

International Employment Statistics for People with Intellectual Disability – The Case for  
Common Metrics

:

Rosemary Lysaght<sup>1</sup>, Jan Šiška,<sup>2</sup> and Oliver Koenig<sup>3</sup>

<sup>1</sup>Queens University, Kingston, Ontario Canada, <sup>2</sup>Charles University, Prague, Czech  
Republic, <sup>3</sup>University of Vienna, Austria

Corresponding Author

Rosemary Lysaght

Queen's University

School of Rehabilitation Therapy

31 George Street

Kingston, Ontario K7L 3N6

Canada

Tel: + 1 613-533-21341; E-Mail: lysaght@queensu.ca

Date Received: 10-Mar-2014

Date Accepted: 05-Nov-2014

Title:

Correspondence :Lysaght, Rosemary

Corresponding Author

Queen's University - School of Rehabilitation Therapy

31 George Street , Kingston, Ontario K7L 3N6

Canada.

Keywords: employment, intellectual disability, statistical reporting, World Report on Disability

JPPID Special Issue on Topics Related to the World Report on Disability

**International Employment Statistics for People with Intellectual Disability – The Case for Common Metrics**

*Abstract* The World Report on Disability identifies employment as an important element of social participation. The Report also points to the need for research that crosses national boundaries to identify and address central areas of concern. However, such efforts are hampered with respect to intellectual disability, however, by inconsistencies in the population definitions used, the definition of employment or employability, and metrics of employment participation. The authors explore the varied ways in which employment participation rates for people with ID are determined and reported in jurisdictions around the world, and note that with respect to employment metrics, there remains substantial variation in the methods used in data collection and reporting across agencies and countries and note that close inspection of methodologies is required in order to interpret data from any official statistical agency (as even when methods and definitions are explicit, the variations in approaches make comparisons difficult). Recommendations for harmonizing disparate definitions and metrics include a systematic analysis of the terminology and methods used in national surveys that would assist in identifying which data are comparable, agreement on a protocol and process for examining employment outcomes in the ID population, and the creation of an international panel on employment and ID charged to identify common terminology and population parameters to be specified in sample selection and description in localized research and studies.

## INTRODUCTION

The World Report on Disability (WHO, 2011) highlights the importance of employment as a means of social participation for people with disabilities, and as a pathway out of poverty. This focus clearly resonates for people with intellectual disability (ID), who present with high levels of unemployment relative to the general population, and often live in economic deprivation. Emerson (2007) provided evidence of the increased risk of poverty in families raising a child with ID and asserted that poverty is both a cause and effect of ID. This association renders the role of employment particularly important for this population, and calls for factors that can improve outcomes with respect to work..

The World Report noted that a “disabling barrier” preventing full participation of people with disabilities is the lack of data and evidence that are comparable across contexts. They assert that, “understanding the numbers of people with disabilities and their circumstances can improve efforts to remove disabling barriers and provide services to allow people with disabilities to participate” (p. 21). While a number of interventions and policy efforts are identified in the World Report that help advance employment rates for people with disabilities, the relative impact of these initiatives, and their importance with respect to particular populations, such as people with ID, cannot be known without systematic research. The Academic Network of European Disability Experts (ANED) reports that there has been surprisingly little evidence of substantial or ambitious reform at the national level towards full participation in employment for people with disabilities (Priestly, 2009). Given the considerable equality gaps in employment outcomes for people with disabilities, and the high strategic priority placed on labor market engagement as a means to social inclusion, this raises challenging policy questions. Indeed, two

recommendations emerging from the World Report address the need for improved data collection and enhanced disability research.

There are some compelling reasons to track employment indices internationally. 1. They provide a means for interpreting changes in employment rates over time within a jurisdiction relative to the local population. This helps the research community answer important questions concerning how economic and other political and environmental conditions may differentially affect employment for adults with disabilities. Sound employment data are particularly useful as outcome metrics when systematic efforts are undertaken to improve employment outcomes within a country, such as stigma reduction campaigns, education system reform, employer incentive programs, or supported employment schemes.

2. They provide an opportunity to compare employment statistics across regions and/or international boundaries. Such comparisons can help identify cultural and/or socio-political factors impacting on employment for special populations. For example, such statistics are of interest when comparing the effects of disability-related income compensation policies for people with disabilities in different political jurisdictions and their impact on work participation of people with ID and other conditions. As indicated in the World Report (p. 42), without strong data on labor market participation and productivity for persons with disabilities that can be controlled for age, sex, and education level, it is impossible to estimate the cost of unemployment to families and communities.

While there is a clear need for improved reporting of relevant data and indicators of progress in creating social inclusion for people with disabilities, including both outcome indicators and indicators of improved accessibility in the environment and infrastructure, ANED pointed out

that guidance and support may be needed to assist states in developing and reporting such measures (Priestly, 2009).

