

Social Indicators Research Series 61

Barbara M. Altman *Editor*

International Measurement of Disability

Purpose, Method and Application
The Work of the Washington Group

 Springer

Social Indicators Research Series

Volume 61

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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

School, North East London Polytechnic (BSc Psychology), London School of Economics (MSc Sociology), and Hull University (PhD). In 1979 he was appointed principal social survey officer, Social Survey Division, Office of Population, Censuses and Surveys (later becoming the Office for National Statistics), and promoted in 2004 to deputy divisional director, Health and Care Division. During his time at OPCS/ONS, he masterminded the national survey of disability in the late 1980s. Thanks to Howard's survey design skills Britain now has a unique mental health survey program which no other country has surpassed. This program of national mental health surveys of adults, children, carers, prisoners, and homeless people (www.mentalhealthsurveys.co.uk/) has made major contributions to the improved understanding of prevalence, risk, and protective factors for different illnesses and has been used to inform national policy on mental health and disability. The standards he set for survey design have had a major international influence.

In 1991 Howard began development and pilot work in Leicestershire on survey methods for measuring the prevalence of psychosis in adults. This work which was implemented in a general survey of Great Britain in 1993, with repeat surveys in 2000 and 2007, made possible the first and only survey of autism in adults in the general population in 2007. In 2006 Howard left the civil service and took up his academic chair as professor of mental health and disability in the Department of Health Sciences, University of Leicester.

Internationally, Howard made substantial contributions to the work of the Washington Group. He presented ideas, wrote papers, and often played devil's advocate in the discussions and decision-making processes that accompanied the development of survey modules on disability. He was particularly concerned with the measurement of disability among children and actively participated in the workgroup on child functioning and disability. The results of that work are included in this volume. While his contributions to our work are sorely missed, his spirit lingers as we continue to consider "what Howard would have said" in our ongoing deliberations. We are fortunate to be able to publish one of his last papers in this volume.

After work was done, Howard, the consummate gentleman, was a bon vivant of sorts enjoying the wine, cuisine, and shopping opportunities offered by the countries hosting the Washington Group meetings. He joined in spirited conversation on a wide range of topics with his colleagues. Howard always was well read and witty with a warm heart and a twinkle in his eye. We will miss all this as much as we feel the loss of his intellectual contributions. He is survived by his wife, Sylvie, two stepdaughters, Sophie and Claire, of whom he was immensely proud, and his brother, Edwin.

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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.

He received his academic degrees from the University of Mumbai and professional qualifications from management institutes in India.

Alessandra Battisti is researcher at ISTAT (Italian Institute of Statistics) since 2000. Alessandra has a degree in Demography and Statistics Sciences from the University of Rome “La Sapienza,” 1998. Alessandra has collaborated on the project “Information System on Disability,” and she has developed considerable expertise in the management of surveys on different issues. Alessandra has also developed considerable expertise in the analysis of health data and indicators. At the international level, she has participated in many groups aimed to harmonize health statistics at the European level and in many international projects on disability (Washington Group on Disability Statistics, Budapest Initiative).

Alicia Bercovich is a demographer with a PhD in social sciences and MSc in mathematics. She was the coordinator of the Population Census Committee at the Brazilian Bureau of the Census (IBGE) for 13 years. She also coordinated the participation of Brazil in the Joint Population Census for the Mercosur countries, Bolivia and Chile. She was head of the Population Division in the 1990s and head of the Research and Data Preparation Division of the Census in the 1980s. She was a member of the Planning and Organization Commission for the Brazilian Census. She is a member of the Washington Group on Disability Statistics since its creation in 2001. Currently, she is an associate member of the Institute for Studies on Labor and Society (IETS). She has a wide experience in population censuses and large-scale surveys. She has published several papers, chapters, and reports on demographic topics: demographic discontinuities, disability, population structure, the youth wave and its impact on the labor market, and the demography of violence.

Emmanuelle Cambois is a senior researcher at the French demographic institute INED (Institut national d'études démographiques) and member of the research unit on “mortality, health, and epidemiology.” Her research is in the field of public health and the population health measurement, with a specific interest to disparities, more particularly looking at social/gender health and mortality inequalities. Her current research is on the disablement process to identify mechanisms and factors leading from chronic diseases to functional limitation and activity restrictions, with national and European databases, on gender and health differentials and educational gaps in disability across Europe. She is in charge of the health expectancy indicators for France. She is involved in various working groups on measurement of health and disability on population-based survey and contribute to effort for an international harmonization of population health information.

