# STATUS AND PROSPECTS:

## AN INTERNATIONAL REVIEW OF THE STATE OF INTELLECTUAL DISABILITY SURVEILLANCE

Country Report: Indicators and Indices for

# INDIA

This India summary is part of a larger project exploring the feasibility of creating national benchmarks on the status and prospects of people with intellectual disabilities. The review included the identification and evaluation of national statistical systems that could capture the status of persons with intellectual disabilities from census systems, service registries, and specialized household surveys based on an organizing theme of equalization of opportunity.

Other nations included in the review were Brazil, China, Egypt, Germany, Ireland, Japan, Nigeria, Northern Ireland, Russia, South Africa, and the United States.

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# 1 *Country Report: India*
## EXECUTIVE SUMMARY

What are the status and prospects of persons with intellectual disabilities (ID) across the globe? Simply put, we do not know. The current state of monitoring allows only the most basic portrait; a data-driven characterization of life experiences and life quality cannot be produced, but there are compelling reasons for trying. In the *World Programme of Action concerning Disabled Persons*, the UN resolution recognizing the rights of persons with disabilities to full participation as a core international goal, the statistical monitoring of national progress was seen as an essential step in effecting successful implementation (United Nations, 1982).

Significant progress has been made in the international assessment of disability generally. Yet, a quarter century after the publication of the *World Programme*, the world's citizens with intellectual disabilities remain largely ignored by national statistical agencies.

### Status of Indian Data on Intellectual Disabilities

Our review of Indian data systems reveals very little ID data based on recurring surveillance but a surprising degree of sophistication and depth of information on intellectual disabilities embedded in special studies and reports. India has a tradition of developing sophisticated and detailed status reports on disability across multiple indicators of potential interest to a benchmarking initiative including employment, housing, and marital status across core demographics and regions of the country (National Sample Survey (NSS), 2003). It appears the infrastructure is in place for relatively sophisticated statistical benchmarking.

**What gets counted gets noticed; what gets counted gets done.**

### Future Directions

- Expand disability type. Our central recommendation is to expand impairment codes in current census and household survey systems to include intellectual disabilities. India has a capable surveillance infrastructure but one that does not identify ID.
- Coordinate centralized statistical functions. A coordinating body focused on disability statistics should work with statistical operations of the ministries and departments of the Central Government to enhance the uniformity of the large scale national systems.
- Coordinate local statistical operations. Since the Indian statistical system is based on local district and state government systems, it will be critical to coordinate priorities for how persons with ID are defined and the core indicators collected.

# 2 *Data Systems*
## ID IN RECURRING DATA SYSTEMS

Our review of Indian data systems included: (1) identification and evaluation of statistical systems that were national in scope, (2) identification of systems that capture either general disability or intellectual disability, and (3) a review of indicators currently captured in these data systems. The review included census systems, service registries, and specialized household surveys.

**Of 128 recurring data systems across the 12 nations, 66% included general disability; only 27% identified ID. And most of these systems were simply census counts.**

### Data and Intellectual Disabilities

- The Indian system of statistics is decentralized, largely based on reporting from district to the state government and the relevant national ministries. There are five sources of recurring national data: International Institute for Population Sciences (IIPS, Mumbai, India), Ministry of Home Affairs (MHA), Ministry of Statistics & Programme Implementation (MSPI), National Council of Educational Research & Training (NCERT), and National Institute of Educational Planning & Administration (NIEPA).
- Inspection of ID data in India reveals a nation with a history of disability data collection extending back to the 19th Century (Center for International Rehabilitation, 2005) and a relatively well developed contemporary census and survey monitoring system. Disability epidemiology is well represented in the scientific literature. Yet much of the official statistical data on disability is met with skepticism (Khandelwal, Jhingan, Ramesh, Gupta, & Srivastava, 2004). The decennial census-based data (NSS, 2003) yielded prevalence rates for all forms of disability comparable to many national estimates of ID alone (1.85%). Critics suggest that because disability is a sensitive topic, the surveyors require greater training and personal commitment. In addition to the decennial Census, there are probability-based household surveys of social and economic status variables.
- A meta-analyses of 13 psychiatric epidemiological studies yielded an estimate of 0.69%, though the rates from individual studies range widely (Reddy & Chandrashekar, 1998).

| **INDIA** | | **Features** | | | | **Indicators Included** | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Surveillance System** | Type | GD | ID | Agency | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
| All India School Education Survey | PS | ✓ | ✓ | NCERT | varies | | | ✓ | | | | |
| District Information System for Education | R | ✓ | | NIEPA | 1 yr | | | ✓ | | | | |
| Census of India | C | ✓ | | MHA | 10 yrs | ✓ | ✓ | ✓ | | ✓ | | ✓ |
| National Family Health Survey | PS | | | IIPS | 5 yrs | ✓ | ✓ | ✓ | ✓ | | | |
| National Sample Survey | PS | ✓ | | MSPI | 10 yrs | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey; **GD** = general disability screened; **ID** = intellectual disability screened; International Institute for Population Sciences (IIPS, Mumbai, India), Ministry of Home Affairs (MHA), Ministry of Statistics & Programme Implementation (MSPI), National Council of Educational Research & Training (NCERT), National Institute of Educational Planning & Administration (NIEPA); **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

# 3 *Benchmarks*
## INDICATORS & INDICES

Apart from prevalence rates and regional employment, indicators are rarely employed in international summaries of disability data. With the exception of the EUMAP (education and employment) and *Pomona* (health) initiatives, both in Europe, there have been no cross-national ID evaluations based on statistical indicators (European Intellectual Disability Research Network, 2003; Pomona, 2006).

### National Indicators

As the summary of data systems indicates, ID is limited to educational data in the recurring Indian national statistical programs. In lieu of a common set of internationally comparable statistical indicators, we developed an ad hoc benchmark based on common disability indicators: % school-age children having access to education, % school-age children in integrated schools, % children in inclusive education, % employed (open and sheltered), and national disability policy as evaluated through the Standard Rules. The selection of these domains was driven by practical rather than conceptual reasons; these are statistics commonly studied and most likely to be reported. Important outcome domains were omitted due to lack of data, and the derived index should be treated only as an illustration. (see Appendix 3).

