Social Indicators Research Series 61

Barbara M. Altman *Editor*

International Measurement of Disability

Purpose, Method and Application
The Work of the Washington Group

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The Work of the Washington Group

This volume provides an informed review of the accomplishments of the Washington Group on Disability Statistics (WG) in the provision of international data and statistics on disability. It does so within the context of the UN Convention on the Rights of Persons with Disabilities. The volume includes a description of the development and testing of a short set of questions for Censuses, now used in approximately 29 countries and recommended in the U.N.'s Principles and Recommendations for Population and Housing Censuses: The 2020 Round, which includes disability as a core topic to be collected in censuses. It discusses the experiences of several countries on the use of the WG questions and how this has impacted on national agendas in the area of disability. It follows the development and testing of an extended set of questions for use in national surveys other than censuses and examines the challenges of translation and the importance of generating comparable question sets in different languages and within different cultures. It studies the examination of cognitive testing techniques in a variety of countries, and presents the results of the first round of censuses in 2010 in countries using the six question set. The volume includes discussions of the new development of question modules on a broad range of child disability and functioning, and the environmental contexts of participation that are part of the current work of the WG. In addition, it contains a reflection on the use of the WG's functionality approach to identifying disabilities by humanitarian agencies to identify disabilities in populations of displaced persons. A thoughtful conclusion addresses what the development of cross-nationally comparable data can mean for the improvement of circumstances for all persons with disabilities.

Social Sciences

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Social Indicators Research Series

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This series aims to provide a public forum for single treatises and collections of papers on social indicators research that are too long to be published in our journal Social Indicators Research. Like the journal, the book series deals with statistical assessments of the quality of life from a broad perspective. It welcomes research on a wide variety of substantive areas, including health, crime, housing, education, family life, leisure activities, transportation, mobility, economics, work, religion and environmental issues. These areas of research will focus on the impact of key issues such as health on the overall quality of life and vice versa. An international review board, consisting of Ruut Veenhoven, Joachim Vogel, Ed Diener, Torbjorn Moum and Wolfgang Glatzer, will ensure the high quality of the series as a whole. Available at 25% discount for International Society for Quality-of-Life Studies (ISQOLS). For membership details please contact: ISQOLS; e-mail: isqols@mail.vt.edu Editors: Ed Diener, University of Illinois, Champaign, USA; Wolfgang Glatzer, J.W. Goethe University, Frankfurt am Main, Germany; Torbjorn Moum, University of Oslo, Norway; Mirjam A.G. Sprangers, University of Amsterdam, The Netherlands; Joachim Vogel, Central Bureau of Statistics, Stockholm, Sweden; Ruut Veenhoven, Erasmus University, Rotterdam, The Netherlands.

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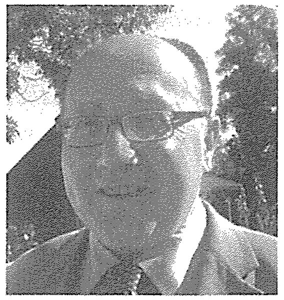

Howard Meltzer
22 March 1951–23 January 2013

(This picture is published with kind permission of the author's beneficiary Sylvie Voirin)

Professor Howard Meltzer was an outstanding social researcher in the field of disability and an expert in the design, implementation, and analysis of national health surveys. As a charter member of the Washington Group on Disability Statistics representing the Office of National Statistics of England, he contributed enthusiastically and tirelessly to the improvement of disability statistics for international use. Born in Manchester, England, he was educated at North Manchester Grammar

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Biography

Barbara M. Altman is a sociologist with a PhD from the University of Maryland. Retired from the National Center for Health Statistics, CDC, where she served as Special Assistant on Disability Statistics to the Office of the Director, she also worked at the Agency for Healthcare Research and Quality on the Medical Expenditure Panel Survey. She currently serves as a consultant on disability statistics issues. She has been involved with the work of the Washington Group, an international group working under the auspices of the United Nations, since its inception. She was also co-leader of the interagency committee which developed the questions on disability currently used in the American Community Survey which have also been adopted by other agencies such as the Bureau of Labor Statistics and the Justice Department. Her disability research interests focus primarily on disability definition and measurement, access and utilization of health-care services by persons with disabilities, and disability among minority groups, particularly Native Americans. She is the author of numerous articles and book chapters on disability topics including the recent *Disability and Health in the United States Chartbook* and currently is coeditor of the series *Research in Social Science and Disability*.

Sathi Alur is a development economist with professional qualifications in finance and management, accounting, and jurisprudence. He has worked with multinational corporations in Sweden and India, with many governments and in the international social development sectors—education, health, water, and disability—and international development agencies such as the World Bank and UNICEF. He was among the early pioneers in India (late 1970s) bringing professionalism into the finance and project management areas of NGO operations and service delivery in India. His work has focused on addressing sustainable, scalable, and replicable initiatives particularly in the context of restricted public finances, the absence of universal entitlements, and lack of social protection. Currently in India his work examines improved methodologies of data collection and analysis as a basis for more efficient and cost-effective ways of organizing and delivery of vital services for persons with disabilities particularly and of social services generally. He is also a member of the World Cerebral Palsy Initiative and of international professional management institutions.

conditions, and the effects of these conditions on function. Dr. Rasch has coauthored over 50 articles. She is a member of the Editorial Board for the Disability and Health Journal and the Physical Therapy Journal. In 2009 and 2011, she was honored with Clinical Center's Director's Awards in science from NIH.

