







# COSP15 Side Event: Research and data for advancing the rights of children with disabilities

17 June 2022, 10.00-11.15 EST; 16.00-17.15 CET Contact: Gavin Wood gawood@unicef.org



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The Office of Research-Innocenti (UNICEF-Innocenti) is the dedicated research office of UNICEF. It undertakes and commissions research on emerging or current issues of relevance for children to inform the strategic directions, policies and programmes of UNICEF and its partners. The Office explores next generation issues, identifies research gaps, brings together existing researchers, and supports or undertakes research and data collection to address critical questions and to inform global debates. It also facilitates research and knowledge management on the best evidence for children and convenes experts and leaders around next generation issues for children and young people.

UNICEF-Innocenti is delighted to be hosting this COSP15 Side Event on the topic of "Research and data for advancing the rights of children with disabilities" co-hosted by the Norwegian Agency for Development Cooperation (Norad) and the International Disability Alliance.

The Chair for the side event is Dr. Gavin Wood who leads the research on children with disabilities at UNICEF-Innocenti, who is joined by a senior panel of experts who will discuss the critical gaps and opportunities of research and data for guiding investment in effective interventions to support the inclusion and rights of children with disabilities:

- Paul Richard Fife, Director, Department for Human Development, Norad (Norwegian Agency for Development Cooperation)
- 2. Federico Martire, Deputy Program Director, International Disability Alliance Secretariat
- 3. Rahma Mustafa, independent consultant, representing the International Disability Alliance
- 4. Hannah Kuper, Professor of Epidemiology, London School of Hygiene and Tropical Medicine
- 5. Bronagh Byrne, Co-Director of the Centre for Children's Rights and co-founder of the Disability Research Network





Also joining the side are speakers from UNICEF who will present an evidence and gap map (EGM) and a maturity model for producing inclusive data systems:

- 1. Shivit Bakrania, Knowledge Management Specialist, UNICEF Office of Research Innocenti
- 2. Anilkrishna Bjorn Thota, Consultant Evidence Synthesis, UNICEF Office of Research Innocenti
- 3. Claudia Cappa, Senior Advisor for Statistics and Monitoring, UNICEF Data and Analytics

# **Background**

UNICEF engages with children and youth with disabilities, to understand their thoughts, motivations, challenges, the everyday obstacles, and the opportunities they face. Their voices are carried through in UNICEF's Disability Inclusion Policy and Strategy (DIPAS) and into its Global Research Agenda for Children with Disabilities. It is also important to learn about their visions for a better world for children and adolescents with and without disabilities, how they would like to contribute to improve their situation, how they can best voice and have UNICEF amplify their opinions, and how UNICEF can contribute to achieve their full potential.

We are increasingly putting inclusive services and provisions in place for children with disabilities so that they can participate and enjoy their rights equally with all children. However, knowing what is needed is one thing, but do we know what works? As a global community of engaged stakeholders, how do we know if what we are doing is effective, or making the positive difference as intended?

In preparation for the eighth conference of state parties in 2015 (COSP-8) the COSP Secretariat prepared an expert-led document to facilitate a round-table discussion on the theme of "Improvement of disability data and statistics: objectives and challenges". It called for qualitative information to be collected, analysed and used to complement quantitative data to provide a fuller understanding of disability, perceptions and attitudes. It also underlined that persons with disabilities and their organisations should be included in ongoing and future efforts to improve national statistics and research data and should be consulted in the analysis and reporting of research data. Such consultations and co-creation is at the heart of our Global Research Agenda and Platform for Children with Disabilities, informed in part by our Children with Disabilities Speak Out report, co-developed with the International Institute for Child Rights and Development, Collective Impact, and UNICEF (https://tinyurl.com/2p9a95mk).

In this side event we will pay attention to both data and research and to ask that we focus on our children.