**There are compelling reasons for development of statistical benchmarks for intellectual disability. Commitments on paper are common but serious implementation requires monitoring and evaluation of national effort.**

**INDIA**

| | Index Values [a] | | |
|---|---|---|---|
| **Indicators** | **All India** | **Disability** | **ID** |
| Access to education [b] | 1.00 | 0.62 | 0.23 |
| Integrated schools [c] | 1.00 | 0.95 | 0.68 |
| Inclusive classrooms | 1.00 | -- | -- |
| Labor Force Participation [d] | 1.00 | 0.65 | 0.14 |
| Non Sheltered Employment | na | -- | -- |
| Policy Implementation [e] | na | 0.40 | 0.40 |
| Non-Institutionalization | na | -- | -- |

see reference notes for data sources; (--) data not available;

Based on a standard 0 to 1.0 scale, where 1.0 approximates full inclusion or equity with the general population on an indicator, India averaged 0.36 for persons with intellectual disabilities and 0.66 for general disabilities; averages for the other nations in the review (excluding Nigeria) were 0.46 for persons with intellectual disabilities and 0.63 for general disabilities.

### Notes on Index Scoring and Scaling

[a] We employed a modification of the general approach used in the UNDP's Human Development Index [HDI] (United Nations Development Programme, 2007). The HDI is a standardized measure, scaled and normalized against a pre-established international standard. The standard score formula reduces statistical indicators measured on different scales to a common 0 to 1.0 scale (Jahan, 2002). In contrast to the HDI, we employed a mixture of absolute and relative indicators. Absolute indicators focused on national performance relative to a fixed value. Relative indicators measure performance relative to the national average. Combining absolute and relative values is an indirect method for accounting for local circumstances; absolute national performance is not compared but rather the equalization of access and opportunity.

### Standard Rule Scoring

The UN Standard Rules provide a useful international convention for an indicator representative of policy and legislation (United Nations, 1993). The Standard Rules emerged from the World Programme of Action (United Nations, 1982). There are a total of 22 rules, which are legally non-binding standards for nations aspiring to achieve equalization of opportunity. The 22 rules are organized across three domains: (1) preconditions required for equalization, (2) targeted areas for equalization actions, and (3) actions to ensure implementation. The Rules are widely used as criteria for evaluation of nations (Michailakis, 1997; South-North Center for Dialogue and Development, 2006). We employed a content analysis methodology in which over 1,000 reports, studies, and other

narratives were reviewed. “Narrative units” were extracted; these were evaluations, commentaries, statistical references, and similar material in the reviewed documents. Three analysts worked independently to rate each nation on five-point implementation scale (0 = no evidence to 5 = full implementation). Major discrepancies were discussed and resolved. For the purposes of creating an index, the same score was assigned to both ID and general disability populations.

[b] General population rate is likely higher since it was based on 6-14 year-old enrolment vs 5-17 years for disability; (Ministry of Human Resources Development, 2004. Disability access from NSS (2003). Access for rural children aged 5-17 years was estimated by taking enrolment rates per 1,000 for each of the diagnostic groups broken down across rural and urban areas. (NSS, 2003).

[c] Data from school enrollment rates reported in the NSS for urban and rural students by diagnostic group. Population totals for each group were estimated to compute proportions.

[d] Labour force participation included the "informal" economy as well as regular paid employment including self employed in agriculture and non-agricultural activities and casual labour. Level of participation for the population was based on the 2001 Census: a total of 402.5 million employees and "marginal" workers out of a base population of 1.025 billion (Census of India, 2001).

[e] We employed a content analysis methodology in which reports, studies, and other narratives were reviewed and “narrative units” related to any of the 22 Standard Rules for the Equalization of Opportunity was extracted. Three analysts worked independently to rate each nation on five-point implementation scale (0 = no evidence to 5 = full implementation). Major discrepancies were discussed and resolved. For the purposes of creating an index, the same score was assigned to both ID and general disability populations.

# 4 *Implications*
## CONTEXT, NUMBERS & PROSPECTS

While it is widely acknowledged that persons with intellectual disability are disadvantaged, excluded, and denied throughout the world, the intellectual disability movement lacks simple indicators of national policies or progress. While statistical data cannot directly impact policy change, it is one of the most potent tools advocates and policymakers can use to inform and galvanize the actions of the agents of change.

The quality and scope of population statistics on intellectual disability is problematic throughout the world. Rich and poor nations alike fail to monitor intellectual disability to any degree of rigor or depth. The project initially set out to develop a working index based on data drawn from the surveillance systems, but even the most rudimentary demographic data were difficult to access in the national systems. The need for greater interest by national surveillance agencies and ministries is the most salient message to be drawn from our effort.

The task of developing a broad-based index using common international indicators will require advocacy to elevate the prominence of intellectual disabilities within national data systems. The development of an index appears feasible, though significant additional data integration would be required beyond what is currently available. Nonetheless, some general observations can be drawn from the limited data. First, the disadvantage of all persons with disabilities is consistent internationally, in poor and rich countries alike. Secondly, there are even greater disparities for those with intellectual disabilities; persons with ID remain among the most marginalized groups. Our data suggest the importance of not neglecting intellectual disability in the broader push for rights and access in the international disability movement.

The lack of quality data on the life circumstances of the world's citizens with intellectual disabilities should command our attention. Information per se cannot change policy, but it can dramatically affect the nature of choices made by governments (Braddock, Hemp, & Fujiura, 1987). At its most fundamental level, policy making is the allocation of limited national resources among many competing interests.  And the compilation of national statistics can influence political debate.

# A1 *Supporting Appendices*
## WHO HAS ID?

Who has an intellectual disability? The simplicity of the question belies the profound complexity of the answer. Who is identified will depend on the purposes and structure of measurement. There are multiple reasons for the uncertainty, mostly discussed in terms of the technicalities of definition and method of measurement. These details have been the source of debate for generations, and the matter of identification is only compounded across cultures in international assessments.

