# Submission to the Special Rapporteur’s questionnaire on the right of persons with disabilities to the highest attainable standard of health

*March 2018*

This submission focuses on providing input to questions 1, 2 and 3 in the Special Rapporteur’s questionnaire on the right of persons with disabilities to the highest attainable standard of health. It draws on evidence from a number of countries and Sightsavers’ programmes. Much of the submission is based on internal policy context analysis documents, which collate findings based on conversations with disabled people’s organisations, civil society organisations, programme staff, health workers and government officials. The below submission draws extensively from evidence gathered during recent visits to Malawi, Senegal, Sierra Leone, Tanzania and Uganda.

### Question 1: Please provide information on existing or planned legislation and policies to ensure the realization of the right to health of persons with disabilities, including current challenges and good practices.

In **Senegal**, the **Social Orientation Law** adopted in 2010 following ratification of the CRPD includes the rights of persons with disabilities to healthcare and employment. The **Equal Opportunities Card** covers costs of transport and 80% of the healthcare costs of persons with disabilities, although there are some regional differences in the proportion of healthcare costs that are covered; some DPOs explained this can be as much as 100%.

DPO representatives also highlighted that due to initial unclear guidelines some groups of persons with disabilities had not been included in the eligibility criteria of the cards, for example, people with albinism. However, this has been corrected by a later communication from the government. A lack of expertise in assessing eligibility for the card has also resulted in some persons with disabilities not having been able to benefit from it. General practitioners had initially been in charge of undertaking assessments, but the responsibility is now getting passed on to designated medical staff.

In **Nigeria**,the **National Health Policy** from 2016 has a **short section on disability**, including ensuring easy access to healthcare services. DPOs flagged that this is yet to be realised in practice and people with disabilities’ health needs are rarely accommodated or provided for.

Disability was generally felt as an issue of **low priority**. It was consistently raised by CSOs and DPOs that disability is not yet recognised as a cross-cutting issue, which had **implications for access to health** for persons with disabilities. Government and development partners tend to view disability as a standalone issue, led by one government Ministry and DPOs tend to believe that health leads ‘don’t do disability’. The Department responsible for rehabilitation was recognised as a small unit that gets little attention and a very small budget. The scale of the challenges in **accessing health services**, including how to employ sign language interpreters in hospitals, the shortage of assistive devices and how to address discrimination are all recognised as priority issues. The lack of awareness of disability across government also results in significant gaps, for example in ongoing humanitarian response work, and in available data.

**Sierra Leone** has a **Disability Act** from 2011 which states that every person with a disability will be provided with **free medical services** in public health institutions. Other categories of people who are excluded from paying for health services include children under five, lactating mothers, and pregnant women, and malaria treatment is free for everybody who is in need of it.

However, the information about the Disability Act had never been properly passed down, resulting in **very little awareness of the Act** amongst both health workers and persons with disabilities themselves. Health workers are often unaware they had to give free treatment to people with disabilities. Most people with disabilities or their carers were also said not to know about the Act, so they do not demand their rights.

In addition, there is a **lack of resources and supply of medication** that prevents access to healthcare overall. A healthcare worker that we talked to said that available resources are a huge challenge. They are unable to refer people to hospital when they need it because there’s no funding to pay for their treatment. If an ambulance is needed to take someone to hospital in an emergency they have to advise them to charter one, an expense far beyond the means of most people in an extremely poor community. The healthcare worker has no means to visit people with disabilities in their own homes when they need help, and no free medication to give them.

*“We don’t even have eye drops for the under-fives…It will be amazing for you to know we don’t even have paracetamol for children here”.*

Healthcare worker, Bo Region, Sierra Leone

In **Tanzania**, the **National Health Insurance (NHI) cards** cover health expenses. The NHIF was established by the act of the Parliament no. 8 of 1999 and began its operations in 2001. It was intended to cover public servants but recently, there have been provisions which allow private membership, to pre-pay for treatment. Medical treatment are supposed to be free of charge for certain groups (women, children, and older persons).

There was a circular from the Ministry of Health that states that health services for older people and persons with disabilities are free of charge. However, participants in our *Voices of the Marginalised[[1]](#footnote-1)* study reported that in some regions, this circular has never been received and healthcare workers were unaware.

Participants say that despite exemption based on policy documents, people are still incurring some medical expenses related to the purchase of drugs. If you go to the hospital, the doctor tells you that your prescribed drugs are not available but can be purchased in the drug shop. Participants acknowledged that although there was a very good policy in place dealing with issues related to the rights of older people and persons with disabilities in Tanzania, it had not yet been properly implemented.

