



Abstract Book

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Workshop 1: 11:30-13:00, Tuesday 5th November 2019

| Access to Health | | | |
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| Presenter | Title | Authors | Abstract |
| Andrea Pregel | Collaborating with people with disabilities to conduct accessibility audits in healthcare facilities in low and middle income settings: tools and approaches | Andrea Pregel, Karen Smith, Cristina Abudo Pires, Camilo Moreira, Aurora Antunes | <p>Limited accessibility of health infrastructure represents a major barrier preventing individuals with physical, sensory, intellectual, psychosocial or other impairments from equitably accessing health facilities in low and middle income settings.</p> <p>As part of an inclusive health project in Nampula Province, Mozambique, Sightsavers worked with the Forum of Organisations of Persons with Disabilities of Mozambique (FAMOD), the Ministry of Health and the Ministry of Gender, Children and Social Welfare to develop and test an accessibility audit package.</p> <p>Guidelines, checklists, report templates, training materials and a participatory scoring methodology were developed by Sightsavers, combining Mozambican accessibility standards with universal design principles and recommendations from the 2010 American with Disabilities Act Standards for Accessible Design.</p> <p>The package was translated to Portuguese and provincial representatives of FAMOD and the government were involved in the review and field testing of the tools in Nampula. The scoring matrix was developed by participants based on their experiences and perceptions. The resources were subsequently revised and finalised based on feedback and observations.</p> <p>The accessibility audit package was used in seven public health facilities in Nampula Province. Several barriers were identified, including inaccessible toilets, steep ramps and lack of information materials in accessible formats. Plans for infrastructural renovation were developed based on scores and reports compiled for each facility.</p> <p>Experience from this initiative demonstrates that the accessibility audit package is an effective instrument to assess the level of accessibility of health facilities in low and middle income settings and support planning of infrastructural renovations through participatory approaches.</p> |
| Sarah Polack | Feasibility and acceptability of an educational intervention to improve uptake of ear and | Sarah Polack, Antonia Baum, Wakisa Mulwafu, Mwanaisa Phiri, Tess Bright | <p>Introduction</p> <p>Previous research has found low uptake of referral for ear and hearing services for children in Malawi. A multi-component educational intervention was developed to address poor uptake, using a structured approach drawing on Medical Research Council guidance. The aim of this study was to explore feasibility and acceptability of the intervention.</p> |

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| | hearing services in Malawi | | <p>Methods An information booklet and personalised counselling by a community health worker and expert mother was provided for caregivers of eligible referred children (<18 years) at ear and hearing outreach camps in Thyolo. Text message reminders were sent to caregivers after the camps. After 4 weeks, caregivers were visited and interviewed using a structured questionnaire and in-depth interviews.</p> <p>Results 30 children were recruited, and 53% took up the referral. Interviews found counselling with a booklet was acceptable. It provided motivation, enabled a two-way conversation, and helped dispel fear. It allowed information to be shared with social networks, initiating conversations about raising funds. The text message reminder was reported to be a valued prompt. Challenges to feasibility included low network coverage, and time needed for counselling. Residual barriers included the costs of transportation.</p> <p>Conclusion Counselling with an information booklet was feasible and acceptable, and resulted in a higher uptake compared to previous studies. Some adaptations could improve the intervention before it is tested in a trial. The intervention also has applicability for different populations, including adults and children with other impairments.</p> |
| Kirsty Smith | Perceptions of persons with disabilities towards healthcare in two areas of Nigeria | Olusola Alonge, consultant, for CBM and Seeing is Believing | <p>The purpose of this baseline study was to assess the perceptions of inclusiveness of health services amongst persons with disabilities, and for the findings to guide planning, programming and policy formulation. It will also be used in conjunction with an endline survey to evaluate progress on inclusion in two pilot health facilities.</p> <p>Methods Both qualitative and quantitative data collection methods were used. The quantitative study involved a household survey of persons with disabilities and healthcare providers, plus street-based surveys; while the qualitative research included focus group discussions and in-depth interviews.</p> <p>Results</p> |

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| | | | <p>Just over a third (34.53%) of respondents with disabilities reported it was hard or very hard for persons with disabilities to access health facilities; and in comparison more difficult to access than the workplace or educational institutions. Most respondents with disabilities (81.82%) reported satisfaction with healthcare services in their area, although only half (52%) reported waiting times to be good or very good, with the perception that this was because healthcare workers made assumptions about the ability of people with disabilities to pay for services. Most interviewees mentioned the need for healthcare personnel to improve their attitudes in delivering services to persons with disabilities.</p> <p>The study also revealed a gender imbalance in the population sample, with far fewer women identified as having a disability in the second stage of sampling; and the presentation would provide further analysis of this in relation to context and methodology.</p> <p>Conclusions The research concludes that the inclusion of persons with disabilities in the two areas of Nigeria studies in relation to health-care services needs improvement, and highlights a gap in perceptions between persons with disabilities and healthcare providers, with the latter's attitude constituting a threat to inclusion.</p> |
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| Participatory Methods | | | |
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| Presenter | Title | Authors | Abstract |
| Jackie Shaw | Inclusion works! Disability inclusive participatory action learning groups: building better solutions and change practices | Jackie Shaw, Brigitte Rohwerder, Stephen Thompson, Mary Wickenden | Inclusion Works! is researching how disabled people can better access formal sector employment in Bangladesh, Kenya, Nigeria and Uganda. We describe our experiences of setting up participatory action learning groups to ensure disabled people are at the centre of intervention planning, implementation and programme learning. Complex disability issues are unlikely to be resolved through linear solutions generated without understanding people's lived realities. Participatory action research (PAR) involves participants and researchers working together to explore problems in-situ. PAR's theoretical underpinnings complement the 'nothing about us, without us' philosophy of the disability movement, because participants' concerns drive the solutions. During PAR participants make sense of their experiences, identify shared agendas and lead improvement action. |

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| | | | <p>However, despite PAR aspiring to ensure the views of marginalised groups are central, disabled people are rarely included meaningfully in PAR in LMICs. Neither has PAR been conceptualised or practiced as avowedly disability inclusive. There is little practical guidance on making the processes fully accessible, and PAR often only engages with people with certain impairments, from particular socio-economic backgrounds and from ‘easier’ locations. This leads, probably accidentally rather than deliberately, to the exclusion of many, especially the most marginalised.</p> <p>In addressing how inclusive participatory approaches can contribute to both better disability practices and innovatory solutions, we reflect on the reality of setting up inclusive participatory action learning groups in Bangladesh, Kenya, Nigeria and Uganda. We describe the underlying approach, methods and practical adaptations aiming to include all. We discuss the practical challenges of finding local facilitators, engaging with DPOs, developing facilitation skills, reaching marginalised participants, providing remote support, and embedding meaningful participation and the ethical conundrums and difficulties translating reflexive learning within and from these groups into programme implementation. We illustrate the value of disability inclusive PAR, whilst generating critical insight on navigating the inherent tensions within it.</p> |
| Shanthi Ameratunga | Inclusive Streetscapes – a community-based participatory research project stimulating disability-inclusive transport policies | <p>Shanthi Ameratunga, Julie Spray, Anneka Anderson, Janine Wiles, Malakai Ofanoa, Whaea Julie Wade, Whaea Dolly Paul, Roshini Peiris-John, Karen Witten, Bridget Burdett, Esther Willing</p> <p>Host institution: School of</p> | <p>Background: Notwithstanding the rhetoric of active travel and age- and disability-friendly cities, transport environments influence the wellbeing of people with disabilities across multiple intersecting dimensions. We explored the lived experiences of disabled people navigating streetscapes and transport systems in Auckland, New Zealand, particularly including influences of advancing age, ethnicity and socio-economic status.</p> <p>Methods: The community-based participatory research study employed approaches aligned to Kaupapa Māori (indigenous) Research and Pacific methodologies to gather data from 62 people who were differently challenged by their environments in four socio-culturally, ethnically, economically, and topographically diverse case study areas. Qualitative data from sit-down and ‘go-along’ interviews in seven languages (supplemented with photovoice) were thematically analysed.</p> <p>Results: Participants who were able to access their communities expressed strong connections to their neighbourhoods, finding the places, relationships, and resources supportive of their wellbeing. However, many participants, especially those in low-income neighbourhoods, reported</p> |

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| | | Population Health, University of Auckland, Auckland, New Zealand | <p>difficulties navigating their environments, and relied heavily on families to overcome transport challenges. Indigenous communities saw the legacy of transport infrastructure changes as disruptive and damaging, with major consequences for their physical, cultural and emotional wellbeing. Participants in richer neighbourhoods with higher levels of education, computer literacy and systems knowledge expressed more confidence in navigating barriers and advocating for themselves, demonstrating the influences of power, affluence and privilege.</p> <p>Discussion: The findings identify prevalent structural injustices in urban environments and transport systems influencing the wellbeing of people with disabilities. The project's next phases engage transport professionals and community stakeholders in an active, participatory co-learning process designed to stimulate disability-inclusive transport policies.</p> |
| Margo Greenwood | Disability-focused community-based participatory research (CBPR): how is methodological learning shaping design and approach? | Margo Greenwood | <p>Background</p> <p>For the last four years, Sightsavers and its partners have been implementing disability-focused community-based participatory research (CBPR) to inform projects in East and West Africa. What have we learnt from this methodology and how is this learning shaping our approaches to participatory research? Successes and challenges will be shared alongside specific examples of how CBPR findings have informed interventions.</p> <p>Methods</p> <p>CBPR equitably involves community members, project implementers and researchers, enabling them to share power and resources and draw on the unique strengths that each partner brings. It aims to integrate increased knowledge and understanding into action, policy and social change. In practice, CBPR involves recruiting community researchers, involving them in planning and offering them training to undertake interviews and observations in their context. They are also part of the analysis and dissemination process, and continue to work with local partners after projects and research have finished.</p> <p>Findings</p> |

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| | | | <p>Our experiences show that to join partners with diverse expertise requires much planning, diplomacy, and critical, reflexive thought, while emphasising the necessity of generating local ownership of findings. There also needs to be a translation of knowledge into a catalyst for disability-related policy change. With the right support for community research teams, peer-to-peer interactions enhance richness of data, local ownership and more equal distribution of power.</p> <p>Conclusion</p> <p>CBPR and methodological learning from it is a vital part of working towards the 2030 Agenda. It fosters shared responsibility, mobilizes all available resources and recognizes all as crucial enablers of sustainable development and change.</p> |
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| Measurement | | | |
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| Presenter | Title | Authors | Abstract |
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| Ruth Sanders | Using the Washington Group Short Set for monitoring access to eye care services by people with disabilities. | Ruth Sanders, Programme Monitoring and Evidence Advisor, Sightsavers UK Karen Smith, Senior Monitoring, Evaluation and Learning Advisor, Sightsavers UK Cristina Abudo Pires, Programme Officer, Sightsavers Mozambique Leena Ahmed, Programme Officer, | <p>Sightsavers programmes aim to reduce avoidable visual impairment and ensure that people with disabilities have equitable access to eye health services. We are developing approaches to delivering inclusive eye health services and methods to monitor and evaluate them. One indicator tested in the past few years is the proportion of patients attending services who report a disability. In 2018 we developed new inclusive eye health projects in Bangladesh, Pakistan and Mozambique and measured disability among patients attending the eye care services in these projects.</p> <p>In each country, data were collected from cataract patients over three months using the Washington Group Short Set to determine disability. Using the recommended cut off points (a lot of difficulty or cannot do at all) we measured any disability and 'non-visual disability', i.e functional difficulty other than seeing. Prevalence of any disability among cataract patients varied from 54% in Pakistan to 89% in Bangladesh. Prevalence of non-visual disability was 39% in Pakistan and 40% in Bangladesh. Women, older people and those attending outreach camps were more likely to report a disability.</p> <p>The data is useful to understand the magnitude and type of functional difficulties experienced by patients attending eye care services. Although the data suggest that people with disabilities access services in relatively high numbers, it is important to ensure they access services that cater for</p> |

