

1. People With Intellectual Disability in the Member States

1. 1. Background

While a standard terminology is not employed in the field of intellectual disability (Schroeder *et al.*, 2002), ‘intellectual disability’ is now emerging as the preferred term for what is referred to as ‘mental retardation’ in the United States and ‘learning disability’ in the United Kingdom (Lin, 2003). This report will adopt the term intellectual disability throughout except where a direct quote warrants otherwise.

Intellectual disability is a lifelong condition with multiple aetiologies (Harris, 1995). Gustavsson (1997) describes intellectual disability as an arrest of intellectual development and a condition that affects the brain during the development years. There are no specific personality or behavioural characteristics that are specific to intellectual disability (American Psychiatric Association, 1994). Severe levels of intellectual disability or syndromes associated with a specific phenotype, such as Down’s Syndrome, can be identified early in childhood. Less severe levels of intellectual disability may not become apparent until the school years when children may fail to reach certain developmental milestones.

Prior to the development of intelligence testing, there was no method of diagnosing intellectual disability. By the beginning of the 20th century, the concept of intellectual quotient (IQ) became the main criteria for diagnosing intellectual disability (Detterman, Gabriel & Ruthsatz, 2000). The emphasis on intelligence quotient indicated that people with intellectual disability were incapable of learning or acquiring anything more than basic cognitive skills. By the 1960s however a new paradigm focusing on ‘adaptive behaviour’ indicated that intellectual disability comprised not only a deficit in intellectual capacity but also in social and adaptive functioning. Adaptive functioning is defined as the effectiveness to which an individual meets standards of personal independence and social responsibility expected for his or her age and cultural background (Grossman, 1983; Luckason *et al.*, 1992). Intelligence quotient alone is no longer sufficient criteria for determining intellectual disability: adaptive functioning must also be assessed. A variety of diagnostic tools are available to determine levels of adaptive functioning. Adaptive skills assessed by these protocols include self-care, social skills, use of community facilities, health & safety, engagement in inappropriate behaviours and work skills (American Association on Mental Retardation, 1992)

1. 2. Definitions of Intellectual Disability

There are many definitions of intellectual disability but, according to ‘Usage of the Term Mental Retardation, Language, Image and Public Education Report’ (Schroeder *et al.*, 2002) four are most prevalent within the field:

- (1) the American Association of Mental Retardation (1992 & 2002) definitions,
- (2) the DSM IV (American Psychiatric Association, 1994) definition,
- (3) the ICD 10 (World Health Organisation, 1992) definition and
- (4) American Psychological Association (Jacobson & Mulick, 1996) definition. These definitions will be briefly reviewed.

1.2.1. The American Association of Mental Retardation (AAMR; 1992 & 2002)

The American Association of Mental Retardation (1992) states: “*Mental retardation is not something you have, like blue eyes, or a bad heart. Nor is it something you are, like short or thin. It is not a medical disorder, nor a mental disorder. Mental retardation is a particular state of functioning that begins in childhood and is characterised by limitation in both intelligence and adaptive skills. Mental retardation reflects the ‘fit’ between the capabilities of individuals and the structure and expectations of their environment*”. (www.aamr.org)

The most recent AAMR definition of ‘mental retardation’ (2002) states: “*Mental retardation is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18*”.

The AAMR Definition of Mental Retardation

Five assumptions are essential to the application of the definition:

- 1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.*
- 2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors.*
- 3. Within an individual, limitations often co-exist with strengths.*
- 4. An important purpose of describing limitations is to develop a profile of needed supports.*
- 5. With appropriate personalised supports over a sustained period, the life functioning of the person with mental retardation will generally improve.*

1.2.2. DSM IV: Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (1994)

DSM IV (1994) states that ‘*this mental disorder is diagnosed in individuals who, from whatever cause have intelligence below an arbitrary level beginning before adulthood and whose adaptive functioning is impaired in any of a variety of area*’ (American Psychiatric Association, 1994).

