International Disability and Development Consortium

Inclusive Health Task Group

Are we serious about leaving no one behind? Advancing on the SDGs with persons with disabilities, health and rights for all

IDDC contribution for the United Nations High Commissioner for Human Rights report on the right to health and the health related SDGs

Persons with disabilities (approximately 1/7 of the global population – 19% amongst female population and 12% amongst male population) are vulnerable to exclusion in accessing their right to health. Persons with disabilities frequently face stigma and discrimination, violation of rights, lack of adequately targeted and accessible health services, exclusion in access to water and sanitation and other health determinants, and have lower income levels which can all increase their vulnerability to diseases. They can be at greater risk of communicable diseases, such as HIV and AIDS and non-communicable diseases, such as neglected tropical diseases and mental health conditions, accidents and injuries. Persons with disabilities are two times more likely to find skills and facilities inadequate, three times more likely to be denied health care and four times more likely to be treated badly in the health care system[i]. Women with disabilities can be more vulnerable to diseases, such as due to greater risk of sexual violence, and experience intersectional discrimination in accessing the healthcare they need including in relation to their sexual and reproductive rights.[ii] Persons with disabilities can be disproportionately marginalized in accessing their right to health in emergencies, natural disasters, conflict and displacement. The tendency for multiple adversity to concentrate on particularly vulnerable populations and groups must be recognised and specifically targeted in interventions, programmes and policies on health if we are to realise the commitment to 'leave no-one behind' in a meaningful way.

As the SDGs recognise building on learning from the MDGs, much more needs to be done to reach people who are most in need. There are references throughout Agenda 2030 to the fact that persons with disabilities and vulnerable groups need particular efforts to address their needs so they are not left behind.iii The Agenda references disability in five goals and seven targets, including commitments in relation to disaggregating data on disability. The emphasis on ensuring no one is excluded is central to the Health Goal '"Ensure healthy lives and promote wellbeing for all at all ages" and this centrality is also evident in the inclusion of the universal health coverage target. To achieve these and other health related targets, and given the inter-connectedness of the agenda (which mirrors the inter-relatedness of the rights framework) advance progress on education and work goals and targets amongst others,

absolute priority must be given to strengthening and making more equitable health systems and simultaneously addressing gaps in geographical and key population groups' coverage. Appropriate attention to rights including the right to health, by all actors – States, policy-makers, international decision-makers, civil society organisations, the private sector involved in working towards the Goals is essential and will reap major dividends. As the rights framework is about promoting equity, tackling underlying structural differences and engaging and empowering people all of which will be necessary for achieving health for all.

The inclusion of the Universal health coverage target and efforts underway to progress on UHC around the world is commendable, including the necessary reforms to financing. Affordability is a major barrier to health services for vulnerable people and removing the financial barrier alongside strengthening health systems will have a major impact. However services will need to be delivered in a manner that addresses remaining barriers in keeping with the right to health, be they attitudinal, physical, sensory, communication related or other. Further in efforts to prioritise services this will need to include rehabilitation, and palliative care (neither of which are covered currently by the proposed global indicator to measure progress towards UHC) and other specific services which are needed by persons with disabilities. Participatory processes are necessary including the involvement of persons with disabilities, and vulnerable groups, to help prioritise what can be delivered and how best to do that to ensure that efforts improve and also don't worsen the current inequity. Further efforts to measure equity on UHC must go beyond income which will veil discrimination.

The Treaties applicable to the health of persons with disabilities include the Convention on the Rights of Persons with Disabilities, the International Covenant on Economic Social and Cultural Rights and the International Convention on the Elimination of Discrimination Against Women. The principles of equality and non-discrimination are crucial and articles related to ethical acceptability and consent. Further as well as the texts of these Treaties, General Comment No. 14 (2000) on the ICESCR is a useful framework for highlighting the kinds of barriers that need to be tackled to ensure access to health such as accessibility including physically and information accessibility and affordability.

A rights-based approach to mental health

People with mental health conditions leading to psychosocial disabilities represent an extremely marginalised and abused group. Despite their very high prevalence (depression represents the single greatest cause of disability globally), very low levels of resources have been allocated to them in health and other services, which reflects in itself a form of discrimination. It has become socially acceptable for mental health services to be of a much lower standard than other health services, and for people within them to be treated in an undignified way that would be unacceptable to others. The inclusion of mental health within the SDG 3.4 is a positive step in recognizing the importance of addressing mental health appropriately. Further, the recent resolution by the UN Human Rights Council on the Right to Mental Health[iv], based on a report by the Special Rapporteur on the Right to Everyone to the Enjoyment of the Highest Attainable Standard

of Physical and Mental health, represents a paradigm shift away from accepting such different standards. It specifically cites the QualityRights toolkit[v] as a practical example of steps that can be taken to transform services. QualityRights is aligned to the CRPD and other international human rights standards, and is an example of a structured process to realise real impacts on the lives of people as they access and realise rights in structures that have previously denied this possibility. In doing so, it both promotes measureable progress to universal health coverage, and equity before the law.