The World Report on Disability demonstrated disparities in the area of employment. The authors provide data from the National Longitudinal Study, an American study that provides data on the educational and post-secondary outcomes of special education students (Sanford et al., 2011). Their data revealed that youth with intellectual impairments were among the most severely disadvantaged of all disability groups relative to labor market participation after graduation, and more likely to work in sheltered settings. This finding suggests the need for intervention, but also raises questions for researchers in the U.S. and abroad to aid interpretation: how did the study define “intellectual impairment”? What did they include in the definition of “labor market participation”? Where was the sample drawn from, and did it distinguish between youth with different levels of intellectual disability? Only when such data are clearly identified (as they were in the study reported) can researchers draw valid assumptions, and attempt to make comparisons between countries or over time.

This paper will explore the varied ways in which employment participation rates for people with ID are determined and reported in various jurisdictions around the world, and will highlight the policy and practice implications of the evident lack of common metrics. It will uncover the many potential sources of variance in statistical reporting, based on differences in definitions, sampling procedures, and issues inherent in reporting on a broad and complex population such as ID. It will conclude with recommendations for future practice.

## MEASURING EMPLOYMENT PARTICIPATION FOR PEOPLE WITH INTELLECTUAL DISABILITIES

*Employment Statistics - Counting Employment*

The World Report begins the section on employment by pointing out the breadth of the term “work” and what it comprises. Internationally, government agencies use a variety of terms to define and measure employment and unemployment in the formal economy. The International Labor Organization (ILO) defines employment as when “persons who during a specified brief period such as one week or one day, (a) performed some work for wage or salary in cash or in kind, (b) had a formal attachment to their job but were temporarily not at work during the reference period, (c) performed some work for profit or family gain in cash or in kind, (d) were with an enterprise such as a business, farm, or service but who were temporarily not at work during the reference period for any specific reason (ILO, 1988). The National Office of Statistics (NOS) in Great Britain reports, “employment consists of employees, self-employed people, unpaid family workers and people on government supported training and employment programmes” (Office of National Statistics, 2014). In the U.S., official employment data are calculated based on “persons on establishment payrolls who worked or received pay for any part of the pay period that includes the 12th day of the month” (Bureau of Labor Statistics, 2014). This suggests that only workers who have an employer who reports to the Federal Government are included in these statistics. The International Classification of Status in Employment defines different classifications of employment. Their designation defines employees as individuals who “get a basic remuneration not directly dependent the revenue of the employer”, and also acknowledges four other forms of employment, including self-employment (with or without employing others), members of workers’ cooperatives, workers in family-owned businesses, and persons performing work that is not classified under any other category (International Labor Organization (ILO), 1993). These varied definitions demonstrate the complexity of the

relationship between workers and the labor market, and the difficulties this presents in terms of calculating and comparing employment rates.

Weathers II and Wittenburg (2009) point out that employment rate estimates vary greatly depending on the way questions are posed on surveys, and that often several “official” data collection agencies in the same country can report highly divergent findings. Both the time period explored (i.e., number of weeks) and the extent of employment (i.e., number of hours worked) become dimensions that can vary across methodologies. They identify three approaches to collection of employment data that have been used by official agencies in the U.S.: *reference period* (i.e., individuals who had any earned employment income in the previous 1 week, 2 weeks, 4 weeks, etc.); any *annual employment* (worked at least a certain number of hours, e.g., 52, in the past year); and *full-time annual employment* (workers who had full time employment (>35 hours per week) during the past year. In Austria, most official agencies use a reference point sample, generally all persons who were employed on the first day of the month in question. All of these approaches have value at some level in understanding labor market participation, but are not comparable. “Any annual employment” measures will clearly yield higher employment rates than those gathered through reference period approaches, and both will capture workers who have seasonal part time, and casual employment. “Full-time annual employment” approaches would report on only workers with strong workforce attachment, and are much lower than rates obtained using the other approaches. Weathers II and Wittenburg’s study of employment rates reported by four U.S. agencies revealed participation rates for people with disabilities ranging from 9.4% to 61.1% depending on the definition of employment used by the agency.

The World Report notes that the “labor force participation rate” is calculated based on those individuals who are actively looking for work or working. In Canada, for example, the designation “not employed” refers to “persons who are neither employed nor unemployed”, and includes “students, homemakers, retired workers, and seasonal workers in an off- season who were not looking for work, and persons who could not work because of a long-term illness or disability” (Statistics Canada, 2006). Employment figures typically ignore people with disabilities who are in this “not employed” category and who have given up seeking work, or who due to self stigma or family perceptions do not see themselves as capable of work. In Europe, individuals who are “not in employment, education, or training” are referred to as “NEETs” (European Foundation for the Improvement of Economic and Working Conditions (EFIEWC), 2012. p. 1). NEETs are typically missing from official figures, but are an important group given the potentially negative impact of this status on individuals, the economy, and society in general. A recent report suggests that apart from the social alienation often experienced by persons in the NEET category, the economic burden to society is substantial – estimated at over €150 in a single year in Europe. Persons with disabilities are reported to be 40% more likely to fall into this category than other youth (EFICWC, 2012).