DSM IV Diagnostic criteria for Mental Retardation

- A. Significantly subaverage intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgement of significantly subaverage intellectual functioning).*
- B. Concurrent deficits or impairments in present adaptive functioning (i.e. the person’s effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.*
- C. The onset is before 18 years.*

*Code based on degree of severity reflecting level of intellectual impairment:
317 **Mild Mental Retardation:** IQ level 50-55 to approximately 70*

*318.0 **Moderate Mental Retardation:** IQ level 35-40 to 50-55*

*318.1 **Severe Mental Retardation:** IQ level 20-25 to 35-40*

*318.2 **Profound Mental Retardation:** IQ level below 20 or 25*

*319 **Mental Retardation, Severity Unspecified:** When there is strong presumption of Mental Retardation but the person's intelligence is untestable by standard tests.*

1.2.3. ICD 10: The International Statistical Classification of Diseases and Related Health Problems (1992)

The International Statistical Classification of Diseases and Related Health Problems (ICD-10: World Health Organisation, 1992) defines intellectual disability using four classifications ranging from mild intellectual disability to profound intellectual disability.

International Statistical Classification of Diseases And Related Health Problems

(ICD 10)

Mild intellectual disability – ICD 10 F70: *Ability to use speech in everyday situations; usually full independence in self care; IQ range 50-69. Difficulties in identification of this population arise, as those with borderline disability may not be in contact with service providers.*

Moderate intellectual disability – ICD 10 F71: *Slow in comprehension; supervision of self care, retarded motor skills; IQ between 35-49*

Severe intellectual disability – ICD 10 F72: *Marked impairment of motor skills; clinically significant damage to CNS; IQ between 20-34 points*

Profound intellectual disability – ICD F73: *Severely limited understanding; Immobility or restricted mobility; Incontinence; requires constant supervision; IQ less than 20; usually organic aetiology.*

1.2.4. Jacobson & Mulick, American Psychological Association (1996)

Jacobson & Mulick (1996) retain the mild, moderate, severe and profound classification system employed in both DSM IV and ICD 10.

Jacobson & Mulick (1996)

A. Significant limitations in general intellectual functioning

B. Significant limitations in adaptive functioning, which exists concurrently

C. Onset of intellectual and adaptive functioning before the age of 22 years.

Mild Mental Retardation is defined by IQ range between 55-70 (-2 SD) with the extent of concurrent adaptive limitations in two or more domains.

Moderate Mental Retardation is defined by IQ range between 35-54 (-3 SD) with the extent of concurrent adaptive limitations in two or more domains.

Severe Mental Retardation is defined by IQ range between 20-34 (-4 SD) with the extent of concurrent adaptive limitations in all domains.

Profound Mental Retardation is defined by IQ below 20 (-5 SD) with the extent of concurrent adaptive limitations in all domains.

1.2.5. The International Classification of Functioning, Disability and Health (World Health Organisation, 2001a)

A more recent and additional diagnostic criteria should also be cited. The World Health Organisation is currently in the process of introducing the International Classification of Functioning, Disability and Health (ICF – previously termed ICIDH 2). The ICF is described as the World Health Organisation's framework for health and disability. The ICD 10 classification system cited above identifies an aetiological framework for the classification, by diagnosis, of a health condition. The ICF in contrast classifies functioning and disability associated with health conditions. The ICD-10 and ICF are therefore deemed complementary and the use of both classification systems is encouraged.

The classification aims to stress the health status of individuals, as opposed to any potential disability. The system is based on a bio-psychosocial model that integrates both medical and social models of disability, where disability and functioning are defined in terms of the outcomes of interactions they afford between health conditions (e.g. disorders) and contextual factors (e.g. societal attitudes, age, experience, etc.). The domains listed below identify the three levels of human functioning classified by ICF: functioning that occurs at the level of a body part, functioning that occurs at the level of the whole individual, and functioning that occurs at the level of society. The ICF records the presence and severity of a problem in functioning at these three levels; body, individual, society. Further information on the ICF is available at www.who.int.

***The International Classification of Functioning, Disability and Health
(World Health Organisation, 2001a)***

Body Functions are physiological functions of body systems (including psychological functions)

Body Structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual.

Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation Restrictions are problems an individual may experience in involvement in life situations.

Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

In addition to the four definitions of intellectual disability outlined above, two other definitions warrant mention: (5) the Swedish Model of Classification and (6) Administrative definitions.