Mary Chamie, Ph.D. private consultant with Population Associates, Inc., is the former assistant director of the United Nations Statistics Division and Chief of Branch of Demographic and Social Statistics. She coordinated the development of internationally agreed standards and methods for the collection of official demographic and social statistics through the use of population and housing censuses,

national household surveys, and civil registration systems. She has worked extensively in the area of statistical classifications, with special attention to human functioning and disability. Dr. Chamie developed the international statistical program on disability for the United Nations Statistics Division and since her retirement from the United Nations continues to lecture and consult on this subject matter. She has published numerous reports and articles on disability in scientific journals under her own name and has also prepared a series of books and reports on human functioning and disability under the authorship of the United Nations.

Roberta Crialesi is the director of research (*dirigente di ricerca*) for Health and Social Care Statistics at ISTAT, the National Institute of Statistics in Italy. Roberta has a bachelor's degree in demography and statistics sciences (with focus on methodology and epidemiology) from the Università degli Studi di Roma "La Sapienza," 1987. She has extensive experience in the development of social statistics involving research, analysis, survey methodology, and data collection in the main domains of health, disability, and health care. Roberta is a member of several national and international working groups (socioeconomic inequalities in morbidity and mortality: a comparative study; EURO REVES; European Disability Measurements (EDM) di Eurostat; Washington Group on Disability Measurement (WG); Eurostat Working Group on Public Health; Eurostat Morbidity Statistics Development Group (MSDG); OECD Project "Costs of care for elderly populations"). Roberta is the author of several publications in a variety of fields including social care, health and disability, hospitalization, and cause of death.

Mary Crock is professor of public law at the University of Sydney. She has worked in the area of immigration and refugee law since 1985. An accredited specialist in immigration law, she has been chief examiner/head assessor in various specialist accreditation programs in immigration law across Australia since 1994. In 1989, she helped to establish a community legal center, known now as the Refugee and Immigration Law Centre Inc. (Vic). Author of 11 books and reports and over 60 articles, she has made issues around vulnerable migrants (especially children and persons with disabilities) a special focus in her research. Mary was the lead investigator in the AusAID-funded "Protection of Refugees with Disabilities" Project (2012–2015). Her projects on refugee children include the *Seeking Asylum Alone* and *Small Mercies, Big Futures* projects funded through the Australian Research Council and the MacArthur Foundation.

Elena De Palma is senior researcher at ISTAT (Italian Institute of Statistics) since 2001. She is currently working at the implementation of a "Statistical Information System on Disability," whose main aim is to set up a comprehensive statistical database, to be used for planning and monitoring of policies on disability. Elena has also experience in survey design on disability, cognitive tests (conducted for Washington Group, Eurostat, Task Force WHO/Eurostat/UNECE), and international projects on disability (European Disability Measurement (EDM) Project, Washington Group on Disability Statistics, Budapest Initiative). Elena has a degree in psychology (1989)

and a master's degree in "data sources, methods and tools for social research" (2005)—both from the University of Rome "La Sapienza"—plus a master's degree in "human resources management" (2006) from the Third University of Rome. She has been a junior fellow within the "International Philanthropy Fellowship Program" at the Johns Hopkins University (USA, 1995–1996), where she completed also the "training of trainers for non-profit organizations" program (1996–1997).

Jessamyn O. Encarnacion is the interim assistant national statistician of the social sector statistics services of the Philippine Statistics Authority. She completed her bachelor's degree in statistics at the University of the Philippines and master's degree in public policy at Hitotsubashi University in Japan. She has earlier served as director of the Social Statistics Office of the Philippines National Statistical Coordination Board. She also served as temporary regional advisor on Statistics at the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) from 2013 to 2014. She has written/presented/published more than 70 papers/articles and has served as resource person/speaker in various local and international seminars/workshops, trainings, and forums on poverty statistics, gender statistics, millennium development goals (MDG) indicators, happiness index, child development index, and middle-income class. She is also a member of various statistical interagency and technical committees (IACs/TCs) in the Philippine statistical system and at the international level. In the Philippines, she served as member of IACs/TCs on population and housing, health and nutrition, education, poverty, gender and development, and labor and productivity statistics. At the international level, she serves as a member of the UNESCAP technical advisory group on population and social statistics. She has also participated in various international expert group meetings such as the U.N. Interagency and Expert Group on Gender Statistics and the U.N. Expert Group Meetings on the MDG Indicators.

Cordell Golden is a health statistician at the National Center for Health Statistics (NCHS). He earned his degree in sociology from the University of Maryland at College Park. His career at the NCHS began as a student intern in 1995. Since then, he has worked on an array of projects related to the collection and dissemination of NCHS's data products. He currently works in the Special Projects Branch linking NCHS survey data with administrative records, specializing in Medicare and Medicaid enrollment and claims data. In addition to his role with the NCHS Record Linkage Program, he also serves as the primary point of contact for the Secretariat of the Washington Group (WG), an international group working on disability measurement under the auspices of the United Nations (UN). The WG Secretariat serves as the central communications contact for the full WG membership and subcommittees representing nearly 120 national statistical offices, and collaborators from U.N. agencies, international disability, and other organizations.