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| | | Sightsavers Pakistan Rafiqul Islam, Senior Programme Officer, Sightsavers Bangladesh | their needs. It may be feasible to integrate the WGSS into routine data systems, however, questions around why certain people face more barriers than others remain. |
| Donna Koolmees | Developing a Needs Assessment Tool for Community Based Inclusive Development (CBID): Assessing and monitoring needs for case management. | Chandalin Vongvilay, Donna Koolmees, Manjula Marella, Wesley Pryor, Fleur Smith, Somphet Keovongxay, Bernard Franck, Samantha Pike, Somphet Keovongxay, Chantavad Nalesouphan | <p>Background Globally, there is limited evidence of the effectiveness of CBID on individuals' levels of functioning. Whilst various CBID activities have been implemented in Laos data collection on the individual needs of persons with disabilities has been imprecise and inconsistent. With the USAID Okard CBID Demonstration Model, World Education and Nossal Institute of Global Health developed a CBID 'Modular Tool' (MT) to address this gap to accurately measure needs at individual and household level, and changes in function, participation and wellbeing following CBID interventions.</p> <p>Methods The MT was developed, translated, pre-tested, digitized and linked to the CBID database. Eight key areas for measurement of needs were determined related to CBID interventions; Function and assistive products, health conditions, mental health, access and utilization of healthcare, caregiver needs, economic participation, education and wellbeing. Review of international tools led to the selection of questions. Algorithms and decision trees were developed to raise 'red flags' to identify priority needs.</p> <p>Results CBID facilitators will administer the MT to accurately assess needs. Priority needs will be identified for planning individualized CBID interventions. The MT will be repeated following interventions to measure changes over time.</p> <p>Conclusions Data will be available to support CBID teams and USAID Okard to track progress, impact and lessons learned for iterative improvement of the CBID Demonstration Model and provide evidence to the Government of Laos that effective changes in inclusion of persons with disabilities can happen at community level, when persons with disability and their family, community-based</p> |

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| | | | associations (NPA) and government authorities work together to implement the National Disability Inclusion Policy and Strategy. |
| Kate Miller | Count Me In, an mHealth app, promotes nutrition and safe feeding for children with disabilities | Kate Miller, Zeina Makhoul, Jon Baldivieso | Children living with disabilities that impact feeding (e.g., cerebral palsy, developmental disabilities), suffer at an alarming rate from preventable malnutrition and dangerous feeding practices (e.g., supine feeding, altered bottle nipples, inappropriate food textures) that place them at risk for aspiration, pneumonia, and premature death. Caregivers are often not equipped with the knowledge and skills to safely nourish them and appropriate tools and services in low-resourced settings are often lacking. In addition, children with disabilities are often not counted in global nutrition programs contributing to a longstanding gap in data-driven programming. Count Me In is an mHealth app that enables caregivers to assess and monitor feeding difficulties, growth, and anemia status of children with disabilities over time and generates individualized care plans for each child. It also generates, in real-time, key performance indicators to assist with decision-making. To date, 220 children with reported disabilities, 40% of whom are below the age of 5 years, have been assessed at least once with Count Me In. The baseline prevalence of stunting, wasting, underweight, and anemia were 77%, 21%, 74%, and 62%, respectively. Preliminary data show that, over a mean period of 7 months, the prevalence of wasting and anemia attributed to iron deficiency have decreased by 47% and 44%, respectively, while the prevalence of stunting and underweight narrowly changed. About three out of four children screened based on developmental milestones had feeding difficulties related to safety, efficiency, and skill-building. Positioning, identified as the most common challenge impacting feeding, improved for 75% of children. Our data suggest that Count Me In establishes a path to positive health outcomes for children with disabilities by building structure and process to address children’s nutrition and feeding difficulties and providing a clinical recommendation engine that takes into account individual needs. |
| Education | | | |
| Presenter | Title | Authors | Abstract |
| Emma Jolley | A mixed-methods study investigating child development outcomes in community-based | Emma Jolley, Elena Schmidt, Ingrid Gercama, Paul Lynch | Background With 250 million children in low-income settings at risk of not fulfilling their developmental potential, evidence of what works in early childhood development and education (ECDE) is crucial but currently lacking, particularly for marginalised children including those with disabilities. Methods |

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| | early childhood settings | | <p>We used mixed methods to appraise, adapt and evaluate a disability inclusive training programme for ECDE caregivers in Malawi. Community based participatory methods were drawn on to understand the provision of early childhood development and inclusive education in rural Malawi and adapt an existing ECDE training programme to encourage more disability-inclusive approaches. We conducted a cluster randomised control trial to measure the effect of the intervention on the primary outcome: proportion of children with developmental delay, using the Malawi development assessment tool (MDAT). Forty-eight community-based childcare centres (CBCCs) were allocated randomly to the control and intervention arms and 20 children per CBCC were selected randomly for baseline and endline measurements. Disability was measured using the UNICEF/ Washington group child functioning module (WGCFM).</p> <p>Results Developmental delays were assessed among 933 children at baseline and 881 at endline. 10.7% and 6% of children respectively had a disability. At endline, the prevalence of developmental delay in the intervention CBCCs decreased from 11.7% to 6.3% compared to only a marginal change in the control areas (11.9% to 10.0%). Similar changes were observed when the results were disaggregated by the type of delay with more prominent impact in the language domain. Qualitative data corroborated CRCT findings showing that the training improved caregiver engagement, interactions with children and communication skills.</p> <p>Conclusions Inclusive caregiver training can improve child development outcomes. Further research is needed to understand the sustainability of effects and longer-term impact on functional difficulties. Combining research methods is important to understand not only what works, but the pathways through which change occurs.</p> |
| Nidhi Singal | Evidence on disability and education: the geo-politics of knowledge generation, | Nidhi Singal | This presentation will provide a critical engagement with the present status of research, and notable evidence gaps, in relation to the education of children/young people with disabilities in the Global South. Drawing on three different data sets: (i) semi-structured interviews with 19 individuals working in Northern based policy organisations and International Non-Governmental Organisations; (2) small group discussions with 54 stakeholders: national/international non-governmental organisations, aid/developed agencies, academics and government officials in the South Asian Region; and (3) analysis of nearly 153 disability focused articles in the African |

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| | evaluation and communication | | Education Research Database (an online open access database hosted by the REAL Centre, Faculty of Education, University of Cambridge), this presentation will critical engage with the processes of how evidence is being generated in relation to addressing issues around education of children/young people with disabilities in the Global South. It will identify patterns of what kind of questions are being researched, kind of methodologies being valued over others, and the role of persons with disabilities in shaping the research agenda. The presentation will conclude with reflections on the critical evidence gaps in the field, as identified by different stakeholders. It will also propose ways in which greater South-South collaborations in generating evidence can contribute to collective advocacy and change in efforts towards making education a reality for all children, including those with disabilities. |
| Elena Schmidt | Costing inclusive education of children with disabilities: analysis of expenditures of an inclusive education pilot in Senegal | Elena Schmidt, Thomas Engels, Shaneez Chatharou, Astou Saar, Salimata Bocoum | <p>Background</p> <p>The United Nations Convention on the Rights of Persons with Disabilities states that children with disabilities should have access to an inclusive, quality and free education. However the number of children with disabilities not attending school remains high. Inclusive education is often considered financially challenging for resource poor settings but there is little empirical data to make accurate budgetary projections. This study sought to identify the incremental expenditure of including children with disabilities in mainstream primary schools in Senegal, West Africa.</p> <p>Methods</p> <p>The data was collected from three pilot schools in Dakar, where a total of 290 children - primarily blind or severely visually impaired, were enrolled in mainstream schools in September 2011 -June 2017. The expenditure analysis was conducted retrospectively using accounting systems of the project partners.</p> <p>Results</p> <p>The total expenditure of the pilot over six years was FCFA 548,181,885 (1,077,618 USD). The average expenditure per child with disability academic year was FCFA 765,617 (1,505 US Dollars) ranging from FCFA 3,185,675 (6,760 US Dollars) in year one to FCFA 531,633 (893 US Dollars) in year six. The highest expenditure was for teaching support (40%), followed by education materials/assistive devices (15%). The largest expenditure input was personnel (26.1%) followed by event management (22%).</p> <p>Conclusion</p> |

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| | | | The study provides useful information, which can be used to make estimates of resources required to scale up inclusive education in Senegal and similar settings. However, more accurate prevalence data and an analysis of education budgetary allocations will be required to facilitate the scale up. |
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Workshop 2: 14:30-16:00, Tuesday 5th November 2019

| Humanitarian | | | |
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| Presenter | Title | Authors | Abstract |
| Nathaniel Scherer | Disability and common mental disorders among Syrian refugees in Sultanbeyli, Istanbul | Nathaniel Scherer ¹ , Shaffa Hameed ¹ , Isotta Pivato ² , Ammar Hasan Bek ² , Bodour Alassil ² , Selin Volkan ² , Ceren Acarturk ³ , Sarah Polack ¹ ¹ London School of Hygiene & Tropical Medicine, London, United Kingdom ² Relief International | <p>Introduction: Turkey hosts 3.6 million Syrian refugees. A recent survey in Sultanbeyli District, Istanbul found a relatively high prevalence of common mental disorders (CMD) among adult refugees. However, data on disability (all-ages) and mental health in children is lacking, hindering service planning for this population. This study aims to i) estimate the prevalence of disability (all-age) and CMD (children) and associated needs for physical rehabilitation and mental health and psychosocial support (MHPSS) among Syrian refugees in Sultanbeyli and ii) explore the impact of disability on key life areas.</p> <p>Methods: A population survey will be conducted in Sultanbeyli. Participants, selected through cluster-randomised sampling, will be screened for disability (Washington Group questions), physical impairment (Rapid Assessment of Musculoskeletal Impairment tool) and CMD (children only). Physical rehabilitation and MHPSS services needs will be assessed. A nested case-control survey will compare key life areas (education, work, health, participation, quality of life) among refugees with and without disabilities and/or CMD. Qualitative interviews will explore priority needs, coping strategies and community attitudes towards disability and mental health.</p> <p>Results: Data collection and analysis will be conducted from August-October 2019. Prevalence estimates will be stratified by age, gender and symptom severity. Multivariate</p> |