Jean-Marie Robine is a research director at INSERM, the French National Institute of Health and Medical Research (http://www.inserm.fr), within the CERMES Research group in Paris and the Unit 710 in Montpellier where he heads the research team biodemography of longevity and vitality. He is also a study director at the advanced school Ecole pratique des hautes études (http://www.ephe.sorbonne.fr) in Paris. He studies human longevity, with the aim of understanding the relations between health and longevity. In particular, he measures the impact that the increase in adult life durations may have on the health status of the elderly population. Since its creation in 1989, he has been the coordinator of the International Network on Health Expectancy (REVES), which brings together more some 100 researchers worldwide (www.reves-network.org). He was the project leader of the European Joint Action EHLEIS (2011–2014) which provided analysis of disability-free life expectancies in the European Union (www.eurohex.eu). He is co-responsible for the development of the International Database on Longevity (IDL) in association with the Max Planck Institute for Demographic Research (Rostock) and INED (Paris). He is the project leader of the healthy longevity project granted by AXA Research Fund: the Five-Country Oldest Old Project (5-COOP). He is one of the Directors of the new French Research Consortium on aging and longevity (GDR CNRS 3662, 2014–2017).

Marguerite Schneider, Ph.D. is a researcher in the field of disability studies and project manager at the Alan J Flisher Centre for Public Mental Health, University of Cape Town. Her early career was in Speech-Language Pathology and Audiology before moving into broader social science research focusing on disability studies. She obtained her PhD at the School of Public Health, University of the Witwatersrand, with a thesis entitled: "The social life of questionnaires: Exploring respondents' understanding and interpretation of disability measures." She has published on disability measurement and disability in relation to poverty and social protection.

Laura Smith-Khan is a doctoral candidate in linguistics at the Macquarie University, Sydney, Australia. She has bachelor degrees in law and arts from the University of Sydney where she is employed as a research assistant and sessional associate-lecturer. She has a master's degree in applied linguistics from Monash University in Melbourne. Laura is the lead researcher on Professor Crock's projects that have a disability focus. She is a coauthor of many of the articles written for the AusAID-funded "Protection of Refugees with Disabilities" Project (2012–2015).

Herman Van Oyen is director of the Operational Directorate Public Health and Surveillance of the WIV-ISP (Scientific Institute of Public Health, Belgium). He is professor epidemiology at the department of Public Health, University of Ghent. His research in the field of epidemiology and public health focus among others on epidemiological methods and survey research, methods of measuring population health, especially Summary Measures of Population Health (SMPH), and health inequality. He is member of the Belgian Superior Health Council and chair of the expert group on Public Health Genomics. He has been the promoter of the health expectancy indicators estimations in Belgium. Examples of his on-going research activities are the estimation of the impact of smoking on disability and disability-free life expectancy and the development of time series on socio-economic inequalities in Healthy Life Years (HLYs). He is a member of several national and European working groups on measuring health in populations.

Romulo A. Virola was secretary general of the National Statistical Coordination Board of the Philippines from 1991 until his retirement in July 2012. He completed his PhD in statistics at the University of Michigan in Ann Arbor, USA. He served on the faculty of statistics and mathematics at the University of the Philippines, has written/presented more than one hundred and fifty papers, and has served as resource person/speaker in local and international forums on various topics. He served as associate editor of the International Association for Official Statistics Journal and as editor of the *Philippine Statistician*. He was one of the ten achievement awardees of the National Research Council of the Philippines in 2007. He was a member of the Board/Executive Committee/Bureau/Steering Committee of the Partnership in Statistics for Development in the 21st Century, the UNESCAP Committee on Statistics, and the Washington Group on Disability Statistics, among others. He was a member of the jury of the 2012 Mahalanobis International Award of the International Statistical Institute, the Friends of the Chair of the U.N. Statistical Commission on the Fundamental Principles of Official Statistics, the International Advisory Group on Agricultural Statistics of the FAO, the Advisory Group of the Marrakech Action Plan for Statistics, and the Statistical Advisory Panel on the 2012/2013 Human Development Report. He has served as consultant for the U.N., the World Bank, the Asian Development Bank, the OECD, and various local institutions in the Philippines.