Judith Heumann is an internationally recognized leader in the disability community and a lifelong civil rights advocate for disadvantaged people. In June 2010, she was appointed to her current position as the special advisor for International

Disability Rights at the US Department of State. As the special advisor, Heumann leads the department efforts to encourage and assist foreign governments and civil society organizations to increase their commitment and capacity to protect the rights, and ensure the inclusion and full participation of, persons with disabilities. She served as the World Bank's first advisor on Disability and Development and served in the Clinton Administration as the assistant secretary for the Office of Special Education and Rehabilitative Services in the Department of Education from 1993 to 2001. She previously worked with numerous disability rights organizations including co-founding the World Institute on Disability and the Center for Independent Living in Berkeley, California.

Carol Jagger is the AXA Professor of Epidemiology of Ageing at Newcastle University. Her research spans demography and epidemiology with a focus on mental and physical functioning in aging, and she is the leading UK researcher on healthy life expectancy. Carol has been involved in the design or analysis of most major UK cohort studies of aging, in particular the MRC Cognitive Function and Ageing Study and the Newcastle 85+ study. Within Europe she sits on the Scientific Advisory Board of the Joint Programming Initiative "More Years, Better Lives" and the EU Task Force to improve the Healthy Life Years indicator. She sits on the Steering Group of REVES, the International Network on Health Expectancy and the Disability Process, and has been co-investigator on the majority of Euro-REVES projects including the European Health Expectancy Monitoring Unit (EHEMU) and the Joint Action Healthy Life Years (JA EHLEIS). Nationally she has advised the Office for National Statistics and the Scottish Public Health Observatory on Healthy Life Expectancy and has provided evidence to the House of Lords report "Ready for Ageing," government Works and Pensions Committee, the Health Committee, and the Scottish Finance Committee. Carol is a chartered scientist, a fellow of the Faculty of Public Health, and an honorary fellow of the Institute and Faculty of Actuaries on whose Mortality Research Steering Committee she sits.

Mitchell Loeb is a health scientist in the Office of Analysis and Epidemiology at the National Center for Health Statistics, Centers for Disease Control and Prevention. In addition to his work in the U.S.A., he has carried out epidemiologic research in Canada, Norway, and several developing countries in sub-Saharan Africa and Southeast Asia. He is currently concentrating on the analysis of disability data from various U.S. health surveys and continues his international commitment to the development of culturally comparable disability measures through his work with the Washington Group on Disability Statistics (WG). He routinely trains statisticians from National Statistical Offices around the world in understanding and adapting the WG approach to disability measurement for use in their own national censuses and surveys.

Jennifer H. Madans, Ph.D. has been the associate director for science, National Center for Health Statistics, since May 1996, and is responsible for the overall plan and development of NCHS's data collection and analysis programs. Since Dr.

Madans joined the center, she has concentrated her research efforts on data collection methodology, measurement of health and functioning, and health services research. She has directed two national longitudinal studies (NHANES I Epidemiologic Follow-up Study and the National Nursing Home Follow-up Study) as well as the redesign of the National Health Interview Survey questionnaire, and she was one of the designers of the DHHS Survey Integration Plan. She is a founding member of two U.N.-sponsored initiatives to develop internationally comparable measures of disability and health, the Washington Group on Disability Statistics and the Budapest Initiative on the Measurement of Health Status, and has chaired the steering committee of both groups since their inception. Dr. Madans is a graduate of Bard College (BA) and the University of Michigan (MA and PhD in Sociology). She completed a postdoctoral fellowship in the Department of Epidemiology and Public Health at Yale University. She has served as an adjunct associate professor in the Division of Biostatistics and Epidemiology, Department of Community and Family Medicine, Georgetown University School of Medicine and in the Department of Demography at Georgetown. She is a fellow of the American Statistical Association and an elected member of the International Statistical Institute and served as a vice-president of the International Association of Official Statistics.

Howard Meltzer was professor of Mental Health and Disability at the Department of Health Sciences, University of Leicester from 2006 to 2013. Previously, he spent over 25 years at the Office for National Statistics (ONS) in the UK specializing in epidemiological surveys of disability and mental health among adults and children and latterly as Deputy Divisional Director of the Health and Care Division at ONS. He also acted as a consultant to various international and supranational organizations on the collection of disability and mental health statistics.