In **Malawi**, the **Disability Act** was enacted in 2012. It sets out to promote and protect the rights of people with disabilities. It covers a broad range of issues **including health**, employment and transportation. The Act is meant to be a domestication of the CRPD, and includes many of the provisions set out in the CRPD. For example, it includes the commitment to establish a Disability Trust Fund and Focal Person.

DPOs expressed concern that the Act was not yet being implemented. Respondents felt that this was because the government may have concerns of the financial implications of putting the Act into practice. A National Council for Disability Affairs (NCDA) was set up to implement the Disability Act, and is made of different actors, of which 60% are from the government. At the moment, there are concerns about how the structure is working, and it is not clear what role the NCDA would play in the future. The Act is currently under review.

The government has drafted a **National Disability Mainstreaming Strategy (NDMS)** to promote inclusive development through mainstreaming disability. The draft NDMS, cuts across ministries and will focus on mainstreaming disability in six thematic areas **including health**, education, livelihoods, empowerment and social inclusion. The Strategy is seen as a component of implementing the Act.

The Ministry of Health has recently developed a **2017-2022 Health Sector Strategy**. From the strategy, the government are in the process of developing a number of plans to cover different thematic areas. The Government intend to use these plans to prioritise, to see where there are gaps and where support is needed. The plans should also contain a series of targets. Government representatives feel Malawi has *‘embraced Universal Health Coverage,’* and aims to provide free health care to the whole population.

### 2. Please provide any information and statistical data (including surveys, censuses, administrative data, literature, reports, and studies) related to the exercise of the right to health of persons with disabilities in general

As well as with particular focus in the following areas:

* Availability of barrier-free general healthcare services and programmes, which take into account all accessibility aspects for persons with disabilities;
* access to free or affordable general healthcare services and programmes, including mental health services, services related to HIV/AIDS and universal health coverage;
* access to free or affordable disability-specific healthcare services and programmes; and
* access to free or affordable health-related habilitation and rehabilitation goods and services, including early identification and intervention.

Sightsavers are working to make our health programmes more inclusive. We have used the Washington Group Short Set of Questions (WGSS) on functional limitations in a number of our programmes, as a tool to disaggregate data on disability and assess how we can make our services more accessible[[2]](#footnote-2). We performed pilot studies using the WGSS in India, Tanzania, and Malawi. Below are short summaries of the studies.

#### India

Methods:

We integrated the WGSS and the Indian national census question on disability (‘*Are you disabled?*’) into an Urban Eye Health programme, and at vision centres, outreach camps and an NGO eye hospital. This pilot collected data on 24,518 patients over a 16-month period.

Results:

* 16.7 per cent of respondents identified as people with disabilities.
* Even excluding the sight domain – which we would expect to be high in our programmes – the prevalence was nearly 9 per cent.
* This compared to just 0.6 per cent of people who responded ‘yes’ to the national census question: ‘*Are you disabled?*’

Conclusions:

* The value of using the WGSS for more accurate data was clearly demonstrated.
* Collecting data on disability is the first step in a process towards full inclusion
* To make a proper assessment for addressing the needs for access and planning health services, the right questions need to be asked. We assessed functionality instead of asking the more value-loaded question of the national census.
* These data will help us make our programmes more inclusive[[3]](#footnote-3).

#### Tanzania

Method: We used the WGSS in a neglected tropical disease (NTD) elimination programme, specifically integrating data collection into trachoma trichiasis (TT) camps. In this pilot we collected data on 1,439 patients who attended the camp over a four-month period.

Results:

* Our data showed a high prevalence of people with disabilities attending NTD camps at 19.3 per cent.
* Our data also revealed that 10 per cent of people who attended TT camps had a wide range of functional limitations and needs that are not met by services offered at the camps.

Conclusions:

* Qualitative information collected alongside the WGSS confirmed that due to the low accessibility to services in rural Tanzania, people with disabilities were attending outreach camps seeking general health services.
* This informed health workers and led to them more efficiently identifying and meeting the needs of the rural community.

#### Malawi

Method: We integrated the WGSS into data collection systems at a TT camp in our Coordinated Approach to Community Health project. In this pilot, we also used the Equity Tool, which allowed us to disaggregate data by socio-economic status using an asset-based measure of wealth. We collected data on 545 patients over a six-day period.

Results:

* The majority of patients were in the second wealthiest quintile (28 per cent),
* A minority of patients fell into the poorest quintile (11 per cent).
* Although the numbers were small, the data also indicated that people in the lower wealth quintiles were more likely to report being ‘disabled’ than wealthier people.