Julie D. Weeks a sociologist with a PhD from the University of Maryland, has been at the National Center for Health Statistics since 1989 and currently serves as the Chief of the Aging and Chronic Disease Statistics Branch in the Office of Analysis and Epidemiology. Since Dr. Weeks joined the center, she has concentrated her research efforts on trends in the health of older persons, including the measurement of health and functioning in this population. She was assistant project director for the 1984–1990 Longitudinal Study of Aging (LSOA), project director for the 1994–2000 Second Longitudinal Study of Aging (LSOA II), and a member of the design committee for the 1994–1995 National Health Interview Survey on Disability. More recently, her focus has broadened to include disability and functioning measurement and analysis and incorporating standard measures into both national and international data collections. Her current work also includes leading the Quality of Life and Well-Being work group for the DHHS Healthy People initiative, as well as serving on both the Disability and Health and Older Adults work groups; she has membership on both the Washington Group on Disability Statistics and the Budapest Initiative on Measuring Health State and is serving as a member of the American Statistical Association's Committee on Statistics and Disability.

Washington Group on Disability Statistics (WG). (2012). *Budapest Initiative (BI) & United Nations Economic & Social Commission for Asia & the Pacific (UNESCAP)*. Development of disability measures for surveys: The extended set on functioning. http://www.cdc.gov/nchs/washington_group/wg_documents.htm. Accessed 9 Apr 2013.

WHO –World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.

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Chapter 16
Swift and Systematic? Identifying and Recording Disability in Forced Migration

Mary Crock and Laura Smith-Khan

Persons with disabilities who find themselves displaced by human conflict have been described as "too often invisible, too often forgotten and too often overlooked" (António Guterres, cited in WRC 2008, p. 1). As an agency of the United Nations – and therefore bound by international law, the United Nations High Commission for Refugees (UNHCR) has embraced the paradigm shift in approach demanded by the Convention on the Rights of Persons with Disabilities (CRPD) (2008). In this chapter we explain how the work of the Washington Group has been used in multi-country fieldwork to explore the adequacy of the systems used by UNHCR and other agencies to identify disabilities in populations of displaced persons. The overall aim of the research was to encourage these humanitarian actors to improve the accessibility of their operations (Crock et al. 2013, p. 737). The project provides an interesting illustration of how the "functionality" approach pioneered by the Washington Group can be used in diverse field situations.

The importance of identifying and recording accurate and comprehensive information about disability is widely acknowledged. Article 31 of the CRPD creates an explicit duty in states parties to collect statistics and data "to enable them to formulate and implement policies" to promote Convention rights. In 2010, UNHCR's Executive Committee recommended that states and UNHCR undertake:

> a swift and systematic identification and registration of refugees and other persons with disabilities, with particular attention to those who cannot communicate their own needs, in

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This chapter draws on an article prepared during an early stage of the "Protection of Refugees with Disabilities" Project. See: Smith-Khan et al. 2015a.

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> order to identify their protection and assistance needs, including as part of a global needs assessment (ExCom 2010).

While data collection is a global challenge, displacement situations throw up particular problems. There are a range of reasons why people living in fear of persecution or in situations of extreme deprivation may be reluctant to present themselves to local host authorities or to agencies like UNHCR. Refugees and displaced persons may be unaware of the benefits of registering with these agencies. They may have lost critical identity documents in the course of their flight. Services may be inaccessible to those with disabilities (Hart et al. 2014, p. 149). In the result some may be overlooked (HelpAge International and Handicap International 2014, p. 16). Even for those who register with UNHCR and its implementing and operational partners (different government agencies, NGOs and IGOs in the various countries), our experience suggests that disability can be overlooked or not accurately recorded (Smith-Khan et al. 2015a, b; HelpAge International and Handicap International 2014, p. 16).

The chapter begins with a brief overview of our research and the methodologies used in collecting data in the various countries in which fieldwork was undertaken. Thereafter we use a discussion of the disability data collected by the support organisations studied to outline apparent shortcomings in the systems being used. We then critique in greater detail the practices and tools used for identifying and recording disability in displacement situations, drawing out examples of good and bad practice. The chapter concludes with some reflections on the benefits of using the Washington Group question sets, as well as other important factors in facilitating identification and information sharing.

Outline of Project

This chapter shares findings from a project conducted by a team based at the University of Sydney's Faculty of Law. The work involved predominantly qualitative research, combining a critical review of existing studies, tools and standards, with multi-site fieldwork in six host countries: Malaysia and Indonesia in 2012, Pakistan and Uganda in 2013 and Jordan and Turkey in 2014.

These countries were selected to allow for the study of disabilities in a variety of displacement situations. In Malaysia and Indonesia, the research was focused on refugees and asylum seekers living in urban settings. Critically, the presence of these people was tolerated but not supported by government. In Uganda, refugees living in the capital city of Kampala were compared with persons living in government-sponsored refugee settlements who receive subsistence support and services. In Pakistan, UNHCR provided us with survey data that provided an overview of the diverse refugee population living in urban, rural and camp-like settings. Finally, research in Jordan and Turkey involved a case study of raw and fresh displacement scenarios: refugees fleeing ongoing conflict in Syria living in both camp and urban refugee settings. Unlike the other research countries where refugees came from a variety of countries, the refugees studied in Jordan and Turkey generally shared similar cultural and linguistic backgrounds. While Uganda is the only one of these countries to have unconditionally ratified the Refugee Convention (1951) and its Protocol (1967), all are parties to the CRPD.[1]

