

**Title:** SDGs, Inclusive Health and the Path to Universal Health Coverage

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The Sustainable Development Goals (SDGs) are a set of goals designed to improve the social, economic and well-being of all, while maintaining global and environmental sustainability. Health is one of the 17 goals, and focuses not only on addressing morbidity and mortality, but also on improving access to healthcare services for all through Universal Health Coverage (UHC). While disability is not specifically mentioned in this goal, a focus on people with disabilities is important given the inclusive nature of the SDGs and the fact that people with disabilities make up the largest minority group in the world. This paper aims to critically consider what the health goal could mean for people with disabilities and advocates for inclusive health. It discusses the complex relationship between disability and health, and why people with disabilities are more vulnerable to poor health are discussed, and then considers factors that impact access to quality healthcare for people with disabilities and how these impact on the achievement of the targets in SDG Health Goal and the main principles of UHC. The paper argues that developing an inclusive approach to healthcare will not only improve achieving good health for all, but is also important since experiencing poor health may reduce quality of life and participation (e.g. in education, employment or community activities). Poor quality of life and participation can exacerbate disability, poverty and exclusion in addition to increasing suffering, morbidity and early mortality. The paper concludes that an inclusive UHC will not only fulfil the fundamental rights of people with disabilities to health and rehabilitation, as emphasized within the UN Convention on the Rights of Persons with Disabilities, but also contribute to the achievement of the SDGs.

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## **SDGs, Inclusive Health and the path to Universal Health Coverage**

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The Sustainable Development Goals (SDGs) are a set of goals designed to improve the social, economic and well-being of all, while maintaining global and environmental sustainability. Health is one of the 17 goals, and focuses not only on addressing morbidity and mortality, but also on improving access to healthcare services for all through Universal Health Coverage (UHC). While disability is not specifically mentioned in this goal, a focus on people with disabilities is important given the inclusive nature of the SDGs and the fact that people with disabilities make up the largest minority group in the world. This paper aims to critically consider what the health goal could mean for people with disabilities and advocates for inclusive health. It discusses the complex relationship between disability and health, and why people with disabilities are more vulnerable to poor health are discussed, and then considers factors that impact access to quality healthcare for people with disabilities and how these impact on the achievement of the targets in SDG Health Goal and the main principles of UHC. The paper argues that developing an inclusive approach to healthcare will not only improve achieving good health for all, but is also important since experiencing poor health may reduce quality of life and participation (e.g. in education, employment or community activities). Poor quality of life and participation can exacerbate disability, poverty and exclusion in addition to increasing suffering, morbidity and early mortality. The paper concludes that an inclusive UHC will not only fulfil the fundamental rights of people with disabilities to health and rehabilitation, as emphasized within the UN Convention on the Rights of Persons with Disabilities, but also contribute to the achievement of the SDGs.

**Keywords:** Disability; Universal Health Coverage; Sustainable Development Goals

### **Introduction**

The Sustainable Development Goals (SDG), established in 2015, are a set of 17 goals put together to help achieve the 2030 agenda for global sustainable development. The SDGs were

developed in response to the progress and the challenges of the previous Millennium Development Goals (MDG) (2000-2015). While the SDGs aim to address similar goals to the MDGs, they have broadened their scope to focus globally rather than just on low and middle income countries, and also encompass environmental sustainability. The SDGs recognize that individuals and communities are not only affected by their own personal and socioeconomic circumstances, but also by a complex interplay of structural forces that influence an individual's place in society and his/her wellbeing. Hence, the SDGs aim to incentivise development efforts towards the removal of these structural barriers, by addressing and reducing poverty, and improving health, education and employment for all. An additional new aspect in the SDGs is the emphasis on increased inclusion across the spectrum of goals and sectors so that we can 'Leave no one behind'. In order to ensure inclusion of all in development efforts, the SDGs have not only tried to include the most vulnerable populations in the various specific goals, but have also identified a goal which explicitly states: 'By 2030, empower and promote the social, economic and political inclusion of all, irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status.' (UN, 2015 Goal 10.2). Persons with disabilities are an important 'disadvantaged and marginalized' group to consider within the SDGs, as they are a large group, making up an estimated 1 billion people worldwide, and they experience a range of exclusions owing to multiple forms of discrimination and inaccessible environments in many spheres of life, including those that are targets of the SDGs (e.g. health, education, employment) (WHO and World Bank, 2011).