Conclusions

* Individuals who were attending the TT camps were relatively richer than the general population in Malawi.
* This highlighted that the outreach services may not always be reaching the poorest and most excluded people.
* Using the WGSS alongside The Equity Tool was possible and useful, and were able to gain a deeper insight in to the relationship between poverty and disability affecting people accessing our programmes.

Our data from the three pilot studies also showed that age was positively associated with disability, and that female patients had a greater likelihood of reporting functional limitations but a lower likelihood of self-identifying as people with disabilities than male respondents.

* The WGSS have provided a critical first step to improving the accessibility of our programmes.
* Our experience demonstrates that they are an appropriate tool for collecting disability disaggregated data in health programmes.

By limiting references to disability in data collection and referring to difficulty in functioning it is possible to reinforce the link between accessibility and functional limitations, and to protect against negative attitudes and discrimination which can influence the way questions are asked and responded to.

### 3. Please provide information on discrimination against persons with disabilities in the provision of healthcare, health insurance and/or life insurance by public or private service providers.

In Sightsavers’ experience from our country analyses, persons with disabilities often experience both **direct discrimination** as a result of negative attitudes and lack of understanding of disability, and **indirect discrimination**, where persons with disabilities or specific health needs are a low priority. In low-income countries a lack of resources and multiple development challenges mean health systems are not always prioritised. In this submission we talk about indirect discrimination to describe when persons with disabilities are at disadvantage in comparison to the general population, without considering the status of the health system over all.

#### Institutional discrimination

In many of the countries where we work disability is generally not recognised as a high **priority**. The failure to recognise disability as a cross-cutting issue has implications for access to health for persons with disabilities. Government and development partners tend to view disability as a standalone issue, led by one government Ministry that is often under resourced.

The **failure to collect data on disabilities**, and the methodology to collect data, often leads to underestimation of disability, which can lead to a failure to allocate resources, plan and provide inclusive health services.

#### Accessibility to health services

The **distance and cost** required to travel to access health services can be extremely challenging for persons with disabilities in rural areas. In most cases health centres are difficult for the majority of people to access. This is particularly the case for persons with disabilities, who face additional barriers due to the wider inaccessible environment.

**Accessibility** to health care settings, including health centres, clinics, and hospitals were often not appropriately set up for persons with disabilities.

* Persons with disabilities may travel **long distances** to their nearest health facility but upon getting there, may not be treated because the clinic is not accessible to support persons with disabilities.
* Main hospitals and departments are also **physically inaccessible** as many were built many years ago. Outpatients departments are also typically not accessible. For example, persons were reportedly being dismissed early from care because some departments where they needed continued treatment were not accessible by lift.
* Some **infrastructure and equipment such as [hospital]** **beds** are not suitable for people with disabilities. For example, persons with physical disabilities may find that examination tables and beds are not height adjustable. Maternity wards are often raised as another barrier, as beds with adjustable heights are in short supply. Access also depends on the attitudes of health workers, and whether they help persons with disabilities into bed.
* **Inaccessible communication and information** is another common form of discrimination. People with sensory impairments are often unable to access health information as signs and guidance are not available in accessible formats. Communication is also a problem faced by persons with hearing impairments who cannot be understood by health workers. There are also often difficulties in having to explain sensitive and personal issues through a sign language interpreter, particularly for women with disabilities who have no choice but to discuss their health problem with male health workers. Critically, there are serious **confidentiality** issues arising from these challenges. As information is inaccessible many patients with disabilities have to check their requirements and treatments with other people.
* The lack of **private space** for people with disabilities to see health workers poses further challenges. Persons with disabilities may also require assistance but their access to health care is often **not prioritised**. Persons with disabilities may be forced to stay in the queue for long periods of time. Sometimes people with disabilities may even miss the service they went to the health facility for, because of, for example, medicine stocks running out in public health facilities.

#### Access to health information

Access to information on health can be a major challenge, with access to preventative information a particularly important issue.

**Public health awareness** is rarely accessible to people with sensory impairments:

* Preventive and family planning information is sometimes run only by poster campaigns, which are inaccessible to people with visual impairments.
* In some countries, public health announcements are usually made via radio, with little effort to engage people with hearing impairments and use other formats. Access to the right information is particularly important given some of the wrongful assumptions around public health, for example, in Uganda in some areas there is a common belief that people with disabilities are immune to HIV/AIDS.

Information about family planning is not always given, as health workers sometimes assume that a person with disability is not in need of these services.

#### Availability and cost of treatment

A shortage of medicines is often among the main challenges facing persons with disabilities in health facilities.