In each country, we met and interviewed representatives from UNHCR; UNHCR's partners and local Disabled Persons Organisations (DPOs). In Uganda, Pakistan, Jordan and Turkey we also met with government officials. In every country but Pakistan we conducted individual and focus group interviews with refugees and asylum seekers. Critically, for present purposes, our research tools used drew heavily on the *International Classification of Functioning, Disability and Health* (ICF) developed by the World Health Organization (WHO). As many in this volume attest, the ICF reflects and operationalizes the CRPD approach to disability. It seeks to capture not only a person's impairment or health condition, but also the environmental barriers that create disability (WHO 2011, p. 4). The ICF conceptualises disability as difficulty in any one of three interconnected areas: *impairments* ('problems in body function or alternations in body structure'); *difficulties in executing* activities – for example, walking or eating; and *participation* ('problems with involvement in any area of life') (p. 5).

The ICF forms the basis for a number of national and international identification tools (WHO 2011, p. 25), including question sets developed by the Washington Group on Disability Statistics. These include a basic set of questions:

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even when using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remember or concentrating?
5. Do you have difficult with self-care, such as washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating (for example, understanding or being understood by others)? (WHO 2011, p. 26)

For each of these questions, responses range on a scale from "No difficulty" to "Cannot do at all" (WHO 2011, p. 26). Questions about anxiety and depression, fatigue and pain are also included (Washington Group 2011, pp. 9–11).

Having tested ICF-based surveys extensively, WHO (2011) recommends the adoption of the ICF as an international standard. Further, it advocates a "difficulties in functioning" approach in place of an "impairment" approach, recommending that disability questions be added to existing surveys as a "cost-effective and efficient" implementation strategy (p. 45).

The individual questionnaire included a disability identification tool based on the ICF and Washington Group questions. As WHO recommends (2011, pp. 40–1), we asked questions about assistance with functional difficulties, fatigue, pain and

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[1] Turkey is a party to the Refugee Convention, but limits its application to refugees from Europe. Malaysia ratified the CRPD on 19 July 2010; Indonesia on 30 November 2011; Pakistan on 5 July 2011; Turkey on 28 September 2009; Jordan on 31 March 2008. Uganda acceded to the Refugee Convention and its Protocol on 27 September 1976. Turkey ratified the Refugee Convention on 30 March 1962 and acceded to its Protocol on 31 July 1968.

affect, as well as access to income, food, water, education, health care and experiences of discrimination. After asking basic demographic questions, the tool asked whether the interviewee had a disability and, if so, to describe it. Responses to this open ended question could then be compared with the data collected using the functionality questions.

In total, the following individual interviews were conducted with refugees: in Malaysia – 151; in Indonesia – 58; and in Uganda – approximately 80. In Uganda, we also collected over 900 questionnaires that were either self-completed, or completed in French or English with the assistance of an interpreter. This occurred because so many people approached us expressing a desire to participate in the research that we finally distributed the remaining paper surveys we were carrying with us. The refugees located photocopiers in the settlement and reproduced the documents for further distribution over a 3 day period. This response, in itself, indicated the extent to which the interviewees regarded themselves as forgotten refugees.[2]

The disability identification questionnaire was used with a further 11 individual participants in Jordan. We also conducted four focus groups, each of approximately 40 people, in Uganda and Indonesia; and of around 20 people in Malaysia, Jordan and Turkey. In each instance we asked questions about functional difficulty and accommodation for persons with disabilities.

In Pakistan, constraints of time and personnel did not permit research within the refugee communities. However, interviews were conducted with UNHCR and with government officials. Most importantly, UNHCR provided us with data from its 2011 *Population Profiling Verification and Response* (PPVR) exercise where a tool was used that included questions similar to those in the Washington Group's basic set (see CCAR and UNHCR 2011). In Malaysia, Indonesia and Uganda, we were given data extracted from UNHCR's Profile Global Registration System '*ProGres*' (UNHCR 2004), listing persons identified as having a disability, and data from UNHCR's partners. Finally, in anticipation of our arrival in 2012, UNHCR in Malaysia commissioned an internal report on disability (Sario 2012). This provided background into the existing data and identification procedures there.

The fieldwork across the six countries visited threw up many challenges. Limitations of time and a modest budget lead us to use purposive sampling techniques to locate most of our participants: we were not in a position to implement our questionnaire randomly over a large sample. Accordingly we make no claim that the questionnaire data is statistically valid (Bloch 2007, p. 233). Relying on gatekeepers, like UNHCR and other staff and community leaders, may have also excluded some persons (Harrell-Bond and Voutira 2007, pp. 288–9; Bloch 2007, p. 235). In some instances, the information gathered was self-reported by participants, meaning its accuracy cannot always be verified: see also note 2 above.