1.2.6. Swedish Model of Classification (Kylén, 1974, 1981, 1985)

Kylén (1974, 1981, 1985) has defined intellectual disability as a combination of intelligence, age (biological) and social ability. Kylén outlines three levels of cognitive functioning according to this model.

Swedish Model of Classification

(Kylén, 1974, 1981, 1985)

A Severe: Limited perspective of time and space – acting and thinking are related to the present and verbal communication is not present. Communication is based on simple non-verbal signals (equivalent to IQ of approximately 10 and profound levels of intellectual disability)

B Moderate: Limited understanding of local space with verbal skills. The ability of cognitive structure of thoughts in relation to individual experiences has been developed (equivalent to IQ ranging approximately >10 to 40 and severe to moderate levels of intellectual disability)

C Mild: Literacy and basic mathematical skills are present. The ability to rearrange, structure and perform concrete cognitive operations has been developed (equivalent to IQ ranging >40 to 70 and mild levels of intellectual disability)

1.2.7. Administrative Definition (as outlined by Gustafsson, 2003)

The administrative definition of intellectual disability defines individuals as having an intellectual disability on the basis that they are in receipt of specialised services. Individuals in receipt of services are entitled to these services because they meet specific requirements regarding their limitations in intellectual functioning and adaptive behaviour. It must be acknowledged however that there are a myriad of cultural and historical differences relating to the attitudes, practices and allocation of resources in the judgement of who should be eligible for such services (Sonnander *et al.*, 1993).

1.3. Prevalence of Intellectual Disability

Prevalence figures are vital to the allocation of funding and the development of appropriate service provision for people with intellectual disability (Horwitz, Kerker, Owens & Zigler, 2001). Prevalence estimates vary markedly however in terms of the methodologies employed, (such as census or sample survey), and in terms of the population parameters employed (such as population based samples or registered service users). These differences can result in substantial variations in prevalence estimates and raise important issues for those attempting to estimate prevalence.

1.3.1. Extrapolated prevalence estimates of intellectual disability

The *World Health Organisation Report 2001- Mental Health: New Understanding New Hope* (World Health Organisation, 2001b) estimates that the prevalence of intellectual disability is between one and three per cent of the population:

“The prevalence figures vary considerably because of the varying criteria and methods used in the surveys, as well as differences in the age range of the samples. The overall prevalence of mental retardation is believed to be between 1% and 3%, with the rate for moderate, severe and profound retardation being 0.3%”

Extrapolating from these figures*, a minimum of 4.5 million people with intellectual disability are estimated to live in the 25 Member States of the European Union. By working from a prevalence figure of 0.3% for moderate, severe and profound intellectual disability and either 1% or a conservative 2.5% for all levels of intellectual disability (Gillberg & Soderstrom, 2003), prevalence estimates of 1.3 million people with moderate, severe and profound intellectual disability and between 4.5 - 11.3 million people with all levels of intellectual disability can be extrapolated.

Country	Population (millions)	Moderate, Severe & Profound Intellectual Disability 0.3%	All Intellectual Disability at 1%	All Intellectual Disability at 2.5%
1. Austria	8.1	24,300	81,000	202,500
2. Belgium	10.2	30,600	102,000	255,000
3. Cyprus	0.2	600	2,000	5,000
4. Czech Republic	10.3	30,900	103,000	257,500
5. Denmark	5.3	15,900	53,000	132,500
6. Estonia	1.4	4,200	14,000	35,000
7. Finland	5.1	15,300	51,000	127,500
8. France	60.4	181,200	604,000	1,510,000
9. Germany	82.0	246,000	820,000	2,050,000
10. Greece	10.5	31,500	105,000	262,500
11. Hungary	10.2	30,600	102,000	255,000
12. Ireland	3.7	11,100	37,000	92,500
13. Italy	57.6	172,800	576,000	1,440,000
14. Latvia	2.4	7,200	24,000	60,000
15. Lithuania	3.5	10,500	35,000	87,500
16. Luxembourg	0.43	1,290	4,300	10,750
17. Malta	0.44	1,320	4,400	11,000
18. Netherlands	15.8	47,400	158,000	395,000

* (Population figures taken from Eurostat www.europa.eu.int Oct 2004)