A German study recently demonstrated that the portion of the population that is in a position of “non-employment” – including those who see themselves or are legally defined as “permanently sick or disabled” – is dealt with differently by the various official statistics agencies (Erlinghager & Knuth, 2010). The authors point out that international studies of labor force participation cannot be based on simplistic comparison of employment and unemployment rates. Similarly, a Norwegian study revealed that many individuals who receive disability insurance payments are in fact displaced workers who have exited the labor market due to a loss



of employment opportunities (Bratsberg, Fevang & Røed, 2010). They conclude that unemployment rates in that country are artificially low due to this reclassification of workers who could otherwise be gainfully employed. Workers who exit the labor market due to disability are not counted in the overall rates of employment, and this may in fact artificially inflate general population employment rates for a jurisdiction and reduce reported unemployment rates for people with disabilities. In Austria, it is estimated that as many as 20,000 individuals are ignored in employment statistics because they are legally considered to be unable to work. These examples of creative statistical reporting likely represent only the “tip of the iceberg” with respect to the way official agencies manage statistics for political purposes.

The definition of what constitutes employment is a further source of error in official reporting. For example, based on the NOS definition in Britain, persons who work without pay in the home could be classified as “working.” In Canada, the national census agency, Statistics Canada, counts people who are engaged in unpaid family work, such as farming, as employed, but stipulates that this category does not include “unpaid housework, unpaid childcare, unpaid care to seniors and volunteer work” (Statistics Canada, 2006). Since individuals in the general public who are paid relative to non-traditional models (i.e., non-waged self employment, commission, sub-minimum wage plus gratuities, etc.) are counted as “employed” by national statistics agencies, how official statistic collectors deal with reported work that does *not* meet accepted community minimum wage or other standards is unclear. In addition, many persons with disabilities work in the “informal” labor market, particularly in the developing world. For example, it is estimated that up to 87% of persons with disabilities in India have work outside the formal labor market (Mitra & Sambamoorthi, 2006). Clearly, none of these workers are captured by the various employment measurement approaches of official government agencies which

were described earlier. Overall, it becomes clear that the means for defining employment, methods of data collection, and who is counted in each category differs based on definitions of employment both within and across jurisdictions.

Another source of error in international comparisons on labor market participation of people with intellectual disability is the different and non-standard forms work can take relative to a particular segment of the population. A broad range of employment options exist for people with intellectual disability which do not fit with conventional definitions of employment, such as enclaves, social firms, and sheltered employment. Only “supported employment” has a clear and generalizable definition due to the work of Bond et al. (2012) in the U.S. but compliance with this definition is not universal, and a plethora of interpretations of this term are found in practice internationally.

Sheltered employment provisions, which in many countries represent the major field of employment or day care activity for people with ID, are particularly difficult for authorities to differentiate from other work. This difficulty has been acknowledged by Leichsenring/Stümpel (1994), who wrote: “what makes discourse about sheltered work so difficult is, that each country has its own specific variation of what sheltered work actually is: what is called an occupational therapy service in one country is a sheltered workshop in another. Sheltered workshops between [sic] countries differ in their clients, sizes and priorities as well as in their workers` labour status, pay and insurance. Also the abundance of sheltered workshops differs greatly between countries” (p. 17).

In a comparative study, Visier (1998) distinguished between three different structural forms of sheltered employment/day care provision, which differ mainly in relation to the employment status of the workers. On the basis of Visier’s distinctions, Koenig differentiated

four different models which can be used to describe national approaches to sheltered employment provisions / jurisdictions and are of relevance in an analysis of labor market participation of people with ID. In *therapeutic models* workers are seen as clients or trainees, do not hold real employment relationship with their employer and thus have neither access to social security benefits or real pay. *Intermediary models* represent an in-between approach between therapeutic and wage-models wherein workers usually have direct access to social security benefits derived from their working contract, but do not receive sector-specific collective wages or fall under national minimum wage legislation. In *wage-models*, workers are basically considered to be employees. In *dual models*, which apply in most European countries, several types of employment status are in place which vary according to the nature of the sheltered employment structure, the degree of disability, and whether the employer is party to a collective agreement. The result is that certain workers are considered students, trainees, or clients, while others enjoy employee status and all the associated rights. Koenig (2008) calculated that approximately one million workers in Europe were working in one of these forms of sheltered employment: approximately 450,000 in therapeutic models, 270,000 in intermediary models (mainly in Germany, and predominantly people with ID) and 280,000 workers in wage-models. The final category was the only form of employment where people with ID have been underrepresented. Variet forms of sheltered employment are also found in other regions of the world. In Australia, for example, very high rates of employment are reported for people with ID; however, many of these work in “disability enterprises”, where they can be paid based on productive capacity. These workers may be paid less than minimum wage if they do not work at a competitive rate under the Supported Wage System (SWS) (Pointon et al., 2009).