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[2] See further below. The behaviours exhibited may also reflect the aspiration of the participants that involvement in the survey could deliver a benefit, for example in terms of resettlement to a third country. This was despite every effort on our part to explain the nature of the research and what participation in the survey would (and would not) mean for them.

Ensuring voluntary informed consent was another challenge: our status as Western researchers created a power imbalance (Abdel-Messih et al. 2008, p. 36). We stressed that there was no obligation to participate and that our research could not produce improved protection outcomes for individuals interviewed. Ensuring participants' privacy during interviews was also challenging as we often had limited options in terms of venue and accommodation. The problems were particularly acute in Uganda where our presence attracted considerable curiosity. We endeavoured to hold our interviews in private areas or at some distance from gatherings. Even so, the environment for the research was less than ideal.

In Uganda, the pressure of numbers meant that we resorted to distributing 300 questionnaires for self-completion. Returning some days later we were astonished to find that the refugees had made more copies, returning close to 900 completed questionnaires. As we processed these, we observed some comprehension issues which led us to revise the wording of the questionnaire for subsequent use. The experience also reinforced the importance of providing ample training for community leaders and interpreters or anyone else responsible for implementing such tools. Providing questionnaires in refugee languages would also help overcome comprehension issues and facilitate inclusion (Bloch 2007, p. 239). Again, we were unable to address all of these issues because of funding and time restraints.

Current Data on Refugees with Disabilities

As noted earlier, UNHCR in Malaysia, Indonesia and Uganda shared with us statistics extracted from the *ProGres* database on "persons of concern" recorded as having a disability. These are the people registered with the agency for whom UNHCR has some level of responsibility. As of June 2012, UNHCR in Malaysia reported caring for 202 refugees with a disability (Sario 2012). This amounted to 0.21 % of the 94,000 registered persons of concern at the date in question. In September 2012, UNHCR in Indonesia reported caring for 51 such persons, or 0.64 % of approximately 8000 persons of concern (UNHCR 2012). The situation in Uganda was broadly similar. Of 66,589 refugees and persons of concern living in Nakivale Settlement in September 2013, only 309, or 0.46 %, were recorded as having a disability (UNHCR 2013b, p. 1). In neighbouring Oruchinga Settlement, 99 persons with disabilities were recorded out of a population of 5799, equating to 1.71 % of the resident refugees. As percentages, these figures fall well below the WHO global estimate of 15.6 %, and even the 2.2 % estimate for severe disability. The estimates are removed even further from WHO's estimates for developing countries, even though a number of our research locations were in such countries (WHO 2011, p. 27). In spite of early suggestions from some UNHCR staff interviewed in 2012 that persons with disabilities do not travel, it was clear to us from the outset that the data collected in UNHCR's initial registration processes was not capturing the disabilities of the persons in their care.

Happily, our research coincided with major initiatives by UNHCR to revise its methodologies for collecting data on disabilities. The *ProGres* data from Malaysia, Indonesia and Uganda contrasts sharply with the results of the PPVR in Pakistan.[3] In that exercise, UNHCR and its government partners conducted home visits that covered 974,961 Afghans living throughout Pakistan. The total survey resembled a census, asking a range of questions of a principal informant about the members of their household. The disability section drew on the ICF and used questions resembling the Washington Group set. This was the first location in which we saw this approach used, and the results reflected the change in approach. Of the 974,961 persons reviewed, 79,954 were identified as having functional difficulties. This equates to 8.2 % of the population surveyed.

The WHO estimate of 15.6 % as the global average for the incidence of disability is based on adults (aged 18 years and older). Impairments were found to be significantly higher amongst adults and the elderly than amongst the young (WHO 2011, p. 27). When data covers a complete population, the percentage would be expected to fall. When limited to adults, disability prevalence in the PPVR rises from 8.2 % to 14.97 %, close to the WHO estimate. Given that the *ProGres* data includes refugees of all ages, this could account for *slightly* lower percentages. However, the significantly low percentages suggest that even if the data for children were removed, the percentages would still remain incongruously low.

Although the PPVR was an exceptional verification exercise, it demonstrates the value of adopting an approach embracing internationally-recognised standards. The contrast between the *ProGres* and PPVR data suggests strongly that UNHCR's standard procedures may not be capturing all those with disabilities, even at the crudest of levels. We say this, acknowledging that disability is an inherently difficult concept to capture: it is occurs on a continuum and so cannot be accurately dichotomised. The Washington Group questions at least allow for a range of responses, encouraging responses where labelling serves to deter those who do not perceive their impairment as serious.

Procedures and Tools

UNHCR's *Registration Handbook* (2003) states that registration is "crucial for identifying those at risk and those who have special needs" (p. 7) and that persons with disabilities should be given priority for registration and interviews (p. 145). However, it provides no further guidance on how persons with disabilities or their assistance needs are to be identified during registration.

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[3] We have not obtained *ProGres* data from UNHCR Pakistan, so it was not possible to compare the data collected during the PPVR with standard *ProGres* data on disabilities in Pakistan. However, even if this were available to us, the majority of refugees in Pakistan are not registered with UNHCR, but rather in the Government of Pakistan's database (interview with UNHCR Islamabad, 9 April 2013) meaning that comparative value would be limited.