19. Poland	38.6	115,800	386,000	965,000
20. Portugal	10.8	32,400	108,000	270,000
21. Slovakia	5.4	16,200	54,000	135,000
22. Slovenia	2.0	6,000	20,000	50,000
23. Spain	39.4	118,200	394,000	985,000
24. Sweden	8.9	26,700	89,000	222,500
25. UK	58.6	175,800	586,000	1,465,000
All	451.3	1,353,810	4,512,700	11,281,750

1.3.2. Population based prevalence estimates of intellectual disability

Population based prevalence studies of intellectual disability are not common. A sample of such studies conducted throughout the European Union is presented below. Methodological issues compromise the comparability of these prevalence figures. Population definitions vary across Member States to include those in receipt of intellectual disability services, those eligible to receive intellectual disability services, those presenting to generic health services, and those within a specific age range. It should be noted however that many of the prevalence estimates cited below (e.g. Finland 0.13%; Netherlands 0.82%; Sweden 0.4%) are considerably lower than those reported by the World Health Organisation (2001b).

Member State	Prevalence Estimate	Reference
Denmark	Prevalence estimates of 3.38 per 1,000 of severe intellectual disability were reported for a population based study of 50,667 children (Bernsen, 1976)	Bernsen, A. H., (1976). Severe mental retardation among children in the country of Aarhus, Denmark: A community study on prevalence and provision of service. <i>Acta Psychiatrica Scandinavica</i> , 51, 43-66
Finland	<p>Prevalence estimates for severe to profound levels of intellectual disability are reported by Arvio & Sillanpaa as 0.13%.</p> <p>Ruppila (1966) and Tarvainen (1966) report the prevalence of severe and profound intellectual disability ranging 0.09% to 0.2%</p> <p>Prevalence rates are reported for those with severe intellectual disability (IQ <50) as 6.3 per 1,000; mild (IQ 50-70) as 5.6 per 1,000 and borderline + (IQ 71-85) as 13.7 per 1,000 (Rantakallio & von Wendt, (1986).</p> <p>A comparison of two cohorts (1966 and 1985-1986) in Northern Finland revealed no change in total incidence (12.62/1,000 in both cohorts) or in total prevalence (11.03/1,000 versus 11.23/1,000), (Heikura et al., 2003)</p>	<p>Arvio, M., & Sillanpaa, M., (2003). Prevalence, aetiology and comorbidity of severe and profound intellectual disability in Finland. <i>Journal of Intellectual Disability Research</i>, 47 (Pt 2) 108-112.</p> <p>Heikura, U., Taanila, A., Olsen, P., Hartikainen, A.L., von Wendt, L., & Jarvelin, M.R., (2003). Temporal changes in incidence and prevalence of intellectual disability between two birth cohorts in Northern Finland. <i>American Journal of Mental Retardation</i>, Jan 108 (1) 19-31.</p> <p>Rantakallio, P., & von Wendt, L., (1986). Mental retardation and subnormality in a birth cohort of 12,000 children in Northern Finland. <i>American Journal of Mental Deficiency</i>, 90, 3807</p> <p>Ruoppila, I., (1966). The mentally retarded and their needs of services in Finland, Psychological Part II. <i>Official Statistics of Finland XXXII</i>, 26.</p> <p>Tarvainen, L., (1966). The mentally subnormal in Finland and their needs for care, Social Part I. <i>Official Statistics of Finland XXXII</i>, 26.</p>
Ireland	Initial estimates from the establishment of the database in 1995 indicate 27,193 individuals	Mulcahy, M., Mulvany, F., & Timmons, B., (1996). Preliminary report from the Irish Intellectual Disability Database. <i>Irish Medical Journal</i> , May- Jun 89