The 2012 ANED synthesis report states that employment and unemployment rates across European Union (EU) countries are insufficient to present a picture of the situation of people with disabilities in the labor market. Workforce participation must be considered, instead, in light of economic activity data. In this area, there are significant differences between member states that mirror differences in employment, for example, with very low rates in Malta, Romania, and Hungary, compared to higher rates in Germany and Denmark. It is noticeable that states with similar activity rates for people without declared impairments may have widely differing activity rates for those with impairments. There appears to have been a slight (but insignificant) increase in the economic activity of people with disabilities up to 2010, despite a difficult economic environment, but patterns are not closely related to those for the general workforce (ANED, 2012). Again, it is unclear whether these economic data provide a valid and realistic interpretation of employment patterns for persons with disabilities.

### *Defining Disability*

The concept of disability is one that is difficult to capture, particularly when contemporary definitions of disability are used. In the spirit of the International Classification of Functioning, Disability and Health (WHO, 2001) designation, disability with respect to employment should be based not on impairment, but on work-related disability (i.e., restrictions in ability to participate in work activity due to the effects of impairment). Many of the national statistics agencies have begun to use participation rather than impairment to identify people with disabilities on census questionnaires, but even here, specifics vary. For example, in Australia, the question is, “Do you have any limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities”, thus putting greater

emphasis on the duration of the condition than the functional implications. The Austrian Microcensus asks, “Do you feel restricted in the activities of your daily life because of a health-related impairment? Do you have this impairment for a period longer than have a year” (Leitner 2008). The Office for National Statistics in Great Britain identifies people with disabilities by their response to the question, “Do you have any long-term illness, health problem or disability which limits your activities or the work you can do?” Second level surveys, like the Canadian Survey on Disability (CSD), which does in-depth interviews with a sample of those who report participation limitations, drill down to the context and type of activity participation that is restricted, including work. The Canadian survey acknowledges that they have changed data collection to align with the social model of disability, rendering the resulting data incomparable with the previous survey, the Participation and Activity Limitations Survey (PALS) (Statistics Canada, 2006). As the documentation states, “the CSD ... allows respondents to determine whether they face activity limitations as a result of these difficulties or impairments. Some people who indicate that they have some difficulty with certain tasks or have an impairment of some type go on to indicate that this never interferes with their daily activities. In PALS, these individuals were considered to have a disability, but in the CSD, they are not”.

In many countries, there is also effort to examine the source of participation restriction, which is helpful if a particular population, such as persons with ID, is of interest. A range of classifications is used to segment the population of people with disabilities, however. In the U.S., three of the official agencies break down the population into the impairment groupings of mental, physical, and sensory limitation (Weathers II & Wittenburg, 2009). In Australia, the groupings are sensory, intellectual, physical, and psychological (Australian Bureau of Statistics, 2012). The variation in groupings makes comparisons across countries difficult, as do variations

in the definitions used within these categories. In the EU, disability measures typically do not distinguish between disability types at all, instead distinguishing between severe and mild disability. In Germany, for example, the official national census identifies only persons with severe disability, while the Austrian Microcensus, a household survey of a representative sample of 1% of the population, identifies both mild and severe disability (Waldschmidt & Lignau, 2007).

The selection of the indicator set for disability reporting used in Europe prioritizes those items that are most relevant to monitoring progress against the EU2020 Strategy objectives and within the themes of the actions and implementations contained in the EU Disability Strategy 2010-2020. There have been several attempts in the EU to examine prevalence of disability. One of the approaches used is prevalence of self-reported impairment. However, different factors may affect the prevalence of self-reported impairment (such as personal characteristics, education, occupation, and income). Some authors argue that self-assessed status may be distorted by what is called justification bias. For example, due to social pressures, people who are unemployed or inactive may be incentivized to misreport the extent of their activity limitations in order to justify their social condition (Grammanos, 2011). The Austrian Microcensus of 2007 collected, for one time only, self reported data on different impairment types. Sensory and mobility impairments were grouped as mild, moderate, and severe, and additional population delimiters, such as wheelchair use, were included. However, no such differentiations were made for mental health issues. Intellectual and learning disabilities were grouped together in one category.

#### *Defining Intellectual Disability*

IASSIDD defines ID as “a significant intellectual deficit present from birth, or which originates at an early age or during the developmental period” (IASSID, 2014). While this

definition may provide common language and meaning for researchers, the construct remains vague, and variably defined by practitioners and policy makers throughout the world -- a fact which creates considerable difficulty in comparing measures of social participation, including employment. As is commonly known, researchers are faced with a “grab-bag” of terms to describe ID, even within the English language countries. The terms “developmental disability” (Canada; United States), “intellectual disability” (Australia, United States), “learning disability” (Great Britain, Ireland) all persist as terms for ID despite international efforts to standardize, and their definitions vary. Statistical agencies and government departments in these countries all use different terms for identifying ID. Table 1 shows some of the terms and definitions in use.