Kristen Miller, Ph.D. senior methodologist, directs the Question Design Research Laboratory within the National Center for Health Statistics (NCHS), CDC. Her writings have focused on question comparability, including question design and equivalence for lower SES respondents and the improvement of evaluation methods for cross-cultural and cross-national testing studies. Dr. Miller holds a PhD in Sociology from the University of Delaware.

Daniel Mont is an international expert in disability and development, specializing in disability measurement issues and monitoring and evaluating inclusive development programs. He has worked with many governments and international agencies on indicator development and the implementation of more inclusive social protection, anti-poverty, and education programs, and has published widely on issues pertaining to disability and the relation of disability to poverty. Currently he is an honorary senior research associate at the Leonard Cheshire Disability and Inclusive Development Centre at University College London. Prior to that, he was a senior economist at the World Bank for 10 years. While at the World Bank, he was also the chair of the Analytical Working Group of the U.N. Statistical Commission's Washington Group on Disability Statistics. He also was a principal analyst with the

U.S. Congressional Budget Office and an assistant professor at Cornell University. He is a member of the National Academy of Social Insurance and was a recipient of a Joseph P. Kennedy Public Policy Fellowship. He received his PhD in economics from the University of Wisconsin-Madison and his BA from Swarthmore College.

Andres Montes is population affairs officer at the United Nations Economic and Social Commission for Asia and the Pacific. Prior to this, he worked as a statistics specialist at the United Nations Development Programme's Human Development Report Office. He also worked at the Office of the Chief Economist of the Inter-American Development Bank, at the Office of the President of Mexico as Director of Statistics Center of the Presidency, and at Mexico's Ministry of Social Development as Director of Foreign Affairs. Mr. Montes holds a master's degree in public policy administration for the London School of Economics and is a PhD candidate in migration studies at the University College London. He is an expert on public policy planning, social development, disability, and international migration.

Wilma Nusselder, Ph.D. is an assistant professor at the Department of Public Health, Erasmus MC. She is a demographer with long research experience working at the intersection between public health and demography. Her main interest is in population health, including health expectancy (simulations), trajectories and predictors of disability, and (old age) mortality and health impact assessment. She has extensive experience in life table analysis, including the Sullivan and Multi-State method, in analysis of micro-level (longitudinal) data, and in health impact assessment using the DYNAMO-HIA tool. She has (co)authored about 60 papers on a wide range of topics, including studies on health expectancy trends and gaps, health expectancy method development and simulation studies. She has developed and disseminated tools that increase the public health relevance of health expectancy. She advises Statistics Netherlands (CBS), the National Institute of Public Health, and the Environment (RIVM) on health and life expectancy issues. She has been a member of REVES, the International Network on Health Expectancy and the Disability Process, since 1993, and has been co-investigator of several Euro-REVES projects including the European Health Expectancy Monitoring Unit (EHEMU). She is a core member of the Joint Action on EHLEIS (JA EHLEIS).

Elizabeth K. Rasch is a Staff Scientist and Chief of the Epidemiology and Biostatistics Section in the Rehabilitation Medicine Department at NIH. She received her BS in Physical Therapy (PT) from the University of Delaware, MS in PT from the University of Southern California, and PhD in Rehabilitation Science with a concentration in Epidemiology from the University of Maryland, Baltimore. As Section Chief, she currently supports major projects involving multiple collaborations with academic institutions as well as other Federal agencies, and oversees the work of 15 scientists and fellows. Her research is directed toward promoting the health, participation, and full inclusion of people with disabilities in family and community life by informing and impacting health services, programs, and policies. More specifically, she studies the development and consequences of secondary conditions among adults with disabilities, health care delivery related to these

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.

Introduction

In 2015 as this book is written, the Washington City Group on Disability Statistics (WG) will have been in existence for 13 years having had their first meeting in February 2002. It was called into being at the end of a large international meeting on the status of disability statistics which was organized by the United Nations Statistical Division (UNSD). Over those 13 years, 130 countries have been involved with the group's work, at one point or another (see Chap. 3). Recently it became obvious to those involved in the work that we had been so busy working on improving disability measurement cross-nationally that a lot of the details of the work associated with the focus on developing internationally comparable measurement of disability were not getting disseminated as widely as they should. Although the work in progress and the presentations from each meeting are disseminated through the United Nations and the National Center for Health Statistics (NCHS) websites (http://www.cdc.gov/nchs/washington_group.htm) and a report is made to the United Nations Statistical Commission annually, the finished products such as testing protocols, new methodologies, country experiences, and results from use of questions in national censuses have not been distributed widely, particularly in research literature. Therefore, in order to provide more detailed information to the statistical and research communities and to find another source to inform the international public, particularly the international population with disabilities and organizations working with populations with disability, the focus of this volume is to provide details about the products and ongoing activities of the Washington Group. We have included finished products, national experiences, methodology advances, and first results from census uses of questions developed by the WG, and finally we provide information on future plans of the Washington Group.