	<p>were in receipt of or in need of intellectual disability services.</p> <p>There were 25, 557 people registered on the National Intellectual Disability Database in 2003, representing a prevalence rate of 6.52 per 1,000. The administrative prevalence for mild is 2.38 per 1,000 and the prevalence rate for moderate, severe and profound is 3.72 per 1,000.</p>	<p>(3) 101-3.</p> <p>Barron, S., & Mulvane, F., (2004). National Intellectual Disability Database Committee Annual Report 2003. Health Research Board, Dublin.</p>
Netherlands	<p>The total prevalence of people with intellectual disability identified through a General Practitioner database was 0.82%.</p> <p>Combining service data and GP registrations, a prevalence estimate between 0.643 and 0.699 % was reported.</p>	<p>Schrojenstein Lantman-de Valk, H.M., van, Metsemakers, J.F., Soomers-Turlings, M.J., Haveman, M.J., & Crebolder H.F., (1997). People with intellectual disability in general practice: case definition and case finding. <i>Journal of Intellectual Disability Research, Oct, 41 (Pt 5) 373-9</i></p> <p>Schrojenstein Lantman- de Valk HMJ van, Heurn-Nijsten EWA van, Wullink M, Dinant GJ, Crebolder HFJM, Metsemakers JFM. Prevalentieonderzoek mensen met een verstandelijke beperking in Nederland. Universiteit Maastricht, Maastricht 2002.</p>
Sweden	<p>Prevalence rates of 0.4% were reported for a primary diagnosis of intellectual disability and 0.8% for a secondary diagnosis.</p>	<p>Haldin. J., (1984). Prevalence of mental disorder in an urban population in central Sweden. <i>Acta Psychiatria Scandinavia Jun 69 (6) 503-18</i></p> <p>Gruenwald, K., (1979). Mentally Retarded Children and Young People in Sweden. Integration into society: The progress in the last decade. <i>Acta Paediatrica Scandinavia Supplemental. 275: 75-84</i></p>
United Kingdom	<p>Prevalence estimates of between 0.2%-0.7% were reported for intellectual disability.</p> <p>Whitaker & Porter, (2002) report that 0.29% of the population of West Yorkshire is registered as having intellectual disability.</p>	<p>Corbett, J.A., (1979). Psychiatric morbidity and mental retardation. In: James FE, Snaith RP (Eds) <i>Psychiatric Illness and Mental Handicap: Psychiatric Illness in Mental Handicap</i>. London. Gaskell</p> <p>Goh, S., & Holland, A.J., (1994). A framework for commissioning services for people with learning disabilities. <i>Journal of Public Health Medicine 16, 279-285</i></p> <p>McGrother, C., Bhaumik, S., Thorp, C., Watson, J., & Taub, N., (2002). Prevalence, morbidity and service need among South Asian and white adults with intellectual disability in Leicestershire, UK., <i>Journal of Intellectual Disability Research, 46, (4), 299-309.</i></p> <p>Rutter, M., Tizard, J., Yule, W., Graham, P., & Whitmore, K. (1976). Isle of Wight Studies 1964-1974. <i>Psychological Medicine 7 313-332</i></p> <p>Whitaker, S., Porter, J., (2002). Letter to the Editor on Valuing People, a New Strategy for Learning Disability for the 21st Century. <i>British Journal of Learning Disability, 30, 133</i></p>

1.3.3. Variation in prevalence estimates

Any interpretation of prevalence estimates of intellectual disability must consider the issue of definition. The seven definitions of intellectual disability outlined in Section 1.2 (above) could each produce differing prevalence figures. Whitaker (2004) has recently highlighted this issue. In the United Kingdom, for example, the Government's White Paper document 'Valuing People' (Department of Health, 2001) estimates that some 1.2 million people in England have mild to moderate intellectual disability using a population estimate of 2.5%. This figure is contrasted with a prevalence study conducted in West Yorkshire in England where only 0.29% of the population were identified as having intellectual disability (Whitaker & Porter, 2002). The authors suggest the reason for the disparity is that while the former figure is extrapolated from population figures, the latter figure is based on the number of people registered as having intellectual disability and as such, known to service providers. Both positions have support. The *World Health Organisation Report 2001- Mental Health: New Understanding New Hope* cites prevalence estimates up to 3% (World Health Organisation, 2001b). In contrast, register-based findings consistent with Whitaker & Porter (2004) include Farmer *et al* (1993) who report a prevalence of 0.23% in the United Kingdom, and Borthwick-Duffy & Eyman (1990) who report a prevalence of 0.23% in the United States. On the basis of these disparities, Whitaker (2004) identifies four different, but overlapping groups of people with intellectual disability (p.141).