[Insert Table 1 here]

Review of Table 1 reveals a myriad of terms in use, often within the same country. Of particular concern, similar terms may mean something quite different. In the U.S., for example, the term “developmental disability” refers to persons with any type of impairment that emerges during the developmental period (AIDD, 2000). The inclusion of physical impairment (often in the absence of mental impairment) makes this group as defined in U.S. terms different to interpretation of “developmental disability” in other countries, as in the Ontario definition, thus eliminating the comparability of associated data points. Likewise, when people with autism spectrum disorders and other disabilities that affect social functioning but may or may not involve cognitive impairment are included in some studies or surveys, but not all, comparability of employment outcomes is lost.

#### *Evidence of Disarray*

Even in the context of the World Report on Disability we find conflicting and confusing statistics. For example, the Report provides a number of statistics comparing employment rates

and levels of earned income between persons with disabilities and the general population, across countries, and between low and high income countries (p. 238). These statistics are presented in order to highlight disparities, to drive dialogue concerning the reasons for observed differences, and to encourage change. The statistical tables presented draw their numbers from a broad array of studies, however, and the authors note that there may be differences in reporting, in part because “definitions of working age differ across countries”. Because the sources for the rates reported were derived from separate studies, the comparability is hampered by the varying methodologies and definitions that were used. In our experience, reports on employment of persons with intellectual disability have even greater sources of variability, making comparisons flawed at best.

A comparison of data gathered from agencies in a range of countries through a Canadian study (Lysaght, et al., 2011) demonstrates the difficulty in drawing conclusions based on reported employment rates. Differences in the sample parameters and definitions of employment render comparisons impossible. Even within a single country it is possible to find a range of reported employment rates for persons with ID in the general population. For example, the UK Office of National Statistics (2004) reported employment of persons with ID at 32% (Dempsey & Ford, 2009), while the Centre for Disability Research estimates the number at approximately 8% (Emerson & Hatton, 2008).

[Insert Table 2 here]

Most EU countries cannot provide statistics on labor market participation of people with ID, since, as noted earlier, statistical agencies do not distinguish between types of disability. However, the average EU employment rate of people with disabilities (i.e., people reporting activity limitations in the EU-SILC data) remained stable even in the face of a pervasive difficult



economic environment following the onset of the economic crisis of the early 2010s (at 45.7% compared to 45.8%). At 17.7%, the average EU unemployment rate of people with disabilities (i.e., people reporting activity limitations in the EU-SILC data) is approximately double that of people without disabilities (9.2%). A number of member states exhibit an average employment rate close to, or higher than, 70% (for the total population), but there is a significant disability employment gap in all member states. These data suggest trends that likely apply to persons with ID; however, specific comparative figures are not available, except within the EU.

## IMPLICATIONS FOR POLICY & PRACTICE

There remains much work to do if people with ID are able to participate fully in the labor market. The World Report highlights a range of interventions that are being used to move this agenda forward, most of which require legislative change and funding to be broadly implemented. The underlying political will to make such change happen will require clear demonstration of the need for change, based on comparative international benchmarks. From an evaluative standpoint, legislators, service providers and researchers alike need valid and reliable data with which to track the success of local efforts over time. The World Report recommends that we must use “internationally agreed (for example ILO) labor market indicators to measure and monitor the labor market status and livelihood experiences of people with disabilities” (p. 251). While cross-border comparators are essential, data must also be sensitive to and report on the local context, including the nature of community economic activity, typical forms of paid employment in the region, and labor market participation rates across age, gender, cultural, and socioeconomic groups.

Weathers II and Wittenburg (2009) observed with respect to measurement of employment participation across federal agencies in the U.S. that the major sources of incomparability arise from three factors: differences in definitions of disability, differences in definitions of employment, and differences in methodology. These same categories summarize the major confounds to comparability of data on the employment of persons with ID, with two additional concerns. One is the major variability in defining ID, with the field still being far from consensus on how ID is classified and identified. The other lies in the variability in all three areas that exists at the level of research and evaluation, where much of the evidence pertaining to specific employment interventions such as school-to-work transition and supported employment lies.

