Disability Inclusion in Universal Health Coverage

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Photo: Shuman Ahmed

Link to the Mental Health and Social Support brief

Worldwide there are one billion people with disabilities. Persons with long-term mental health conditions and psycho-social impairments form a big part of this group. Over 10 per cent of the world's population live with a mental health condition, causing 7 percent of all global burden of disease, and 19 per cent of all years lived with disability, and these occur in low-, middle- and high-income countries. The prevalence of mental health conditions among people affected by conflict is especially high and stands at 22 per cent.

Within the group of persons with disabilities, persons with mental health conditions belong to the groups that are most stigmatised. Moreover, there are strong myths about mental health conditions and there are hardly any specific services available for these groups in low- and middle-income countries. Persons with mental health conditions and psychosocial disabilities, especially children and adolescents are among the most vulnerable groups experiencing marginalisation and human rights violations. They are not well represented in the disability movement, so their voice is often not heard by policymakers and often do not receive treatment and care, especially in low- and middle-income countries.

About this brief

This brief will focus on how to improve access to health for persons with disabilities in general (including people with mental health conditions and psychosocial impairments) while the Mental Health brief will focus on the interventions needed to support this specific group.

Importance of Disability Inclusion in Universal Health Coverage

The Sustainable Development Goals (SDGs) urge us to Leave No One Behind. SDG 3 specifically aims to ensure healthy lives and promote well-being for all at all ages. But the reality is that despite all efforts to promote Universal Health Coverage (UHC), persons with disabilities are still left out. They face higher healthcare needs, more barriers to accessing services, and less health coverage, resulting in worse health outcomes.[1]

1. Kuper, H. and Heydt, P. The missing Billion. Access to health services for 1 billion people with disabilities. 2019

What is Universal Health Coverage?

Universal health coverage (UHC) means that all people and communities can use the promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality to be effective, while also ensuring that the use of these services does not expose the user to financial hardship.

Mental Health and well-being

The 2010 World Disability Report of the WHO estimated that there are **a billion people with severe or moderate disabilities worldwide**. The majority of this group is living in low- and middle-income countries and they often belong to the poorest sections of society.[2]

Persons with disabilities experience **higher health care needs**, since they may need specialised medical care related to the underlying health conditions or impairment (e.g. physiotherapy, hearing aids). They are also more vulnerable to poor health, because of their higher levels of poverty and exclusion. At the same time they also **need access to general healthcare services like anyone else**, such as vaccinations or sexual reproductive health services.

What is Disability?

Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

UNCRPD 2008

Why is inclusion so important?

- Without better health services for the 1 billion people with disabilities, UHC and SDG 3 cannot be achieved.
- All the SDGs are inter-linked. Enhancing inclusion of persons with disabilities in health will contribute to achieving all SDGs.[2]
- Access to healthcare for people with disabilities is also a human right issue. The UN Convention on the Rights of Persons with Disabilities Persons states that persons with have the right to free or affordable health care, including sexual and reproductive health and population-based public health programmes. And they also have the right to access disability specific health services .
- If people with disabilities have access to services, it will also prevent unnecessary costs for the health system.[3]
- When the health systems are designed according to the principles of Universal Design everyone will benefit.

In this brief practical guidance will be given what measures can be taken to improve inclusion of persons with disabilities in health programmes and how the needs of persons can be taken into account in Universal Health Programming. Often people think that inclusion of persons with disabilities is costly and difficult, but this is not true. In this brief we will highlight simple steps that can be taken immediately and that do not require significant additional budget.

Key Facts

There is a huge health gap for persons with disabilities. The following figure, retrieved from the publication The Missing Billion[4] shows that on almost all indicators of SDG 3, persons with disabilities have lower health outcomes or higher risks. For example, children with disabilities are more likely to be malnourished and die from malnutrition or suffer from severe diarrhoea.