There is, however, a more profound reason for the ambiguity. Intellectual disability is not a "thing," invariant across time, places, and cultures. Rather, it encompasses overlapping groups of considerable diversity, sharing a core of set of features related to impaired cognitive function. This is more than a challenge of methodology and measurement. Intelligence, functioning, adaptation, and other dimensions of ID are so contextually bound that the exercise of dichotomizing a population as having or not having an ID will always be subject to challenge for all but the most profoundly impaired.

### Estimates

Our review evaluated censuses, recurring household surveys, and registries. More often than not, these data systems were inadequate sources for ID data and we turned to local surveys and other epidemiological studies to better understand the occurrence of ID in the country. Rates ranged from 0.36% in Japan to 2.7% in Egypt, where parental consanguinity is a widely acknowledged etiological risk factor. The consolidated prevalence rate was 1.02% across the 12-nation population base of 4.2 billion persons. Although ID is often referred to as a “low prevalence” condition, the label conservatively applies to some 42 million citizens in these 12 countries.

### Notes on National Prevalence Estimates

**BRAZIL:** “Mental Disability” is captured in the decennial Census, National Household Sample Survey, and School Census. There were approximately 2.83 million people with mental disability representing a prevalence rate of 1.67% in the 2000 Census (IBGE, 2002).

**CHINA:** ID is an evolving diagnostic concept in China (Tao, 1988) and thus identification is highly variable across the few systems that attempt to code for it. The first population estimate was established in the 1987 Survey of Disabled People with an overall prevalence of intellectual disability of 1.27%. A 0.43 prevalence rate was reported in the Second China National Sample Survey on Disability: the higher rate in the 1987 survey is likely attributable to the inclusion of those with mild intellectual impairments; rates by level of severity were 0.63% mild, 0.41% moderate, and 0.23% severe (Xu, Wang, Xiang, & Hu, 2005). Higher rates (1% - 1.27%) have been derived in epidemiological studies (Li, Li, & Qian, 1994; Wang et al., 2002; Zhang & Ji, 2005).

**EGYPT:** A relatively high 0.27% general population prevalence rate was derived in a regional (the Assiut Governorate) epidemiological screening of 3,000 randomly selected urban and rural Egyptians. Reported values were much lower in the 1996 census (0.08%), and 0.33%% among children in the Egypt Multiple Indicator Cluster Survey (El Tawila, 1997), where survey rather than screening procedures were employed (Temtamy et al., 1994).

**GERMANY:** There are no official ID statistics apart from those registered with a “handicapped service pass” (Pomona, 2006) which yielded a value of about 0.3% general population. In contrast, the four large professional associations for ID in the Federal Republic estimated a rate of nearly 0.6% (approximately 420,000 persons in 2001), a value more in line with epidemiological screenings in Western nations.

**IRELAND:** Ireland’s ID database carries the caveat that it does not represent a "true prevalence" since those with mild levels of intellectual impairment are not typically in contact with the service system (Dawson, 2006). Based on service registries, the prevalence is estimated at 0.65%, a figure comparable to most ID prevalence figures for severe ID in developed countries. The most recent Census (Central

Statistics Office Ireland, 2006) included for the first time an ID screen, which yielded a rate of 1.7% for learning and intellectual disabilities.

**JAPAN:** The Basic Survey of Persons with Mental Retardation is the primary source of official prevalence data for Japan and reported a prevalence rate of 0.36%. Epidemiological studies of childhood ID have yielded higher rates among children and youths averaging approximately 0.7% (Suzuki, Aihara, & Sugai, 1991; Yoshida, Sugano, & Matsuishi, 2002).

**NORTHERN IRELAND:** Two systems are the primary sources of service registry data: the Child Health System and SOSCARE. The health system includes children with special needs who are monitored into adulthood. SOSCARE tracks all persons in contact with social services. ID is coded in both systems (McConkey, Spollen, & Jamison, 2003). Administrative prevalence was reported to be 0.7% for persons aged 20+ years (McConkey, Mulvany, & Barron, 2006) and 1.63% for children aged 0-19 years (McConkey et al., 2003). Administrative coverage is considered comprehensive for those in need of services.

**RUSSIA:** ID data (and social data generally) is problematic for Russia; concepts and yield terminology differ from international standards as do the diagnostic approaches. Some reports have yield prevalence rates for "mental defects" far higher than typically reported and likely represent use of imprecise terminology and a diagnostic process that can be arbitrary in labeling (Mental Disability Rights International, 1999). The primary official sources of data come from State Reports on population health that incidentally report on ID. A prevalence rate of 0.633% was reported in the State Report on population health in the Russian Federation (Koloskov, 2001).

**SOUTH AFRICA:** The primary base for ID data is taken from the 2001 Census and most recently the 2007 Community Survey. Prevalence was estimated at 0.5% in 2001 and 0.27% in the 2007 survey. As in all our reviews of national figures, these conservative values have been challenged as undercounts (Statistics South Africa, 2005). Two large-scale epidemiological efforts found significantly higher rates generally, 1.1% across all age cohorts (Community Agency for Social Enquiry, 1997). Christianson (2002), however, found major differences across subpopulations with rates as high as 3.5% among rural children).

**UNITED STATES** There is no primary base of ID data but rather different estimates taken from different federal systems. Survey based identification converges on a 0.7% rate though identification is based on self report in the major federal systems (Fujiura, 2003).

# A2 *Supporting Appendices*
## OTHER NATIONAL DATA SYSTEMS

The quality and scope of population statistics on intellectual disability is problematic throughout the world. Rich and poor nations alike fail to monitor intellectual disability to any degree of rigor or depth.