Researchers and advocates in the area of ID have engaged in ongoing efforts to standardize terminology related to this population. As a result of these efforts and widespread change in internationally accepted definitions of disability, both the DSM-5 and the ICD-11 have eliminated the term “mental retardation”, and are adopting new terms and broader definitions of ID (Harris, 2013). Both resources identify measurement of intellectual function as part of diagnostic practice; however, the emphasis is shifting away from intelligence testing towards assessment of adaptive functioning in major areas of life participation. The ICD-11 is using the term “intellectual developmental disorders” (IDD) which it defines as 'a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behavior and skills' (Harris, 2013). They propose continuing use of the categories mild, moderate, severe, or profound. While this new terminology and definition could potentially become a world standard, its inclusiveness may still result in heterogeneous samples that will require sub-categorization. The emphasis on cognition

and adaptive behavior should, if applied correctly, remove individuals with developmental disorders that do not involve impairment of cognition (such as Asperger syndrome and cerebral palsy) from comparative samples. It is important when countries are adopting employment-enhancement practices, such as supported employment, use of natural supports, social firms, competency-based pay rates, and others, and appraising the evidence base for these strategies, that the evidence supporting these as “best” or “promising” practices clearly defines the populations studied and the contextual situation for the research so that the applicability to different groups and cultures can be fairly and accurately interpreted.

In terms of employment metrics, there remains substantial variation in the methods used in data collection and reporting across agencies and countries. Close inspection of methodologies is required in order to interpret data from any official statistical agency. Even when methods and definitions are explicit, the variation in approaches makes comparison difficult. ANED, for example, is one source for both targeted, national disability surveys and shared modules in the EU. However, isolated surveys over time are not always comparable (e.g, measures of the employment rate for people with disabilities in Denmark rose from 53% in 2002 to 56% in 2005, but studies since then are not quite comparable). Common methodologies would be of great assistance in targeting specific topics of interest in different countries. However, it is a matter of great concern that so few states include a disability variable in their national labor force surveys. The inclusion of relevant questions to identify people with disabilities should also be encouraged for member states in the next census round. In this respect it is encouraging to learn that a number of states now plan to harmonize census questions using items developed by the Washington Group (Madans, Loeb & Altman, 2011). This will not influence reporting for the

2010 National Statistical Reports but will facilitate the possibility of improved national reporting in future OMC cycles.

## RECOMMENDATIONS

While any efforts to bring data collection and reporting into alignment on an international level are necessarily complex and long term, there are some actions that would help to improve work in this area.

1. In the absence of opportunity to influence the agencies responsible for collection of national census data concerning the design of disability-focused surveys, it may be that systematic analysis of the terminology and methods used in national surveys would assist in identifying which data are comparable, and which require must be interpreted in the light of specific population parameters that are artifacts of the data collection protocol. The process used by Weathers II and Wittenburg could be followed to clearly outline the sources of discrepancy in employment figures. This would at a minimum remove the potential for artificial comparisons based on faulty assumptions of data commonality.
2. A protocol and process for examining employment outcomes in the ID population should be defined. This might include identification of a limited number of metrics that could be collected under an international authority such as IASSIDD, the ILO, or the OECD, or promoted by these agencies to large international bodies.
3. An international panel on employment and ID should be created to identify common terminology and population parameters to be specified in sample selection and description in localized research and studies. For example, if researchers are collecting or analyzing data based on school board or agency populations, there would be common

terms used to identify the sample studied, and standards for describing differences in participation capacity. IASSIDD is potentially an organization that could organize such an effort, and the results could be subsequently promoted internationally among researchers in this field.

Overall, there are many options for data sharing and communication that are possible if national agencies are willing to contribute to international studies. International agencies such as the World Health Organization and the International Labor Organization are pushing towards common standards. Researchers and advocates in this field need to be a vocal and assertive part of this movement if measurement of participation outcomes experienced by people with ID is to receive attention by such agencies. Increased transparency and explicit use of a common language around ID will assist in identifying environmental conditions that systematically disadvantage people with ID, as well as promising practices and programs.

## REFERENCES

- Academic Network of European Disability Experts (ANED). (2012). *Targeting and mainstreaming disability in the context of EU2020 and the 2012 annual growth survey*. Leeds, UK: Author.
- Administration on Intellectual and Developmental Disabilities. (2000). *The Developmental Disabilities Assistance and Bill of Rights Act 2000*. Retrieved from:  
[http://www.acl.gov/Programs/AIDD/DDA\\_BOR\\_ACT\\_2000/p2\\_tI\\_subtitleA.aspx](http://www.acl.gov/Programs/AIDD/DDA_BOR_ACT_2000/p2_tI_subtitleA.aspx)
- Bizier, V., Brennan, S., Foisy, M., Foucreault, J., Lanoue, M., Fournier-Savard, P., . . . , & Velleux, L. (2008). *Participation and activity limitation survey 2006: Labour force*