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| | | 3 Istanbul Sehir University and Koç University | <p>regression analysis will compare key life areas between people with and without disabilities and/or CMD. Thematic analysis of qualitative data will be conducted.</p> <p>Implications: Results will inform advocacy for and planning of disability-inclusive and specialist rehabilitation and MHPSS services at the local level, as well as inclusive humanitarian action nationally and globally.</p> |
| Klaus Minihuber | Inclusive Humanitarian Aid for Girls, Boys, Women and Men with Disabilities in Response to Cyclone Idai | Mirian Wester and Judith Baart | <p>In March 2019, cyclone Idai hit Mozambique. It is estimated that 111 thousand girls, boys, women and men with disabilities are affected (INE, FAMOD & SINTEF, 2009). Although there exists some anecdotal information that persons with disabilities are being left out from humanitarian response, no study has been conducted yet that provides empirical evidence on the situation of persons with disabilities in the aftermath of Cyclone Idai. This research aims to address this issue by investigating the common facilitators and barriers experienced by persons with disabilities in accessing humanitarian aid.</p> <p>Qualitative research will be conducted between June and July 2019 in Sofala province, Mozambique. Interviews will be carried out amongst persons with disabilities and caregivers of children with disabilities, who were affected by cyclone Idai. In addition, focus group discussions will be held with staff members of both, governmental and non-governmental organisations involved in humanitarian aid. From this data, inductive analysis will be performed to reveal the themes, patterns and meaning that emerge from the various stories. This information will be complemented by a quantitative analysis of secondary data derived from mainstream humanitarian actors on the inclusion of persons with disabilities in their response activities.</p> <p>Research has commenced recently, and analysis and finalization will take place in September 2019. The output will be a policy paper which addresses the common individual and environmental factors that either facilitate or hinder the inclusion of persons with disabilities in humanitarian aid. This will be used to advocate for greater attention towards the situation of persons with disabilities who are affected by disasters.</p> |

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| Daniel Mont | Long Lasting Consequences of War on Disability | Michael Palmer, Nguyen Viet Cuong, Sophie Mitra, Daniel Mont, Nora Groce | This article investigates the impact of exposure to US bombing during 1965–75 on the disability status of individuals in Vietnam in 2009. Using a combination of national census and US military data and an instrumental variable strategy which exploits the distance to the former North–South border as a quasi-experiment, the article finds a positive and significant impact of bombing exposure on district level disability rates 40 years after the war. The overall effect of bombing on the long-term disability rate among the Vietnamese population is highest among heavily bombed districts. Districts in the top bombing quintile experience a 25% relative increase in the rate of disability attributable to bombing compared with districts in the lowest bombing quintile. Effects are highest on the prevalence of severe disability and among cohorts before the war’s end. A smaller, yet significant, effect is found among cohorts born after the war. The article finds further evidence of indirect channels through which bombing may have impacted on long-term disability including adverse effects on nutritional environment and human capital attainment. These findings add to the evidence from Vietnam and indicate that wars inflict costs on the health of human populations that last longer than those relating to economic growth and welfare. |
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Employment

| Presenter | Title | Authors | Abstract |
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| Stevens Bechange | Evaluation of a model for the economic empowerment of youth with disabilities in rural Uganda | Stevens Bechange, Eron Laurence, Emma Jolley, Margo Greenwood, Winnie Kyosaba & Elena Schmidt | <p>Background The Uganda Population and Housing Survey 2014, estimated that 12.4% of Ugandans live with a disability. Young men and women with disabilities are most vulnerable – coping with stigma, neglect and inequitable access to opportunities for employment and livelihoods.</p> <p>Methods Sightsavers is working with the Uganda Ministry of Gender, Labour & Social Development, the National Union of Disabled Persons of Uganda and Uganda National Union of the Blind to increase opportunities for employment and access to financial services for youth with disabilities in rural Uganda. This paper presents longitudinal data for a cohort of project participants collected in the first 12 months of the project. The data has been supplemented with 72 qualitative interviews.</p> |

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| | | | <p>Results</p> <p>Findings from both parts of the study show both positive and negative experiences and outcomes, reflecting complex nature of this type of intervention and variability of project benefits within the target group. Thus, while a large number of participants reported positive experiences, including getting a job, accessing financial services and receiving community support, some project beneficiaries reported feeling frustrated, as they were not better off than before the intervention dealing with high rent of business premises, broken equipment and lack of opportunities for expansion. Quantitative data also suggests that while some people found a new job or opened a business, for others, there were no changes in the incidents of job losses, collapse of businesses or discrimination.</p> <p>Conclusion</p> <p>A modest package of economic empowerment interventions can result in some positive outcomes in livelihoods and employability of youth with disabilities in resource-poor settings. However, interventions of larger scale and more rigorous and longer-term approaches to monitoring and evaluation are required to better understand who benefits from such interventions and who does not and why.</p> |
| Mary Wickenden | Promoting disability inclusive formal sector employment: preliminary explorations in preparation for an intervention in Bangladesh, Kenya, Nigeria and Uganda | Mary Wickenden, Stephen Thompson, Brigitte Rohwerder, Jackie Shaw | <p>If disabled people in LMICs can overcome barriers to employment and find work this is usually in the informal sector, where work is generally precarious and low paid. Formal sector employment offers more security, status, career progression and higher wages and should be fully open to disabled people and accessible, as outlined under Article 27 of the UNCRPD. However, the scant data suggests that for example only 1.3% of the formal sector workforce in Uganda and only 1.2% of the public sector in Kenya were disabled. Comparable data is not available for Bangladesh and Nigeria, although research suggests that there disabled people’s participation in formal sector employment is also low. The DFID Inclusion Works! Programme, is a consortium of partners working to increase opportunities for disabled people in formal sector employment in these four countries.</p> <p>We present findings from preliminary participatory workshops with disabled people’s organisations and other relevant stakeholders from government and the private sector</p> |

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| | | | <p>held in the four countries, as well as secondary desk-based research, and learnings gathered from the first stages of programme implementation beginning in July 2019. We examine the identified barriers that people face in entering formal sector employment in each country, the ways in which these barriers might be removed and potential facilitators.</p> <p>The workshop participants identified the need for a holistic, multi-pronged approach, tackling both supply and demand issues. Priorities included building partnerships across private, public and civil society organisations to promote inclusive employment; enhancing the skills of disabled people to access formal employment; working with employers to make their practices inclusive; strengthening capacity of the disability movement to support disabled people to realise their right to work; and working with governments on inclusive employment policies and their implementation. Plans for the interventions based on these findings will be introduced.</p> |
| Angel Perez | Technology based solutions for the inclusive employment of persons with disabilities in Bangladesh and Kenya | Angel Perez; Ola Abu Alghaib; Sakunthala Mapa | <p>People with Disabilities (PwD) experience higher levels poverty and socioeconomic disadvantages, resulting in low rates of employment. Economic and technological advancements are often underutilised, leaving behind PwD. The Innovation to Inclusion (I2i) programme conducted a series of studies to assess the impact of digital and technology-based interventions at work, aimed at addressing access barriers and support PwD in employment in Kenya and Bangladesh.</p> <p>A mixed methods approach was carried out to understand assistive and digital technology use and availability, with participatory/action research involving disabled people organisations (DPOs) and AT users. The study aimed to address the following research questions; What are the barriers to access assistive technology within the private sector faced by PwD?; What type of technology solutions are required to support PwD in employment?; What are the barriers to access employment faced by PwD which could be overcome through technology interventions?</p> <p>The business case for involving PwD in the workforce has led many employers to offer AT-related support to employees with disabilities. Advancements in mainstream and AT, increasingly positive trends in device use, Internet use and literacy levels, growing</p> |

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| | | | <p>availability of job opportunities within the ICT sector are also influential enablers addressing access barriers to employment. I2i will develop, test and validate promising technology solutions identified to address access barriers to employment.</p> <p>The studies recommends further work be carried to investigate AT usage alongside its existing service range in four areas; adopt an online digital presence; adopt and adapt current AT and technology based solutions; contain AT products, services and systems endorsed by and renowned by PwD; and use available online as well as traditional face-to-face services.</p> |
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| Politics and Empowerment | | | |
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| Presenter | Title | Authors | Abstract |
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| Bhavisha Virendrakumar | Disability inclusive elections in Africa: A systematic review | Bhavisha Virendrakumar, Elena Schmidt, Emma Jolley | <p>Background The right to vote is critical to democracy. The United Nations Convention on the Rights of Persons with Disabilities advocates for equal opportunities for participation of people with disabilities in political life, but evidence on experiences and practices of political participation of people with disabilities in low income settings is limited. This systematic review aimed to identify and synthesise evidence on political participation of people with disabilities in Africa region.</p> <p>Methods All main electronic databases were searched for published literature. Relevant websites and experts were contacted to identify unpublished sources. Studies were included if they contained empirical data, were written in English, French or Portuguese, focused on political participation of people with disabilities, were conducted in Africa and were published from 2006 onwards. Two reviewers independently extracted data and appraised the quality of the studies.</p> <p>Results In total, 54 documents were included. The studies were diverse in design and content, nine focused on the region; and 45 were country specific. The findings suggest that although most African countries ratified disability-focused legislation, its implementation varies greatly. Challenges experienced by people with disabilities described in the literature were broadly categorised into three groups: (i) lack of education and financial resources; (ii) stigma and negative social attitudes; and (iii)</p> |

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| | | | <p>inaccessible physical infrastructure. Specific interventions to support inclusive political processes were described in several documents but the theory of change underpinning these interventions was generally poorly articulated and the effect of interventions was not reported.</p> <p>Conclusion</p> <p>There is a paucity of high quality studies on political participation of people with disabilities in Africa and particularly the effectiveness of interventions to improve the inclusiveness of political processes. Governments and international NGOs should be encouraged to use rigorous methods to evaluate the impact of interventions they support.</p> |
| Vladimir Pente | Political participation and disability in Cameroon and Senegal: a cross sectional population based survey | Vladimir Pente; Rachel Murphy; Karen Smith; Ezekiel Benuh; Joseph Oye; Emma Jolley and Elena Schmidt | <p>Background and objective</p> <p>This study aimed to measure the level of political participation of people with disabilities in urban areas of Cameroon and Senegal and investigate to what extent these countries deliver on their legal obligations under the United Nation Convention on the Rights for People with Disabilities.</p> <p>Methods</p> <p>A cross-sectional household survey was conducted in 4 cities in Senegal and 3 cities in Cameroon. Household residents of voting age were eligible for inclusion. Several aspects of political participation we measured, including: registered to vote, ever voted and registered with a political party. Disability was assessed using the Washington Group Short Set of questions.</p> <p>Results</p> <p>A total of 3,761 people in Cameroon and 3,874 people in Senegal participated in the study. Disability prevalence in the sample was 16.5% and 11.7% respectively. Multivariate analyses revealed that people with disabilities were less likely to be registered to vote in both Cameroon (aOR=0.55; 95%CI [0.38-0.81]) and Senegal (aOR=0.60; 95%CI [0.43-0.85]) and were less likely to report that they had ever voted but only in Senegal (aOR=0.68; 95%CI [0.48-0.96]) but no differences observed in Cameroon. People with disability were also less likely to have a birth certificate in both countries (aOR=0.65; 95%CI [0.48-0.89] and aOR=0.56; 95%CI [0.34-0.93] respectively).</p> |

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| | | | <p>Conclusion</p> <p>This study is one of the first to provide empirical evidence on the extent of participation of people with disabilities in political processes. It highlights that gaps in political participation between people with and without disabilities do exist and calls for urgent actions to address these inequalities.</p> |
| Ana Maria Sanchez Rodriguez | Scaling for social change and inclusion of persons with disabilities- a case study in Lao PDR | Ana Maria Sanchez Rodriguez | <p>The purpose of this paper is to critically analyze how scaling happens in a small organization working to improve the live conditions of persons with disabilities, and it will do so using empirical data from an ethnographic qualitative research conducted in Lao PDR from 2018 to 2019. This study is part of larger research on scaling social community innovations in the context of Lao PDR.</p> <p>Scaling is influencing, repeating, adapting and ensuring social change, and as such it relies in different factors, making it complex and hard to attain. Scaling is also not a linear process that takes a single path, it is embedded in multiple complex systems, which makes it difficult to anticipate and to plan for any organization. Furthermore, every organization goes through a unique process that is influenced by the context where they work in. This research focuses in small organizations that work with vulnerable populations such as persons with disabilities, filling the gap of limited research on scaling social community innovations for persons with disabilities. The first part briefly explores a conceptual framework that addresses four types of scaling and a four-stage model to scale. The second part describes the Association for Autism as a case study, an organization working in Lao PDR, to demonstrate how scaling is happening. In the end, the discussion aims to raise awareness of the organizational difficulties to achieve social change and promote inclusion for persons with disabilities through scaling.</p> |
| Parent Support | | | |
| Presenter | Title | Authors | Abstract |
| Angelique Keste | Grassroots, family-based services for children with | Angelique Kester, Léa Guignard, Adri | <p>Background:</p> <p>In their impact study on the Liliane Foundation's support to children with disabilities and their caregivers, Holle et al. (2013) report a significant positive effect on their lives.</p> |