In the context of the Convention on the Rights of Persons with Disabilities (CRPD) and the Millennium Development Goals (MDGs), the measurement of disability in national censuses and surveys is more important than ever. Understanding the age, gender, participation and locations of persons with disabilities, and the types of functional limitations they experience will help tremendously with the promotion and protection of the full and equal enjoyment of human rights, dignity, and freedoms for all persons with physical, mental, intellectual, or sensory impairments

throughout the world. Measurement or counting through censuses and/or surveys can contribute immeasurably to policy development and monitoring improvement in regional, national, and international promotion of equalization of opportunities for persons with disabilities. Hopefully this volume will act as a stimulus for the inclusion of disability measurement in censuses and surveys by all Member States of the United Nations and encourage the production and dissemination of information about persons with disability by the Member States. In 2003 the United Nations Statistical Commission emphasized the need to insure the collection of internationally comparable statistics on disability and approved the collection of disability statistics on a regular basis through the United Nations Demographic Yearbook system using the Human Functioning and Disability Questionnaire developed by UNSD for this purpose. The Principles and Recommendations for Population and Housing Censuses, Revision 2, the current revision underway, not only recommend the inclusion of disability characteristics as a census topic, but the incorporation of the Washington Group Short Set as an example of an acceptable set of questions (United Nations, 2015). It is important that Member States who have not yet begun collecting data about disability in their nations begin to do so and that all Member States contribute this information to the Demographic Yearbook on a regular basis so that the CRPD and MDGs have this information available for their activities.

The Washington Group is trying to improve the measurement process so that Member States can address the needs of their populations with disability. As the authors of the Chap. 17 indicate, the Washington Group “tackles contentious issues related to complex matters of definitions, concepts, classifications, statistical methods, tabulation and analysis plans and policy relevance of data” which makes the transparency of the work and the decision-making processes even more important (Chap. 17). An earlier volume described the status of disability measurement cross-nationally prior to the founding meeting along with descriptions of the early work of the WG (Altman and Barnartt 2006); however, much has happened in the last 9–10 years and hopefully this volume will begin to document the continuing progress that has been made.

This volume is divided into four sections: (1) Origin of the Washington Group and Issues in Disability Data Collection; (2) Census/Survey Questions: Purpose, Process and Testing; (3) Moving Forward: Extended Question Sets and Methodological Advances; and (4) Conclusions: Outcomes and Place of the Washington Group Measures in International Data. Those sections give a little background on the origins of the Washington Group and how it organizes and implements the work it takes on, and the many problems associated with measurement of disability. It also includes the development of purpose and highlights the extensive testing processes and protocols that have developed providing an interesting example of the testing process that utilized the cooperation of three South American countries. It highlights the work that has taken place over the more recent period providing both a rationale for developing questions that focus on children and detailing that process and also addressing the issue of measurement of the environmental context which will be a future activity. Finally, in the last section, there is documentation of statistics using the WG questions in censuses from the recent

census cycle, an example of one national experience through their involvement with the Washington Group and two examinations of the Washington Group's contribution to disability statistics. There is also a significant chapter that indicates the use and importance of the WG questions for assessing the disability population among recent refugees so that their needs can be addressed.

Highlights of the Parts

Part I: Origin of the Washington Group and Issues in Disability Data Collection

Chapter 1 introduces the conceptualization of City Groups as defined by the United Nations and provides the background of the creation of the Washington City Group elaborating the early decisions that have guided the work of the group since its inception. Particularly informative for those who have not followed the work of the Washington Group or who may have been unfamiliar with its existence, this chapter provides concise descriptions of the early implementation of the Washington Group work and focus on providing culturally comparable measures of disability for cross-national use.

Chapter 2 explores the challenges that can make cross-national measurement of disability very difficult and provides the reader with a much greater understanding of the more common as well as some less common problems that can occur when trying to collect data on this subject. How loss of function is recognized, defined, and adapted to cross-culturally can be very different and seriously impact its measurement. Factors that create these differences can include the cultural conceptualization of disability and the complexity of the various types of disability. Its measurement can also be influenced by the context of surveys, potential sources of error in surveys, and how these are managed based on a growing body of evidence testing disability questions in different social, cultural, and geographic contexts. Dr. Schneider's chapter examines the broad range of issues that can affect measurement and provides the reader with an effective picture of the context in which the Washington Group seeks to do their work highlighting some of the very basic problems they need to address.