Health is a core focus of the SDGs, with goal 3 aiming to 'ensure healthy lives and promotion of well-being for all at all ages', in part through the target to 'achieve universal health coverage' (UN, 2015). This Goal is an important and ambitious aspiration as the WHO estimates that 400 million people worldwide lack access to healthcare services (WHO and World Bank, 2011). Access is lower still for certain vulnerable or marginalised groups defined by age, gender, income, ethnicity, sexual orientation and disability. Foremost here, may be people with disabilities, as evidence shows that 80% of people with disabilities live in low income countries, are poor, and have limited access to healthcare (ibid , 2011). However, this goal and its targets do not specifically mention persons with disabilities. This absence is part of a broader trend, as unfortunately, people with disabilities are often not discussed or included in the development of strategies for improving access to healthcare services or in the development of programs or initiatives that may play an important role in provision of healthcare for the general population and for disabled people. This is demonstrated by the lack of literature including people with disabilities as a group of consumers who could benefit from changes in healthcare services or health policies that aim to improve access and ease of service provision, both at regional and global levels (Hashemi, 2006; Swarts and Bantjes, 2016). Thus, there is a clear need to take a closer look at the factors impacting on disabled people's health, how they access services and the quality of care.

This paper will critically reflect on how people with disabilities as a large and excluded

minority group with particular health needs should be actively and specifically included in activities aimed at meeting the SDG Health Goal. We propose that the concept of ‘inclusive health’ is a useful adjunct to the aim of universality, because it will help to focus on the need for adaptations and accommodations in the delivery of healthcare by providers, to enable disabled people to experience access to good quality care alongside the general population. We will argue that achieving good health for all is important since experiencing poor health can reduce quality of life and participation (e.g. in education or employment), and thereby exacerbate disability, poverty and exclusion in addition to increase suffering, morbidity and early mortality (Callaway et al. 2015). Improving access to healthcare among people with disabilities will also ensure that the fundamental rights of people with disabilities to health and rehabilitation, as emphasized within the UN Convention on the Rights of Persons with Disabilities (see Textbox 1 below) (UN, 2006), are met and will contribute to the achievement of the SDGs.

*Textbox 1: UNCRPD Articles related to health*

**UNCRPD Article 25 Health**

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

**UNCRPD Article 26 Habilitation and Rehabilitation**

States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services...(UN, 2006:18-19)

**Disability and Health**

The two concepts of health and disability are clearly related, but exactly how, varies across cultures, and the way they intersect and impact on each other has been the subject of confusion and misunderstanding in recent decades. Both disability and health have had varying definitions and are used differently by lay people and experts from different disciplines. The medical model of disability was criticized for equating disability solely with

a health condition, focusing just on individuals' impairments as the cause of disability, while ignoring society's disabling role (Marks, 1997). The social model responded to these concerns by conceptualizing disability as an outcome of society's lack of acceptance of difference and failure to adapt to different types of needs and to provide opportunities for inclusion. The social model therefore downplayed the idea of a direct relationship between health and disability (Oliver and Barnes 2012). The International Classification of Functioning, Disability, and Health's (ICF) model, by contrast, has provided a framework for recognizing the combined impact of a health condition and society's responses in the disablement process. The ICF model combines the medical and social aspect by defining disability as an evolving concept resulting from the interaction between an individual's impairments, the presence of appropriate support and relevant contextual factors such as the attitudinal, social and physical environments (WHO and World Bank, 2011). An underlying health condition (e.g. diabetes) is therefore a defining feature of the disablement process. The health condition may lead to an impairment (e.g. visual impairment) and possibly to difficulties in completing activities (e.g. walking) and being able to participate (e.g. shopping). These functional difficulties may be exacerbated by the social and cultural environment in which the person lives. Poor accessibility or lack of reasonable accommodations, as examples, can limit a person's opportunities to participate in many or all aspects of society on an equal basis with others. On the other hand, people with impairments and functional difficulties who have appropriate supports and an accessible environment, will be more likely to participate fully in employment, education, social life and so on.