- experience of people with disabilities in Canada*. Ottawa, Canada: Statistics Canada.  
Retrieved from <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2008007-eng.htm>.
- Bond, G.R., Peterson, A.E., Becker, D.R., & Drake, R.E. (2012). Validation of the revised individual placement and support fidelity scale (IPS-25). *Psychiatric Services*, 63(8), 758-763.
- Brault, M. W. (2010). *Disability among the working age population: 2008 and 2009 – American community survey briefs*. U.S. Census Bureau. Retrieved from:  
<http://www.census.gov/prod/2010pubs/acsbr09-12.pdf>
- Bratsberg, B, Fevang, E. & Røed, K. (2010). Disability in the welfare state: An unemployment problem in disguise? *IZA Discussion Series Paper No. 4897*
- Bureau of Labor Statistics. (2014). Current Employment Statistics – CES (National).  
Washington, D.C.: United States Department of Labor. Retrieved from:  
<http://www.bls.gov/web/empsit/cestn.htm#section4a>
- Commonwealth of Australia. (2008). *Australian government disability services census 2007*.  
Canberra, Australia: Australian Government. Retrieved from:  
<http://www.fahcsia.gov.au/internet/facsinternet.nsf/disabilities/services-censusreports.htm>.
- Dempsey, I., & Ford, J. (2009). Employment for people with intellectual disability in Australia and the United Kingdom. *Journal of Disability Policy Studies*, 19(4), 233-243.
- Developmental Services Ontario (2013). *What is a developmental disability* Retrieved from:  
<http://www.dsontario.ca/whats-a-developmental-disability>.
- Emerson, E. (2007). Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Review*, 13(2), 107-113.

- Emerson, E. & Hatton, C. (2008). *People with learning disabilities in England*. Lancaster, UK: Centre for Disability Research.
- Erlinghagen, M. & Knuth, M. (2010). Unemployment as an institutional construct? Structural differences in non-employment between selected European countries and the United States. *Journal of Social Policy*, 39(1), 71-94.
- European Foundation for the Improvement of Living and Working Conditions (2012). *NEETs - Young people not in employment, education or training: Characteristics, costs and policy responses in Europe*. Dublin, Ireland: Author.
- Forrester-Jones, R., Gore, N., & Melling, K. (2010). How many people with intellectual disability are employed in the UK? *Tizard Learning Disability Review*, 15(1), 56-58.
- Grammenos, S. (2011). *Indicators of disability equality in Europe* (Task 4: Update and extend the piloting of quantitative implementation indicators -- Comparative data on a selection of quantitative implementation indicators). Leeds, UK: Academic Network of European Disability Experts.
- Harris, J. C. (2013). New terminology for mental retardation in DSM-5 and ICD-11. *Current Opinion in Psychiatry*, 26(3), 260-262.
- International Labor Organization (ILO) (1993): *Fifteenth International Conference of Labor Statisticians, Report of the Conference*. ICLS/15/D.6 (Rev. 1). Geneva, Switzerland: International Labor Office.
- International Society for the Scientific Study of Intellectual and Developmental Disabilities (2014). *Frequently asked questions*. Retrieved from: <https://iassid.org/frequently-asked-questions>.

- Koenig, O. (2008) Europäische Modelle eines institutionalisierten Ersatzarbeitsmarktes zwischen Entwicklung und Bewahrung. [European models of an institutionalized replacement labor market between development and preservation ] In G. Biewer, M. Luciak, & M. Schwinge (Hrsg.), *Begegnung und Differenz. Menschen – Länder – Kulturen [Encounter and difference. People - Countries – Cultures]* (pp. 440-452). Bad Heilbrunn, Germany Klinkhardt,.
- Leichsenring, K, & Strümpel, C. (1994): *Mandatory employment or equal opportunities? employment policies for people with disabilities in the UN-European region*. Vienna, Austria: European Centre for Social Welfare Policy and Research.
- Leitner, B. (2008): *Menschen mit Beeinträchtigungen. Ergebnisse der Mikrozensus-Zusatzfragen im 4. Quartal 2007 [People with disabilities. Results of the micro census supplementary questions in Q4 2007]*. Statistische Nachrichten [Statistical News] 12/2008, 1132-1141.  
Online:  
[https://www.bmask.gv.at/site/Soziales/Menschen\\_mit\\_Behinderungen/Menschen\\_mit\\_Beeintraechtigungen\\_Ergebnisse\\_der\\_Mikrozensuszusatzfragen](https://www.bmask.gv.at/site/Soziales/Menschen_mit_Behinderungen/Menschen_mit_Beeintraechtigungen_Ergebnisse_der_Mikrozensuszusatzfragen)
- Lysaght, R., Cobigo, V. & Ouellette-Kuntz, H. (2011). *Maximizing social inclusion, choice and independence through productivity options – Report 1: Employment-related best practices*. Kingston, Canada: Multi-Dimensional Assessment of Providers and Systems.
- Mitra, S. & Sambamoorthi, U. (2006). Government programmes to promote employment among persons with disabilities in India. *Indian Journal of Social Development*, 6, 195-213.
- Office for National Labour Statistics (2014). *Statistical Bulletin: Labour Market Statistics, February 2014*. Author. Retrieved from:  
[http://www.ons.gov.uk/ons/dcp171778\\_350998.pdf](http://www.ons.gov.uk/ons/dcp171778_350998.pdf).