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| | neurological disorders and their families at home in Uganda: an intervention study. | Vermeer, Kenneth Nangai | <p>However, the study also identifies opportunities for improvement in the quality of care, such as by connecting children, caregiver, and other stakeholders, exchanging experiences and knowledge, as well as providing more knowledge and skills for mediators such as local partners and fieldworkers. Thus, the STEP pilot, which stands for Support Tools Enabling Parents, was initiated for fieldworkers from four African countries. STEP is an intervention package consisting of three training loops and supportive coaching tools.</p> <p>Methods: A pilot intervention study was carried out on the effect of STEP on the lives of children with a neurological disorder (mostly Cerebral Palsy), caregivers and fieldworkers, in Uganda. Eleven case studies were selected. Data was collected for each of these children, their respective caregivers, and fieldworkers before the launch of the pilot, during, and at the end in June 2019. Quantitative and qualitative evaluation methods were used: COPMs, caregiver surveys, and training questionnaires. In addition, log books were reviewed as well as field notes from trainers. Preliminary outcomes were discussed in focus groups with fieldworkers and caregivers.</p> <p>Results: An increase of daily skills of the child was found as well as an increase in knowledge, confidence, and skills of the caregiver and the fieldworker. The study showed STEP is a good start in providing home-based services provided that these, along with hospital-based services, are connected and that referrals to specialists, parent support groups, and income generating programmes are made when needed</p> <p>Conclusions: STEP had positive outcomes on the lives of children, caregivers, and fieldworkers. The study led to recommendations for the upscaling of STEP to other local organisations within the pilot countries and beyond.</p> |
| Heather Michelle Aldersey | Assessing Priority Support Needs of Families of Children | Heather Michelle | Families are often the first and most enduring support for persons with disabilities. This is particularly the case in low- and middle-income countries where there is often less access to or availability of formal supports for persons with disabilities and their |

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| | with Disabilities in Addis Ababa, Ethiopia | Aldersey & Ansha Nega | families. This presentation will share the results of a study that explored the disability-related needs of families of children with intellectual and developmental disabilities attending a special school in Addis Ababa, Ethiopia. Using an exploratory qualitative descriptive approach, we conducted semi-structured interviews with 16 family members (five biological fathers, nine biological mothers, one adoptive mother, and one aunt) to understand (a) how they currently meet their disability-related support needs; (b) their most pressing unmet disability-related support needs; and c) their perception of their present capacity to meet those disability-related support needs. Findings demonstrated that families draw from range of sources to meet their needs, including their own family, charitable and religious organizations, peer networks (e.g., other parents who have children with disabilities) and government sectors. Pressing unmet needs included various emotional, instrumental, financial, and informational needs. Families expressed significant challenges in meeting their present disability-related support needs. We anticipate that the findings of this exploratory study will provide evidence for family advocacy and public policy change. These findings will also help to guide the development of future larger-scale participatory action research projects with family leaders in the community for the design and implementation of evidence-based solutions. |
| Karen Bunning | Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms | Karen Bunning, Joseph K. Gona, Charles R. Newton 7 Sally Hartley | Background: Bringing up a child with disabilities in a low-income setting is challenged by inadequate resources, limited psycho-social support and poverty. Not surprisingly, many caregivers experience fatigue, distress and isolation. To address and investigate these issues, action was taken to set up twenty self-help groups focusing on caregiver empowerment. Methods:A realist evaluation design was adopted to evaluate impacts associated with the self-help process and to identify mechanisms determining the outcomes. Monthly monitoring visits were conducted to the groups during a ten-month set-up period, at the end of which eleven active groups of caregivers remained, nine having dissolved due to disputes, corruption and extreme environmental conditions. A facilitated intervention was delivered to the eleven active groups (N=154) over a six-month period. The members were guided to review and discuss topics such as economic empowerment, personal situation, peer support, community inclusion, access to health and education. Evaluation employed mixed methods using questionnaires (n=75) and semi-structured interviews(n=32) pre- and post-intervention. Results: The |

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| | | | burden of caregiving, (characterised by aloneness, challenges, stigma and discrimination), was transformed towards caregiver agency (defined by togetherness, capacity-building, acceptance and well-being). Impacts associated with caregiver perceptions included increased social support, reduced severity of child's disability and decreased impact of extrinsic factors affecting the caregiver's role. Mechanisms of 'handling goods and money' and 'social ties and support' appeared to underpin the outcomes. Conclusions: This study contributes to the evidence relating to self-help groups recommended in the World Health Organisation guidelines for community-based rehabilitation. |
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Workshop 3: 11:30-13:00, Wednesday 6th November 2019

| Poverty and Voice | | | |
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| Presenter | Title | Authors | Abstract |
| Morgon Banks | Impact of the Disability Allowance in the Maldives | Shaffa Hameed, Morgon Banks, Sofoora Kawsar, Hannah Kuper | <p>Introduction:</p> <p>Social protection is an important strategy for addressing poverty amongst people with disabilities in many low and middle income countries (LMICs), including in the Maldives. This study aims to assess the impact of the Disability Allowance on poverty, quality of life and participation of people with disabilities and their families.</p> <p>Methods:</p> <p>A quasi-experimental study design was used, with analysis through difference-in-difference. Participants were recruited in 2017 through a nationally-representative population-based survey of disability (Washington Group Extended Set). All participants in the survey identified as having a disability (n=380) were matched by age-sex-location to a person without disabilities (n=331) as part of a nested case-control study. Additionally, new recipients to the Disability Allowance were recruited through routine enrolment (n=171).</p> <p>At endline, participants were revisited and asked similar questionnaires as in baseline. Primary outcome indicators include consumption poverty, quality of life (WHO QOL-BREF) and participation (SINTEF scale).</p> |

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| | | | <p>Further, semi-structured qualitative interviews were conducted at baseline and endline with people with disabilities who were and were not receiving the Disability Allowance.</p> <p>Results:</p> <p>Endline data was collected in April-June 2019 and analysis is ongoing. Multivariate regression analysis will compare outcome indicators between new recipients of the Disability Allowance compared to people without disabilities and people with disabilities not receiving the Allowance. Thematic analysis of qualitative data will be conducted.</p> <p>Implications:</p> <p>Results will inform the design and delivery of social protection both in the Maldives and internationally.</p> |
| Mohammad Rashidul Islam | Poverty Graduation Model targeting persons with disabilities from extreme poor families: RCT baseline findings from Bangladesh | Shakhawat Hossain, Sudarshan Neupane, Rashidul Islam, Shahadat Hossain, Aude Brus, Angela Kohama | <p>The work presented is part of a project of Humanity & Inclusion's Bangladesh office under a UK Aid Direct Project, which is a multifaceted graduation program. It has incorporated livelihood, social protection and promotion components, with the goal of sustainably "graduating" persons with disabilities sustainably from social safety nets to sustainable income generation. Innovations in targeting and selecting the beneficiaries with disabilities living in the extreme poor households were used introducing a range of 14 multidimensional extreme poverty indicators. HI aims to conduct a research to evaluate the impact of this Project using a Randomized Evaluation.</p> <p>The sample for the baseline survey was selected to be statistically representative of the Project. The Random Control Trial approach is the experimental research design, which comprises both treatment and control groups. Training, pretests, and pilot tests were conducted to test the questionnaire and ensure the preparedness of the data collection team. Fieldwork took place during a four-week period from February, 2019. Interviews were conducted in 686 households (242 treatment household , 444 control households). Randomization was conducted at the household level. A qualitative study was conducted concurrently with the household survey (i.e., February 2019). It took place across 2 upazilas (sub-districts) and consisted of 12 IDIs, 16 FGDs and 8 KIIs.</p> <p>All households are living below the USD2 per day income poverty line; 69% are unable to meet their basic needs, around 24% people with disabilities were affected by other</p> |

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| | | | <p>health issues. All this indicate challenges for the extreme poor families that have a member with disabilities to graduate out of extreme poverty.</p> <p>The same approach will be replicated at the endline in 2021. At this time, researchers will apply the difference-in-difference methods for measuring impacts of the Project. The first information generated has been used to identify strategies to promote resilient livelihoods.</p> |
| Meenraj Panthee | Strengthening the voices of Adolescent with disabilities. | Meenraj Panthee (Inclusion specialist), Plan International Nepal. | <p>This research, commissioned by Plan International, CBM and London School of Hygen and Tropical Medicine was carried out by trained adolescents with disabilities having backup support by research experts in the year of 2018. The aim of the research was to understand what was important for the well-being of adolescents with disabilities (AWD) in Nepal. This research gathered information from a total of 52 young people 14-19 years old across four districts in Nepal through in-depth interviews, Focus group discussions and interview with 12 parents and teachers.</p> <p>Some of the key findings:</p> <p>A supportive family is extremely important for AWD. Many feel loved and cared for by their family. For some young people, there is a communication gap, especially for young people who are deaf. Many AWD describe a difficulty in transitioning to secondary school due to distances to travel compared to attending a local primary school. It was found issue of poor quality education, lack of accessibility. Sports activities in schools are not inclusive, or little or no sports is provided to them, even in special school settings.</p> <p>Early Marriage and Disability: Children are vulnerable to many forms of violence and child marriage is one of them. However, there is limited knowledge and understanding of the phenomenon of child marriage among Children with Disabilities; whether it affects them and if so, how? Therefore, an exploratory research was conducted in Nepal sometime ago commissioned by Plan International Norway, first to understand if at all disabled children are affected by child marriage, and if so,how? It was found that a large number of disabled children are impacted by child marriage due to a variety of reasons and hardship is further.</p> |

| | | | I will make a detail presentation on findings of here mentioned both researchs along with efforts of Plan International Nepal to use of research findings in the conference. |
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| Rehabilitation and Assisive Technology | | | |
| Presenter | Title | Authors | Abstract |
| Sureshkumar Kamalakannan | Non- Inclusive Health system for Disability Inclusive Development: Lessons from India | Sureshkumar Kamalakannan Shailaja Tetali Jayanthi Sagar | <p>Background: Disability inclusive development is an immense challenge for India, the second most populous country in the world with 1.3 billion that believes to have only 2.1 % of persons with disabilities (PWD). Several advances have been made to strengthen and improve the existing health system in the country with primary focus on the health care demands imposed by demographic, socio-cultural and epidemiological transitions. However, there is no scientific evidence about the inclusiveness of the health system to address the rehabilitation and care needs of the PWDs.</p> <p>Methods: Literature review was carried out to investigate this and obtain in-depth insights.</p> <p>Results:</p> <p>Rehabilitation Service Delivery: The concept of disability rehabilitation was restricted physiotherapy services at government tertiary hospitals and private hospitals located in urban areas. Child development centers (non-regulated) managed by individual or a couple of child development professionals are exponentially increasing in the Indian cities.</p> <p>Rehabilitation Workforce: Very few academic institutions run standardized academic courses related to disability, rehabilitation and social care. There is an acute shortage of allied health workforce in the country.</p> <p>Disability information system: There is paucity of evidence and data related to disability in India. Discrepancies in terms of the exact prevalence of disability (15% Vs 2%) exist.</p> <p>Access to assisive technology: Most of the assisive technology available for PWDs are related to lower limb orthoses, prosthesis and basic model wheelchairs. Available</p> |