Given the complexity of disability, it is no surprise that most people continue to use the terms disability and impairment interchangeably or even think of disability itself as a health condition. In many cultural contexts, someone with an impairment may be described as 'ill', and from this localised (mis)understanding, follow expectations about cures, thus reinforcing narrow medical model approaches to supporting and caring for people with disabilities. The ICF model therefore helps provide a structure for broader and more holistic, multi-factorial, multi-sector discussions around impairment, functioning and disability. It can be used as a lens to address people's needs both at the individual and community level. This will entail developing appropriate adaptations and accommodations as part of inclusive policies and programmes. Easy to access and good quality healthcare is then one component in a system which facilitates and contributes to everyone's participation and inclusion.

Over the past 20 years, global research from diverse settings has shown that on average, people with disabilities are more likely to experience poor general health than people without disabilities. As an example, non-communicable diseases, including chronic conditions such as obesity, hypertension, and mental health conditions, are all more prevalent amongst people with disabilities (Froehlich-Grobe et al. 2016; Kinne et al. 2004; Wilber et al. 2002; AIHW, 2010; Reichard et al. 2011). There is also evidence from a US study showing that adults with disabilities are four times more likely to report their health to be fair or poor than people

without disabilities (40.3% vs. 9.9%) (Altman and Bernstein, 2008). While most of these studies have been conducted in high income settings, these trends are also apparent and often exacerbated in poorer settings, although data here is more sparse. As examples, a study across 30 low and middle income countries found that children with disabilities were significantly more likely to report a serious illness than children without disabilities (Kuper et al. 2014), while a study in Chile showed the percentage of people reporting good health was twice as high among nondisabled people (54%) than those with disabilities (20%) (Rotarou and Sakellariou, 2017).

While the presence of a health condition is the original cause of an impairment, there are many other reasons why people with disabilities may experience worse health than people without disabilities. People with disabilities often experience disadvantaged and marginalised structural positions in society, and on average are poorer than those without disabilities (Banks and Polack, 2014). Social deprivation is well recognized as a factor contributing to worse health through a multitude of routes including poorer diet, unhealthier living conditions and poorer access resources including healthcare (Rotarou and Sakellariou, 2017; Wilkinson and Marmot, 2003; Marmot 2005). Furthermore, people with disabilities are often excluded from opportunities for productive living such as employment, while unemployment is linked to worsening of mental health and poor physical health, consequently leading to premature death (Marmot, 2010; Emerson, 2011).

Their sociopolitical disadvantage, in addition to the exclusions that people with disabilities experience, may result in poorer health through adverse health behaviours. Studies show that on average, people with disabilities are more likely to be physically inactive (Ko et al. 2011; Froehlich-Grobe et al. 2016; AIHW, 2010), smoke, (Froehlich-Grobe et al. 2016; *ibid*, 2010) and use illegal drugs (Gilson, et al. 1996; NARIC, 2011; Glazier and Kling, 2013). However, there is some circularity here, and the direction of causation is not necessarily straightforward. While this evidence is primarily from high income countries, this may also be a trend occurring in more urban settings in low and middle income countries where there is increasing prevalence of non-communicable diseases, and tobacco and illicit drug use (Uchtenhagen, 2004). Evidence also shows that people with disabilities around the world are more likely to experience injury and violence. Systematic reviews indicate that people with disabilities are 1.5 times more likely to be a victim of violence than those without a disability, with those living with mental health conditions having nearly four times the risk (Hughes et al. 2012; Jones et al. 2012). While highly related on cultural context, this vulnerability to violence is particularly apparent for women and children with disabilities (Jones et al. 2012; UN Enable, n.d.; Kiani, 2009; Smith et al. 2004). For example, a survey in Orissa, India in 2004 found that virtually all of the women and girls with disabilities were beaten at home and that 25 per cent of women with intellectual disabilities had been raped (UN Enable, n.d.).

Sociopolitical disadvantage may also result in poorer access to health. For example, a survey of people with serious mental disorders, showed that in high income countries, between 35% and 50% of people, and in low/middle income countries, between 76% and 85%, received no treatments in the previous year (WHO 2016a). In another study, data from four Southern African countries found that only 26–55% of people with disabilities received the medical rehabilitation they needed, and only 17–37% received the assistive devices they needed (e.g. wheelchairs, prostheses, hearing aids) (WHO and World Bank, 2011).

