STATUS AND PROSPECTS:

AN INTERNATIONAL REVIEW OF THE STATE OF INTELLECTUAL DISABILITY SURVEILLANCE

Country Report: Indicators and Indices for

GERMANY

This Germany 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, India, Ireland, Japan, Nigeria, Northern Ireland, Russia, South Africa, and the United States.

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1 *Country Report: Germany*

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 German Data on Intellectual Disabilities

Our review of German data systems reveals minimal intellectual disability information available from recurring national data sets. What data are available reported through special reports, private associations, and service registries (Pomona, 2006); there is no official federal designation for the category of intellectual disability (European Intellectual Disability Research Network, 2003) and no integration into recurring surveillance. There are significant impediments to the development of quality statistical indicators, mostly related to the federal structure of German governance not technical matters of surveillance.

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

Future Directions

- Expand impairment codes in current systems to include intellectual disabilities. Germany is an outlier among nations in the study - a country with established recurring national data systems but virtually no attention given to intellectual disabilities.
- Coordinate with the states. As a first step, the German Federal Statistical Office (Statistisches Bundesamt Deutschland) should work with the statistical offices of the 16 federal states to establish a consensus survey definition for ID.
- Establish basic status statistics by incorporating ID identification into the microcensus program and its associated data programs.
- Integrate with the NGOs. Data coordination and reporting among the non-governmental associations that provide residential, work, and other support services should be pursued.

2 *Data Systems*
ID IN RECURRING DATA SYSTEMS

Our review of German 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.

Data and Intellectual Disabilities

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.

- There are seven primary, recurring national data systems managed by the 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). While disability codes exist, reported in the form of limitations in work capacity or identification of disability pension, there are no ID-specific codes.
- Consequently, there are no official ID statistics apart from those registered with a "handicapped service pass" (Pomona, 2006) which yielded a prevalence value of about 0.3% general population. In contrast, the four large professional associations for ID in Germany estimated a rate of nearly0.6% per 1,000 (approximately 420,000 persons in 2001), a value more in line with epidemiological screenings in Western nations (European Intellectual Disability Research Network, 2003).
- The development of quality statistical indicators for a German ID benchmark may present significant challenges, mostly related to the character of national governance not technical matters of surveillance. Services are fragmented across local and central governments; thus, funding streams and reporting requirements work against informational integration.

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)

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 invisible in the recurring German 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.

GERMANY	Index Values [a]		
Indicators	**All Germany**	**Disability**	**ID**
Access to education [b]	1.00	1.00	1.00
Integrated schools [c]	1.00	0.15	0.03
Inclusive classrooms [d]	1.00	0.15	0.03
Labor Force Participation [e]	1.00	0.32	--
Non Sheltered Employment [f]	na	0.83	0.10
Policy Implementation [g]	na	0.63	0.63
Non-Institutionalization [h]	na	0.99	0.81

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, Germany averaged 0.43 for persons with intellectual disabilities and 0.58 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] Education is compulsory for all children age 6-17. The population value is set at 100% even though actual attendance rates are somewhat lower. No disability rates were available (National Center for Education Statistics, 2007).

[c] In 2003-2004, there were a total of 63,396 special needs students in mainstreamed classes and 429,325 in special schools. Those with "mental development" needs were 1,991 in mainstream schools and 70,286 in special schools (Secretariat of the Standing Conference, 2006).

[d] Data from the Secretariat of the Standing Conference (2006).

[e] Disability labor force participation based on a survey by the Federal Statistics Office (Federal Ministry of Labour and Social Affairs, 2000). This survey reported 1.1 million of 6.6 million "severely" disabled persons involved in working life; of these 865,300 were in open employment, the balance in sheltered work). Labour Force Participation totals for the general population were gathered from the U.S. Department of Labour (2007).

[f] ID non-sheltered rate from the Secretariat of the Standing Conference (2006); no raw data presented.

[g] Expressed as number per 100,000 general population, and based on estimated numbers in large institutions (58,000) and persons with ID living in large psychiatric facilities or medical institutions. (European Intellectual Disability Research Network, 2003).

[h] 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).

INDIA: Much of the official statistical data on disability is met with scepticism within the Indian disability community. Recent decennial, census-based data (from 2001) yielded prevalence rates for all forms of disability comparable to many national estimates of ID (1.85%). The 2002 National Sample Survey (NSS) reported the prevalence at 0.09% population (NSS, 2003). In contrast, a meta-analysis of 13 psychiatric epidemiological studies yielded an estimate of 0.69% (Reddy & Chandrashekar, 1998). Similar results were found in other meta-analyses of psychiatric conditions though rates were wildly variable in the individual studies, ranging from 0.14% to 2.53% (Madhav, 2001).

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	Features: GD	ID	Freq	Indicators Included: Hf	Wrk	Ed	He	Inc	Sp	Ss
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	Features: GD	ID	Freq	Indicators Included: Hf	Wrk	Ed	He	Inc	Sp	Ss
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	Features: GD	ID	Freq	Indicators Included: Hf	Wrk	Ed	He	Inc	Sp	Ss
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)

INDIA

Surveillance System	Type	GD	ID	Agency	Freq	Hf	Wrk	Ed	He	Inc	Sp	Ss
		Features				Indicators Included						
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**;** 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); **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

Surveillance System	Type	Agency	GD	ID	Freq	Hf	Wrk	Ed	He	Inc	Sp	Ss
			Features			Indicators Included						
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

Surveillance System	Type	Agency	GD	ID	Freq	Hf	Wrk	Ed	He	Inc	Sp	Ss
			Features			Indicators Included						
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	PS	SSA	✓		3 yrs	✓	✓	✓	✓	✓		✓

Survey												
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*
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