# **Speakers**

# Speaker topic 1. Evidence and Gap Mapping

Shivit Bakrania and Anil Thota will introduce UNICEF's work, funded and supported by Norad and IDA, on an Evidence and Gap Mapping (EGM) of inclusive interventions for children with disabilities in low- and middle-income countries. The presentation will focus key messaging on the rigour and function of the EGM work as a global good for good to guide investment in research, evidence synthesis and impact evaluations; and for informing research, including the UNICEF-led Global Research Agenda and Platform on Children with Disabilities. It will highlight the coverage but focus more on the gaps and opportunities to strengthen inclusion of children with disabilities

# Speaker topic 2. Disability-inclusive data systems

Claudia Cappa will speak to disability-inclusive data systems. Administrative data systems are the products of government programs that deliver services or benefits to eligible people. As the cost of collecting the





data is born by the system, the marginal costs of using the data for statistical purposes is minimal making this an attractive source of information. However, because the data are tied to the administrative system, their use for other purposes might be limited. It is possible, however, to construct systems or modify existing systems so that useful data on children with disabilities can be obtained. The presentation will describe the characteristics of disability-inclusive data systems – from the definitions used to identify eligibility and service users to the interoperability of such systems – and discuss how to overcome constraints to ensure that the collected data can be used to promote equal access for children with disabilities.

## Panel discussion

Our expert panellists (see above) will discuss the topic of research and data, giving their perspectives on the most important gaps in research on children with disabilities and why they think so many gaps remain. We will hear from Dr. Byrne on the motivation for setting up the Disability Research Network and discuss why it is important to have researchers who identify themselves as persons with disability involved in conducting research. The panel discussion will conclude with statements on what needs to be done to invest more in research and data on children with disability, including and especially at national levels and Global South.

# Zoom link instructions (for public registration)

Register in advance for this webinar: https://unicef.zoom.us/webinar/register/WN\_vpNmeat0TTiyk4FNkSCIKw

Or an H.323/SIP room system:

H.323:

162.255.37.11 (US West)

162.255.36.11 (US East)

221.122.88.195 (China)

115.114.131.7 (India Mumbai)

115.114.115.7 (India Hyderabad)

213.19.144.110 (Amsterdam Netherlands)

213.244.140.110 (Germany)

103.122.166.55 (Australia Sydney)

103.122.167.55 (Australia Melbourne)

209.9.211.110 (Hong Kong SAR)

64.211.144.160 (Brazil)

69.174.57.160 (Canada Toronto)

65.39.152.160 (Canada Vancouver)

207.226.132.110 (Japan Tokyo)

149.137.24.110 (Japan Osaka)

Meeting ID: 955 3015 7457

SIP: <u>95530157457@zoomcrc.com</u>

After registering, you will receive a confirmation email containing information about joining the webinar.

Please visit our microsite: www.unicef-irc.org/children-with-disabilities





## Panelist bios

## Hannah Kuper

Professor Hannah Kuper is the co-Director of the International Centre for Evidence in Disability, a research group at the London School of Hygiene and Tropical Medicine (LSHTM) together with Professor Tom Shakespeare. Prof. Kuper's research interest is disability in low- and middle-income countries, with a particular focus on access to healthcare for people with disabilities and measuring the effectiveness of development interventions. Prof. Kuper co-founded the Missing Billion Initiative, which focuses on improving access to healthcare for people with disabilities globally, by working with governments, donors, healthcare systems and people with disabilities. Prof. Kuper has an undergraduate degree from Oxford University in Human Sciences and a doctorate from Harvard University in epidemiology. She joined LSHTM in 2002 as a member of the International Centre for Eye Health, undertaking research into the prevalence, impact and control of blindness. Her worked focussed on other types of impairments, and on quantitative research about disability. Prof. Kuper was the co-director of the International Centre for Evidence in Disability 2010-2017, and the director since 2017.

## Paul Richard Fife

Dr Paul Richard Fife is the Director for Human Development in Norad - the Norwegian Directorate for Development Cooperation. In this function, he contributes to Norway's international engagement and oversees the implementation of aid investments in global health, education, higher education and research, human rights and gender equality. Dr. Fife has represented the Government of Norway on various Boards, including of the Global Partnership for Education (GPE), the Vaccine Alliance GAVI and the Global Financing Facility (GFF). From 1995-2003, he worked on vaccines and health systems strengthening with UNICEF in Eritrea, Cambodia and at UNICEF HQ in New York. A Norwegian national, he trained as a medical doctor in Norway and holds a master's degree in Public Policy and Management.

# Bronagh Byrne

Dr Bronagh Byrne is Senior Lecturer, School of Social Sciences at Queen's University Belfast. Bronagh is the co-Director of the Centre for Children's Rights and co-founder of the Disability Research Network. Bronagh's research expertise lies in the implementation of international disability rights and children's rights to national policy and practice with a particular focus on the application of the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. She is also interested in the rights and experiences of disabled and d/Deaf children and young people, inclusive education, transitions, and disability theory. Bronagh has published in a range of journals including International Journal of Children's Rights, Children and Society, International Journal of Inclusive Education and Disability and Society.