People with disabilities may also have more difficulty accessing preventive healthcare, so that health conditions that could be avoided are not, or are diagnosed at a later stage. This can result in chronicity, comorbidities and other complications, making treatment more difficult, and possibly resulting in additional impairments. Evidence supporting this assertion is that people with disabilities attend fewer routine health examinations (Chun et al. 2012), and are less likely to receive preventive care (Diab and Johnston, 2004; Iezzoni et al. 2000; Reichard et al. 2011; Taegtmeier et al. 2009), including anti-hypertensive drugs (Park et al. 2008). Again, data from poor settings is limited, with some notable exceptions. For instance in Zambia women with disabilities are often excluded from reproductive health services, resulting in increased vulnerability to sexually transmitted infections (Smith et al. 2004). In addition, people with disabilities, due to their disadvantaged position in society and related poverty, often need to make tough decisions about where to use their limited resources or funds, resulting in delays in seeking healthcare services.

While limited, evidence also suggests that when people with disabilities do seek healthcare, they receive poorer quality services, contributing in turn to worse health (Smith et al. 2004; Rotarou and Sakellariou, 2017; Grech, 2015). This is partially due to factors such as negative stereotyping and prejudice both due to disability or other cultural factors and partially due to healthcare professionals' lack of knowledge about how to medically treat or approach the needs of a person with a disability (Smith et al. 2004; *ibid*, 2015). The lack of skill and potentially fear of additional complications due to a client's disability, may also result in local healthcare professionals referring people with disabilities to more specialized facilities in urban settings (Smith et al. 2004). Access to these facilities is often more difficult for those with mobility limitations, limited funds, or from more rural settings related to poverty, who worry about both the direct and indirect costs related to accessing healthcare services, alongside potentially cultural differences and prejudice (Taegtmeier et al. 2009; *ibid*, 2015).

There are yet more explanations for a link between disability and poor health. The underlying health condition may have other knock-on effects on health, for instance, poorly controlled diabetes causes blindness due to diabetic retinopathy, but also increases the risk of kidney and heart disease. The underlying impairment may also cause further health problems, for example people with mobility impairments being more vulnerable to bed sores. Finally,

people with disabilities are on average older, and so more vulnerable to poor health. People with disabilities are therefore sometimes described as having a narrower margin of health (Shakespeare and Kleine, 2013) related to the primary health condition linked to their impairment and sometimes to secondary conditions.

Overall, then, there is sufficient data showing that people with disabilities are more likely to experience poor health. For each individual, it is likely that there will be a mixture of causes contributing towards more or less vulnerability to poor health, some directly linked to the impairment, some to the person's lifestyle, and some that are a direct or indirect result of the responses of the society in which he/she lives. The consequence is that people with disabilities will often have an increased need for health services, either in frequency or specialty or both, increasing the financial burden and limiting access (Grech, 2015). The World Health Surveys conducted across 51 countries, support this assertion, with results indicating that people with disabilities were consistently and significantly more likely to seek inpatient or outpatient care than their peers without disabilities (WHO and World Bank, 2011). These broad figures may be an over-simplification and conceal geographic trends. For instance, it is extremely unlikely that many people with disabilities who live in more rural areas and face either poverty or cultural barriers based on their racial or ethnic affiliations within a country/region would be making more visits to health centers on a consistent basis. Given the above evidence and considerations, it is therefore important to critically reflect on what factors influence access to health care for people with disabilities.

### **General versus specific healthcare needs of people with disabilities**

When considering access to healthcare services it is crucial to recognize that not all people need the same level or type of care, yet they should all be able to receive the level and quality of care they need, as suggested by the global call for Universal Health Care in the SDGs. Health services cover the full spectrum from preventive services and health promotion, through primary, secondary and tertiary care, including rehabilitation and palliative care. All people, regardless of their impairments, need general healthcare services. Basic health services include health promotion activities and preventative measures such as immunisations, nutritional and exercise advice. These are in addition to treatment of a range of general conditions that may affect anyone, including but not limited to, sexual and reproductive health, minor or major injuries, infections and management of non-communicable diseases such as cardiac and respiratory conditions, cancer and diabetes, and mental health conditions. These needs will change at the various stages of the life course.