- *"People who, if assessed, would have a measured IQ below about 70 (or two SD [standard deviations]^ϕ below the mean for the population as a whole), but who are not necessarily known to services. They make up about 2.5% of the population as a whole. The people in this group could be termed as people with intellectual disabilities.*
- *People who, if assessed, would meet the dual criteria for learning disability of having both an IQ below about 70 and additional deficits in adaptive skills, but are not necessarily known to services. Although more difficult to estimate, they may represent about 1% of the population. The people in this group could be termed as people with intellectual and adaptive disabilities.*
- *People who have the learning disability label and are known to services. They make up about 0.25% of the population, and probably include a small number of people who would not fall into either of the above two groups (cf. Whitaker, 2003). The people in this group could be termed as people with identified learning disabilities.*
- *People who would meet a criterion for having a learning disability if they were to be assessed, but are not known to services. Based on the above estimates, they would make up between 0.75% and 2.75% of the population as a whole, which is between 3 and 10 times greater than the proportion of the population who are labelled as having a learning disability. The people in this 'hidden learning disability' group (cf. May & Hogg, 1999) could be termed as people with unidentified learning [hidden] disabilities".*

The issues surrounding definition have implications for those attempting to estimate the prevalence of intellectual disability. Using the dual criteria of an IQ less than 70 and deficits in adaptive behaviour as the definitive definition of intellectual disability, for example, a population based prevalence study would require each individual to undertake several hours of assessments in addition to requiring their consent. As Whitaker (2004) states it is unlikely that such a study would be undertaken, particularly given that over 95% of the sample are likely to be identified as 'non-cases'. In addition, identifying a person as having an intellectual disability raises ethical issues when the individual in question may want neither the label itself, nor any of the associated service provision.

Despite these difficulties, current endeavours at both national and international levels continue to identify and profile the needs of those with intellectual disability. Christianson *et al.*, (2002) highlight the importance of this data:

"The collection of epidemiological data on intellectual disability is essential so that appropriate healthcare, social welfare and educational strategies can be planned and implemented for the benefit of affected people. In addition, such statistics will be of value as indicators of general health status as the significance of indicators like infant and childhood mortality declines"(p.180)

^ϕ *parenthesis added by author*

1.3.4. Current international efforts to estimate prevalence

The United Nations pioneered the call for the collection of systematic and comparable international data regarding people with disabilities. This ongoing work seeks to develop a valid instrument that will accurately estimate the international prevalence of 'various' disabilities. Such a model may provide a useful template from which the European prevalence of intellectual disability could be examined.

The United Nation's "World Programme in Action concerning Disabled Persons" (1982; p.10 of 10) states:

"The Statistical Office is urged, together with other units of the Secretariat, the specialized agencies and regional commissions, to cooperate with the developing countries in evolving a realistic and practical system of data collection based either on total enumeration or on representative samples, as may be appropriate, in regard to various disabilities, and, in particular, to prepare technical manuals/ documents on how to use household surveys for the collection of such statistics, to be used as essential tools and frames of reference for launching action programmes in the post-LYDP (International Year of Disabled Persons) years to ameliorate the condition of disabled persons" (<http://www.un.org/esa/socdev/enable/diswpa00.htm>. Oct 2004)

Following the recommendations outlined in the "World Programme in Action concerning Disabled Persons" document, the United Nation's General Assembly adopted the "Standard Rules on the Equalization of Opportunities for Persons with Disabilities". While these twenty-two rules are not legally binding they represent a commitment by Governments to attain equalization of opportunities for persons with disabilities. Rule13 addresses the need for basic population data on people with disabilities:

Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Chapter III. Implementation Measures: Rule 13. Information and research

States assume the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities.

States should, at regular intervals, collect gender-specific statistics and other information concerning the living conditions of persons with disabilities. Such data collection could be conducted in conjunction with national censuses and household surveys and could be undertaken in close collaboration, inter alia, with universities, research institutes and organizations of persons with disabilities. The data collection should include questions on programmes and services and their use.

States should consider establishing a data bank on disability, which would include statistics on available services and programmes as well as on the different groups of persons with disabilities. They should bear in mind the need to protect individual privacy and personal integrity.

States should initiate and support programmes of research on social, economic and participation issues that affect the lives of persons with disabilities and their families. Such research should include studies on the causes, types and frequencies of disabilities, the availability and efficacy of existing programmes and the need for development and evaluation of services and support measures.

States should develop and adopt terminology and criteria for the conduct of national surveys, in cooperation with organizations of persons with disabilities.