There were three primary sources of national data: national or regional censuses, sample-based surveys, and administrative registries. Censuses were an enumeration of every person in a national population. The detail and depth of information in censuses tends to be severely limited due to the great cost and substantial data collection demands of national coverage. Sample-based surveys were systematic data collections conducted to provide national estimates on very specific characteristics of the population. While these specialized surveys provide greater detail on topics of relevance to the status of persons with intellectual disability, they typically fail to identify forms of disability, and the topics are largely limited to health status and employment. The third major category is the service registry, essentially an administrative tally of individuals who are the recipients of public services or benefits. While an important source of information on access to government programs or extent of service need, registry data often represents only a small fraction of the total population.

**Lessons drawn from our review and analysis indicate that comprehensive and timely data on intellectual disability populations does not exist in even the most data rich developed nations of the world.**

In total, we identified 128 systems (22 census, 76 recurring sample surveys and, 30 registries). Across these systems, 65.6% identified general disability in some form, while only 26.6% separately coded persons with intellectual disabilities. Thus, while the nations in our analysis have extensive systems of statistical surveillance, intellectual disability is not typically monitored.

Monitoring of ID by Domain

| **Domain** | % Data Systems That Monitor: | |
|---|---|---|
| | General Disability | Intellectual Disability |
| Household Demographics | 70.5 | 27.9 |
| Work | 61.3 | 20.0 |
| Education | 76.9 | 29.5 |
| Health | 75.9 | 32.8 |
| Income | 60.4 | 18.9 |
| Social Participation | 58.3 | 33.3 |
| Services and Supports | 84.1 | 45.5 |

In addition, the identification of intellectual disability in 26.6% of all systems reviewed in our canvas vastly overstates our national capacity to actually quantify status and prospects. When assessed, ID is typically found in sampling systems where the numbers are too small to extrapolate stable national estimates from and the type of data collected are often very limited.

## BRAZIL

| Surveillance System | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Features | | | Indicators Included | | | | | | |
| Annual Relations of Social Information | C | ML | ✓ | | 1 yr | | ✓ | | | | | |
| Communications of Work Accidents | R | MSS | ✓ | | 1 yr | | ✓ | | | | | |
| Demographic Census | C | IBGE | ✓ | | 10 yrs | ✓ | ✓ | ✓ | ✓ | ✓ | | |
| Hospital Information System | R | MH | | | 1 yr | | | | ✓ | | | |
| National Household Sample Survey | PS | IBGE | ✓ | | 1 yr | ✓ | ✓ | ✓ | ✓ | ✓ | | |
| School Census | R | ME | ✓ | | 1 yr | | | ✓ | | | | |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** IBGE [National Statistical Office], Ministry of Education (ME), Ministry of Health (MH), Ministry of Labor (ML), and Ministry of Social Security (MSS); **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## CHINA

| Surveillance System | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Features | | | Indicators Included | | | | | | |
| 1st National Survey of Disability | PS | multiple | ✓ | ✓ | 1987 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| 2nd National Survey of Disability | PS | multiple | ✓ | ✓ | 2006 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| China National Population & Housing Census | C | NBS | ✓ | | 10 yrs | ✓ | ✓ | ✓ | | | | |
| Comprehensive Labour Statistics Reporting System | C | NBS | | | 1 yr | | ✓ | | | ✓ | | |
| Education Statistics | R | MOE | ✓ | ✓ | 1 yr | | | 3 | | | | |
| Health & Nutrition Survey | PS | CCDCP | ✓ | ✓ | 3 yrs | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| National Health Services Survey | PS | MH | | | 5 yrs | | | | ✓ | | | ✓ |
| Poverty Monitoring Survey | PS | NBS | | | 1 yr | ✓ | ✓ | ✓ | | ✓ | | |
| Rural Household Survey | PS | NBS | | | 1 yr | ✓ | ✓ | ✓ | | ✓ | | ✓ |
| Statistical Reporting System Training & Employment | R | MLSI | | | 1 yr | | 3 | | | | | |
| Urban Household Survey | PS | NBS | | | 1 yr | ✓ | ✓ | | | ✓ | | |
| Urban Labour Force Survey | PS | NBS | | | 1 yr | | ✓ | ✓ | | ✓ | | |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** China Centers for Disease Control & Prevention (CCDCP), Ministry of Education (MOE), Ministry of Health (MH), Ministry of Labour & Social Insurance (MLSI), and National Bureau of Statistics of China (NBS); "multiple = CCDCP and NC Chapel Hill Carolina Population Center; **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## EGYPT

| Surveillance System | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | Features | | | Indicators Included | | | | | | |
| Census of Population | C | CAPMAS | ✓ | ✓ | 10 yrs | ✓ | ✓ | ✓ | ✓ | | | |
| Demographic & Health Survey | PS | MHP | | | 3 yrs | ✓ | ✓ | ✓ | ✓ | | ✓ | |
| Labor Force Sample Survey | PS | CAPMAS | ✓ | | 6 mos | | ✓ | | | ✓ | | |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** Central Agency for Public Mobilization & Statistics (CAPMAS) and the Ministry of Health & Population (MHP); **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## GERMANY

Features | Indicators Included

| Surveillance System | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| KG8 Statistics | R | BG | ✓ | | 1 yr | | ✓ | | ✓ | | | |
| Microcensus (Mikrozensus) | PS | SB | ✓ | | 1 yr | ✓ | ✓ | ✓ | ✓ | | | |
| Labor Market Statistics | PS | BA | ✓ | | 1 yr | | ✓3 | | | | | |
| German Socio Economic Panel Survey | PS | IZA | ✓ | | 1 yr | ✓ | ✓ | ✓ | ✓ | ✓ | | |
| National Health Examination Survey | PS | BGS | ✓ | | 7 yrs | | | | ✓ | | | |
| Questions on Health | PS | FG | ✓ | | 4 yrs | | | | ✓ | | | |
| Sample Survey on Income and Expenditure | PS | SB | | | 5 yrs | ✓ | ✓ | ✓ | | ✓ | | |
| Statistics on the Severely Handicapped | R | SB | ✓ | | 2 yrs | ✓ | | | ✓ | | | ✓ |
| Statistics on the number of retired people | R | DRV | ✓ | | 1 yr | | | | | ✓ | | ✓ |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** Bundesministerium fur Gesundheit/Federal Ministry of Health (BG), Statistisches Bundesamt (SB), Bundesministerium fur Gesundheit/Federal Employment Agency (BA), Bundes Gesundheitssurvey (BGS), Fragen zur Gesundheit (FG), Deutsche Rentenversicherung Bund/German Annuity Insurance Federation (DRV), and Institute for the Study of Labor (IZA); **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## IRELAND

