Disability in the SDGs: Forming Alliances and Building Evidence for the 2030 Agenda

18th-19th February 2016, London School of Hygiene and Tropical Medicine

Session Summary and Call to Action

Disability and SDGs – Plenary 1

Session Summary: The focus of the first plenary session was to set the scene for the Symposium through presentations on achieving disability inclusion in the 2030 agenda. This included presentations from the following invited Key Note speakers:

- *Alarcos Cieza, Coordinator of Disability and Rehabilitation World Health Organisation*
- *Catalina Devandras Aguilar, United Nations Special Rapporteur on the Rights of Persons with Disabilities*
- *Liz Ditchburn, Director of Policy Department for International Development United Kingdom*
- *Priscille Geiser, Head of Civil Society Handicap International*

Call to Action:

1. Persons with disabilities have **historically been invisible** in both the human rights and development discourses

2. The SDGs combine both **sustainability** and **development**, and **global partnerships** should be revitalised for sustainable development

3. **'Leave no-one behind'** is a unique promise, but we need to determine how to **translate** this promise **into reality –** for example national implementation of the SDGs must be underpinned by **disability-inclusive policies** that **address barriers** and **discrimination,** and **buy-in from mainstream actors**

4. There is an **urgent need with respect to disability inclusion** to
   a) Make the case
   b) Say what needs to be done
   c) Offer tangible entry points
   d) Demonstrate what works
   e) Translate results into policy

5. Access to equitable health services is a human right and **universal health coverage** (UHC) is a powerful tool to achieve this within the 2030 Agenda

6. **Collection and coding of data on disability inclusion** should be facilitated within official development assistance programmes.

Disability Measurement – Plenary 2

The Symposium's second plenary session concentrated on the measurement of disability in populations. Representatives from the World Health Organisation (WHO), Washington Group, International Centre for Evidence in Disability and SINTEF discussed the tools their teams had developed and the information these captured.

1. There is a need for **more good data,** and that data needs to be **comparable**

2. The WHO **Model Disability Survey** (MDS), the **Washington Group questions on functioning** and modules to identify **impairments** and **participation restrictions** all provide valuable information

3. Each methodology has its strengths and limitations; they address different questions and have different purposes; **they are complementary** rather than **duplicative**

4. It is important that all good quality data on disability is made available to stakeholders for **advocacy, policy formulation and planning of services,** and that these stakeholders are aware of the **information captured** by **different tools**

5. **Data disaggregation** can be achieved and should be promoted at the **programme level**

Evidence in Disability Inclusive Development – Plenary 3

The third plenary established evidence of good practice in disability inclusive development from Pakistan, India and Tanzania. This session also reinforced the universal right to health and presented the economic evidence on the costs of exclusion and gains of inclusion of people with disabilities.

1. There is **strong economic rationale** for the **inclusion** of persons with disabilities in addition to **rights-based arguments**

2. Engagement of **mainstream development actors** is imperative in ensuring **inclusive development** that is **not tokenistic**

3. Evidence from the eye health sector shows that **investment** in inclusive health must be for **entire health institutions** as opposed to specific departments to ensure **sustainability** and **universality of access.**

4. **Accessibility** of health and other systems requires **inclusive communication** in addition to **inclusive buildings**/physical access

5. The key to inclusive health is **strengthening** of the **public health system**

Access to Health and Rehabilitation – Workshop 1

This session included academic researchers and presenters from disability-focused non-Governmental Organisations. The focus of the session was to share evidence on the barriers experienced by people with disabilities in accessing health and rehabilitation, and identifying sustainable solutions.