States should facilitate the participation of persons with disabilities in data collection and research. To undertake such research States should particularly encourage the recruitment of qualified persons with disabilities.

States should support the exchange of research findings and experiences.

States should take measures to disseminate information and knowledge on disability to all political and administration levels within national, regional and local spheres.

<http://www.un.org/esa/socdev/enable/dissre00.htm> (October 2004)

In a response to both the “World Programme of Action concerning Disabled Persons” and the “Standard Rules on the Equalization of Opportunities for Persons with Disabilities”, three further documents were produced by the United Nations:

- Manual for the Development of Statistical Information for Disability Programmes and Policies (United Nations publication, Sales No. E.96.XVII.4).
- Guidelines and Principles for the Development of Disability Statistics (United Nations publication, Sales No. E.01.XVII.15)
- Principles and Recommendations for Population and Housing Censuses, Revision 1 (United Nations publication, Sales No. E.98.XVII.8).

These publications aim to promote the collation of disability statistics by addressing methodological issues and provide guidelines relating to data collection, through surveys and censuses and also on the compilation, dissemination and usage of data on disability.

In particular, the “*Guidelines and Principles for the Development of Disability Statistics*” identify three primary data collection methods from which information regarding the number and profile of people with disabilities can be gathered; sample survey, census, and administrative records.

1.3.4.1. Sample Surveys

Sample surveys by definition do not aim to identify every ‘case’ in the population. Rather they aim to identify a representative sample from which generalisations can be made to the total population. Surveys offer flexibility in the depth and range of topics that may be covered, they are relatively easy to organise and they limit the geographical coverage needed for data collection. The typical survey design however provides challenges for those wishing to collect data in the field of disability. Many surveys are household based and therefore may exclude a significant proportion of people with disabilities who reside in institutional-type settings. In addition, a very large sample is required to capture an adequate number of people with disabilities given the relatively low prevalence rate of disability among the general population.

1.3.4.2. Census

An alternative methodological tool is the collection of data via a census. The aim of a census is to enumerate each person within a population. Universal enumeration of this type typically provides valuable information regarding demographic, social and economic factors. Although a broad range of topics can be included within a census, most are covered briefly due to financial, personnel and time constraints. The United Nations document “*Principles and Recommendations for Population and Housing Censuses, Revision 1*” suggests disability as a topic that may be included in a census. Challenges are however presented by using a census to collect disability data. The census method, as with the survey method cited above, is household based and therefore has the potential to exclude those in institutional care settings. Additionally there are financial implications of including items to a census that will be applicable to only a small minority of respondents.

1.3.4.3. Administrative Records

Finally, administrative records and registers are cited by the United Nations' Guidelines as a third source of data regarding people with disabilities. Typical registers include population registers, vital registration systems, social security systems, occupational injuries registries, rehabilitation programmes and other services for people with disabilities. Issues faced by statisticians wishing to access this type of data include the fact that, in general, this type of data is collated for reasons other than statistical. There may therefore be legal impediments regarding the use of this data for statistical purposes. In spite of these challenges, administrative data, in conjunction with other data sources can provide a rich source of data regarding people with disabilities.

The United Nations acknowledge that, to date, the compilation of disability statistics, by census, sample or register, has been based on a review of publications available in the United Nations and other statistical libraries, or by data submitted on behalf of specific national statistic officials or government bodies (United Nations Publication, 2003, ESA/STAT/AC.91/6).[†] This collection is defined as being made 'on an ad hoc basis' (p.2). Four activities involving the collection of disability data are identified: (1) the Development of Statistics of Disabled Persons: Case Studies, (2) the development in 1988 of DISTAT, the first international database of disability based on published national data from population censuses, household surveys and registration systems from 55 countries, (3) DISTAT 2, providing disability prevalence data from 179 national studies, and (4) the 1991 Demographic Yearbook Special Questionnaire on Ageing, the only occasion on which disability data was collected as part of the Demographic Yearbook data collection process.