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| | | | <p>products are not affordable. Outdated equipment like axillary crutches and clubfoot boots are still in use.</p> <p>Health System financing: There is not a specific budget or allocation for each states in terms capacity building, training and service provision for PWDs in either public or private health care systems.</p> <p>Leadership and governance: There is no coordinated efforts between the department of health and social welfare. Much of the benefit that is provided are not accessible by PWDs. There is no regulation for institutional training, service provision, practice, professions related to providing care and support for PWDs.</p> <p>Conclusions: The existing health system must be inclusive of a responsive system for Disability rehabilitation and social care for PWDs in India.</p> |
| Tess Bright | Assessing need for ear and hearing services in Malawi using the rapid assessment of hearing loss survey protocol | Tess Bright, Wakisa Mulwafu, Mwanaisha Phiri, Hannah Kuper, Islay Mactaggart, Jennifer Yip, Sarah Polack | <p>Introduction No previous population-based surveys of hearing loss in Malawi have been conducted. Population-based data is required to plan services. A Rapid Assessment of Hearing Loss (RAHL) protocol has been developed to obtain this data in a more rapid and low-cost manner than conventional all-age surveys. This study aimed to i) estimate the prevalence and likely causes of hearing loss in people aged 50+ in Ntcheu district, Malawi using the new RAHL survey protocol ii) field test the RAHL protocol in a rural African setting.</p> <p>Methods A cross sectional population-based survey was conducted in November 2018. 38 clusters were selected using probability-proportionate-to-size sampling. Within each selected cluster, 30 people aged 50+ were selected using compact segment sampling.</p> <p>All participants underwent a hearing screening using smartphone-based audiometry (hearTest). Thresholds were obtained at 500, 1000, 2000 and 4000Hz. Otoscopic examination alongside a structured questionnaire was used to assess likely causes. Prevalence was estimated using WHO definitions of \geqmild and \geqmoderate hearing loss in</p> |

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| | | | <p>the better ear (pure tone average >25dBHL and >40dBHL respectively). Those who had identified hearing loss or ear disease were asked about previous care-seeking, and barriers to access. The time to complete the protocol on each person was recorded.</p> <p>Results 1080 of 1153 (93.7%) eligible participants completed the survey. Prevalence of ≥mild hearing loss was 35.6% (95%CI=31.4-40.1); and ≥moderate 9.9% (95%CI=7.8-2.4). The majority was likely sensorineural in nature. The main barriers to accessing services included lack of awareness of need and service availability. Hearing aid coverage was <1%. The survey was completed in 24 days. The median duration per participant was 26.7 minutes (IQR=18.8-75.30).</p> <p>Conclusion The need for services in Ntcheu is high. The RAHL is simple, quick and provides information about the magnitude and likely causes of hearing loss which can be used to plan and monitor services.</p> |
| Dorothy Boggs | Estimating assistive technology need through population-based surveys; an analysis of data from Cameroon & India and overview of proposed tool | Dorothy Boggs Sarah Polack | <p>Background: According to the World Health Organisation 1 billion people globally are in need of assistive technology (AT). However reliable, comparable data on population-level AT need in different settings is lacking hindering service planning. Improved survey methods are needed to close this data gap. Different approaches to estimating AT need in population-level surveys exist including self-report and detailed clinical assessment. This study will i) estimate AT need related to vision and hearing impairments in The Gambia and ii) explore the relationship between self-report and clinical assessment approaches.</p> <p>Methods: Approaches to estimating AT need related to vision and hearing have been identified through literature review and expert consultation. We will analyse data collected as part of The Gambia National Eye Survey conducted February-July 2019. Survey participants (n=10,800) aged >35 years, selected using standard sampling methods, are being screened for vision and hearing impairment, self-reported AT use and unmet need.</p> |

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| | | | <p>Participants with vision and hearing loss are being assessed by a clinician to determine cause and service needs, including glasses and hearing aids.</p> <p>Results: We will describe advantages and disadvantages of different methods used for estimating population level AT need. Using The Gambia survey data, we will estimate the need, unmet need, coverage and awareness of each AT product stratified by age, sex, socio-economic status and impairment severity. We will also explore the relationship between data on AT need captured through clinical assessment and through self-report.</p> <p>Conclusions: There is a need to close the AT data gap by building up the evidence base, and the data on estimated AT in The Gambia will allow for evidence-based policy making and planning of appropriate services. Development of survey tools in the SDG era to estimate AT need, unmet need and coverage will play a key role in data collection and monitoring progress towards 2030.</p> |
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Stigma

| Presenter | Title | Authors | Abstract |
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| Chandalin Vongvilay | Prevalence and attitudes towards disability in Laos: Informing World Education Laos' CBID approach through findings from a household survey | Wesley Pryor, Liem Nguyen, Chandalin Vongvilay, Donna Koolmees*, Alounny Keosouvanh, Chantavad Nalesouphan, Somphet Keovongxay | <p>Background National disability surveys in Lao PDR in 1994 and 2005 respectively, found 7% and 1% of the population have a disability. Using a screening process and comprehensive questionnaire, prevalence and correlates of disability, as well as community attitudes were studied in two districts. The study provided both a baseline for the USAID Okard Community Based Inclusive Development (CBID) demonstration model districts, and valuable information to refine the approach, and these combined will be the focus of this paper.</p> <p>Methods Approximately 7000 people were screened from 15 villages in two districts. A household survey determined basic sociodemographic characteristics and categorised persons as at risk of disability, or no risk of disability using the Washington Group Short Set, using 'a lot of difficulty' or greater in any domain as a cut-off. Second stage sampling determined</p> |

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| | | | <p>eligible persons with and without risk of disability, for a comprehensive questionnaire. The questionnaire comprised modules about general information and consent, sociodemographics, health information, wellbeing, access to community, and knowledge and attitudes on disability. We used age-appropriate modules for age groups 5-9, 1-14, and 15+). 648 people including 301 males (age 43.9±22.7) and 347 females (age 42.7±22.9) were surveyed.</p> <p>Results Our presentation will report findings including prevalence and correlates of disability, relative access to services, and community attitudes to disability. We will briefly outline how the findings have informed CBID programming in the USAID Okard Activity.</p> <p>Conclusions We have employed robust population-level assessments to understand disability in Laos and inform the project’s CBID approach.</p> |
| <p>Maria Zuurmond</p> | <p>Exploring stigma and discrimination related to cerebral palsy in Burkina Faso</p> | <p>Maxime Compaore, Carole Bambara Congo, Félix Compaore, Lenie Hoegen Dijkhof, Sarah Polack, Cally Tann, Maria Zuurmond.</p> | <p>Background Levels of stigma and discrimination experienced by children with disabilities and their families in West Africa is high. This qualitative study explored experiences of stigma among caregivers of children with cerebral palsy in Burkina Faso in order to identify possible approaches to mitigate the levels of stigma experienced, and to gather data for advocacy.</p> <p>Methods A total of 38 in-depth qualitative interviews and two focus group discussion were conducted with family members (of children with cerebral palsy, as well as community members. A participatory workshop with 31 key stakeholders was held to review the research findings and discuss locally relevant responses</p> <p>Results Key drivers of negative attitudes and discrimination are a lack of understanding the causes of cerebral palsy and deep-rooted prejudices (e.g. attributing it to punishment from god, fault of mother), the level of independence of the child, and poverty. The impact is social exclusion, often hiding disabled child at home, forced migration, feelings of guilt and anxiety, and loss of income. Positive examples of family and community</p> |

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| | | | <p>support promoting child participation were also identified. Proposed strategies identified were multifaceted, from the family to the policy level .</p> <p>Conclusions</p> <p>There is a need for a multi-faceted and context specific interventions to address the different and interacting types and levels of stigma and discrimination evident in this setting.</p> |
| Ruth Nalugya | Developing a multi-level intervention targeting disability stigma with children with cerebral palsy and their families in Uganda | *Ruth Nalugya, Maria Zuurmond, Prof. Janet Seeley, Prof. Cally Tann. | <p>Background</p> <p>Family and community members have an influential role in perpetuating or reducing stigmatizing attitudes towards disability. Our aim was to build the evidence and understanding on experiences of stigma related to children with cerebral palsy (CP) in Uganda to inform the development of a parent training module on stigma.</p> <p>Methods</p> <p>We used in-depth interviews (IDI) and focus group discussions (FGD) with purposively selected caregivers and community members from two districts in Uganda. 24 IDIs (16 caregivers, 6 community members) and four FGDs comprising of 6-8 primary care givers were conducted between March-May 2019. Data were transcribed and thematic content analysis conducted. A workshop was held to share findings and explore approaches addressing childhood disability stigma. A training module was developed and will be piloted in July 2019.</p> <p>Results</p> <p>Children with CP and their families experience stigma at family, community and service providers level. Cultural-perceptions, limited medical services, and lack of information on the cause and management contributed towards stigmatization. Most of the participants mentioned feelings of worthlessness, contempt, denial of services, relationship breakups, economic insecurity, social exclusion and labeling, and compromised quality of life because of stigmatization. Approaches identified during the workshop to address stigma included economic empowerment activities within families and communities, peer-to-peer parent support groups, engagement of male figures, and regular community engagement meetings with key stakeholders.</p> |

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| | | | <p>Conclusions</p> <p>Stigma affects the physical, economic, and psycho-social well-being of CP children and their families. There is need for a social ecological approach to stigma-targeted interventions at all levels.</p> |
| Wash and Girls | | | |
| Presenter | Title | Authors | Abstract |
| Islay Mactaggart | Water, Women and Disability in Vanuatu: Results from a mixed methods study | Islay Mactaggart, Jane Wilbur, Phil Sheppard, Luke Bambery, Relvie Poilapa, Judith Lakavai, Headly Aru, Sannine Shem | <p>Background:</p> <p>Access to safe drinking water, sanitation and hygiene (WASH) are essential to human health and well-being, but may be inaccessible to over a billion people with disabilities globally, including across the Pacific. Access to WASH is particularly important for menstrual hygiene management, and for those who experience incontinence. Persons with disabilities who menstruate or experience incontinence may find it more difficult to access safe WASH for a variety of reasons including physical inaccessibility, taboos or attitudinal barriers.</p> <p>Methods:</p> <p>We undertook a mini-census of disability and WASH in two provinces of Vanuatu: Torba and Sanma, combined with 1) a quantitative case-control study and 2) an in-depth qualitative study of menstrual hygiene and continence management. All eligible household members across the two provinces aged 2+ were assessed for disability status using the Washington Group Short Set. Participants identified to have disabilities and age-sex matched controls were invited to participate in the nested case-control study to determine WASH needs and access. Participants from the nested case-control study were selected purposively for enrolment into the qualitative component.</p> <p>Results:</p> <p>Data analysis is ongoing. Of 48,667 respondents aged 2+ enumerated across the two provinces, all-age disability prevalence was 2.7% (95% CI 2.5 – 2.8), increasing with age to 8.3% (7.6 – 8.9) in the population 50+. 864 cases and 703 controls were enrolled in</p> |