| | | Features | | | | | Indicators Included | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Surveillance System** | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
| Annual Census of Primary Schools | R | DES | ✓ | | 1 yr | | | ✓ | | | | |
| Census of Population | C | CSO | ✓ | ✓ | 5 yrs | ✓ | ✓ | ✓ | ✓ | | | |
| Disability Living Allowance | R | DSCFA | ✓ | | 1 yr | | | | | | | |
| National Disability Survey of 2006 | PS | CSO | ✓ | ✓ | note | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| National Employment Survey | PS | CSO | ✓ | | 10 yrs | ✓ | ✓ | ✓ | | | | |
| Quarterly National Household Survey | PS | CSO | ✓ | | 3 mos | ✓ | ✓ | | | | | ✓ |
| National ID Database | R | DHC | ✓ | ✓ | 1 yr | ✓ | | | ✓ | | | ✓ |
| Physical & Sensory Disability Database | R | DHC | ✓ | ✓ | 1 yr | ✓ | ✓ | | ✓ | | | ✓ |
| Post Primary Data | R | DES | ✓ | | 1 yr | | ✓ | | | | | |
| EU Survey on Income & Living Conditions | PS | CSO | ✓ | | 1 yr | | ✓ | ✓ | ✓ | ✓ | | |
| Survey of Lifestyles, Attitudes, Nutrition | PS | DHC | ✓ | | 4 yrs | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** Central Statistics Office (CSO), Department of Social, Community & Family Affairs (DSCFA), Department of Education & Science (DES), and Department of Health & Children (DHC); **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## JAPAN

| | | Features | | | | | Indicators Included | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Surveillance System** | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
| Basic Survey on MR | PS | MHLW | | ✓ | 5 yrs | | ✓ | ✓ | | ✓ | | |
| Basic Survey on Physically Disability | PS | MHLW | ✓ | | 5 yrs | ✓ | ✓ | ✓ | | ✓ | | ✓ |
| Basic Survey on Wage Structure | PS | MHLW | | | 1 yr | | ✓ | | | ✓ | | |
| Comprehensive Survey of Living Conditions | PS | MHLW | | | 1 yr | ✓ | ✓ | | ✓ | ✓ | | |
| Employment Status Survey | PS | IAC | | | 5 yrs | ✓ | ✓ | ✓ | | ✓ | | |
| Family Income & Expenditure Survey | PS | IAC | | | 1 mo | ✓ | ✓ | | | ✓ | | |
| Household Survey on Long-term Care | PS | MHLW | | | varies | | | | ✓ | | | ✓ |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Labour Force Survey | PS | IAC | | | 1 mo | | ✓ | | | | | |
| Longitudinal Survey of Babies | PS | MHLW | | | 6 mos | ✓ | ✓ | ✓ | ✓ | | | |
| Monthly Labour Survey | PS | MHLW | | | 1 mo | | ✓ | | | ✓ | | |
| National Nutrition Survey | PS | MHLW | | | 1 yr | | | | ✓ | | | |
| National Survey on Family | PS | NIPSSR | | | 5 yrs | ✓ | | | | | ✓ | ✓ |
| National Survey of Family Income | PS | IAC | | | 5 yrs | ✓ | | | | ✓ | | |
| National Survey on Household Changes | PS | NIPSSR | | | 5 yrs | ✓ | | | ✓ | | | ✓ |
| Patients' Behaviour Survey | PS | MHLW | | | 3 yrs | | | | ✓ | | | |
| Patient Survey | PS | MHLW | | | 3 yrs | | | | ✓ | | | |
| Population Census | C | IAC | | | 5 yrs | ✓ | ✓ | ✓ | | | ✓ | |
| School Basic Survey | C | MECSST | ✓ | | 1 yr | | | ✓ | | | | |
| School Health Survey | C | MECSST | ✓ | ✓ | 1 yr | | | ✓ | ✓ | | | |
| School Teachers Survey | C | MECSST | ✓ | | 3 yrs | | | ✓ | | | | |
| Social Education Survey | C | MECSST | | | 3 yrs | | | ✓ | | | | |
| Survey on Social Security | R | NIPSSR | | | 5 yrs | | | | | | | |
| Survey of Salary in the Private Sector | PS | NTAA | | | 1 yr | | ✓ | | | ✓ | | |
| Survey on Time Use & Activities | PS | IAC | | | 5 yrs | | ✓ | | | | ✓ | |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** Ministry of Education, Culture, Sports, Science & Technology (MECSST), Ministry of Health, Labour & Welfare (MHLW), National Tax Administration Agency (NTAA), National Institute of Population and Social Security Research (NIPSSR); **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## Nigeria

| | | | Features | | | | | Indicators Included | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Surveillance System** | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
| Census of Agricultural Holdings | PS | NBS | | | 1 yr | | ✓ | | | | | |
| Core Welfare Indicators Questionnaire | PS | NBS | ✓ | | varies | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| Demographic & Health Survey | PS | NPC | | | varies | ✓ | ✓ | ✓ | ✓ | | | |
| Employment Exchange Registry | R | NBS | | | 1 yr | | ✓ | ✓ | | ✓ | | |
| General Household Survey | PS | NBS | | | 1 yr | | ✓ | | ✓ | ✓ | | |
| Labour Force Sample Survey | PS | NBS | ✓ | | 4 mos | | ✓ | ✓ | | ✓ | | |
| Ntl Agricultural Census | C | NBS | | | 5 yrs | | ✓ | ✓ | | ✓ | | |
| Ntl Survey of Households | PS | NBS | ✓ | | 1 yr | | ✓ | ✓ | ✓ | ✓ | | ✓ |
| Annual Population Census of Schools | C | FME | | | 1 yr | | | 3 | | | | |
| Rural Agriculture Survey | PS | NBS | | | 1 yr | | ✓ | | | | | |
| Professional and Executive Registry | R | NBS | | | 1 yr | | ✓ | | | | | |
| Population & Housing Census | C | NPC | ✓ | 3 | 10 yrs | ✓ | ✓ | ✓ | ✓ | | | |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** Federal Ministry of Education (FME), National Bureau of Statistics (NBS), National Population Commission (NPC), and the Universal Basic Education Commission (UBEC); **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## Northern Ireland

