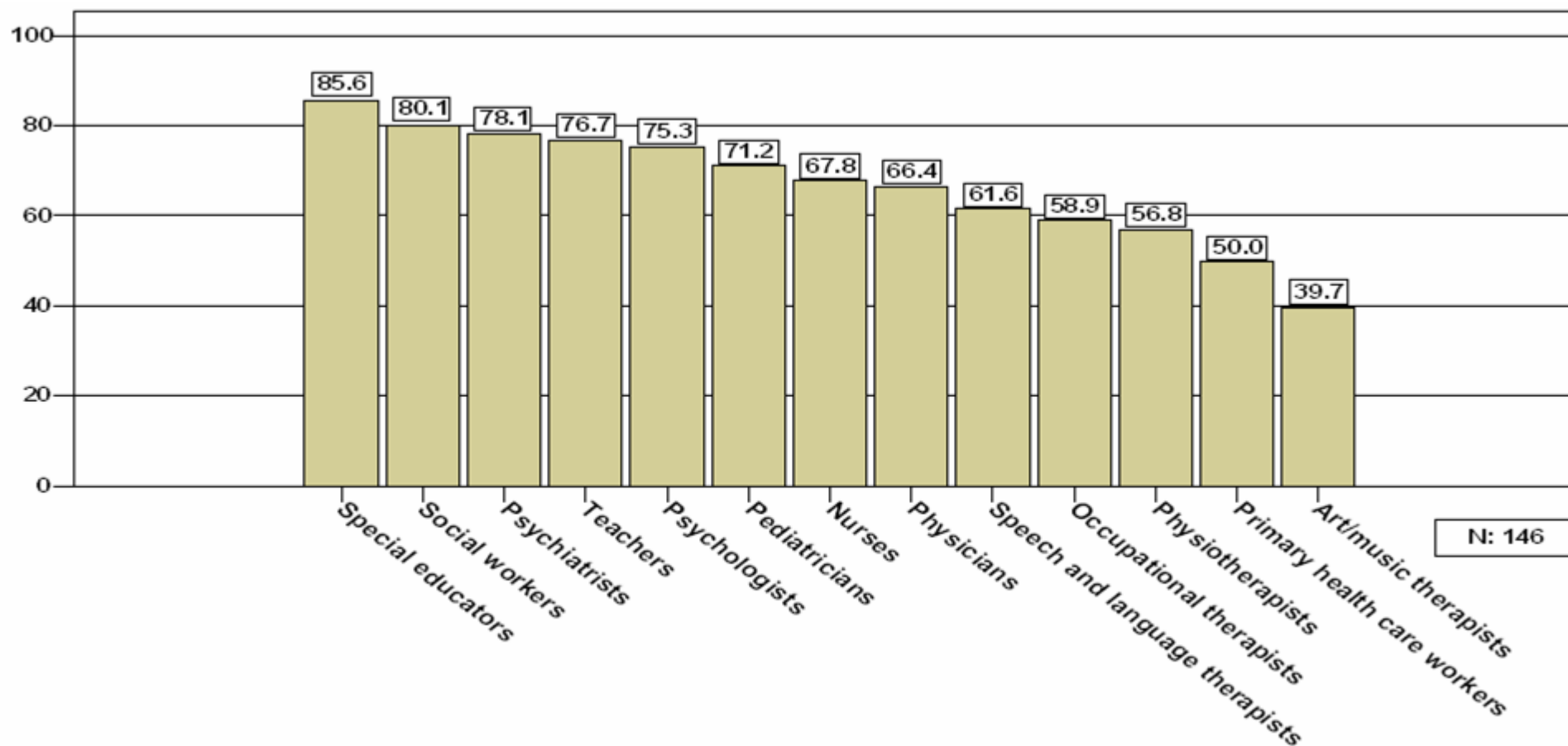
Indicators to MONITOR development



● Preventive efforts



● Provision of services by primary health care workers



● In-service training for primary health care workers (MH: 59.7% of countries)