1. Connect **sustainability** of health and rehabilitation services to the **WHO Disability Action Plan**

2. Begin to tackle the challenge of **referrals** through **awareness raising**

3. There should be a focus on **scaling up interventions** and examples of good practice through **knowledge transfer** and **sharing**

4. Need to **reach the other voices** – for example the **mainstream** public health and Water and Sanitation communities to **ensure their buy in**

5. Access to **rehabilitation services** should be considered as an **SDG indicator** and promoted via the new WHO Rehabilitation 21st Strategy

Humanitarian Response – Workshop 2

This session included examples and evaluations of inclusive humanitarian response during recent humanitarian incidents such as Typhoon Yolanda in the Philippines and the Nepal Earthquake. Speakers praised recent improvements in inclusion in the humanitarian sector and addressed the need for scale up of inclusive strategies

1. Nothing can be achieved without **participation**, so use **networks, engage in dialogue with other actors** (DPOs, mainstream orgs., governments etc.) and identify a **"disability champion"**

2. **Before** a humanitarian disaster occurs,
   -Develop **international standards** for action and training programmes in:
   - Disability **inclusion in the main emergency sector**, including in disaster preparedness programmes (under development by ADCAP) and guidelines for accessible emergency operations (e.g. food distribution, camp management etc.)
   - **Data collection** in disasters (e.g. treatment registry, functional limitations)
   -Provision of **medical** and **surgical care** in disasters
   - Review National Plans on Disability at the country level to ensure humanitarian response is included

3. **During** a humanitarian disaster,
   - **Reinforce** inclusive response **training of the mainstream actors** and **adherence to international standards** (to be developed as per the above)
   - **Develop accessible service information tool** for circulation
   - **Review accessibility** of emergency operations

4. **After** a humanitarian disaster,
   - Consider reconstruction as an **opportunity for promoting accessibility**
   - Complete a **post-action review** of inclusion in the response, including **lessons learnt** and how to achieve this in a **cost-effective** way

Poverty – Workshop 3

The poverty workshop contained innovative multi-country quantitative findings on the relationship between disability and poverty, and introductions to new research in this area.

1. Ensure people with disabilities are **routinely included in community level poverty tracking** (such as community scorecards), and **develop mechanisms** to enable the **disability movement** to feed into **national poverty strategies** and **SDG planning processes**

2. Explore **alternative** and **participatory data collection tools** to examine the relationship between poverty and disability, including more **nuanced understandings** for advocacy and policy

3. Develop **guidance** on the **complexity of disability** for mainstream poverty actors, and encourage **trans-disciplinary** research

4. Encourage further research into **extreme poverty** and its relationship with **disability**

Disability Measurement in Children – Workshop 4

This session included animated discussions on the different methodologies developed to identify children with disabilities, including an introduction to the UNICEF/Washington Group Child Functioning Module, and ongoing field testing of this tool.

1. Field-tests of the new UNICEF/ Washington Group child functioning module show **positive results**, and ongoing efforts to **validate** this module and **promote its usage** should be continued

2. Work must focus not just on **finalising the tools** but also **building the capacity** of DPOs, National Statistical Offices and Program Implementers to collect and interpret data on child disability

3. A **repository of translations** and **cognitive test results** for the Washington Group modules (adult and child) should be developed for comparison and to **build an evidence base**

4. We need to **increase advocacy** on the need to improve **information about environmental factors** affecting the participation of children

5. We must ensure that **child disability tools** that include **mental health** are promoted

Sexual and Reproductive Health (SRH) – Workshop 5

The Sexual and Reproductive Health workshop included a diverse range of presentations focused on the barriers and enablers to inclusive SRH, examples of best practice and evidence from studies on this topic.

1. The issues faced by persons with disabilities around the world in regard to SRH are often similar even between high and low country contexts – many share the **same experiences and barriers**

2. **Young people**, people with **hearing impairments** and those with **intellectual impairments,** are particularly excluded from SRH information

3. **SRH service providers** need to be **sensitised** and **trained** in the issues faced by people with disabilities

4. Young people with disabilities need to be **empowered** to **advocate** for the services and information on SRH they want

Education – Workshop 6

The workshop explored examples of barriers, facilitators, attitudes and training programmes related to the education of children with disabilities in India, Mali, Malawi, Senegal and Zimbabwe.

