



# Centre of Excellence on Data for Children with Disabilities

*Fostering inclusion through data*

## Mission

To enhance the ability of stakeholders to make timely and data-driven decisions impacting children with disabilities

## Scope

Data on children with disabilities and their families, using impact and programme-level data

## Focus

Support the expansion of inclusive methodologies and the collection, analysis and dissemination of data through the principles of partnership, innovation and inclusivity

## Purpose

Millions of children with disabilities around the world continue to be left behind, despite the near-universal ratification of the Convention on the Rights of the Child, the call for action embedded in the Convention on the Rights of Persons with Disabilities, and the clear mandate set by the Sustainable Development Goals. All too often, these children are ignored or neglected due to limited data. When absent from official statistics, children and adults with disabilities remain politically and socially 'invisible', increasing their marginalization and exposure to rights violations.

While most countries have produced national estimates on the proportion of persons with disabilities, the quality, relevance and usability of such data are questionable due to outdated methodologies and disparate measurement approaches. Recent years, however, have seen a resurgence of interest in generating reliable and internationally comparable disability data. This has led to the development of new tools for data collection and a substantial rise in the availability of disability data, fostering increased data analysis and knowledge-generation.

To capitalize on the current momentum, UNICEF launched the Centre of Excellence on Data for Children with Disabilities in November 2021. The Centre will help fill large data gaps and meet the growing need for coordination, quality oversight and technical expertise in the field. It will support a range of activities to build the capacity of data producers and data users, facilitate the development of new methodologies and tools, and support data collection, analysis, interpretation and use, along with knowledge-generation, emphasizing inclusivity at every stage. In addition, the Centre will support data users in applying data for effective policymaking and programming. It will also provide best practices to ensure that data collection, data use and data-driven policymaking are disability inclusive.

## Priorities

Increase availability of inclusive methodologies

Support inclusive data collection

Fill gaps in data analysis and knowledge

Improve data access

Share knowledge

Use data to support advocacy and policy change

To achieve the priorities listed above, work over the next four years will focus on four main areas and related activities:

### Methodological development

- Identify best practices on inclusive sampling methods
- Identify innovative approaches for inclusive data collection and generate recommendations on how to implement them
- Develop tools to support the updating of the Child Functioning and Inclusive Education Modules and the standardization of their use
- Develop new data collection tools on access to and utilization of services.

### Support for data collection

- Support the implementation of surveys to collect data on children with disabilities by providing funding, coordination, quality oversight, technical assistance and follow-up
- Support the strengthening of administrative systems to generate data on children with disabilities
- Support the disaggregation of data on children with disabilities for programme design, monitoring and reporting on results.

### Support for data analysis

- Develop tools to facilitate analyses of data on children with disabilities
- Launch calls for proposals to promote the use of data and competitively select the most promising approaches to data analysis
- Partner with selected academic research institutions on data analysis projects and courses
- Sponsor young statisticians from national statistical offices and researchers aiming to develop their doctoral research on children with disabilities
- Sponsor fellowships and visiting scholar exchanges to promote knowledge transfer among experts and young researchers/statisticians.

### Promotion of data use for advocacy and policymaking

- Develop tools to promote the dissemination and use of data, including through accessible visualization of complex analyses, so that they can be readily understood by policymakers, advocates, civil society organizations and programme professionals
- Organize dedicated trainings focused on data interpretation and use for advocates, civil society organizations and programme professionals.

## Collaboration

The Centre is hosted at UNICEF Headquarters in New York. Its work is guided by a Strategic Advisory Group (SAG) comprised of individuals from key stakeholder organizations who have the insight and expertise to forge practical and strategic collaborations. Given its central role in establishing the Centre and hosting its activities, UNICEF serves as the technical lead and secretariat.

## Strategic Advisory Group

Strategic Advisory Group members steer the overall direction and focus of the Centre, while providing targeted and strategic advice to facilitate its activities.



### Matias Egeland

Matias Egeland is a Senior Adviser with the Norwegian Directorate for Education, Department of Welfare and Human Rights. He previously worked in the areas of education, social policy, development, trade and state-owned enterprises as a Policy Analyst with the Organisation for Economic Co-operation and Development (OECD). He holds a bachelor of science degree in government and a master's degree in political science and political economy from the London School of Economics.

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### Elizabeth Lockwood

Elizabeth Lockwood works for CBM Global Disability Inclusion and is the CBM Representative to the United Nations in New York. She focuses on developing advocacy strategies to raise awareness, build capacity and lobby for the rights of persons with disabilities at the United Nations level. Her prime areas of interest include the 2030 Agenda for Sustainable Development, disability data and statistics, financing for development, and accessibility. She is partially seconded to the United Nations Department for General Assembly and Conference Management at UN Headquarters, working on accessibility in meetings and conferences.

Ms. Lockwood is also Co-chair of the International Disability and Development Consortium's UN Task Group and an Expert Member of the World Federation of the Deaf Expert Group on Accessibility. She was raised by Dutch and American parents and has lived and worked in North, Central and South America, Asia, Europe and with the Navajo (Diné) Nation. She has a PhD in disability studies and a master's degree in public policy. She signs in five languages and in International Sign, speaks English and Spanish, and is learning French and Maghrebi Arabic.

