



Health, Well-Being and Opportunity for People with Intellectual Disability – A Global Imperative

Status and Prospects of Persons with Intellectual Disability

It has been estimated that persons with intellectual disability comprise from 1 percent – 3 percent of populations around the world (1); estimates in the academic literature indicate that hundreds of millions of children are daily exposed to risks for cognitive impairment (2). While this rough estimate provides a wide range and is subject to incomplete ascertainment, this would still mean that there are an estimated 200 million people with intellectual disability in the world. All nations, all communities and all socioeconomic groups have significant populations of individuals with intellectual disability.

For many decades, even in the most developed nations, efforts to promote inclusion and opportunity for people with intellectual disability in all aspects of community life have met with many barriers, some quite resistant to change. Previous Special Olympics surveys of public attitudes among both adults and youth in a number of countries (3-6) consistently demonstrate attitudinal barriers among the public to inclusion of people with intellectual disability, and, at the same time, perceptions by the public of barriers that society at large and social institutions place in the way of people with intellectual disability.

One of the most fundamental steps in pulling off the veil that hides the degree of discrimination, neglect and stigma faced by marginalized populations everywhere in the world is the development of meaningful data around the status and disparities in opportunity and equity for such populations. People with intellectual disability represent one of the most marginalized and discriminated against groups historically, culturally and geographically.

Without meaningful information about the population with intellectual disability, it is difficult to develop effective programs and policies, or to even advocate for greater consideration of this population by governments and society at large. In order to address the perceived

paucity of information about how well people with intellectual disability are doing in critical life domains, Special Olympics undertook a study of the status and prospects of persons with intellectual disability in a dozen “priority” nations where Special Olympics had previously conducted national surveys on public attitudes toward intellectual disability. The study reported here examined the existence and adequacy of current information systems in a select group of countries to answer the basic question, “How well are people with intellectual disability doing”?

Developing A National Index for Intellectual Disabilities

- **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.**

Special Olympics recently explored the feasibility of developing national indicators as a means of quantifying the status and prospects of people with intellectual disabilities in the countries served by the movement. The exploration involved: (1) identification and evaluation of national statistical systems that could capture the status of persons with intellectual disability in 12 “priority nations”; (2) identification of the major gaps in national statistics; (3) development of recommendations for the creation of national benchmarks on behalf of persons with intellectual disability, and (4) a preliminary summary of nations based on an organizing theme of equalization of opportunity. Indicators could be used in assessments of national status towards benchmark goals for their citizens with intellectual disabilities.

The use of national benchmarks is common across many different areas of economics and human development. The general strategy is to represent broadly a nation's performance using a single quantifiable index that can inform problems and trends and, ideally, help to formulate responses.

Our Review of 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 with any degree of rigor or depth.**

The project identified and evaluated recurring national data systems for a group of “priority nations” included in an earlier multinational study of attitudes: Brazil, China, Egypt, Germany, Ireland, Japan, Nigeria, Northern Ireland, Russia, South Africa and the United States (3). 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 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 specific 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 most often represents only a small fraction of the total population.

Monitoring of ID in National Data Systems (n = 118 systems)

Group	% of Systems that Monitor:
General Disability	65.6%
Intellectual Disability	26.6%

We identified 118 systems (23 census, 72 recurring sample surveys, 23 registries). Across these systems, 66.6 percent identified general disability in some form while only 31.4 percent 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.

- **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.**

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.

Monitoring of ID by Domain

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

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

Illustrating the Potential: An Index of Status and Prospects

- **The development of an index appears feasible, though significant additional data and data coordination would be required beyond what is currently available. We argue that an index can greatly facilitate communication of critical policy themes to policy-makers and encourage the development of accountability benchmarks.**

We developed an exploratory index as a means of evaluating the utility and limitations of existing information drawn from our review of data systems. Given the limited monitoring of intellectual disabilities, we employed the most basic and common indicators: access to education, inclusive education (school and classes), employment (open and sheltered) and institutionalization. Even when limited to these most basic of indicators, complete data were obtained for only three nations. Where national data were unavailable, national statistics were extrapolated from special studies, or reports taken from regional and local surveys. There were many gaps in the final data summaries (primarily in the domains of non-sheltered work and classroom inclusion) and the index values reported in this report should be viewed as illustrations only. A final indicator included in the index was a ranking based on the United Nation's Standard Rules on the Equalization of Opportunities for Persons with Disabilities (7). The standard rule rankings were used as an indicator of the degree of implementation of disability policies. Employing a modification of the approach used in the United Nations Development Program's Human Development Index (8) [HDI], the value of each indicator was compared to a benchmark standard in order to scale and normalize all values into a common 0 to 1.0 scale.