2. L.M. Banks, H. Kuper, S. Polack, "Poverty and disability in low- and middle-income countries: A systematic review," PLoS ONE 12(12)(Dec. 21, 2017)
3. UN. United Nations Convention on the Rights of Persons with Disabilities. Art. 26 & 27. 2006
4. Kuper, H. and Heydt, P. The missing Billion. Access to health services for 1 billion people with disabilities. Page 5. 2019

In the context of SDG3, examples from studies suggest that people with disabilities...

TARGET 3.1 REDUCE MATERNAL MORTALITY

- Have a higher prevalence of **pre-term births** and low **weight** babies (up to 2x)
- Have a higher prevalence of **still births** (1.5x)

TARGET 3.2 END ALL PREVENTABLE DEATHS UNDER 5 YEARS OF AGE

- Are more likely to be **malnourished** (up to 3x) and **die from malnutrition** (2x)
- Are more likely to suffer from **severe diarrhoea** (2x)
- Are more likely to experience **serious illness** in the last year (up to 10x)

TARGET 3.3 FIGHT COMMUNICABLE DISEASES

- Have a higher **HIV prevalence** (2x), and **higher risk of infection**

TARGET 3.4 REDUCES MORTALITY FROM NON-COMMUNICABLE DISEASES AND PROMOTE MENTAL HEALTH

- Have a higher **diabetes** prevalence (up to 3x)
- Have a higher **cardiovascular** prevalence (2x)
- Have higher rates of suicidal ideation

TARGET 3.5 PREVENT AND TREAT SUBSTANCE ABUSE

- Are more likely to **abuse substances**

TARGET 3.7 UNIVERSAL ACCESS TO SEXUAL AND REPRODUCTIVE CARE, FAMILY PLANNING, AND EDUCATION

- Are less likely to use **reversible contraceptives** and more likely to be sterilized

TARGET 3.8 ACHIEVE UNIVERSAL HEALTH COVERAGE

- **Access:** Are less likely to access services (e.g. ANC services, outpatient care when needed, mammograms, assistive devices, etc.)
- **Quality:** Are more likely to find healthcare provider's skills and facilities inadequate (2x)
- **Affordability:** 50% cannot afford healthcare, 50% more likely to suffer catastrophic health expenditure

TARGET 3.9 REDUCE ILLNESSES AND DEATH FROM HAZARDOUS CHEMICALS AND POLLUTION

- Are 30% more likely to live in areas with **environmental risks** (toxins)

Note: 3.6 (road traffic accidents) not included

International frameworks for disability inclusion and UHC

The UN Convention on the Rights of persons with Disabilities that came into force in 2008, has given a strong boost to the debate around disability inclusion in health. In 2011, The World Health Organisation published the World Report on Disability in which it already highlighted the health gap for persons with disabilities and came with concrete recommendations on policy and legislation, financing and affordability, service delivery, Human resources and data and research.[5]

This report was followed by the WHO Global Disability Action Plan 2014-2021. That aimed to remove barriers and improve access to health services and programmes; Strengthen and extend rehabilitation, assistive technology, assistance and support services, and community-based rehabilitation; And also strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services.[6]

The SDGs (2016) and especially SDG 3, further boosted attention for disability inclusion. Although persons with disabilities are not explicitly mentioned in SDG 3, persons with disabilities are implicitly included through the overarching principle: **Leave No One Behind**.

In 2017, the WHO organised a meeting on Rehabilitation 2030 and published the report "Rehabilitation in health systems" which includes recommendations to include rehabilitation in the health system.[7]

In 2019, the WHO published a monitoring report about progress with regards to UHC. The harsh

5. World Health Organization, "World Report on Disability," 2011.
6. World Health Organization. Global disability action plan 2014–2021. 2015
7. World Health Organization. Rehabilitation in health systems. 2017.

conclusion of this report is that if the current trend continues, up to 5 billion people will still be unable to access health care in 2030. Most of those people are poor and already disadvantaged.[8] The report however does not specify who are the people who are left behind. There is almost no data disaggregation by the key dimensions of equity such as gender, age, wealth, ethnicity, disability, geographic location, fragile states and conflict situations, and so on. The Civil Society Engagement Mechanism for UHC2030 (CSEM) calls for concrete actions to identify the people who are left behind, identify their health needs and involve them in the monitoring process.[9]