In the last chapter of Part I, Mr. Golden gives substantial background information on the involvement of nations, DPOs, and other organizations in the activities of the Washington Group, the development and implementation of the governance process for the group, and other details about the accomplishment of the Washington Group over its period of existence to this point. Of particular note is the documentation of the process of developing the short set of questions and the accompanying five documents on methodological guidance developed to facilitate implementation among all the population subgroups who will want to use the data. Chapter 3 also provides information on the development of the extended set, the testing partnership

with the UN Economic and Social Commission for Asia and the Pacific, the development of other extended sets, and the recent development of the UNICEF/WG Module on child functioning and disability. Finally, the chapter documents the supporting technical assistance workshops in countries around the world which has turned out to be an ongoing activity of the WG that was not anticipated at its formation but one that has taken on major importance as the use of WG questions has expanded.

Part II: Census/Survey Questions: Purpose, Process and Testing

Chapter 4 provides an in-depth discussion of the process of developing the primary purpose for which disability measurement is to be constructed. In the context of the World Programme of Action Concerning Disabled Person, the equalization of opportunity approach had taken center stage, and it was important to incorporate that perspective on disability in order to create measures that would move away from the disease/impairment focus that had held sway for so long. Using the newly formatted language of the International Classification of Disability, Functioning and Health (ICF), along with other tools including a matrix to explore the variety of possible underlying purposes for measurement, the Washington Group was able to establish a very firm foundation for its work. By focusing on the equalization of opportunity factor, the WG oriented measurement to identifying persons who are at greater risk than the general population of experiencing restrictions in performing specific tasks or participating in specific role activities due to functioning limitations associated with health characteristics rather than just identifying those who experience a particular participation restriction. In that way they have provided measurement that can act as a social demographic and actually identify equalization of opportunity when data is analyzed appropriately.

A very important element in developing questions to identify persons with disability is the testing of those questions to assure their effectiveness and validity. Chapter 5 is a complete description of the testing that has taken place to this point on all the questions that have been developed by the Washington Group thus far. The chapter documents the difficulties and successes in that process as well as some of the analysis of the data that resulted from the testing. As part of this process, cognitive testing, a technique that is used extensively in the United States has been taught in many countries and a software program for tracking the cognitive testing process has been developed and used to monitor the international testing that has taken place. The testing of questions continues as this volume goes to press and will continue to produce innovations in the testing methodology along with the final product of improved and internationally comparable questions.

The last chapter in this second section provides insight into the cooperation among countries that has been stimulated by the testing of Washington Group questions. Dr. Bercovich's Chap. 6 describes the coordination of the testing of the short set of questions among Brazil, Argentina, Chile, Paraguay, and Uruguay. The

experiences of joint tests in the border areas with observers from most South American countries and Mexico were fruitful and allowed the discovery of similarities and differences among the countries, facilitating question adjustment particularly related to question interpretation and cultural differences.

Part III: Moving Forward: Extended Question Sets and Methodological Advances

The third section of the volume includes many of the additional activities that the Washington Group has accomplished over and above developing and approving a short set of questions to be used in censuses. Chapter 7 describes the development, testing, and approval of the first extended set of questions for use in surveys to broaden the measurement of functioning initiated with the short set. Other basic activity and body function domains could not all be covered adequately by a single question and were thus not included in the short set. These include upper body functioning and the domains of pain, fatigue, and affect (anxiety and depression). All were deemed important for inclusion in the extended set of questions on functioning. Once tested and approved, analyses of the domain specific data and testing of various analytic algorithms have been carried out by the WG to determine the best possible analytic approach to create summary measures for each domain. A few of those domains are examined in detail in Chap. 7.

Chapter 8 describes the cognitive question evaluation and field testing of the extended set that was undertaken jointly by the Washington Group (WG) and the United Nations Economic and Social Commission of the Asia and the Pacific (ESCAP). The WG/ESCAP project aimed to a) raise awareness through regional and in-country workshops, b) develop standards for cognitive and field testing of questions and analyses, c) improve national capacity, and d) improve knowledge management. The participating countries were encouraged and funded to attend the 8th WG meeting held in Manila, Philippines, in 2008, the 9th WG meeting in Dar-es-Salaam, Tanzania, in 2009, and the 10th WG meeting in Luxembourg in 2010. The project afforded an opportunity to learn and improve methods for question evaluation and highlight the benefits of implementing a coordinated testing process and the project allowed for other issues to be raised and documented. Most importantly for the WG, the project generated extensive validation data for the WG's extended set questions.