An important conceptual issue is the use of fixed or relative benchmark standards. Should national progress be evaluated on the basis of a standard international value or country-specific benchmark? For this exploratory effort we employed both approaches. Some intellectual disability indicators (school enrollment and employment rate) represented relative values with a benchmark set at equity ("one") with the general population. Other indicators were treated as absolute values and fixed at 100 percent education in regular schools and classes, non-sheltered employment, and non-institutionalized population.

- **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 an additional disadvantage, even when compared to their compatriots with other disabilities.**

While our data is exploratory at best, the pattern of differences is consistent with the assumption that persons with intellectual disability are marginalized throughout the world. Shown on page 3 in the table 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.

Status and Prospects Index

Domain	ID	Other Disability
Access to Education	.63	.74
School Inclusion	.52	.68
Classroom Inclusion	.10	.47
Participation in Labor	.33	.51
Non-Sheltered Work Opportunity	.14	.64
Institutionalization	.87	.93

Our caveat bears repeating: there were many gaps in the available data and the index values reported here should be viewed as illustrations only.

Policy Implications

- **The lack of quality data on the life circumstances of the world's citizens with intellectual disabilities should command our attention. Information alone cannot change policy, but it can dramatically affect the nature of choices made by governments. At its most fundamental level, policy-making is the allocation of limited national resources among many competing interests. And the compilation of national statistics is very much about informing the debate in the politics of choice-making (9).**

There are reasons for optimism. Through the work of international bodies and advocacy groups such as Special Olympics, nations are gradually assuming greater responsibility for the well-being of persons with intellectual disabilities. But how do we assess progress? How are life experiences encapsulated and governments held accountable? In the United Nation's World Programme of Action concerning Disabled Persons, monitoring and evaluation of national progress was seen as an essential step in effecting successful implementation (7). Three decades later we are still unprepared for such monitoring. The indicators reported here in our pilot study were simple attempts to illustrate how abstracted outcomes such as "status and prospects" could be quantified and employed in national assessments.

A number of logistical, conceptual and methodological challenges will need to be addressed. Our review of national systems presents a mixed picture of opportunities. Generally there is a rich base of existing data systems that could be available if national statistical agencies could be convinced to integrate intellectual disability codes. The capacity for substantially expanding intellectual disability monitoring exists in current, recurring data systems, but the data are not currently available. An index will require identification of meaningful indicators far beyond those used in the pilot effort. This is fundamentally an issue of measurement validity; can we achieve consensus on what the measure should represent and will the statistical indicators be readily available? A second conceptual challenge is finding a proper balance between absolute and relative benchmarks. These are substantive concerns and it is likely that any index for such a complex topic will be limited; however, even a crude proxy can serve to inform the choices of governments and encourage the work of advocates on behalf of their compatriots with intellectual disabilities.

References

1. World Health Organization (2001). *The World Health Report 2001 - Mental Health: New Understanding, New Hope*. Geneva: 178 pp.
2. Olness, K. (2003). Effects on Brain Development Leading to Cognitive Impairment: A Worldwide Epidemic. *Journal of Developmental & Behavioral Pediatrics*. 24(2): 120-130.
3. Siperstein G, Norins J, Corbin, S, & Shriver T. Multinational study of Attitudes toward Individuals with Intellectual Disabilities. Special Olympics, Inc., Washington, DC, June, 2005.
4. Siperstein, G, Norins J, Corbin, S, Engstrom, K. Changing Attitudes Changing the World – A Study of Youth Attitudes about Intellectual Disability. Special Olympics, Inc., Washington, DC, March, 2005.
5. Norins-Bardon, J, Siperstein, G, Parker, R & Corbin, S. Changing Attitudes Changing the World – Attitudes of the Public in South Africa toward people with Intellectual Disabilities. Special Olympics, Inc., Washington, DC, 2006.
6. Siperstein, G, Parker R, Norins-Bardon, J & Widaman, K. A National Study of Youth Attitudes toward the Inclusion of Students with Intellectual Disabilities. *Exceptional Children*:2007;73:No.4, (435-55).
7. United Nations (1982) World Programme of Action concerning Disabled Persons – United Nations Decade of Disabled Persons, 1982-1992. New York: United Nations.
8. United Nations Development Programme (2007). *Human Development 2007*. New York: United Nations.
9. 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.

Special Olympics and its Research Mission

Special Olympics is the worldwide leader in providing high-quality sports training and competition opportunities for people with intellectual disabilities, offering 2.9 million athletes from more than 180 countries the opportunity to participate in 30 Olympic-type summer and winter sports. Special Olympics Programs also promote social competence and self-esteem, acceptance and improved health outcomes. More recently, Special Olympics has emerged as a global leader in cutting-edge research and evaluation to promote better understanding of issues surrounding intellectual disabilities. Research projects commissioned by Special Olympics are designed to provide high-level, externally validated scientific data to:

- Guide improvements in Special Olympics programs and practices;
- Inform audiences about the unmet needs of people with intellectual disabilities worldwide; and
- Inform the public about the competence, value and contributions of people with intellectual disabilities to the world community.

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