| | | | Features | | | | | Indicators Included | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Surveillance System** | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
| Child Health System Module V | R | DHSSPS | ✓ | ✓ | 1 yr | | | | ✓ | | | ✓ |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Child of the New Century Survey | PS | NISRA | ✓ | | cohort | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Community Returns (KARS) | R | DHSSPS | ✓ | ✓ | 1 yr | | | | | | | ✓ |
| Community Returns Children's Order | R | DHSSPS | ✓ | ✓ | 1 yr | | | | | | | ✓ |
| Continuous Household Survey | PS | DHSSPS | ✓ | | 1 yr | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| Family Resources Survey | PS | NISRA | ✓ | | 1 yr | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| Health & Social Wellbeing Survey | PS | DHSSPS | ✓ | | 3 yrs | ✓ | ✓ | ✓ | ✓ | | | |
| Labour Force Survey | PS | DED | ✓ | ✓ | 3 mos | ✓ | ✓ | ✓ | ✓ | ✓ | | |
| Mental Health Inpatients System | R | DHSSPS | ✓ | ✓ | 1 yr | | | | ✓ | | | ✓ |
| N Ireland Population Census | C | NISRA | ✓ | ✓ | 10 yrs | ✓ | ✓ | ✓ | ✓ | | | |
| N Ireland Household Panel | PS | ISER | ✓ | | cohort | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| N Ireland Longitudinal Study | PS | NISRA | ✓ | | cohort | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| N Ireland Omnibus Survey | PS | NISRA | ✓ | | 3 mos | ✓ | ✓ | ✓ | ✓ | ✓ | | |
| N Ireland School Census | C | DOE | ✓ | ✓ | 1 yr | | | ✓ | | | | |
| N Ireland Survey of Activity Limitation and Disability | PS | NISRA | ✓ | ✓ | cohort | | | | ✓ | | | |
| Secondary School Census | C | DOE | ✓ | | 1 yr | | | ✓ | | | | |
| School Leavers Census | C | DOE | ✓ | | 1 yr | | | ✓ | | | | |
| SOSCARE | R | DHSSPS | ✓ | ✓ | 1 yr | ✓ | | | | | | ✓ |
| Travel Survey for Northern Ireland | PS | NISRA | ✓ | | 1 mo | | | | | | ✓ | |
| Young Persons Behavior & Attitudes | PS | NISRA | ✓ | | cohort | | | ✓ | ✓ | | | ✓ |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** Department of Health & Social Services & Public Safety (DHSSPS), Northern Ireland Statistics & Research Agency (NISRA), Department of Economic Development (DED), Department of Education (DOE), Institute for Social & Economic Research (ISER), and Social Services Client Administration and Retrieval Environment (SOSCARE); **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## Russia

| | Features | | | | | Indicators Included | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Surveillance System** | Type | Agency | GD[1] | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
| All Russian Population Census | C | ROSSTAT | | | 10 yrs | ✓ | ✓ | ✓ | | ✓ | | |
| Population Sample Survey on Employment | PS | ROSSTAT | | | 3 mos | | ✓ | ✓ | | ✓ | | |
| Russian Longitudinal Monitoring Survey | PS | ROSSTAT | | | 1 yr | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Sample Survey on Households' Budgets | PS | ROSSTAT | | | 1 yr | ✓ | ✓ | | | ✓ | | |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** [1]All four recurring systems attempt to identify recipients of pensions, within which disability is a code option; **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## South Africa

| | Features | | | | | Indicators Included | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Surveillance System** | Type | Agency | GD | ID | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
| Annual School Survey | C | DE | ✓ | | 1 yr | | | ✓ | | | | |
| Community Survey | PS | SSA | ✓ | ✓ | 5 yrs | ✓ | ✓ | ✓ | | ✓ | | ✓ |
| Demographic & Health Survey | PS | DH | ✓ | | 5 yrs | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| Education Management Information Systems | R | DE | ✓ | | 1 yr | | | ✓ | | | | |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Higher Education Management Information Systems | R | DE | ✓ | | 1 yr | | | ✓ | | | | |
| General Household Survey | PS | SSA | ✓ | ✓ | 1 yr | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| Income & Expenditure Survey | PS | SSA | ✓ | | 3 yrs | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| Labour Force Survey | PS | SSA | ✓ | | 6 mos | | ✓ | | | | | |
| Population and Housing Census | C | SSA | ✓ | ✓ | 10 yrs | ✓ | ✓ | ✓ | | ✓ | | ✓ |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey**;** Department of Education (DE), Department of Health (DH), and Statistics South Africa (SSA) **GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports)