The next two chapters, Chaps. 9 and 10, reflect the beginning of the work with UNICEF on the development of disability questions specifically for children. In Chap. 9, Dr. Meltzer makes the case for the relative dearth of information about disability among children and at the same time how important such information is for policy development and planning. He outlines the many challenges in conducting such surveys among children noting the interaction of conceptual, methodological, and operational difficulties that create barriers to the implementation of child

disability surveys. While some national surveys have been carried out using different approaches, identifying the prevalence of disability among children has both health and economic advantages. Without such surveys, the burden that society puts on disabled children and the negative attitudes that they may face—primarily social exclusion and discrimination—will prevail.

In Chap. 10, the authors describe the process that has been taken by the Washington Group's Children's Workgroup to develop and test questions to address childhood disability cross-culturally. As of the publication of this chapter, the WG-UNICEF survey module on child functioning and disability is still under development, as is a companion manual that will fully annotate its technical properties and provide methodological guidance for its implementation. When finalized, the implementation of this module will aid in the production of comparable data cross-nationally that, in combination with other data collected on education, for example, can be used to determine the degree to which children and youth with disabilities are able to participate in society to the same degree as children and youth without disabilities. These data will support a country's ability to monitor and assess compliance with the U.N. Conventions and, over time, its progress toward the full implementation of the rights of children with disability. The WG meeting in October 2015 in Copenhagen, Denmark, should see the approval of the children's question set as officially endorsed by the Washington Group for use in national censuses or surveys. Full information on the children's questions should be available from the NCHS website by spring of 2016.

Continuing with the emphasis on children, Chap. 11 describes early testing of the Children's Question Set in India. Using a purposive sample of 72 respondents and recognized cognitive testing methodology, the testing took place in Mumbai. The team employed a consensus means of translation whereby groups discussed translation into Hindi and arrived at a consensus that was agreed had captured the true meaning of the question. After the initial translation, the questionnaire was reviewed by the participants prior to being tested, and it was decided to further adapt the translation into the local dialect of Hindi. A series of practice sessions also highlighted various issues such as an inability to accurately understand some questions due to the lack of concrete examples or examples that were alien to Indian culture. This resulted in second round adaptations. Other issues were identified as well, but for the most part, the cognitive interviewing study proved to be a successful endeavor in that it provided important insight into the performance of the child disability module, and a research team was trained on cognitive testing procedures and use of the Q-Notes package. The team conducted a large number of interviews and was able to determine whether the questions worked as intended.

Chapter 12 focuses on the foundational work for developing measures on environment which is another measurement area the Washington Group is pursuing. While surveys and censuses have identified individuals with some impairments for quite some time in order to track different aspects of their existence, age, gender, living arrangements, school attendance, ability to work, and in some instances their location in institutions, the impact of environment on that experience has been generally ignored because we have not had adequate measures of the environment.

Many of the theoretical approaches to the environmental impact associated with disability organize the environmental factors at two different levels, the individual and the societal levels, and thus this chapter examines both areas and also the various sources of environmental measurement that have been created to this point. The chapter also very carefully explores the cross-cultural problems associated with establishing environmental measures because of the many different ways environments are structured in different cultures. Based on extensive work done by rehabilitation professionals and others interested in the impact of environment on participation, the authors identify three approaches to measurement and develop a hierarchy of participation to serve as a basis for further work on developing cross-cultural measures of environment to enrich our understanding of disability.

Finally in Chap. 13, another important issue, the inclusion or exclusion of institutionalized persons in estimates of disability prevalence, is confronted. This is a methodological problem that the Washington Group has been concerned about and seeks to address. In fact, collecting information on both sections of the population, those in private households and those in nursing homes and other forms of housing for persons who need assistance, is difficult and rarely done in one survey. Private households are usually considered to be representative of the population as a whole and a sufficient representation of the population. However, a non-negligible share of the population with disabilities, particularly serious disabilities, lives outside private households. Not accounting for them leads to an underestimation of the level of disability in the population. In this chapter, the scale of this underestimation and the extent to which assumptions can be used to correct estimates are examined.

Part IV: Conclusions: Outcomes and Place of the Washington Group Measures in International Data

Part IV provides some insight into what the Washington Group has accomplished in its 14 years of existence with an example of the experience of an individual country, and with the very first analysis of actual counting of persons with disabilities in the first use of the WG questions in international censuses. The importance of what has also been accomplished in the collaboration among many countries and the many behind the scenes activities are also examined from two different perspectives.

Chapter 14 documents the involvement of the statistical branch of the Government of the Philippines from the beginning of the Washington Group in 2002. Virola Romulo, in his role as Secretary-General of the National Statistical Coordination Board of the Philippines from 1991 until his retirement in July 2012, and Jessamyn Encarnacion who is currently the interim assistant national statistician of the social sector statistics services of the Philippine Statistics Authority, are in a key position to document the impact of the Washington Group work on one of the countries that have actively participated in WG work from the beginning. This chapter presents the development and improvement of disability statistics in the Philippines, in the

context of the efforts of the WG. Providing the background of the Philippine interest in development and use of disability statistics, this chapter provides appreciation for and examples of how the WG work contributed to the Philippine intentions in this area noting particularly the technical support and the regional meetings that the Philippine NSO were able to attend. The improved measurement of disability in the Philippines is definitely acknowledged with specific examples of the developmental and statistical capacity building activities provided.