UNHCR's *Guidance* (published after the making of the CRPD) acknowledges that persons with disabilities may be overlooked, stating that it is "vital to introduce explicit procedures for identifying persons with disabilities" (2011b, p. 9). Later in this document the identification of children with disabilities not attending school is highlighted as essential to ensuring inclusive education (p. 13).

The rollout of UNHCR's *ProGres* has been a particularly valuable step in ensuring uniform and systematic identification and information sharing. At time of writing, the cloud-based program was being used in over 75 countries at registration and thereafter to record details about persons of concern (Microsoft 2015). The information can be shared between multiple UNHCR offices and between units within each office. UNHCR staff are provided with training and guidelines to help standardise the information recorded (UNHCR 2004).

Although *ProGres* provides the framework for data collection, the next challenge is in how the data is categorised by UNHCR. The database includes a section to record "special protection or assistance needs" for persons of concern. The way this operates is explained in the Registration Handbook. The "Disability" category within the area of special protection and assistance needs (coded as "DS") includes "physical, mental, intellectual or sensory impairments" (UNHCR 2009, p. 4).[4] There are further subcategories for different types of disabilities, set out in the table below (Table 16.1).

These subcategories were being used in both Malaysia and Uganda. Our concern is that they operate as labels for impairments that do not align directly with functionality and needs. There are no linked questions about the environment in which the person is living and the assistance available. Without this information the interviewer is not capturing a clear picture of the person's disability or needs. Moreover, the questions do not ensure that like cases are treated alike. When determining whether someone has a severe or moderate physical disability, some guidance is provided. However, the definitions do not capture the role that barriers and accommodation play in creating disability. In practice, similar or identical impairments can have very different effects depending on the accessibility of environment, so like impairments can be very dissimilar in actuality. For example, a person who is paraplegic but who has an appropriate wheelchair and who lives in an area with accessible buildings may be able to function independently. A person with similar impairments who does not have such assistance or who faces barriers in the built environment may be severely restricted. The impairments of the two people may be identical but their situations are different and result in different disabilities (Sario 2012, p. 22). UNHCR's guidance recommends "specialist/qualified personnel" to determine severity (UNHCR 2009, p. 5) which may create an evidentiary (and financial) burden on individuals that is difficult to meet.

UNHCR's guidance recommends that "staff should code each specific need separately, seeking the most appropriate category but avoid multiple vulnerability

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[4] It should be noted that earlier guidance in UNHCR's Registration Handbook mentions only a "Disabled" category for persons of concern who are "physically or mentally disabled" (UNHCR 2003: 169).

Table 16.1 UNHCR disability subcategories (UNHCR 2009: 5–6)

Subcategory	Description	Code
Visual impairment (including blindness)	Person who has a visual limitation from birth or resulting from illness, infection, injury or old age, which impacts daily life, may restrict independent movement, or require on-going treatment, special education or regular monitoring	DS-BD
Hearing impairment (including deafness)	Person who has a hearing limitation from birth or resulting from illness, infection, injury or old age, which impacts daily life, and may require regular treatment, special education, monitoring or maintenance of artificial hearing device. The person may be able to communicate through sign language	DS-DF
Physical disability – moderate	Person who has a physical impairment from birth or resulting from illness, injury, trauma or old age, which does not significantly limit the ability to function independently. This category may include mine victims and persons who lost fingers or limbs, which may be corrected with a prosthetic device	DS-PM
Physical disability – severe	Person who has a physical impairment from birth or resulting from illness, injury, trauma or old age, which severely restricts movement, significantly limits the ability to function independently or pursue an occupation, and/or requires assistance from a caregiver	DS-PS
Mental disability – moderate	Person who has a mental or intellectual impairment from birth or resulting from illness, injury, trauma or old age, which does not significantly limit the ability to function independently and interact, but may require special education, some monitoring and modest medication	DS-MM
Mental disability – severe	Person who has a mental or intellectual impairment from birth or resulting from illness, injury, trauma or old age, which significantly limits the ability to function independently or to pursue an occupation. It requires assistance from a caregiver, and may require medication and/or medical treatment	DS-MS
Speech impairment/disability	Person who is unable to speak clearly from birth or resulting from illness, injury, trauma or old age, which restricts or limits the ability to function independently, and may require speech therapy or medical intervention. The person may be able to communicate through sign language	DS-SD
Mental Illness	NB: Falls within the 'Serious medical condition' category (rather than the Disability category) and captures persons with a 'mental or psychological condition which impacts on daily functioning'	SM-MI