	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

Salient Findings

- **Role of NGOs : 88.2% of countries (MH : 88.2%)**
- **Role of IOs : 62.2% of countries**

Data to ANALYZE practices

• Domains of activities for NGOs and IOs

NGOs (82.2%; MH 88.2%)

- | | |
|----------------------|---------|
| 1. Education | (80.2%) |
| 2. Support/Self Help | (76.2%) |
| 3. Rehabilitation | (73.8%) |
| 3. Advocacy | (73.8%) |
| 5. Family | (69.8%) |
| 13. Housing | (30.2%) |

IOs (62.2%)

- | | |
|-----------------------|---------|
| 1. Advocacy | (65.6%) |
| 2. Policy & Sys. Dev. | (51.6%) |
| 2. Education | (51.6%) |
| 4. Human Rights | (49.5%) |
| 5. Support/Self Help | (48.4%) |
| 13. Housing | (10.8%) |

● Domains of activities for NGOs by income categories

Low-Income (83.3%)

1. Education	(79.4%)
2. Support/Self Help	(73.5%)
3. Advocacy	(73.5%)
4. Family	(70.6%)
5. Rehabilitation	(67.6%)
10. Prevention	(38.2%)
10. Policy & Sys. Dev.	(38.2%)
10. Work / Employment	(38.2%)
13. Housing	(8.8%)

High-income (97.1%)

1. Advocacy	(93.9%)
2. Support/Self help.	(81.8%)
2. Policy & Sys. Dev.	(81.8%)
4. Work/Employment	(78.8%)
5. Family	(69.7%)
5. Human Rights	(69.7%)
5. Education	(69.7%)
11. Housing	(60.6%)
12. Health	(51.5%)
13. Prevention	(48.5%)



THE WAY FORWARD : The case for “informed advocacy”

To what extent the Atlas-ID can support initiatives to:

- Address custodial care institutions
- Build capacity
- Make intellectual disabilities a public-health issue
- Distribute resources between and within countries
- Close gap between needs and financial resources

- Change priorities of governments and civil society
- Clearly identify accountable authorities
- Recognize the role of families
- Enforce human rights and right to health

THE WAY FORWARD

- **Change priorities of governments and civil society**
- **Clearly identify accountable authorities**
- **Close gap between needs and financial resources**
- **Recognize the role of families**
- **Distribute resources between and within countries**
- **Address custodial care institutions**
- **Build capacity**
- **Make intellectual disabilities a public-health issue**
- **Enforce human rights and right to health**

Issues	Actions
Intellectual disabilities (ID) are a low priority for both governments and civil society	<ul style="list-style-type: none"> • Advocacy • Technical assistance for development of policies and programmes, planning, and operational research
Lack of well identified accountable authorities	<ul style="list-style-type: none"> • National action plans • Revision of existing laws to encompass ID • Accountability mechanisms for implementation
Gap between needs and funding FOR ID	<ul style="list-style-type: none"> • Recognition and mobilization of existing resources • Shoestring strategies for efficient use of resources with potential for large coverage
Critical role of families	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Adoption of a right-based approach to disability

Salient Findings

- **Presence of a NGOs : MH, 88.2%**
- **Presence of in-service training for primary health care workers : MH, 59.7%**
- **Presence of a reporting systems: MH, 75.7%;**
- **Presence of an epidemiological data: MH, 60,5%;**

Data to COMPARE with other fields (Mental health)



Salient Findings “Other indicators that ID have a low visibility and low priority (...) included the number of countries without any

- **Presence of a National Policy (MH, 62.1%; ID, 59,2%)**
- **Presence of a Protection law (MH, 78%; ID, 71.2%)**
- **Presence of government benefits (MH, 77.8%; ID,77.4%)**
- **Presence of public funding (MH, 62.8%; ID, 76.0%)**



- **Gaps in resources between countries**

Presence of a policy/program

- Domains of NGOs activities