1. There must be greater **communication** and **cooperation** in the development of inclusive education programmes between **academics**, **implementers** and **donors**

2. Within the general debate about **measurement of learning outcomes**, advocate for a focus on the **specific issues** related to **learners with disabilities**

3. Stronger **cross-sectoral cooperation** is needed to **allocate resources** to **facilitators** of education for children with disabilities such as **health**, **social protection** and **transport**

4. Invest in **targeting/ identifying** the **children with disabilities out of school** in order to ensure access to **quality education**

5. Engage in the wider debate around **"school readiness"** in relation to inclusion to highlight the **importance** of **developmental approaches** to early childhood development, rather than a **premature focus** on **academic skills**

6. Increase **training of teachers** in general and **incorporate inclusive/special needs** education in **all teacher training** programs

Community Based Rehabilitation (CBR) – Workshop 7

The workshop included a review of the current evidence on the impact of CBR and the different methodologies that have been developed to promote and facilitate this.

1. CBR is a complex intervention. It needs to be **disentangled,** and a **conceptualization process** is needed **at the regional and national levels**

2. There is no agreement on the best methodology to conduct research on CBR – including whether or not to use Randomised Control Trials – more **communication** and **knowledge exchange** is needed

3. In general, there is a need for greater **communication between stakeholders** in CBR including **INGOs** and **Research Institutions**

Research in Disability – Workshop 8

This workshop followed a discussion format, addressing the question of how to plan, implement and use disability research. The discussion was led by the ICED co-Director, and representatives of two of the largest disability NGOs – Handicap International and CBM.

1. Each organisation must consider their **own research agenda and strategy**

2. We must **use what information is available**, where possible (e.g. from management systems)

3. We must **avoid duplication** in research, given the large need for more evidence

4. Research should be **linked** to both the **SDGs** and the **UNCRPD**

5. It is imperative that people with disabilities are **actively involved** in research from the start, and that results are **disseminated** in **appropriate** and **accessible formats**

Social Protection and Livelihoods – Workshop 9

Presenters in this session examined both the arguments and evidence on the need for, yet lack of inclusive social protection mechanisms and livelihoods programmes.

1. The **design** and **monitoring** of social protection systems requires active **engagement** by people with disabilities and DPOs. There is a need for **evidence** to support this process –focusing on **overall social impact**, including but not limited to the **monetary benefits** of inclusion.

2. We need to provide **more evidence-based solutions** and **models** on how to develop inclusive livelihoods and social protection systems

3. Greater attention should be paid to connecting services so that there are **strong** and **transparent referral systems** into livelihoods and social protection services

4. We should work together to develop **clear and unified advocacy messages**, backed up with evidence and examples, so that key policymakers can focus on inclusion within social protection services and respond

Violence – Workshop 10

The violence workshop contained examples of qualitative and quantitative research on prevalence and risk factors of violence against people with disabilities, with specific examples of violence reduction and child protection programmes from Uganda and Malawi.

1. Improve **training** of child protection officers, social workers and DPOs around violence against people with disabilities

2. **Test existing** violence prevention **approaches for inclusion** of adults and children with disabilities, including those targeting parents and caregivers

3. Undertake more research to **better understand violence prevention factors**

4. Ensure a **balance of representation** in mainstream justice, and protection forums (e.g. ISPCAN)

Inclusion Promotion & Measurement – Workshop 11

This workshop explored approaches developed towards promoting and achieving full inclusion of people with disabilities both in specific interventions and more generally in terms of the United Nations Convention on the Rights of Persons with Disabilities.

1. We need to further build the **economic case** for inclusion

2. We must **share, compare, use** and **critique existing tools** in order to improve them, build an **evidence base**, and create synergies

3. While building the evidence base through participatory methods, major progress is made just by **using the methodology and doing it!**

Club Foot – Workshop 12

This session focused specifically on Club Foot, a relatively common cause of childhood disability in Low and Middle Income countries. Researchers and practitioners shared evidence of best practice and discussed scaling up of these treatments.

1. National programmes for clubfoot are an **effective** way of delivering **Ponseti treatment** and should be scaled up to meet the urgent need for treatment of children with clubfoot globally

2. There is a **need to collaborate** with child health communities, DPOs and parents/carers in order to improve services for children with club foot

3. Standard **evaluation of treatment outcomes** is required and should include measures of **function** and **participation**

4. The **cost –benefit of treatment** needs to be documented