Disability inclusion within the HIV response

In order to progress on SDG 3.3 and UHC disability needs to be mainstreamed within the HIV response. Handicap International has documented best practices from a number of programmes regarding what works[vi]. The cases highlight steps taken to achieve more inclusive access to HIV services and learnings from programmes, and also challenges. One example from Nairobi, focuses on making IEC materials inclusive for persons with visual impairments. The project benefited from the Kenyan government's National Aids Council's funding for HIV prevention and sensory impairments, recognising that persons with disabilities need to be included within the HIV response. The 'rare' KAP survey carried out for persons with disabilities prior to the programme provided essential information - it found that among persons with visual impairments only 40% had knowledge of HIV and 36% knowledge of condom use. Voluntary counselling and testing uptake was 34%. This initiative in Kenya included significant involvement of persons with disabilities to develop IEC information to be inclusive.vii. This included setting up of a committee of persons with disabilities and DPO representatives to contribute to a consultative body advising and guiding the project and forging partnerships with DPOs. According to HI the participation of the DPOs and persons with disabilities proved key to getting the approach right. Awareness was significantly increased, there were a number of community discussions, and testing uptake increased as a result.

Another case from Cambodia also highlights the importance of involvement of key stakeholders to best overcome barriers to inclusive access. PLA research conducted, found that deaf women were highly vulnerable to sexual violence/ abuse a factor heightening their risk of HIV. The programme included development of a deaf curriculum jointly with Deaf Development Programme of Maryknoll (DDP) on HIV prevention/ sexual violence protection and education. This partnership was identified as a key part of the success in improving inclusiveness. Asides from the necessity of ensuring participation and strong partnerships, some findings from across the report include that a twin-track approach to disability inclusion is essential, that DPOs need capacity building to help realise rights, and the benefits and need for sensitization workshops for health workers on disabilities.

Inclusive approaches to closing the gaps on neglected tropical diseases

As major progress is occurring on the control and management of neglected tropical diseases through success in mass administration of drugs that can protect populations, the imperative to not ignore the needs of people already affected by these disabling conditions has been highlighted. Partners in the NTD NGO Network (NNN) have developed practical means of ensuring that the needs of people affected are considered in a person-centred, comprehensive way. For example CBM, and several organisations working in lymphatic filariasis, leprosy and other NTDs, are integrating approaches to promoting inclusion, access to water and sanitation, wound care, and mental health care within national NTD programmes. Further The BEST Frameworkviii sets out the cross sectoral efforts needed to control and manage NTDs. Social inclusion is one of the four components, focusing on mainstreaming inclusion across all NTD interventions, with accessible infrastructure and support services reaching women, children, persons with disabilities and targeted population groups, empowerment of communities affected, and addressing stigma and discrimination. The BEST Framework also includes diseases management and self-care and ensuring accessible, quality and affordable rehabilitation services recognising amongst others the importance of 'maintaining dignity and maximising independence'. Such rights-based approaches are necessary to improve the likelihood of achieving SDG Goals related to NTDs.

Data, health and inclusion of persons with disabilities

Recognising the lack of data on disability in health programmes and the tendency for exclusion of persons with disabilities within health services and systems, Sightsavers started its work on inclusive eye health[ix], including piloting approaches to collect disability disaggregated data. Integrating disability disaggregated data collection into programmes in Malawi, India and Tanzania, Sightsavers' approach involves testing the Washington Group Short Set of Questions[x] (WGSS) – which focuses on functional limitations – to improve programming and promote better data collection on disability. In Malawi, the WGSS were used alongside The Equity Tool[xi], allowing data to be disaggregated by socio-economic status.

The findings highlight the importance of having good data on persons with disabilities in health for better policy, programmes and practice. In India Sightsavers found significantly higher prevalence of disability using the WGSS compared to the population census where the question was: 'Are you disabled, Yes or No?' However, data also showed that persons with disabilities were not equitably accessing eye health services compared to the rest of the population. Prevalence amongst women to men was also higher in contrast to the census information, but women were less likely to access tertiary eye health services than men. Collecting disability disaggregated data provided tangible evidence of the levels of exclusion faced by persons with disabilities accessing healthcare, and motivated Sightsavers and its partners to develop more inclusive services. Follow up interventions included improving the accessibility of health facilities, building capacity of health staff and community health workers on disability inclusion and gender mainstreaming, developing a stakeholder network with other agencies in the community to increase referrals, and organising targeted outreach activities to identify and screen persons with disabilities living in urban informal settlements.