There is often a **shortage of specific medicines** as priority is given to treatments in common use. Health centres don’t give priority to people with disabilities or their health requirements. For example, in Uganda, epilepsy is one example that health centres often don’t cater effectively for, and in Senegal treatments frequently needed by persons with albinism are not widely available.

The **cost** of accessing health care is often raised as a significant barrier – especially when specialist treatment is required.

Cost in combination with **access and availability of assistive devices** can be a significant challenge**.** In many countries, there are challenges addressing the need for assistive devices, largely due to cost. DPOs often provide support and advice to governments, but they also have limited funds. There is also a tendency from some governments to view the provision of assistive devices as the responsibility of civil society.

#### Shortage of trained staff

Inaccessibility relates to the **shortage of trained staff** **knowledgeable about disability issues**. Health professional often lack the knowledge or experience to treat people with disabilities.

Rural health centres often don't have health workers trained to support people with disabilities, and accessibility of health workers at hospitals can also be challenging.

The lack of knowledge of disability issues is particularly relevant to people with hearing impairments. Because health workers cannot communicate in sign language, deaf persons have sometimes been denied treatment in hospital. For example, mothers with hearing impairment have been denied access to maternity rooms as they cannot communicate.

A lack of sign language interpretation also causes significant problems. For example, in Uganda, DPOs explained that sometimes health workers will just give people with hearing impairments medication in the hope that they leave, without treating them properly.

The lack of knowledge of disability can mean health workers find it challenging even to take blood samples from a persons with disability.

Countries are also often struggling with a shortage of specialist staff to prevent or treat specific conditions. There are often shortages of occupational therapists and cataract surgeons, for example. There is also a shortage of specialists to treat conditions that can be more prevalent in persons with disabilities (e.g. skin cancer for people with albinism)

#### Negative attitudes

Persons with disabilities across a range of countries have explained how negative attitudes impact how they are treated and access health care. For example, they may be asked “what’s wrong with you?” when greeted by health workers, rather than asking how they are feeling like other patients.

Persons with disabilities have also reported sometimes being met by abusive language from health personnel. Some healthcare professionals have refused to assist people with disabilities and have used discriminatory language towards them. The negative attitudes of family members sometimes also prevent relatives with disabilities from seeking healthcare.

Pregnant women with disabilities are also often greeted by negative attitudes or questions about how they could have become pregnant. Women may be asked “who did this evil thing to you?” or “how did you get pregnant?” as health workers cannot understand why women with disabilities are having children.

Women who are deaf also faced additional barriers, as staff cannot communicate with them. A DPO in Uganda explained that: “If a mother who goes in to the maternity room is deaf, if they can’t communicate, they’ll be chased out”. In this case, health workers were thought to want to help, but were scared to, as they did not have the right skills.

A respondent in our *Voices of the Marginalised* project in Tanzania, informed us that they knew of a pregnant woman who was blind who went to give birth at the health facility. She delivered twins but reported that she was given one baby only.

### References and further information

The above submission references from findings across a number of Sightsavers’ policy, research and programme documents, including:

[Everybody Counts - Sightsavers' Disability Data Disaggregation Report (2017)](https://www.sightsavers.org/wp-content/uploads/2017/09/Everbody-counts_ACCESS-2.pdf)

Further information at <https://www.sightsavers.org/everybodycounts>

[Hear my voice: old age and disability are not a curse. A community-based participatory study gathering the lived experiences of persons with disabilities and older people in Tanzania](https://www.sightsavers.org/wp-content/uploads/2016/10/votm_summaryreport_web.pdf) (2016)

Further information at [www.sightsavers.org/voices](http://www.sightsavers.org/voices)

Connecting the Dots – Evidence and policy analysis (2015)

Further information at [www.sightsavers.org/connectingthedots](http://www.sightsavers.org/connectingthedots)

It also draws a number of internal policy context analysis from Malawi, Senegal, Sierra Leone, Nigeria and Uganda. Further information is available on request.

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1. For further information and full references please refer to: [Hear my voice: old age and disability are not a curse. A community-based participatory study gathering the lived experiences of persons with disabilities and older people in Tanzania](https://www.sightsavers.org/wp-content/uploads/2016/10/votm_summaryreport_web.pdf) (2016) [↑](#footnote-ref-1)
2. For further information please visit: [www.sightsavers.org/everybodycounts](http://www.sightsavers.org/everybodycounts) [↑](#footnote-ref-2)
3. For further information please visit: <https://www.sightsavers.org/programmes/inclusive-eye-health/> [↑](#footnote-ref-3)