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codes for the same characteristic" (UNHCR 2009, p. 1). The response of officials in different countries suggested to us that it was unclear to staff whether this means that disability should be coded once only or whether there is scope for recording different types of disabilities, with multiple sub-categories for a single individual. In Uganda, an officer working at the PSN desk during a verification exercise told us that she believed she was expected to record only one disability code for each person. She recognised that in some cases persons do have multiple difficulties. She acknowledged that failing to note each disability undermines the supporting organisations' ability to provide appropriate assistance (interview, September 2013). We observed a similar tendency to record only one disability against persons of concern in Malaysia and Indonesia. In Malaysia, UNHCR's list included cases in which persons with cerebral palsy were identified simply as having a "mental disability", a categorisation that may or may not have been accurate. The list also included individuals recorded as having one impairment (paraplegia) who also had difficulty seeing and hearing. The less obvious impairments were not recorded.[5]

In Indonesia, disability was categorised as either mental or physical by UNHCR and its implementing partner CWS in the documents provided to us. A separate list was constructed for "medical" cases (interviews, UNHCR and CWS September 2012). Where disability or any other vulnerability was identified by UNHCR staff, these persons were referred to CWS for assessment and support.

In practice, UNHCR staff reported that questions asked during initial registration were often truncated because of time and resource constraints. In Indonesia staff reported collecting basic bio-data and asking only one open question about the person's protection claim during initial interviews. Questions regarding physical and mental wellbeing are only asked at Refugee Status Determination (RSD), potentially more than 12 months after initial contact (interview, UNHCR, September 2012). In Malaysia, disability may be identified through basic vulnerability assessments that are carried out during registration. However Sario (2012) writes that "there are no tools specifically designed for registration staff to detect disabilities… They rely primarily on both visual perceptions as well as the information provided by the individuals themselves" (p. 16).

In Malaysia, Indonesia and Uganda, some measures were in place to identify disability beyond registration. UNHCR's *Heightened Risk Identification Tool* (HRIT) was being used as a basis for needs assessments in Malaysia. The HRIT includes one question about whether the person has any "health problems, conditions or disabilities" (UNHCR 2010, p. 9). This provides a basic starting point for identifying impairments.

In Uganda, UNHCR was using the more recently developed *Resettlement Assessment Tool: Refugees with Disabilities* (UNHCR 2013a) as sensitisation for staff, encouraging them to include refugees with disabilities as potential candidates for resettlement. UNHCR and its partners were also undertaking participatory assessments in the refugee settlements, guided by UNHCR's *Age, Gender and Diversity Policy* (UNHCR 2011a).

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[5] Cognitive functioning of persons with cerebral palsy is a complex area, with varied ability reported: see Fennell and Dikel (2001) for a description.

In contrast, we noted significant developments in Jordan. There, UNHCR and its partners were developing and implementing the *Refugee Assistance Information System* (RAIS) and the *Vulnerability Assessment Framework* (VAF). These tools deliver a more comprehensive picture of the lived experience of refugees in Jordan, identifying particular needs and considering impairment or illness contextually. Individuals and families are assessed holistically, with home; family and social networks; income; and personal attributes all taken into account. The RAIS is implemented through systematic and repeated house-to-house visits. This means that there is less chance of someone falling through the cracks, and assessments can record changing circumstances. Special attention was also being paid to information-sharing between organisations. At the time of our research the several organisations assisting refugees were negotiating which information to share and how to synchronise their records. While presenting significant challenges, these measures demonstrated a more sophisticated approach to disability identification and assistance.

Relying on Self-Identification

Without detailed and systematic procedures for identifying disability it becomes important for individuals to step forward and offer information about themselves. This is especially the case for those with disabilities that are not easy to identify visually (Davis 2005, p. 153). However, as the UNHCR Registration Handbook (2003) observes, those with special needs are "often the least likely to come forward and make their needs known" (p. 7).

We found a number of factors that can impede self-identification. First, understandings of disability can vary across groups or cultures (see discussion in WHO 2011, chapter 1). This may mean that individuals may not believe that they have a disability, even though they may meet organisational definitions. This is borne out in the results of our questionnaire, as we discuss below (see box story). The discrepancy between responses to open-ended questions about disability and responses to questions about functionality were sometimes very marked.

Social stigma can operate to deter disclosure. This is especially so with many psychosocial conditions (Garand et al. 2009, p. 114), and may vary between groups. For example, we observed a particular stigma around epilepsy in Uganda. Sexual violence and the effects thereof was also something that elicited shame and a reluctance to disclose. Bureaucratic requirements for proving disability can also act as a barrier. This is a particular concern in development contexts where refugees may lack the financial or logistical means to access specialist services required to document or attest impairments. Those with disabilities are often the poorest members of a community. In a tragic "Catch-22", this can make them less likely to have the resources necessary to obtain the evidence they need to access services (including financial assistance). The final obstacle concerns access to information. We encountered individuals who expressed the view that disclosing their disability to refugee support organisations would be of little benefit to them. Indeed some seemed to believe that disclosure would have negative outcomes such as being rendered ineligible for consideration for resettlement.