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### Jennifer H. Madans

Jennifer H. Madans recently retired from the National Center for Health Statistics, the United States' principal statistical agency. Most recently, she served as the Center's Associate Director for Science and Acting Director. She has concentrated her research efforts on data collection methodology and the measurement of health and functioning. Currently, she is a disability statistics consultant and Senior Associate with the Center for Inclusive Policy (CIP). She also serves on the Board of Trustees of the Population Reference Bureau.

Ms. Madans is a founding member and has been the chair of the steering committees for three UN-sponsored initiatives to develop internationally comparable measures of disability and health, including the Washington Group on Disability Statistics. Since 2002, she has worked extensively with national statistical offices, government development agencies, NGOs and organizations of persons with disabilities to advance the availability and quality of disability statistics. She has conducted numerous training sessions, provided extensive technical assistance and carried out analyses of disability data at the country, regional and international level.

Ms. Madans is a graduate of Bard College and holds a master's degree and doctorate from the University of Michigan. She is an elected Fellow of the American Statistical Association and an elected member of the International Statistical Institute. She also served as Vice President of the International Association of Official Statistics. She received the 2015 Roger Herriot Award for Innovation in Federal Statistics from the American Statistical Association and the 2016 Excellence in Public Service Award from the Population Association of America.



### **Sarah Malelu**

Sarah Malelu is the technical lead of the Global Disability Summit (GDS)-Team at the German Development Agency (GIZ) and member of the GDS Secretariat. She is responsible for all disability-data-related activities in connection with the GDS such as the Global Disability Inclusion Report, the Disability Data Hub and the preparation of the Disability Data Forum that will take place prior to the GDS2025. Sarah has been working for GIZ for 18 years and has a background in network management.

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### **Diane Richler**

Diane Richler has worked for more than 50 years supporting organizations of persons with disabilities and their families to be agents for social change. She has linked disability to broader issues of social policy, human rights, democratization, and the strengthening of civil society, in Canada and internationally.

Diane coordinates the Joseph P. Kennedy Jr. Foundation International Fellowship program. She is the Past-President of Inclusion International and was one of the civil society leaders in the negotiation of the Convention on the Rights of Persons with Disabilities. She is a former chair of the International Disability Alliance (IDA) and was the co-chair of the GLAD Network Working Group on Inclusive Education, a member of the Advisory Board of the Human Rights Initiative of the Open Society Foundations and a member of the International Advisory Council of the Ruderman Foundation. She has been a consultant to governments and the Inter-American Development Bank, the World Bank, the Organization for Economic Cooperation and Development (OECD), the World Health Organization, UNICEF, and UNESCO, and an invited speaker and trainer in over 60 countries. She was an Erasmus Mundus Visiting Academic in inclusive education at Charles University in the Czech Republic.

Diane is a member of the Order of Canada and the Order of Manuel Amador Guerrero of Panamá.

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### **Elena Schmidt**

Elena Schmidt has over 25 years' experience in health and international development at the national and international levels, including her work for the World Health Organization and the U.K. Department for International Development. She also held a range of academic posts teaching public health and epidemiology. Currently, she is Director of Evidence, Research and Innovations at Sightsavers, an international NGO working to eliminate avoidable blindness and promote equality of opportunity for people with disabilities. Her work includes a broad range of studies and evidence-uptake initiatives in eye health, inclusive education and social inclusion in Africa and Asia.

Ms. Schmidt has co-authored dozens of peer-reviewed publications on health, disability and inclusion and presents regularly at international scientific forums. She holds a bachelor's degree in education, a master's in public health and a doctorate in policy analysis.

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### **Julie D. Weeks**

Julie D. Weeks serves as Chief of the Measures Research and Evaluation Research Branch at the U.S. National Center for Health Statistics. Her research focuses on all aspects of disability and functioning, including measurement development and analysis, incorporating standard measures into both national and international data collections, and population ageing. Ms. Weeks is a member of the following organizations: Secretariat, Washington Group on Disability Statistics; Titchfield Group on Ageing; Inter-Agency Subcommittee on ACS (American Community Survey) Disability Questions; Inter-Agency Committee on Disability Research, Executive Committee; and the American Statistical Association's Committee on Statistics and Disability.

## Secretariat

The Secretariat is responsible for facilitating the Centre's activities.



### **Claudia Cappa**

Claudia Cappa is a Senior Adviser and Unit Chief in the Data and Analytics Section, Division of Data, Analytics, Planning and Monitoring, at UNICEF Headquarters in New York. She is the focal point for data collection, data analysis and methodological work on child disability, early childhood development and child protection from violence, exploitation and abuse. In this capacity she is responsible for the development of survey questionnaires and data collection tools; production of estimations; development of methodologies, indicators, protocols and normative guidelines; design and implementation of capacity-building initiatives; production of data-driven reports; and the delivery and dissemination of final results. She is also responsible for maintaining inter-agency collaborations and partnerships and has been chairing/contributing to several inter-agency technical working groups. She represents UNICEF in the Washington Group on Disability Statistics and is the founder of the Centre of Excellence on Data for Children with Disabilities. Prior to joining UNICEF, she worked at the University of Geneva and at the Institute for Social Studies of the International Labour Organization (ILO). Ms. Cappa has a master's degree and a PhD in development studies from the Graduate Institute of International and Development Studies, Switzerland.