Justifying the need for the international and systematic (as opposed to the current 'ad hoc') collection and dissemination of statistics on disability, the United Nations note the following:

- The increased interest at national and international levels regarding the situation of people with disabilities.
- The development of the *"Guidelines and Principles for the Development of Disability Statistics"* which recommend that countries not only collect data on prevalence rates but also on key social and economic characteristics.
- The development of the ICF, published in late 2001 provides a common conceptual framework for collecting and classifying data on disability.
- Ongoing international work to harmonise the methods used by countries to collect comparable disability data. Following an International Seminar on the Measurement of Disability (New York, June 2001) the Washington Group on Disability Statistics (WG) was established to implement the Seminar's recommendations. Four meetings of this group have taken place since the initial meeting in Washington in February 2002. The most recent meeting, to be held in October 2004 in Bangkok, will discuss a draft set of questions examining the equalisation of opportunity for those with disabilities. <http://www.cdc.gov/nchs/citygroup.htm>

1.3.5. Current national efforts to estimate prevalence

National efforts to identify and profile those with intellectual disability are uncommon and diverse in nature. A sample of prevalence studies conducted in the European Union has been presented previously (section 1.3.2). In addition to these studies however two pilot prevalence studies have recently been completed, one in Ireland and one in the United Kingdom. Both pilot studies pave the way for full national prevalence studies and are presented below as examples of current methods being employed to determine prevalence.

[†] United Nations Publication ESA/STAT/AC.91/6 (2003). *The collection and dissemination of statistics on disability at the United Nations Statistics Division: Proposals for the Future.*

1.3.5.1. Ireland: Pilot prevalence study

In 2002 the Irish National Disability Authority (an independent statutory agency established under the aegis of the Department of Justice, Equality & Law Reform by the National Disability Authority Act 1999) formally proposed that a national disability study be undertaken to establish the prevalence and impact of disability in Ireland. A consortium including the Economic and Social Research Institute, the Centre for Disability Studies, University College Dublin and an independent disability consultant were commissioned to undertake a pilot study in preparation for a full national disability prevalence study. The pilot study was undertaken in 2003-2004 and comprised a telephone survey of 953 households. A filter question was used to identify any person with a disability resident in each household. From a total of 2,439 individuals resident in the surveyed households, 317 people were identified as having a disability yielding a prevalence rate of disability of 13%. These respondents were then invited to participate in a face-to-face interview in their own home with the World Health Organisation's ICF being used as a measure for disability. Overall conclusions from the pilot study were that the use of the ICF as a frame of reference is 'eminently feasible' and that the inclusion of a filter question in the 2006 Irish Census of Population would be favoured over the use of a telephone based survey of a smaller sample, similar to that conducted in the pilot. www.nda.ie

1.3.5.2. United Kingdom: Pilot prevalence study

In March 2001 the Government White Paper "Valuing People; a new strategy for learning disability in the 21st Century" highlighted the need for a survey of people with intellectual disability. In May 2002 the British Department of Health commissioned a consortium including BMRB Social Research, the Institute for Health Research, Lancaster University and Central England People First (an organisation run and controlled by people with intellectual disability) to conduct a feasibility study for a survey of adults with intellectual disability. The sample design for the survey was required to be representative and to allow a repeat survey five years later. With due consideration to these guidelines an approach was taken to identify a sample by accommodation type: specifically targeting those in private households, supported housing, residential care and long-stay/hospital beds. Potential respondents were identified through an array of sources including a filter question on a weekly omnibus survey of adults in the UK, social services records, and registers of those in supported housing, residential care homes and long stay/hospital beds. From these data sources a sample of 3,000 individuals will be identified and will be invited to be interviewed in their home. Interviews will be carried out during 2004 using Computer Assisted Personal Interviewing (CAPI) and may include the presence of a support person as required. A report of the findings is expected in 2005.

1.4 Conclusion

This chapter commenced with an outline of some of the major classification systems that define intellectual disability. The variation in these definitions, ranging from those whose IQ falls within a given span to those who receive special services, provide challenges for those trying to identify this population. As a consequence, basic prevalence figures are difficult to estimate, and where available are rarely comparable. Ongoing efforts by the United Nations to determine the prevalence of disability at international level emphasise the need for harmonisation of the methods used by countries to collect comparable data. In addition to these efforts, work at national level is commencing in some Member States to identify specifically those with intellectual disability. The outcomes of these endeavours will provide valuable feedback regarding the suitability of these methods to determine the prevalence of this hidden population.

1.5 References

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