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| | | | <p>the nested case-control study. Only 15% of participants had access to safely managed water, which did not differ by disability status. However, households with a person with a disability were twice as likely to practice open defecation, and persons with disabilities were three times as likely to come into contact with faeces or urine whilst using the toilet. Women and girls with disabilities were twice as likely to miss activities because of their period. Qualitative data collection is ongoing, with results pending for inclusion in this manuscript.</p> <p>Conclusions:</p> <p>Access to safe WASH in Torba and Sanma provinces is low across the population, and lower for persons with disabilities. Inclusive WASH programming is urgently needed to support the whole population and particularly people with disabilities in accessing safe WASH.</p> |
| Jane Wilbur | Feasibility study of a menstrual hygiene management intervention for people with intellectual impairments and their carers in Nepal | Jane Wilbur, Thérèse Mahon, Belen Torondel, Shaffa Hameed, Hannah Kuper | <p>Background: The Bishesta campaign is a menstrual hygiene management intervention that aims to meet the specific requirements of people with intellectual impairments and their carers. It was designed and delivered in the Kavre district, Nepal. This paper explores the campaign's feasibility and acceptability.</p> <p>Methods: The Bishesta campaign was delivered to ten people with an intellectual impairment and their eight carers. Data on the feasibility and acceptability of the intervention was collected through: structured questionnaire to participants before and after the intervention, process monitoring data, post-intervention in-depth interviews with all carers; key informant interviews with all facilitators and staff involved in the campaign, as well as ranking of the perceived appropriateness and acceptability of campaign components carers and facilitators.</p> <p>Results: The Bishesta campaign is acceptable for the target groups, facilitators and implementers. Participants used most of the campaign components; these made the target behaviours attractive and enabled participants to carry them out with ease. The campaign was implemented as planned and there have been improvements across all</p> |

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| | | | <p>target behaviours. The focus of this study was feasibility, not limited-efficacy. However, indicative positive outcomes from this small sample were observed.</p> <p>Conclusion: Within the small sample size, the Bishesta campaign appears a feasible programme to ensure that one of the groups most vulnerable to exclusion from menstrual hygiene management interventions is not left behind.</p> |
| Mbuso Jama | Using disability data to adapt education programs in marginalised contexts - A Case Study from the Girls Education Challenge (GEC) Project in Zimbabwe' | Mbuso Jama, Senior Impact Adviser Andrew Ware, Technical Specialist Unit Manager | <p>Background This DFID funded project in Zimbabwe, GEC aims to improve the opportunities of 53,795 marginalised adolescent girls through supporting them to improve their learning outcomes. GEC is delivering four outputs focusing on whole school development, community-based education, leadership skills and community engagement. This paper presents the March 2018 baseline and potentially the midline findings (August 2019). It will cover experiences from the project on how disability data was used to refine the project design.</p> <p>Methodology A mixed-methods, quasi-experimental baseline study, with a sample of 3,500 learners from 37 treatment and 37 comparison schools was used. The Washington Disability Group, short set of questions which focused on functional difficulties was integrated into the caregiver, girl survey and learning assessments and data was disaggregated by disability.</p> <p>Results Baseline findings showed that about 10.5% of the girls had some form of disability, with the most common being the cognitive impairment at 4%. This was contrary to the National Statistics, which reflected that 2% of learners have some form of disability. Using regression, disability came out as a significant predictor of literacy and numeracy, at p-value < 0.01. Significant categories were hearing and cognitive impairment.</p> <p>Conclusions The project therefore concluded that there were more learners with disability than it had originally assumed. Using these findings, the project applied low-cost adaptations</p> |

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| | | | which included awareness raising among staff, teachers and partners and embedded disability questions in all monitoring tools and reporting. Teacher professional development materials were made more disability inclusive as part of the adaptation. |
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Posters

| Presenter | Title | Authors | Abstract |
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| Ben Thatcher | Source platform | n/a | <p>Source is involved within the Inclusion Works programme and is currently undergoing reconstruction. In a bid to make more researches and relevant personnel aware of Source's value to them, it would be a great opportunity for Source to have a poster presentation at this conference.</p> <p>What is Source? Source is an International Online Resource centre dealing with matters of Disability and Inclusion. It is designed to strengthen the management, use and impact of information on disability and inclusion in development and humanitarian contexts. Primarily aimed at practitioners and academics, Source features resources that reflect the experiences and priorities in developing countries and includes literature not readily available elsewhere. Source typically does not host resources itself; it provides links to access the resources elsewhere and hosts a smaller amount of resources where copyright permission has been granted.</p> <p>Source's main relevant value is its tagging system, allowing a simple search to find appropriate information in different contexts and in different thematic areas (this is currently being redesigned).</p> <p>Why use Source? As Source is aimed at academics and practitioners it offers the perfect platform to promote and disseminate free online resources, and also for anyone to find other freely available resources from across the web.</p> |

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| | | | <p>Sources remit overlaps multiple areas which the conference intends covers. In particular, the management, use and impact of evidence (and other information) e.g. displaying what evidenced exists.</p> <p>Happy to answer any more questions on Source, if you find it relevant for the conference.</p> |
| Sureshkumar Kamalakannan | Barriers in Accessing Public Transport Services by Persons With Disabilities in Hyderabad, India | Lakshmi Archana Yarasani Sureshkumar Kamalakannan | <p>Background: Globally 15% of the population lives with some form of disability. Persons with disabilities (PWDs) experience difficulty in accessing health care services compared to persons without disabilities. Access to transportation is considered a key barrier to access health. This study aimed to assess the barriers in accessing public transport services for persons with disabilities in Hyderabad.</p> <p>Objectives:</p> <ul style="list-style-type: none"> • To identify the availability of disabled friendly transport services in Hyderabad, • To assess the barriers for PWDs in accessing public transport services <p>Methods: The study followed a cross sectional –mixed methods approach with Quantitative techniques (observation check list) to assess the availability of disabled friendly services and Qualitative techniques (semi-structured interviews) for assessing the barriers experienced by persons with disabilities in accessing the transport services in Hyderabad city.</p> <p>Results: There is lack of public and private transportation services for PWDs in Hyderabad city. Several barriers experienced by persons with different kinds of disabilities were identified. Lack of information on the accessing existing transport services, architectural barriers for access public transport and lack of safe transport policies and programmes prove to be the key barriers.</p> <p>Conclusion: To empower PWDs and ensure their economic productivity, accessible and safe transport services are essential. The existing services are not inclusive to the needs of PWDs.</p> |

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| <p>Timothy O'Fallon</p> | <p>Exploring Access to Health-Related Rehabilitation Services for Persons with Disabilities in the Maldives</p> | <p>Timothy O'Fallon, Shaffa Hameed, Sarah Polack and Nicki Thorogood</p> | <p>Rehabilitation is an important component of health systems, especially in lower- and middle-income countries (LMICs), where, according to the WHO, 80% of persons with disabilities live. Of these, many could benefit from health-related rehabilitation services, including assistive technology. While evidence suggests there is a high unmet need for rehabilitation services, especially in LMICs, more research is required to gain a better understanding of the issues impacting provision of and access to rehabilitation for persons with disabilities.</p> <p>This research study explores access to rehabilitation services, including assistive technology, among persons with disabilities in the Maldives. Specific objectives of this study included: 1) estimating use of and unmet need for rehabilitation services among persons with disabilities; 2) exploring facilitators and barriers to access to rehabilitation services among people with disabilities; and 3) exploring strengths and weaknesses of the delivery of rehabilitation services from the service providers' perspective.</p> <p>A mixed methods approach was used to explore different aspects of access to rehabilitation services from both user and provider perspectives. This included a secondary quantitative data analysis and in-depth qualitative interviews with persons with disabilities and service providers on their perspectives regarding the barriers and access to rehabilitation services in the country.</p> <p>While specific and detailed results of this study are pending, the information collected thus far can be used to inform policy and programme planning in order to strengthen delivery of rehabilitation services in the Maldives and to contribute to the currently limited global data on this topic.</p> |
| <p>Mahbub Kabir</p> | <p>Plan2Inclusivize: Promoting Inclusion, Empowering Children with Disabilities and their Communities through Sports</p> | <p>Mahbub Kabir</p> | <p>Background: One billion people in the world are people with disabilities, with at least 1 in 10 being children and 80% living in developing countries (WHO, 2011). Despite several international human rights and humanitarian treaties, the majority of children with disabilities are still excluded from access to education and social and cultural spaces. Globally only 10% of children with disabilities are in school and only 5% finish primary school (UNESCO, 2017). Within any crisis-affected community and in times of crisis and conflict, children with disabilities are often excluded from humanitarian</p> |

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| | | | <p>assistance and are at a greater risk of neglect, injury and abuse (UN, 2011). Against this backdrop, Plan2Inclusivize (P2I) - a multi-agency collaboration between the UNESCO Chair “Transforming the lives of People with Disabilities, their Families and Communities, Through Physical Education, Sport, Recreation and Fitness” and Plan International launched to promote inclusion and social justice through sport.</p> <p>Implementation: P2I is a 5-day training that has been implemented in refugee camps in Jordan and Ethiopia, in emergencies context in Mali and in development context in Togo, Uganda, Pakistan, Guinea and Guinea-Bissau. Participants include key actors from education, social, disability, civil society and sports sector, having children, girls and boys with disabilities at the centre of their focus. A training-of-trainers ending with a simulation of disability-inclusive sports and an action plan to further implement the training are some of the key activities. The P2I package is available in English, French, Portuguese and in Arabic.</p> <p>Methods: P2I believes in the power of sport as a means to bring positive change. It believes that disability comes from society, not from the human body. Therefore, it aims to change society and social norms. The approach is light and fun. The P2I training uses an active and participative approach and consists of 3 related pillars: changing perception, learning inclusion and taking action.</p> <p>Conclusion:</p> <p>Perception changed in the community;</p> <p>Advocates for inclusion created in the community and government departments ;</p> <p>Multiplier effect: further training in the wider community;</p> <p>Inclusive Sport Taskforce/Working Group established;</p> <p>Demonstrated: sports promotes social inclusion and produces happiness, in any context</p> |
| Ebele Vivien Okoli | Unmet Rehabilitation Needs of Persons with Disabilities in Nigeria | 1st. Okoli, Ebele Vivien 2nd. Ossai, Edmund Ndudi 3rd. Onwuliri, Chinemerem Daniel | <p>Background: Article 26, Habilitation and Rehabilitation, of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) calls for appropriate rehabilitation measures to foster the full inclusion and participation of persons with disability in all aspects of life. However, the WHO Disability Report noted that global data on the need for rehabilitation services and the estimates of unmet need do not exist.</p> <p>Methods: This was a descriptive cross-sectional study conducted in Enugu State Nigeria to assess the Unmet Rehabilitation Needs of Persons with disability in Nigeria. The</p> |