In addition to the CESM report, the Missing Billion Initiative, comes with data about the health gap (as presented in the previous paragraph) and advice on how to improve access to health for Persons with Disabilities.[10]

During the UN High-Level meeting on UHC in September 2019 two important resolutions have been adopted that specifically mention disability. Resolution 25 is calling for gender- and disability-responsive and evidence-based interventions. Resolution 67 calls to strengthen health information systems and collect data disaggregated by income, sex, age, race, ethnicity, migratory status, disability, geographical location.[11]

Barriers to accessing health services

To improve accessibility for persons with disabilities, it is important to understand the barriers that they come across in accessing health services.

The group of persons with disabilities is very diverse, their experiences will be influenced by their type of impairment, gender, age, ethnicity, economic status etc. However, the following categories of barriers can be identified.

Barriers on the demand side:[12]

- People with disabilities often don't seek medical support because of the rejection that they have experienced by health care staff.
- Or they don't go to the clinic because of community beliefs about persons with disability, like "People with disabilities don't have sex/get HIV"
- Lack of transport options and affordability is also a big issue: it is not only the cost for the treatment, but also the cost of getting to the hospital.

Barriers on the supply side:[12]

- Health infrastructures are often not accessible. We are not only talking about entrance doors, but also about examination beds, washrooms and signage. Information and communication is often not accessible.
- The attitude and knowledge of health workers is a big barrier. Persons with disabilities are often rejected and treated badly. Health care staff lack skills on how to communicate and interact with persons with disabilities.
- There is also a shortage of specialised health staff and rehabilitation workers such as physical therapists, mental health professionals, occupational therapists, speech-language pathologists, prosthetic and orthotic practitioners.[13]

Barriers at system level:[12]

- There is lack of data and evidence. Inclusion of persons with disability not monitored nor prioritised.
- Most countries have ratified UNCPRD and have put in place legislation and policies to protect the rights of people with disabilities to healthcare; but these are most of the time not monitored or enforced.
- Lack of budget and funding for disability specific services such as rehabilitation and assistive devices and for making the health services accessible.
- Insurance schemes often do not cover financing challenges of persons with disabilities, for example transport costs. And in some situations, insurance schemes even exclude people with disabilities.
- Many Health Ministries also lack a department or staff member with dedicated responsibility on disability or rehabilitation.

8. World Health Organization. Primary Health Care on the Road to Universal Health Coverage. Monitoring report 2019.
9. Civil Society Engagement Mechanism for UHC 2030. Leaving no One Behind. Delivering on the promise of health for all. 2019
10. Kuper, H. and Heydt, P. The Missing Billion. Access to health services for 1 billion people with disabilities.
11. UN High Level meeting on Universal Health Coverage- Sept 2019. Resolution adopted by the General Assembly on 10 October 2019
12. Kuper, H. and Heydt, P. The Missing Billion. Access to health services for 1 billion people with disabilities.
13. World Health Organization. Rehabilitation in health systems. 2017

Twin-track Approach:

Disability mainstreaming: people with disabilities get access to all existing health programmes and services

Disability specific interventions: access to services that address disability specific health needs

Approaches to disability inclusion

In the process of promoting inclusion the following principles are key:

- To promote inclusion a "twin-track" approach is needed.[14] Disability mainstreaming and disability specific interventions need to go hand in hand.
- Involve persons with disabilities throughout the whole process. Changes must be informed by People with disabilities: Nothing about us Without us.[15]
- It is more efficient to incorporate changes into programs from the planning stage, rather than attempting to adapt existing programs.[16] Making a building accessible after you have constructed is more costly than when you include accessibility in the design. Surveys show that the cost impact for including disability concerns in the construction of new buildings is only 1.12% on average.[16]
- Apply the principles of Universal Design.[14] If a design works well for people with disabilities, it works better for everyone.
- It is also important to use a multi-stakeholder approach. Inclusion of persons with disabilities is a joint responsibility and can only be reached if mainstream organisations, disability specific service providers, organisations of persons with disabilities and government work together.