## United States

| | | Features | | | | Indicators | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Surveillance System** | Type | GD | ID | Agency | Freq | Hf | Wrk | Ed | He | Inc | Sp | Ss |
| American Community Survey | PS | ✓ | | USC | 1 yr | ✓ | ✓ | ✓ | | ✓ | | |
| Annual Report to Congress on IDEA | R | ✓ | ✓ | OSEP | 1 yr | | | ✓ | | | | |
| Behavioral Risk Factor Surveillance | PS | ✓ | ✓ | CDC | 1 yr | | | ✓ | ✓ | | | ✓ |
| Case Service Report | R | ✓ | ✓ | RSA | 1 yr | | ✓ | ✓ | | | | ✓ |
| Current Population Survey | PS | ✓ | | USC | 1 yr | ✓ | ✓ | ✓ | | | | |
| Digest of Educational Statistics | R | ✓ | ✓ | NCES | 1 yr | | | ✓ | | | | |
| Medicaid Statistical Information System | R | ✓ | ✓ | CMS | 1 yr | | | | ✓ | | | ✓ |
| Medical Expenditure Panel Survey [1] | PS | ✓ | | AHCRQ | | ✓ | | ✓ | ✓ | | | ✓ |
| National Health Interview Survey | PS | ✓ | | NCHS | 1 yr | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ |
| National Health and Nutrition Examination Survey | PS | ✓ | ✓ | NCHS | 1 yr | ✓ | | ✓ | ✓ | | | |
| National Residential Information Systems | R | | ✓ | ADD/UMn | 1 yr | | | | | | | ✓ |
| State of the States | R | ✓ | ✓ | ADD/UC | 1 yr | | | | | | | ✓ |
| Survey of Income & Program Participation [1] | PS | ✓ | ✓ | BLS | 1 yr | ✓ | ✓ | ✓ | | ✓ | | ✓ |

**Notes:**
**R**=registry, **C**=census, **PS**=household probability survey **; GD** = general disability screened; **ID** = intellectual disability screened; **Freq** = frequency of administration; **Hf** (housing & family) /**Wrk** (work)/**Ed** (education)/**He** (health)/ **Inc** (income)/ **Sp** (social participation)/ **Ss** (service & supports) /

# A3 *Supporting Appendices*
## INDEX SCORING & SCALING

The construction of national "indicators" is a common application for national statistical data, and one that is growing in importance with the increased integration of the world's economies. The indicator concept is simple, yet challenging in its implementation. National statistics are used as a proxy to represent a dimension of a country in a single quantitative value. Gross domestic product, for example, combines multiple statistics on consumer and government spending, import and export activity, and other indicators as a representation of the size of a nation's economy. Examples of social indicators include development, educational achievement, health, human development, human rights, and others.

### Starting Point

As a starting point we considered a core set of indicators: access to education, education within "regular" schools, inclusive education (integrated classes), employment (open and sheltered), institutionalization, and national disability policy as evaluated through the Standard Rules. While many important domains are omitted in this list (e.g., health, participation, quality of life, and others), others such as education, employment, and deinstitutionalization are core policy objectives for intellectual disability communities across nations and cultures, and as a practical matter, the types of outcomes most likely to be monitored in national statistics.

### Comparing Across or Within?

An important conceptual issue is the benchmark's intended use -- to compare nations on a standard set of criteria, (such as, "no institutions") or to focus on equity within a nation (for example, "equal access to primary education") The former is most often employed in establishing goalposts for nations, but the latter application has the advantage of communicating goals more meaningful to local circumstances.

The index employed in our exploration contained elements of both approaches. Some indicators were based on fixed criteria or outcomes represented in absolute values: persons with ID should be educated with their peers, should not be institutionalized, and the home country should adhere to the Standard Rules. Education and employment, however, cannot be readily set at absolute values without taking into consideration national capacity. If the local economy provides minimal salaried employment, is there utility in promoting a benchmark for full employment for those with intellectual disabilities? This is an extension of the concept of statistically measuring equalization of opportunity recently explored in international disability statistics forums (Altman et al., 2003). Of course, the determination of fixed versus relative is based on our values; indicators employed and the manner in which they are benchmarked ultimately represent a conversation of profound importance for those who measure. For now, the index construction serves, albeit simplistically, the purposes of our exercise.

### Availability of Indicators

Not unexpectedly our access to data and domains of indicators was variable across nations. In the aggregate, international data as currently constructed is not adequate for the construction of a reliable or valid benchmark. Data is limited in both quantity and quality. As our summary of surveillance systems indicates, ID is rarely systematically considered in the national statistical programs. For the most part, the index as shown on the following pages is cobbled together from estimates, imputed values, special studies, and extrapolations.

Number of Computed Indicators by Country [a]

| | ID | Other Disability | | ID | Other Disability | | ID | Other Disability |
|---|---|---|---|---|---|---|---|---|
| Brazil | 5 | 5 | India | 4 | 4 | N Ireland | 4 | 6 |
| China | 6 | 6 | Ireland | 7 | 7 | Russia | 5 | 5 |
| Egypt | 2 | 3 | Japan | 7 | 7 | S Africa | 3 | 5 |
| Germany | 6 | 7 | Nigeria | 1 | 2 | US | 7 | 7 |

[a] many of these indicators were imputed from multiple sources and did not represent official national statistics

## Findings

National data consistently portray a population that is largely marginalized, regardless of national development or wealth. A nation's citizens with intellectual disability are at a significant disadvantage, even when compared those with other disabilities. Shown in the table below are the index scores averaged across nations for persons with intellectual disability and those with other forms of disability. A value of 1.0 would indicate full parity to the general population in the same country. While our data are exploratory at best, they indicate that persons with intellectual disability are marginalized throughout the world.

**Status and Prospects Index Across the 11 Nation Sample [a]**

| **Domain** | Other Disability | ID |
|---|---|---|
| Access to education | .74 | .63 |
| School inclusion | .68 | .52 |
| Classroom inclusion | .47 | .10 |
| Participation in labor | .51 | .33 |
| Non sheltered work opportunity | .64 | .14 |
| Institutionalization | .96 | .87 |

[a] excludes Nigeria for which indicators were not available

# A4 *Supporting Appendices*
## CITATIONS & DATA SOURCES


Altman, B. M., Madans, J., Rasch, E., Me, A., Mbogoni, M., & Palma, E. (2003). *The disability measurement matrix*. Ottawa, Canada: Washington Group.

Braddock, D., Hemp, R., & Fujiura, G. T. (1987). National study of public spending for mental retardation and developmental disabilities. *American Journal of Mental Deficiency, 92*, 121-133.

Braddock, D., Hemp, R., & Rizzolo, M. C. (2004). State of the states in developmental disabilities: 2004. *Mental Retardation, 42*(5), 356-370.