With regards to neglected tropical diseases, in Tanzania 10 per cent of people attending trachoma trichiasis camps had a wide range of functional limitations (asides from sight related). Many of the health services they needed were not provided at TT camps, so health workers adapted their approach to supply basic services and establish referrals. As the report Everybody Counts[xii] states the: 'lack of data often means decisions are made that reinforce existing inequalities, as governments and decision-makers allocate resources in a way that excludes people with disabilities.' Sightsavers' policy brief includes recommendations on data disaggregation resulting from the learnings[xiii].

Progressing on the health related SDGs through rights- based approaches for persons with disabilities

The rights framework as well as being legally binding, offers considerable guidance in terms of what is needed to advance on health for all. Adhering to the rights framework also recognises governments' responsibilities as duty-bearers to their populations as rights-holders, which is key for the advance of universal health coverage or health for all. These responsibilities include promoting freedoms, such as those relating to pre and informed consent for medical procedures and sexual and reproductive freedoms, and entitlements, including access to health and social protection. Persons with disabilities are rights-holders but often in health amongst other areas their rights are not respected, protected, or fulfilled. Neglecting to adhere to the principles of equity, non-discrimination, and participation and the other components of the right to health will render health for all unfeasible. Some recommendations from learnings:

- Various toolkits to help guide inclusive programming - QualityRights, Making it Work[xiv], Light for the World's Towards Inclusion[xv], the UNAIDS Disability and HIV reference report[xvi] can be utilised to learn from experiences.
- An important factor identified in many cases is the lack of accessible health information and how this is reasonably straightforward and cost effectively overcome.
- The right to participation is fundamental to getting inclusion efforts right and avoiding to neglect persons with disabilities – 'nothing about us without us'
- UHC needs to be equitable and inclusive – and this means tackling direct and indirect discrimination in the health system and in health determinants, ensuring persons with disabilities are aware of the services offered, that their needs are taken into account in essential packages and addressed by sensitised workforce with the right skillsets, and that services are delivered in an inclusive way overcoming barriers.
- A twin track approach is necessary with national policies and programmes inclusive as well as targeted efforts to ensure those most likely to be left behind's special needs are addressed.
- Greater evidence is needed - censuses, health surveys need to capture information on persons with disabilities, also diseases specific surveys to have a full understanding on the numbers affected and then how inclusion increases the overall impact. Information needs to be made readily available. Collection, analysis and dissemination should occur with strong collaborations across key

stakeholders including governments, multilateral and donor agencies, CSOs, and DPOs.

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[i] WHO Factsheet on Disability http://www.who.int/mediacentre/factsheets/fs352/en/; WHO Infographic on health access: http://www.who.int/disabilities/infographic/en/

[ii] See for example UN ENABLE Factsheet on women with disabilities - https://www.un.org/development/desa/disabilities/resources/women-with-disabilities-fact-sheet.html

[iii] Transforming our World: the 2030 Agenda for Sustainable Development, United Nations 2015, https://sustainabledevelopment.un.org/post2015/transformingourworld/publication

[iv] https://www.internationaldisabilityalliance.org/resources?f[0]=field_ida_un_group%253Atitle%3AHuman%20Rights%20Council

[v] QualityRights Tool: http://www.who.int/mental_health/policy/quality_rights/guidance_training_tools/en/

[vi] Including disability in HIV policy and programming: Good practices drawn from country-based evidence, Muriel Mac-Seing, Handicap international, http://www.hiproweb.org/uploads/tx_hidrtdocs/DisabilityAndHIV_LL07.pdf

[vii] Including disability in HIV policy and programming: Good practices drawn from country-based evidence, Muriel Mac-Seing, Handicap international, http://www.hiproweb.org/uploads/tx_hidrtdocs/DisabilityAndHIV_LL07.pdf

[viii] http://www.ntd-ngonetwork.org/sites/default/files/uploaded/BEST%20FRAMEWORK%202%20pager_150417.pdf

[ix] Sightsavers work on Inclusive Eye Health: https://www.sightsavers.org/programmes/inclusive-eye-health/

[x] Washington Group on Disability Statistics: http://www.washingtongroup-disability.com/

[xi] The Equity Tool: http://www.equitytool.org/

[xii] https://www.sightsavers.org/wp-content/uploads/2017/09/PolicyDoc_EverybodyCount_Web.pdf

[xiii] Sightsavers work on Everybody Counts – Disability Data Disaggregation, including policy briefings and reports: www.sightsavers.org/everybodycounts

[xiv] https://www.makingitwork-crpd.org/

[xv] http://lab.light-for-the-world.org/publications/towards-inclusion/

[xvi] http://www.unaids.org/en/resources/documents/2017/jc2905_disability-and-hiv