Universal design:

The design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design.

Demystifying disability mainstreaming

People often think that the inclusion of persons with disability in a programme is costly and very complicated, this is not true.

You don't need to be a disability expert to provide disability inclusive services. A three-day disability awareness and inclusive communication training is usually enough for health staff to make their services accessible. The role of the service provider is to make their services accessible by removing the barriers that people with disabilities come across. They don't need to deliver disability specific support, so if a project beneficiary is in need of specialised support e.g. a wheelchair, this person should be referred to a disability specific service provider.

Inclusion can be reached with a relatively small budget. Usually it only takes between 2 and a maximum of 7 per cent of total programme costs to make a programme that is geared to the general population disability inclusive.[17] In the following box you can see what administrative and operational costs are involved.[18]

Budgeting for inclusion in programmes

Administrative Costs:

- Training of staff and managers on disability.
- Workplace adaptations permitting the recruitment of persons with disabilities (e.g. accessible IT and software).

Operational Costs:

- Awareness raising on disability
- Adaptation of buildings or infrastructure built during the completion of the project.
- Making communication accessible e.g. use of sign language interpreters, Braille prints.
- Specific surveys linking disability and the sector area.

14.World Health Organization. Global disability action plan 2014–2021. 2015
15.UN. United Nations Convention on the Rights of Persons with Disabilities. 2006
16.ECHO: A review of Cross-cutting and other key issues, Model Guidelines. 2005
17.Light for the World. Resource book on Disability Inclusion. 2018
18.CBM. Budgeting the inclusion of a disability perspective.

Measures to make health services accessible

Inclusion of persons with disabilities does not happen automatically. You have to deliberately plan for it and take action. Only mentioning that persons with disabilities are part of the target group is not enough. The following actions are suggested by the Missing Billion Initiative:[19]

- Involve people with disabilities to understand the key barriers and gather suggestions for how these may be overcome
- Training of health care staff. Include information about disability awareness in training curricula for all types of health workers (medical doctors, nurses, community health workers, etc.) and in post-qualification training
- Do accessibility audits at health centres
- Make all health information, education and prevention opportunities (e.g. leaflets) accessible for different types of disabilities
- Develop an accountability mechanism, which could also include a UHC metric on access to healthcare for people with disabilities
- Budget: make budget available for disability mainstreaming and disability specific interventions
- Collect data, do research to understand the barriers and facilitators.

Entry points for dialogue with health partners about disability mainstreaming

As previously mentioned, inclusion of persons with disabilities is not costly nor complicated. Simple measures can be taken to promote inclusion.

The grant making process is the ultimate moment to encourage partner organisations to start making their programmes disability inclusive. So make sure the grant making criteria are actively promoting equitable access for people with disabilities and make sure the inclusion of persons with disabilities is also reflected in the evaluation grid for proposals.

In the dialogue with health partners you could ask the following questions:

- Have health staff been trained on disability inclusion?
- Is disability disaggregated data collected?
- Are people with disabilities consulted to identify barriers?
- What measures are taken to remove barriers for people with disabilities?
- Has an accessibility audit been done?
- Are health materials accessible for persons with different kind of impairments?
- Is there a referral system to disability specific service providers?

Good practice on inclusive SRHR services

Marie Stopes Nepal is an SRHR organisation focusing on safe abortion, post-abortion care and contraception. They have made their programme disability inclusive. As a result of this approach, they reached 816 young people with disabilities in the year 2016, compared to only 4 in 2015.