- Pointon, M., Leggett, J., Archer, S-K, Maltman, K., Oung, A., & Leung, E. (2009). *Australian Disability Enterprises: Sector Profile. Research Report No. 10/09*. Sydney, NSW: Australia Fair Pay Commission.
- Priestly, M. (2009). Targeting and mainstreaming disability in the 2008-2010 national strategy reports for social protection and social inclusion. Leeds, UK: Academic Network of European Disability Experts (ANED).
- Sanford, C., Newman, L., Wagner, M., Cameto, R., Knokey, A-M & Shaver, D. (2011). *The post-high school outcomes of young adults with disabilities up to 6 years after high school - Key findings from the national longitudinal transition study-2 (NLTS2)*. Washington, D.C.: National Center for Special Education Research.
- Statistics Canada. (2006). Participation and activity limitation survey 2006: Families of children with disabilities in Canada. Retrieved from : <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2008009-eng.htm>.
- Statistics Canada. (2013). *Canadian survey on disability – CSD*. Retrieved from <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3251&lang=en&d b=imdb&adm=8&dis=2>
- Statistics Canada. (2013). *The 2012 Canadian survey on disability (CSD) and the 2006 participation and activity limitation survey (PALS)*. Retrieved from: [http://www23.statcan.gc.ca/imdb-bmdi/document/3251\\_D6\\_T9\\_V1-eng.htm](http://www23.statcan.gc.ca/imdb-bmdi/document/3251_D6_T9_V1-eng.htm)
- Visier, L. (1998): Sheltered employment for persons with disabilities. *International Labour Review*, 137, 347-365
- Waldschmidt, A. & Lignau, K. (2007). *Report on the employment of disabled people in European countries (Germany)*. Leeds, UK: Academic Network of European Disability Experts (ANED).

Watson, D., Kingston, G. & McGinnity, F. 2012. Disability in the Irish labour market: Evidence from the QNHS equality module 2010. Dublin, Ireland: Equality Authority.

Weathers II, R.R. & Wittenburg, D.C. (2009). Employment. In A.J. Houtenville, D.C. Stapleton, R.R. Weathers II and R.V. Burkhauser, Eds., *Counting Working –Age People With Disabilities* (pp. 101-143). Kalamazoo, MI: Upjohn Institute.

World Health Organization. (2001). International classification of functioning, disability and health. Retrieved from: <http://www.who.int/classifications/icf/en/>

World Health Organization. (2011). *World report on disability*. Geneva, Switzerland: Author.

Table 1. Sampling of international definitions related to intellectual disability

Agency	Term Used	Definition
Australian Bureau of Statistics	Learning disability	Difficulty learning or understanding things (ABS, 2009)
Assessment Act of the Austrian Government (“Einschätzungsverordnung	Cognitive performance restriction (Geistige Behinderung/ Lernbehinderung)	Assessment of the degree of cognitive functioning is to be made independent of its cause and solely dependent on the degree of restrictions in adaptive functions / disorder (Bundesministerium für Arbeit, Soziales und Konsumentenschutz, n.d.)
U.S. Census Bureau	Cognitive disability	Serious difficulty remembering, concentrating, or making decisions (Brault, 2010)
U.S. Administration on Intellectual and Developmental Disabilities	Developmental disability	A severe, chronic disability of an individual that: is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following areas of major life activity: Self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency; and reflects the

		individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated (AIDD, 2000)
Statistics Canada	Developmental delay	Cognitive limitations due to the presence of a developmental disability or disorder, such as Down syndrome, autism or mental impairment caused by a lack of oxygen at birth." (Statistics Canada, 2006)
Developmental Services Ontario, Canada	Developmental disability	A developmental disability is present at birth or develops before 18 years of age; affects a person's ability to learn; is permanent; can be mild or severe. (DSO, 2013)

Table 2. Employment rates for persons with ID reported by international sources

<b>Country</b>	<b>Source</b>	<b>Reported Paid Employment Rate (%)</b>	<b>Population Description</b>
Australia	Commonwealth of Australia, 2008	42	Individuals with ID who have received employment services. Includes workers in “disability enterprises, some working at lower than minimum wage.
Canada	Participation and Activity Limitation Survey 2006 (reported in Bizier et al.,(2008)	32.7	Individuals with “developmental disabilities” in the general population
United Kingdom	UK Office of National Statistics 2004 (reported by Demsey & Ford, 2009)	32	Individuals with “learning disabilities”; sample includes people with autism and conditions such as dyslexia
United States	National Center for Special Education Research, 2011	46	Youth with “mental retardation” who attended special education, up to 6 years post high school