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| | | <p>4th. Egbosionu, Udoka Donald</p> | <p>rehabilitation needs assessed were; Physical Therapy, Surgical/ Medical, Orthotic/ Prosthetic, Mobility device/ Service, Vocational, Mental Health, Educational, Social welfare, Housing, and Communication.</p> <p>Results: Of the 75 respondents, the Mean age was 33.3years. with a standard deviation of +/- 10years. 54.7% were female, a little over half were unemployed and just16 persons had received tertiary education. Almost all the respondents had physical impairment primarily; the most common cause being poliomyelitis. Visual, Intellectual and Hearing/ Speech Impairments were evenly distributed between the remaining 8persons. Social, Housing and Mobility rehabilitation were the highest reported unmet needs at 78.7%, 74,7% and 72% while nearly half of the respondents had unmet need for surgical, Orthotic/ Prosthetic, mental health and communication rehabilitation. Only 4 respondents had ever received mental health services.</p> <p>Conclusion: The respondents were mostly young and unemployed, with a nearly equal gender distribution and physical impairment. Social Rehabilitation was the most reported unmet need while Orthotics/ Prosthesis were the least reported unmet need.</p> |
| <p>Shubha Nagesh</p> | <p>Young girls with developmental disabilities in the Indian Himalayas- barriers to access and utilization of intervention services.</p> | <p>Shubha Nagesh, Amanda Dorsey</p> | <p>Research that explores disability and gender are limited in India, yet the few present speak loud about the double discrimination, impacting access and utilization of intervention services. In Dehradun, the capital of India's Himalayan state, prejudices and norms surrounding young girls are well understood. Data from the Latika Roy Foundation, a non-profit providing intervention services for children with a developmental disability, shows that a higher percentage of males utilize their services, and a higher percentage of females come for an initial assessment, but do not return. To further understand these families decisions to not access intervention services for their child's disability, and how gendered norms may be impactful, 24 families consented to participate in a home based interview. All the participants had been assessed to have a developmental disability at the Latika Roy Foundation, were aged 3-11 years, and are currently living in and around Dehradun. The results showed the families relatively reduced knowledge about the disability, lack of understanding about the urgency of early intervention, and yet a keenness to do everything possible for the daughter, with limitations in the form of remote locations, lack of available transportation, family structures that prevent utilization, and an overall tendency to defer seeking services. All the families reported</p> |

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| | | | <p>significant concern for their daughter with a disability and had a positive approach to the challenges they faced, though they had difficulties physically accessing services. The study data challenges the predominant dialogue around the intersection between gender and disability in the region, which conveys a double disadvantage.</p> |
| Shubha Nagesh | <p>Unearthing the hidden young girls with developmental disabilities from the Indian Himalayas</p> | <p>Dr Shubha Nagesh, Amanda Dorsey</p> | <p>In Dehradun, the capital of India's Himalayan state, prejudices and norms surrounding both young girls and individuals with disabilities stigmatize each population. We hypothesize that both biases interact to further impede access to intervention services for young girls with developmental disabilities. Data from the Latika Roy Foundation, a non-profit providing intervention services for children and families impacted by developmental disability in Dehradun, India, shows that a higher percentage of males utilize their services, and a higher percentage of females come for an initial assessment, but do not return. To further understand these families' decisions to cease continuation of intervention services for their child's disability, and how gendered norms may be impactful, 24 families in Dehradun, India that contain a daughter between the ages of 3 and 11 years with a developmental disability consented to participate in a semi-structured interview. In each case, the daughter was brought to the Latika Roy Foundation for an initial assessment, received a diagnosis, but then never continued accessing intervention services through any organization, as advised. The responses suggest that there is very little information about disabilities, the sense of urgency to seek early intervention is lacking, parents are ready to do anything for their daughters with disability, they would have done nothing differently had their child with the disability have been a son, and if supported with services closer to home, transport facilities, and local resources, they will avail intervention services for their daughters. As assumed based on available literature from the global south, the intersectionality between disability and gender can have parallel even positive perspectives, that allow for girls to be better taken care of by their families, as compared to boys, in families whose children have developmental disabilities. Access and utilization of intervention services can be better improvised by taking services closer to the homes!</p> |
| Ana Paula Corona | <p>Quotas law and profile of people with disabilities in</p> | <p>Ivy Cruz Faislon, Ana Paula Corona,</p> | <p>Background: The Quota law in Brazil grants 2-5% reservation in jobs for people with disabilities (PwD) in companies with 100 or more employees. Although this law was created in 1991, there are few studies about PwD employed in Brazil. The objective of</p> |

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| | the labor market in the state of Bahia, Brazil: a descriptive study | Veronica Maria Cadena Lima | this study was to describe the sociodemographic and occupational characteristics of PwD employed in the labor market in the state of Bahia/Brazil and to compare them with people without disabilities. We also aimed to verify if the Quotas law has been complied in the state. Methods: This is a descriptive study using a secondary database from the Ministry of Labor and Employment/Brazil in 2016. Results: Overall, 0.73% of workers in the Bahia were people with disabilities. Physical impairment was the most frequent disability among the employed population, followed by hearing and visual disabilities. The majority of workers, both with and without disabilities are men, non-white, aged 30-39, who are undertaking or have completed secondary education. Service, sales and commerce sectors, followed by the industrial goods sectors are responsible for the majority of jobs for both groups. Also, the majority of workers with and without disabilities earn between 1-3 times the minimum wage, have employment time over 3 years and work 31-44 hours per week. Conclusions: Workers with and without disabilities have similar sociodemographic and occupational profiles. The percentage of employed PwD is lower than the minimum established by the Quotas law, which indicates the need for an intensified surveillance to guarantee the rights of PwD in Bahia. |
| Yacobu Devabhaktula | DPO VOICES OF CONCERN RAISED THROUGH CITIZEN VOICES AND ACTION [CVA] WV India's experience | Jacob Devabhaktula- National Advisor, Disability Initiatives, World Vision India | According to census of India (2011) there are 26810557 persons with disabilities who include 14987101 males (55.9%) and 11823456 females (44.1%) who constitute 2.21% of the total population of the country. Data of persons with disabilities is a big issue in India. There is no accurate or reliable data on the prevalence of persons with disabilities. Preamble: World Vision India in partnership with state disability networks done 11 state consultations by involving totally 534 People with disabilities representing from 408 DPOs The key issues which were discussed include: education state & central government schemes and social inclusion. Process & Methodology: The consultation has adopted a 5 smiley scale score card starting from very good, good, ok, bad and very bad. DPO representatives mainly from World Vision program areas Observations & reflections: |

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| | | | <ul style="list-style-type: none"> • The consultations reveal that the delivery mechanism of the government is not that effective which it supposed to be. • There is no interdepartmental coordination to leverage schemes and programs. • Majority of the schemes are unreached to remote parts and rural areas of the country and persons with disabilities from rural areas are deprived of those services and facilities. <p>The analyses drawn from the findings clearly reveal that CWDs have still difficulty in accessing education due to various challenges; livelihood schemes and programs are rarely accessible to persons with disabilities; loans and credit is a distance dream; they are lookdown upon at public functions and ceremonies</p> <p>FINDINGS : The primary data collected during the consultation process of DPO representatives clearly reveal that:</p> <ul style="list-style-type: none"> • Majority of the DPO representatives of DPOs in majority of the states that education is rated very low • Majority of the representatives of DPOs from the majority of the states rated that access to livelihood opportunities is very limited • Majority of the participants felt that state and union schemes are not accessible • Majority of the participants strongly felt that the service providers attitudes is a hindrance • Majority of the representatives strongly felt that the stigma and discrimination is the biggest hindrance <p>Conclusions:</p> <ul style="list-style-type: none"> • Inadequate resource allocation and lack of political will ignoring the issues of persons with disabilities; • There are no specific awareness programs to raise the level of awareness about the talents and potentials which is a biggest hindrance; |
| Alison Marshall | The first ever global report on Deafblindness: at risk of exclusion from CRPD and SDGs implementation - | World Federation of the Deafblind and Sense International, with research | This is the first ever global report on the situation of people with deafblindness, some of the most marginalised, even within the disability community. The report, based on prevalence estimates of deafblindness for 22 countries, in-depth analysis of 11 countries, an academic literature review, and surveys, represents over 97.6 million people with deafblindness. Case studies show what is possible when |

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| | inequality and persons with deafblindness | input from ICED, LSHTM and support from IDA. | <p>people with deafblindness are listened to, have access to health, education and training, and are supported to participate fully in the life of their community. The report is framed within the CRPD and is structured in relation to the SDGs. The report presents quantitative and qualitative research on: poverty levels of people with deafblindness (SDG1); health such as the level of additional disabilities (SDG3); education levels and how far children with deafblindness are excluded from school (SDG4); gender issues (SDG5); levels of employment (SDG8); and estimates levels of inequality compared to people without disabilities (SDG10).</p> <p>The research found that the percentage of the world's population affected by deafblindness is greater than previously thought. Despite impressive achievements by individuals and specialist organisations, the report finds that the issues faced by persons with deafblindness have largely been ignored, and persons with deafblindness are being 'left behind', contrary to the principle underpinning the SDGs.</p> <p>The report's recommendations include increasing understanding of deafblindness among governments, consistent definition and measurement of deafblindness with collection of disaggregated data, as well as additional research.</p> |
| Goli Hashemi | Barriers to accessing primary healthcare services for persons with disabilities in low and middle-income countries, a meta synthesis of qualitative studies | Goli Hashemi, Hannah Kuper, Mary Wickenden, Tess Bright | <p>Access to healthcare contributes to the attainment of health and is a fundamental human right. Approximately 400 million people worldwide lack access to healthcare services, with a greater proportion of this population belonging to marginalised groups defined by age, gender, income, ethnicity, sexual orientation and disability. Persons with disabilities are believed to experience widespread poor access to healthcare services due to inaccessible environments, discriminatory belief systems and attitudes. Primary healthcare services are believed to meet around 80-90% the healthcare needs of people across their lifetime. While there has been an increasing number of research on access to primary healthcare services for persons with disabilities over the past decade, the qualitative data on these barriers have not previously been systematically reviewed.</p> <p>A systematic review and meta-synthesis of qualitative studies exploring barriers to primary healthcare services experienced by persons with disabilities in LMICs was undertaken. Included studies were analysed using a thematic synthesis approach. Findings suggest that the persons with disabilities' choice to seek healthcare services or not, is influenced by barriers in three core areas: informational, belief system, and</p> |

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| | | | <p>logistical. The results also indicate that in order to achieve full health coverage at acceptable quality for persons with disabilities, it is necessary not only to consider the individual barriers but their combined effect on persons with disabilities and their households. It is only when the cumulative impact of the barriers is considered that truly disability inclusive strategies and interventions can be developed to improve access to primary healthcare.</p> |
| Theresa Lorenzo | <p>A synthesis review of community based disability practitioners' facilitation of disability inclusive youth development in low and middle income countries.</p> | Theresa Lorenzo | <p>Background: The Sustainable Development Goals, UN Convention on Rights of Persons with Disability and the WHO's Community-Based Rehabilitation Guidelines propose that poverty reduction and social inclusion can be achieved through community-based inclusive development (WHO, 2010).</p> <p>Methodology: The synthesis review will involve three studies: 1. A participatory action research study of disabled youth enabling sustainable Livelihoods in South Africa (Lorenzo, Motau, van der Merwe, Janse van Rensburg and Cramm, 2014) 2. A collective case study that explored the work and living experiences of community-based workers across impoverished rural contexts in South Africa, Botswana and Malawi investigated strategies for poverty reduction and social inclusion (van Pletzen, Booyen and Lorenzo, 2014); 3. An exploratory, intrinsic study of five NGOs serving urban and rural communities in one province in South Africa (Lorenzo, McKinney, Bam, Sigenu and Sompet, 2018).</p> <p>Findings: Four themes emerged from the synthesis of three studies: The knowledge and insight of community-based disability practitioners in understanding disability inclusion is an essential resource that contributes to poverty reduction and social inclusion of persons with disability, especially in rural communities. The importance of family support and friendship networks for youth to access further training and development to succeed. The centrality of accessible communication and information, and complexity of coordinating services and systems at district level emerged. The valuable contribution of community based disability practitioners as research fieldworkers is shared.</p> |