Central Statistics Office Ireland. (2006). *Measuring Ireland's progress, 2006*. Cork, Ireland: Central Statistics Office Ireland.

Christianson, A. L., Zwane, M. E., Manga, P., Rosen, E., Venter, A., Downs, D., et al. (2002). Children with intellectual disability in rural South Africa: Prevalence and associated disability. *Journal of Intellectual Disability Research, 46*(2), 179-186.

Community Agency for Social Enquiry. (1997). *The national baseline disability survey*. Pretoria, South Africa: South Africa Department of Health.

Dawson, F. (2006). *Annex viii: Ireland, the Pomona project: Health indicators for people with intellectual disabilities*. Retrieved 04/10/2007, from http://www.pomonaproject.org/report.php

El Tawila, S. (1997). *Child well-being in Egypt: Results of Egypt's multiple indicator cluster survey*. Cairo, Egypt: UNICEF Egypt Country Office.

European Intellectual Disability Research Network. (2003). *Intellectual disability in Europe: Working papers*. Canterbury, UK: Tizard Centre, University of Kent at Canterbury.

Fujiura, G. T. (2003). Continuum of intellectual disability: Demographic evidence for the "Forgotten generation.". *Mental Retardation, 41*(6), 420-429.

GAO. (2002). *Long-term care: Aging baby boom generation will increase demand and burden on Federal and state budgets*. Washington, D.C.: U.S. General Accounting Office.

IBGE. (2002). *2000 demographic census*. Rio de Janeiro, Brazil: National Statistics Institute-IBGE.

Jahan, S. (2002). *Measuring living standard and poverty: Human development index as an alternative measure*. Amherst: Work Document presented in the Global Labor Standards and Living Wages Group Meeting, University of Massachusetts April 19 and 20.

Koloskov, S. (2001). *Rights of the child in education*. Moscow, Russian Federation: Downs Syndrome Association.

Li, A. L., Li, L. M., & Qian, Y. P. (1994). Preliminary analysis of factors causing mental retardation in China. *Zhonghua Yu Fang Yi Xue Za Zhi, 28*, 284-286.

Madhav, M. S. (2001). Epidemiological study of prevalence of mental disorders in India. *Indian Journal of Community Medicine, 26*(4), 2001-2012.

McConkey, R., Mulvany, F., & Barron, S. (2006). Adult persons with intellectual disabilities on the island of Ireland. *Journal of Intellectual Disability Research, 50*(3), 227-236.

McConkey, R., Spollen, M., & Jamison, J. (2003). *Administrative prevalence of learning disability in Northern Ireland*. Belfast, Northern Ireland: Department of Health and Social Services and Public Safety.

McNeil, J. M. (1993). *Americans with disabilities: 1991-92*. Washington, D.C.: Bureau of the Census, U.S. Department of Commerce.

Mental Disability Rights International. (1999). *Children in Russia's institutions: Human rights and opportunities for reform*. Washington, D.C.

Michailakis, D. (1997). *Government action on disability policy, a global survey*. Stockholm: Sweden: Institute on Independent Living.

National Sample Survey (NSS). (2003). *Disabled persons in India: NSS 58th round*. New Delhi, India: Ministry of Statistics and Programme Implementation, Government of India.

Office of Special Education Programs. (2006). *26th annual report to congress on the implementation of idea*. Washington, D.C.: United States Department of Education.

Olney, M. F., & Kennedy, J. (2001). National estimates of vocational service utilization and job placement rates for adults with mental retardation. *Mental Retardation, 39*(1), 32-39.

Pomona. (2006). *The Pomona project: Health indicators for people with intellectual disabilities*. Retrieved 2/10/2007, from http://www.pomonaproject.org/report.php

Reddy, M. V., & Chandrashekar, C. R. (1998). Prevalence of mental and behavioural disorders in India: A meta-analysis. *Indian Journal of Psychiatry, 40*, 149-157.

South-North Center for Dialogue and Development. (2006). *Global survey on government implementation of the standard rules-results analysis*. Amman, Jordan: South-North Center.

Statistics South Africa. (2005). *Prevalence of disability in South Africa census 2001*. Pretoria, South Africa: Statistics South Africa.

Suzuki, J., Aihara, M., & Sugai, K. (1991). Severely retarded children in a defined area of Japan - prevalence rate, associated disabilities and causes. *No To Hattatsu, 23*, 4-8.

Tao, K. T. (1988). Mentally retarded persons in the people's Republic of China: Review of epidemiological studies and services. *American Journal of Mental Retardation, 93*, 193-199.

Temtamy, S. A., Kandil, M. R., Demerdash, A. M., Hassan, W. A., Meguid, N. A., & Afifi, H. H. (1994). An epidemiological/genetic study of mental subnormality in Assiut governorate, Egypt. *Clinical Genetics, 46*, 347-351.

United Nations. (1982). *World programme of action concerning disabled persons - United Nations decade of disabled persons, 1982-1992*. New York: United Nations.

United Nations. (1993). *Standard rules on the equalization of opportunities for persons with disabilities*. New York: United Nations.

United Nations Development Programme. (2007). *Human development report 2007*. New York: United Nations.

Wang, W., Sullivan, S. G., Yao, J. C., Liu, Y., Che, C. Z., & Bittles, A. H. (2002). The genetic component of intellectual disability in pr China. *Medical Genomics*, from http://hgm2002.hgu.mrc.ac.uk/Abstracts/Pub

Xu, J., Wang, M., Xiang, Y., & Hu, X. (2005). Quality of life for people with intellectual disabilities in China: A cross-culture perspectives study. *Journal of Intellectual Disability Research, 49*, 745-749.

Yoshida, A., Sugano, T., & Matsuishi, T. (2002). Mental retardation incidence in Yokohama city. *Journal of Disability and Medico-Pedagogy, 5*, 16-17.

Zhang, X., & Ji, C. Y. (2005). Autism and mental retardation of young children in China. *Biomedical and Environmental Sciences, 18*, 334-340.