The production of cross-nationally comparable data on disability has been one of the primary goals of the Washington Group since its inception in 2002. Chapter 15 is the first compilation of cross-national data using the Washington Group Census short set measure in either the 2010 census or a recent survey. About 30 countries indicated to the WG that they intended to use the short set of questions on this current (2010) round of censuses. The WG saw this as an opportunity to follow up on the implementation of the questions in practice and sought to collect information from all countries that were using the WG short set of questions (or not) to catalog the actual questions and response options used, the year of data collection and the venue (census or survey), and the prevalence of disability derived. Approximately 120 countries are annually requested to report back to the WG on national activities that relate to disability statistics. Responses are voluntary—and in this most recent request, responses were received from 65 countries. Although countries have reported disparate disability prevalence rates, with few exceptions, those that use the WG *as intended* have reported disability prevalence rates that are comparable. The information and data that are presented in this chapter indicate that WG efforts in fostering international cooperation in the area of health and disability statistics has begun to bear fruit through the development and implementation of a short set of general disability measures suitable for censuses. The data has the potential to provide the evidence that can be used to address whether countries have been successful, or the degree of their success, in meeting the general principles outlined in the Convention (Article 3) including the achievement of equalization of opportunity and accessibility.

The next chapter discusses the pragmatic use of the Washington Group short set of questions that was not originally anticipated by the Washington Group when the work was mapped out, but one that is obviously essential for the well-being of a population with disability. In Chapter 16 the authors reflect on the use of the Washington Group's approach to identifying disabilities in refugees from many areas that have been hit by war. The chapter reports on fieldwork funded by the Australian government and conducted by researchers from the University of Sydney exploring the adequacy of systems used by United Nations High Commission for Refugees (UNHCR) and other agencies to identify disabilities in populations of displaced persons. Humanitarian agencies have relied heavily on either self-reporting by persons with disabilities or on the visual identification of impairments. The inadequacies of this approach are apparent in agency records showing disability rates in refugee populations that fall way below the average suggested by the World Health Organization in its Global Disabilities Report. The authors found that the HCR was accurate in describing persons with disabilities as the invisible and

forgotten refugees and provided dramatically different results achieved when versions of the Washington Group questions were used in a verification exercise in Pakistan. Using a similar approach adopted in refugee registration procedures across the world would generate data that aligns more closely with global standards and produce data on disabilities that is critical to developing accessible programs.

Chapter 17 discusses Washington Group products, implementation of WG data tools, and future activities. The primary aim of the work of the Washington Group was to institutionalize the collection of high-quality disability statistics as collected by national statistical offices. While the development of data tools is still ongoing, it has been an added benefit that the products already produced can be used across governmental agencies, NGOs, international organizations, and researchers. As the activities of the WG get more challenging such as development of environmental measures and the increased need for technical assistance to countries, the Australian Department of Foreign Affairs and Trade is working closely with the UN's Washington Group on Disability Statistics to establish a new 4-year partnership that will support the implementation of the questions developed by the Washington Group in national statistical systems and provide analysis of the data that are produced and dissemination of the information to inform policies and programs to improve the lives of persons with disabilities.

Finally, Chapter 18 asks the question “What if there were no Washington City Group”? In this chapter, the authors, who represent the area of disability statistics and disability policy, look at the accomplishments and the potential of the Washington Group from both the statistical and activists' perspectives. They note the changed approach to definitions and conceptualizations of disability as compared with the past, implemented by the World Health Organization Classification of Human Functioning and Disability (ICF), and the increasing use of disability as a population characteristic. They indicate these shifts in knowledge, attitude, and practices regarding definitions, concepts, and classifications of functioning and disability have far-reaching consequences, socially, economically, and politically. Since statistical methodology and statistics must keep up with these sweeping changes, the Washington City Group was formed by the Statistical Commission at an opportune time to tackle these challenging issues. Like measures of poverty or race, measurement of disability succeeds when it reflects the current state of affairs accurately, both in the present and to the extent possible, over time creating an enormous challenge for statisticians. Will the Washington City Group succeed in setting international standards for data collection and analysis of disability under these constantly shifting conditions and at times controversial situations? The authors have examined the activity of the Washington Group and address that question based on that activity—but I don't want to give away the ending.

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