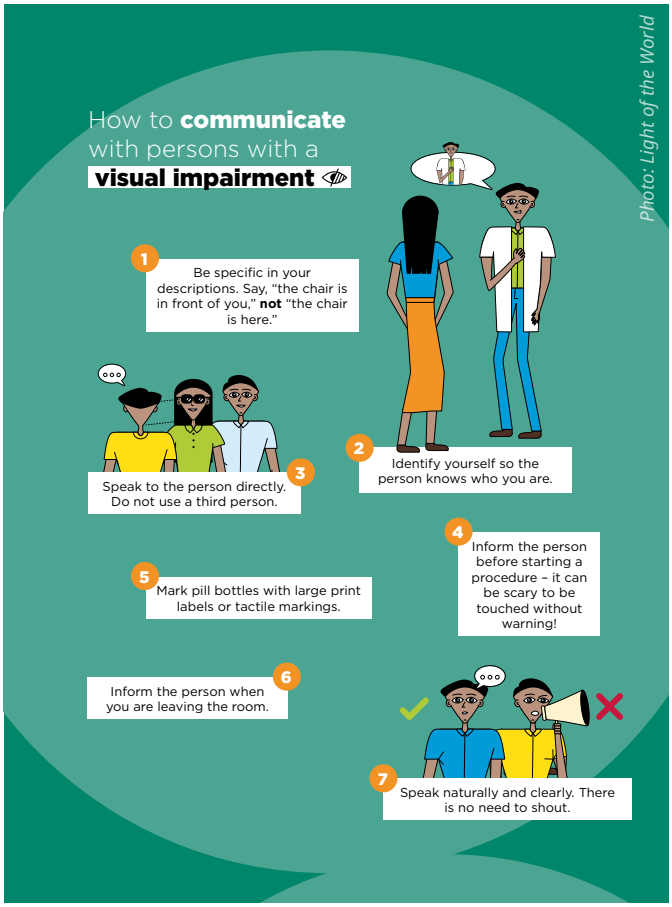
The key points of their inclusion strategy:

- A twin track approach: a combination of targeted actions to reach out to specific groups of youth with disabilities and disability mainstreaming in all existing services
- Disability sensitisation of project team, health staff, counsellors and volunteers
- Research and Documentation using Washington Group questions
- Accessible services and materials
- Volunteers with disabilities who participate in programme design.[20]

19.Kuper, H. and Heydt, P. The missing Billion. Access to health services for 1 billion people with disabilities
20.DCDD. Everybody Matters. Good practices for inclusion of people with disabilities in Sexual Reproductive Health Services. 2017

More detailed questions can be found in the project checklist that is mentioned in the "Recommended Tools" below. You can also browse through the questions of the organisational assessment tool. This assessment tool helps health facilities to check how disability inclusive they are and will help them to make an action plan for improvement. It is a very helpful tool to start with. Doing an organisational assessment will only take half a day.

The other tools in the overview will help partner organisations to take practical steps towards inclusion. Such as organising a disability inclusion training for staff in which staff learns how to communicate and include persons with different impairments in their health services. The Inclusive Health Game is a simple and playful tool that can be used to raise awareness amongst health staff and management in a two-hour workshop. The how-to communicate posters can be hung on the wall of a health clinic and will remind health staff how to communicate in a disability friendly way.



Recommended tools for disability mainstreaming

Type of Tool	Description	Author	Link
Audit	Organisational Assessment Tool on Disability Inclusion for Health Facilities	Light for the World	Disability Inclusion Scorecard for Health Facilities
	Checklist Disability Inclusion in the Project Cycle	Light for the World	Checklist Disability Inclusion in Projects - Page 69
	Accessibility audit for health services	Sight Savers	Accessibility standards and audit pack
Training	Inclusive Health Game. Tool for awareness raising amongst medical staff	Light for the World	Inclusive Health Game
	Poster with communication tips for health staff (available in 6 languages)	Light for the World	How to Communicate posters
Data collection	Guide to collect disability disaggregated data	DFID	DFID's guide to disaggregating programme data by disability
Budgeting	Tips for including disability in a programme budget	MIUSA	Tipsheet Reasonable Accommodations and Budgeting for Inclusion
General	Complete set of practical tools for inclusion in projects and organisations	Light for the World	Resource Book on Disability Inclusion

Measures to improve disability specific health services

People with disabilities have the right to access disability specific services. Access to rehabilitation services and assistive technology, but also early identification of disabilities in children are essential elements.