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| | | | <p>Conclusion: The studies demonstrate that community-based disability practitioners facilitate access to health, education, livelihoods and social development at local government level.</p> |
| Klaus Minihuber | <p>Quality of Life of Persons with Disabilities in Southern Nations, Nationalities and Peoples Region, Ethiopia</p> | Judith Baart, Light for the World | <p>The Regional Government of SNNPR and the Ethiopian Center for Disability and Development are working together to improve the quality of life of persons with disabilities in the region by targeting multiple aspects simultaneously, such as health, education and livelihoods. A survey was carried out in 2018 to measure the current quality of life of persons with disabilities in SNNPR.</p> <p>We used a translated version of the WHO CBR Indicator questionnaire, and incorporated the Washington Group Short Set as our measure of disability. Data was collected in ten towns amongst 966 respondents.</p> <p>Key results included:</p> <p>Health. The majority regarded their health to be good (66%), but if they did need health care more than half indicated they were unable to get needed care, mostly due to the cost of the visit.</p> <p>Rehabilitation. Over half indicated needing rehabilitation care, but not receiving any. Mostly due to cost, but also because they did not know where to go, or the facility was too far away. Only a very small group said that they have a well-working assistive device.</p> <p>Education. Most adults have had no schooling or only primary school, with those with cognitive disabilities least likely to have any school.</p> <p>Livelihood. Adults with disabilities are likely to be self-employed if they have any work at all. 83% say they do not have enough money to meet their needs. A quarter indicate not deciding over their money.</p> <p>Social. 65% say they feel respected by their families, and only 38% feel respected by other people. Very few participate in community meetings. Only just over half belongs to a DPO.</p> |

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| | | | <p>Conclusion. Altogether, quality of life of persons with disabilities seems to be low in all aspects of life. However, large variation is seen amongst different genders as well different levels and types of functioning.</p> |
| Lauren Avery | Disability, Zika and Social Movements in Brazil | Lauren Avery | <p>The research aims to understand the priorities of the movements and organisations involved in citizen advocacy for children born with Congenital Zika Virus Syndrome (CZVS) in Brazil. The social movements led by families of children born with CZVS has attracted worldwide media attention. Considered ‘a thorn in the side of the government’ (Soares, 2018), the parents’ associations have organised themselves on behalf of their children’s rights to inclusion via access to public healthcare and transport, education and citizenship rights (União das Mães de Anjos, 2019; Damasio, 2016) and the rights of families to receive support as carers (Soares, 2018). The potential for the influence and impact of these movements’ on disability-inclusive development is yet unclear.</p> <p>The poster will present progress on a visual ‘mapping’ of the associations in a process to understand the location of movements, priorities, linkages, motivations and relationships. The mapping will show relationships between these organisations; with research organisations; and ideological alignment or affiliation with other rights movements, disability related or other. This mapping will help to investigate the constructed collective consciousness of these movements and identify and understand use of existing frames, e.g. civil rights, disability rights, religion, sexual reproductive rights. The research aims to explore the movements’ roles in highlighting disability rights issues in Brazil and how have they negotiated the right to care, treatment and education for their children.</p> <p>The project is part of an ongoing piece of research that aims to investigate the impacts of major epidemiological events on disability rights and disability-inclusive development.</p> |
| Elena Schmidt | Intersection of gender and disability: results of an exploratory | Soumya Mohanty (Sightsavers, India), Elena | <p>Background</p> <p>Despite legal provisions and policies, people with disabilities in rural India experience low levels of physical mobility and poorer access to services compared with people without disabilities, and women are particularly disadvantaged. Sightsavers India</p> |

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| | <p>qualitative study in India</p> | <p>Schmidt (Sightsavers, UK), RN Mohanty (Sightsavers, India), & Emma Jolley (Sightsavers, India)</p> | <p>undertook a study to investigate the gender-specific needs and barriers to inclusion for men and women with disabilities in community-based programmes.</p> <p>Methods</p> <p>We used a qualitative design with in-depth interviews to collect data. People with disabilities enlisted in social inclusion programmes supported by Sightsavers in States of Odisha, Madhya Pradesh and Rajasthan were sampled to ensure representation of both sexes, different types of impairments and different levels of involvement in local Disabled People’s Organisation (DPO).</p> <p>Results</p> <p>56 people with disabilities (28 men and 28 women) participated in the study. Both men and women reported that disability had a profound impact on their social participation and quality of life but women experienced more challenges. Women were more reliant on their parental families and had fewer opportunities to interact with external environment. Men with disabilities were more likely to report cases of discrimination in employment and access to financial services, while women reported feeling less valued and appreciated as workers. Women were also less likely than men to be engaged in DPO activities and trainings often due to lower levels of education and lower self-esteem.</p> <p>Conclusions</p> <p>The study helped to better understand the pathways through which men and women with disabilities are excluded from society in studied areas and identified a number of intrinsic and extrinsic factors that individually and in combination lead to exclusion. It is important that disability programmes recognise gender specific barriers and develop tailored approaches to support more equitable participation of people with disabilities in social inclusion programmes.</p> |
| <p>Martin Canter</p> | <p>Disability inclusion in complex environments: Theoretical models in practical programming</p> | <p>Dr Martin Canter</p> | <p>Opportunities for girls and children with disabilities (CWD) to engage in inclusive formal schooling is limited by issues of access and quality – not only for CWD to attend formal schooling, but for the provision of appropriate materials and training for teachers to address multiple needs in low-resource environments. The GATE GEC program in Sierra Leone works in conjunction with government and local partners to develop appropriate strategies for mainstreaming disability and gender inclusion. The purpose of this session is to deepen our understanding of affordance and constraints of this practical</p> |

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| | | | <p>application of inclusive strategies in a low-resource environment, and the implications of learning from programming for wider system change. Key questions are:</p> <ul style="list-style-type: none"> • Inclusion into what? How far does the ‘human rights model’ work to reduce the barriers to inclusion and promote opportunities for participation, rather than expecting disabled people to ‘fit in’ as best they can to existing formal systems? • How far do disability inclusion programmes address teacher capacity to address CWDs learning needs? • How far does disability inclusion programming focus on identifying disability (Washington Group questions) rather than addressing the root causes of exclusion or discrimination? |
| Emma Jolley | Monitoring inequalities in health service coverage: experiences of Mozambique, Tanzania, Pakistan and India | Guillaume Trotignon, Sandeep Buttan, Thomas Engels, Munazza Gillani, Muhammad Zahid Jadoon, George Kabona, R.N. Mohanty, Soumya Mohanty, Alemayehu Woldeyes, Elena Schmidt, Emma Jolley | <p>Background Achieving universal health coverage requires innovative monitoring approaches and rigorous but feasible indicators and tools to measure equity. This paper presents results of a meta-analysis of data from ten population-based surveys, which measured cataract surgical coverage alongside disability and wealth, as a proxy measure of equity of access to eye care services.</p> <p>Methods The surveys were conducted in three rural sites in India; one rural site in Mozambique, one rural site in Tanzania and four rural and one urban sites in Pakistan. A total of 28,000 records for adults aged 50 years and above were included in the analysis. Cataract surgical coverage was measured using a standardised approach, Rapid assessment of avoidable blindness (RAAB). The Equity Tool was used to measure relative wealth; and the Washington Group Short Set of questions on disability was used to measure disability.</p> <p>Results Results will be presented for two key outcomes, cataract surgical coverage and effective cataract surgical coverage, which takes into account participant’s quality of vision. Results of the univariate and multivariate analyses will be presented to explore the relationship between coverage and sex, wealth and disability.</p> |

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| | | | <p>Conclusions</p> <p>The study confirms recent calls for more refined approaches to measure equity and more specifically for integrating additional tools in to the standard RAAB methodology as an effective way of understanding complex dynamics around health service coverage.</p> |
| Diego Santana-Hernandez | <p>CBM's experience on Hearing Disability Inclusion Development: the road from global guidelines based on field evidence to implementation of national plans in Ear and Hearing Care.</p> | Dr Diego Santana-Hernandez | <p>Background:</p> <p>CBM applies participatory rights-based approaches and provides technical advice and practical support. Perspectives and experiences from the ground are included in relevant guidelines and tools, through involvement of technical advisors in international working groups.</p> <p>Methods:</p> <p>This presentation shares examples of CBM's experience in ear and hearing care (EHC), alongside partners working in limited-resources settings. It illustrates how facilitating an effective collaboration among stakeholders at global, regional and country levels; particularly to develop EHC comprehensive programmes, contributes towards Disability Inclusive Development.</p> <p>Results:</p> <ol style="list-style-type: none"> 1. Global advocacy as a prerequisite for local action: National EHC/ENT plans are developed in line with World Health Assembly resolution on prevention of deafness and hearing loss, of 2017. This milestone is key to hold governments accountable, it is the result of years of advocacy by civil society, in which CBM and partners played a substantial role. 2. Regional collaboration for networking and joint action: CBM has been instrumental in establishing high-level regional EHC discussion fora in Asia, America and Africa, alongside WHO. The aim is to provide a vehicle for accelerating development and implementation of EHC strategies through a region-wide approach. 3. Country level action within regional and global frameworks: |

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| | | | <p>Specific technical interventions, alongside partners and CBM Country Offices, facilitate involvement and commitment of Ministries of Health. The work of partners will ultimately reach into communities and contribute to change people's lives.</p> <p>Conclusions: This participatory multi-level and multidisciplinary approach has an effective long lasting impact because it is embedded into international and local frameworks and systems.</p> |
| Milan M. Markovic | Sexual and Reproductive Health of Women and Adolescent Girls with Disabilities | Gradimir Zajic; UNFPA Serbia, Organization for Support of Women with Disabilities ... OUT OF CIRCLE Vojvodina | <p>Data on sexual and reproductive health (SRH) of people with disability in Serbia are scarce. Within the joint project "Autonomy, Voice and Participation of Persons with Disabilities" supported by the UN PRPD, UNFPA in Serbia conducted research on the experiences of women with disabilities (WWD) in exercising their SRH rights.</p> <p>The research objective was to assess the awareness, attitudes and experiences of WWD related to their SRH and rights, focusing on three topics: availability of information on SRH; access to SRH services; and attitude towards marriage and family.</p> <p>Research was informed by two theoretical and methodological frameworks: the social model of disability and the human rights of persons with disabilities. Study participants were women aged 18-60, from urban and rural areas of Serbia, with different types of impairments. The research employed both quantitative and qualitative research methods, including questionnaire (162 respondents), ten focus groups and several in-depth interviews.</p> <p>Results showed that more than 40 % of WWD do not have access to quality information on SRHR. Only 19% knows how to get help in case of sexual assault. 27% of WWD are not satisfied with SRH care services and one third thinks that health workers have negative attitudes towards Wwd. One in fourteen of surveyed Wwd is not independent in deciding on marriage and family.</p> |

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| | | | <p>The future activities should be directed to education and capacity building of WwD to exercise their rights related to SRH, removing barriers to health care services and reducing prejudice in the communities.</p> <p>The research has served as a basis for evidence-based advocacy identifying number of recommendations concerning availability of information, access to health services and, awareness and attitudes towards sex, marriage and family.</p> |
| Lucy Delaney | CORE outcome sets for Zika/TORCH infection linking to ICF | | |