It Matters What You Ask

By including an open-ended question in our survey tool, we were able to compare the variation in data gathered by different types of questioning. We observed that richer information could be obtained by asking functionality-based questions. In some cases, this included identifying issues not mentioned at all in response to the open-ended question. For example, the very first participant we interviewed in Malaysia was a man who was paraplegic and used a wheelchair. We could observe visually that he had functional difficulties that affected his mobility. However, it was not until we explicitly asked about his ability to see and hear that we discovered that he had trouble seeing and was completely deaf in one ear. He commented: "no one has ever asked me about that before" (participant interview, Malaysia, 2012).

An analysis of the data from 151 people interviewed in Malaysia showed a clear divergence in the amount of information collected using the initial open-ended question and that gained from asking the same participants the follow-up functionality questions. In total, 36 % of participants failed to mention in their initial description of their disability functional difficulties that were identified subsequently. Most commonly underreported were cognitive difficulties (difficulties remembering or concentrating), which were only reported initially about a third of the time. Nearly half of all reports of difficulties with seeing were only elicited through direct functionality questioning. This may be explained by other data collected during the research. In particular, refugee community leaders in Malaysia explained that sight tests had been carried out amongst some groups. Individual participants also reported these. However, even where participants were told that they had vision problems that warranted glasses, no glasses were provided. This may have contributed to a belief that there was little utility in reporting difficulties with sight.

It is clear that questioning style can play a significant role in determining the type and amount of information collected. The findings suggest that where disability is understood narrowly or where there is little expectation of assistance for certain difficulties, these are likely to go unidentified. This means that only those difficulties perceived as most urgent or most likely to garner assistance will be reported without specific prompting. In some locations, service providers argued that asking these specific questions could raise unrealistic expectations amongst beneficiaries about the types of assistance realistically available. This highlights the need for awareness-raising and training both for staff and refugee communities. Even if assistance cannot be provided at a specific point in time, knowledge of the difficulties faced by a particular group is important. First, in terms of the design of procedures, communication and facilities: if there are a large number of people who have difficulty seeing, design may need adjusting. Second, with competing demands on tight humanitarian budgets, data revealing these types of trends could lend valuable support to targeted funding campaigns.

Making Strides Towards Inclusive Identification

There are clear and significant challenges to identifying disability amongst displaced populations. However, UNHCR and its government and non-government partners are demonstrating their willingness to overcome the difficulties and to make their policies and practices more inclusive. This is demonstrated in a variety of measures we observed across the fieldwork locations.

First, we acknowledge again and stress the value of integrating the Washington Group questions into the PPVR in Pakistan. If a similar approach were to be adopted in registration and verification procedures in UNHCR's operations across the world, we are confident that the agency would be able to generate comprehensive data that aligns more closely with global standards. Such data would be particularly valuable for targeted funding appeals.

However, reforming registration and data collection is by no means sufficient on its own. Throughout our fieldwork, we observed examples of valuable initiatives that help to overcome barriers to identification. As mentioned above, even when asked specific questions, refugees can be reluctant to disclose some difficulties. The nature of displacement lends itself to many unusual if not unique challenges. These reinforce the importance of awareness raising and training, and the dissemination of information in suitable languages and formats. Empowering refugee communities and groups of refugees with disabilities may also create a valuable conduit for referrals.

Much is being done to improve the situation for refugees with disabilities. However, there is still a long way to go. Identifying impairments is not sufficient of itself, although it is a crucial first step. Only through understanding the lived experiences and context of persons with disabilities living in displacement can we can begin to design suitable responses, facilities and procedures. The identification of disability is thus essential to ensuring all refugees have equal access to protection and humanitarian assistance.

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Chapter 17

The Washington Group's Contribution to Disability Statistics and a Look to the Future

Jennifer H. Madans

When the National Center for Health Statistics was asked to organize the first meeting of what would be called the Washington Group on Disability Statistics we were happy to accept. Judging from what we knew about other City Groups, we expected that a modest number of countries would accept the invitation to attend and that the work plan would be targeted and specific. Our expectations were not borne out. At the first meeting of the Washington Group in February 2002 there were over 60 attendees representing National Statistical Offices from 35 countries, as well as Eurostat (coordinating the European Statistical System), the World Health Organization (WHO), the United Nations Children's Fund (UNICEF), the United Nations Statistical Division (UNSD), and International Organizations of people with disabilities. Membership in the Washington Group has continued to be much higher and more diverse than for any other City Group. Attendance at the first and subsequent meetings is a vivid illustration of the interest among national statistical organizations and their partners in improving the quality and availability of disability statistics. Throughout the existence of the Washington Group members have maintained an extremely high degree of interest in the topic and their dedication to the work has not faltered in the group's 13 year history.

The attendees at the first meeting were well aware that they had a difficult task ahead of them. Disability statistics that were available at the time of the meeting were based on different conceptualizations and definitions of disability resulting in disparate estimates of disability worldwide. However, the group was able to benefit from the extensive conceptual work that had been done which provided a framework that could guide the development of high quality statistics. The most recent was the publication of the WHO International Classification of Functioning, Disability and Health (ICF) which the group adopted as an organizing framework.

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