The WHO Rehabilitation report 2017 comes with the following recommendations to improve access to rehabilitation services and assistive technology:

- Rehabilitation services should be integrated in health systems
- Rehabilitation services should be integrated into and between primary, secondary and tertiary levels of health systems
- A multi-disciplinary rehabilitation workforce should be available
- Both community and hospital rehabilitation services should be available
- Hospitals should include specialised rehabilitation units for inpatients with complex needs
- Financial resources should be allocated to rehabilitation services to implement and sustain the recommendations on service delivery
- Where health insurance exists or is to become available, it should cover rehabilitation services.
- Financing and procurement policies should ensure that assistive products are available to everyone who needs them.
- Adequate training should be offered to users to whom assistive products are provided.[21]

These general recommendations are backed up by research, evidence and more detailed suggestions. Unfortunately, It's not possible to work out all these recommendations in details in this brief. It would be interesting for SIDA to further investigate how it can support the following two intervention strategies.

Community Based Rehabilitation. This is an important strategy to promote UHC, because it is an important means of ensuring and improving coordination of and access to health services, particularly in rural and remote areas. Community Based Rehabilitation programmes make the link between more specialised medical care and the everyday support and inclusion needs of persons with disabilities. Community Based Rehabilitation workers can coach and advise parents how to support their child with a disability and support the schoolteachers how to include the child in school.

Early Identification of Disability. Early identification and intervention will have a high impact on the health outcome and lives of children with disabilities.[22] Community Health Workers or Primary Health Care workers can play a key role in early detection of disability, but they need to be trained well in order to fulfil this role.[23] When Community and Primary Health workers are trained on early childhood development and the age-related milestones, they will be able to signal when the development of an infant is lagging behind. For example when the child is coming for vaccinations. In that case the health care worker can refer the parents to look for medical care and support.[24]

What is rehabilitation?

Rehabilitation is a set of interventions needed when a person is experiencing or is likely to experience limitations in everyday functioning due to ageing or a health condition, including chronic diseases or disorders, injuries or traumas. Examples of limitations in functioning are difficulties in thinking, seeing, hearing, communicating, moving around, having relationships or keeping a job.

Rehabilitation services may include physical therapy, occupational therapy, speech and language therapy, cognitive therapy, and mental health rehabilitation services.

What is assistive technology?

Assistive devices and technologies include wheelchairs, prostheses, hearings aids, visual aids, and specialised computer software and hardware that increase mobility, hearing, vision, or communication capacities.

21. World Health Organization. Rehabilitation in health systems. 2017
22. WHO/UNICEF. Early childhood development and disability. A discussion paper. 2012
23. Naidoo. S, Naidoo, D. & Govender. P. Community healthcare worker response to childhood disorders: Inadequacies and needs. African Journal of Primary Health Care and Family Medicine. 2019; 11(1): 1871.
24. Social Fund for Development Yemen. The early detection guide of disability for health workers.

Key Reading

Topic	Name and link to publication	Author	Year
Inclusive Health	**The Missing Billion** Access to health services for 1 billion people with disabilities	Kuper, H. and Heydt, P.	2019
	Rehabilitation in health systems	WHO	2017
	World Report on Disability	WHO	2011
	WHO Global disability action plan 2014–2021	WHO	2015
Inclusive SRHR	**Everybody matters** Good practices for inclusion of people with disabilities in SRHR.	Dutch Council on Disability in Development	2017
	Evidence Gap Map of 'What works' to ensure persons with disabilities have access to SRHR services	UK Aid/WISH	2020
Inclusive COVID-19	**COVID-19 and the disability movement** Resources and tools for action	International Disability Alliance	2020
Early identification	**Early childhood development and disability. A discussion paper**	WHO/UNICEF	2012
	The early detection guide of disability for health workers	Social Fund for Development Yemen	

Photo: S Silberman

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