## Federico Martire

Federico Martire is a European international cooperation practitioner with 13 years of field and HQ experience. Currently working with the International Disability Alliance (IDA) as Senior M&E Manager and





Deputy Program Director, he previously engaged in social inclusion and disability rights projects in Europe, MENA Region, Latin America, and Sub-Saharan Africa. Before joining IDA, he leads for the Spanish Cooperation the EU-funded programme "Bridging the Gap", the flagship initiative of the European Union for the inclusion of persons with disabilities in international cooperation. Born in Aosta, Italy, in 1982, he currently resides in Madrid, Spain, and holds a Master with Distinction in Economics and one with Merit in International Relations.

## Rahma Mustafa

Rahma Mustafa is an advocate and an independent consultant with more than 10 years' experience in disability rights and inclusion at global level with extensive experience in emergency and humanitarian field. She holds a Master of Law Degree in International Comparative Disability Law and Policy from the National University of Ireland, Galway 2017. She has worked for several international organizations in the field of disability inclusion including International Disability Alliance, World Blind Union, ADD International and the EU-funded "Bridging the Gap" project with the Italian Cooperation Agency in Sudan. In the last two years, she conducted and supported many research projects, such as the Situation of Tigray refugees with disabilities in Eastern Sudan Refugees Camps with Islamic Relief Worldwide, the Evidence and Gap Map on Inclusive Interventions for Children with Disabilities with UNICEF-Innocenti, and reviewed CBM International Training Curricula in Disability Inclusive Disaster Risk Reduction DIDRR. Rahma originally from Sudan and she based in Texas, USA.

# Speaker bios

## 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 (WG) 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.

## Shivit Bakrania

Shivit Bakrania is a Knowledge Management Specialist with the Research Facilitation and Knowledge Management Unit at UNICEF's Office of Research - Innocenti. He primarily works on the evidence synthesis





and research capacity building aspects of the unit's work, as well as research governance activities, such as overseeing the research quality assurance procedure implementation and other research knowledge management activities. He is a social research methods specialist and his thematic academic and research interests include: evidence synthesis and translation, political economy approaches to development, youth and political violence, security and access to justice, and governance in fragile and conflict-affected contexts. He has experience in producing evidence synthesis, including systematic reviews, rapid reviews and evidence gap maps, policy analysis, political economy analysis and conflict analysis.

#### **Anil Thota**

Anil Thota is a Team Lead/Evidence Synthesis Specialist at the UNICEF Office of Research-Innocenti leading the production of an Evidence Gap Map (EGM) on interventions for children with disabilities. Prior to this, he worked with the Campbell Collaboration where he completed a large EGM on what works to improve sexual and reproductive health and rights outcomes in sub-Saharan Africa and contributed evidence syntheses to a guidebook for practitioners on child protection interventions. He has also recently published a systematic review on early warning systems for childhood cancer in LMICs working with colleagues at the Hospital for Sick Children in Toronto, Canada. Anil spent nearly a decade at the US Centers for Disease Control and Prevention (CDC) till 2019 where he was acting branch chief and scientific team lead for the Community Guide Branch. He has also worked at Health Quality Ontario (2016-2017) as Manager of Clinical Reviews within the Evidence Development and Standards unit. Anil has a medical degree (MBBS) from the Manipal Academy of Higher Education (India) and a Master of Public Health (MPH) degree from the Johns Hopkins Bloomberg School of Public Health (USA). He is currently enrolled part-time at the University of Oxford in the MSc programme on evidence-based healthcare.

## Moderator

#### Gavin Wood

Dr. Gavin Wood is the Disability Research Manager at UNICEF's Office of Research – Innocenti. A former Senior Research Fellow from Cranfield University in the UK, Gavin has worked for UNICEF since 2010 in support of the Haiti earthquake and for the following nine years worked at UNICEF's Office of Emergency Programmes (EMOPS) leading on data and information strategy and operations in the humanitarian emergency sector with a focus on emergency coordination, assessments and performance measurement and monitoring. Since 2018, Gavin has focused on disability inclusion and moved to UNICEF Innocenti to develop a research portfolio. He is currently leading the development of a Global Research Agenda and Platform for Children with Disabilities to amplify the voice of children and youth with disabilities through a network of academic institutions, researchers, policymakers, donors, and practitioners. <a href="https://www.unicef-irc.org/children-with-disabilities">https://www.unicef-irc.org/children-with-disabilities</a>.