People with disabilities therefore require basic or general healthcare services, and may need these more frequently than others in the population. In addition, many people with disabilities may need more frequent monitoring or interventions and specific healthcare services related to their underlying impairment. The specific services may include access to medication,

surgery, psychological therapy, assistive devices, and therapeutic rehabilitation such as physical, occupational and speech therapy. These services usually do not focus primarily on 'cure' per se, but on preventing secondary impairments and optimising function so that the person can live as active a life as possible with their impairment. The health condition underlying a person's disability may also have additional negative or secondary health consequences that require treatment. As an example, someone with a severe injury to a lower extremity requiring an amputation above the knee, will need acute and longer term rehabilitation and training in how to manage their particular needs. These may include wound care related to the site of the amputation and mobility training related to balance, use of a mobility aid, wheelchair or a prosthesis. Additionally, he/she may be vulnerable to pressure sores from the use of the prosthesis. An impairment or health condition may also cause chronic pain and discomfort which can have a serious impact on the person's everyday quality of life and which will require medical treatment (Thomas, 2004). In many instances, individual needs are more complex and interrelated than this dichotomy between general and specialist healthcare suggests, and someone's need for healthcare may not be easily divided neatly into the two.

There are various barriers that can have an impact on a person with a disability's ability to access health care. People with disabilities are not a homogenous group, and people with different impairments or circumstances may be more vulnerable to certain barriers than others. One commonly observable and arguably most widely recognised and understood barrier, arises from limited physical access to healthcare facilities. Obstacles include not only gaining entry into the facility, but also within, such as having accessible bathrooms, elevators or doorways into treatment rooms that can accommodate wheelchairs. Once inside a health facility, having accessible/adaptable furniture or equipment is also an important concern. If these are not available, people with disabilities may not be examined, or not to the same standards as others. For example, a pregnant physically disabled woman may not be able to get onto a bed for antenatal checks easily or may not feel safe. Lack of accessible transport, or lack of nearby facilities, may also limit people with disabilities' access to health services.

Less well recognised and understood, are other types of barriers to access which are not physical. For example for people who are deaf or have other communication difficulties (e.g. cognitive or psychosocial impairments), lack of sign language or other adapted communication tools (easy read information, pictures, symbols), result in this group missing out on information or not being informed of their options as effectively as others. Thus, they may not have access to general health promotion/prevention information or more personal information during their consultations with health providers.

Negative attitudes can also be an important barrier to people with disabilities accessing healthcare. Stigma against people with disabilities is perceived to be widespread, and as a consequence, people may fear being turned away or poorly treated when they try to access

healthcare and this would disincentivise them for further visits. This can be even further complicated by the person with a disability belonging to a certain racial or ethnic minority group as described by Grech (2015) in Guatemala. In this case, indigenous people with disabilities face a multitude of barriers not only related to their disability but also their social and racial status in the greater Guatemalan context. This exemplifies the intersectional aspects of disadvantage which may have roots for individuals having a combination of devalued characteristics, be it disabled status, gender, race, sexuality or others.

Stigma may also result in many people with disabilities being completely excluded from certain healthcare initiatives. For example, people with disabilities are often incorrectly considered to be asexual or not sexually active and may not receive education and care regarding sexual and reproductive health needs (Tepper 2000; Smith et al, 2004). This may also result in low uptake of certain services by people with disabilities, and be wrongly interpreted as lack of need, rather than resulting from exclusion or barriers to access.

### *Sustainable development goal 3 and disability*

We have argued above that people with disabilities are more vulnerable to poor health, yet face more barriers in accessing healthcare services. What does this mean with respect to the SDG on health? Goal number 3 of the SDGs calls to ‘Ensure healthy lives and promote well-being for all at all ages’, and within this goal, are 13 targets (see Textbox 2 below). The targets focus on two main points, reducing mortality and disease and improving access to healthcare services for all. It is important to note that none of the targets in this goal mention people with disabilities specifically. However, it is unlikely that the Goal can be met unless activities are inclusive of people with disabilities, and specifically designed to target people with disabilities.

*Textbox 2: Sustainable development Goal 3 targets. Source: UN (2015: 18-19)*

1. By 2030, reduce the global maternal mortality ratio to less than 70 per 100,000 live births
2. By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births
3. By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases
4. By 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being
5. Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol
6. By 2020, halve the number of global deaths and injuries from road traffic accidents
7. By 2030, ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes
8. Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all
9. By 2030, substantially reduce the number of deaths and illnesses from hazardous chemicals and air, water and soil pollution and contamination
10. Strengthen the implementation of the World Health Organization Framework Convention on Tobacco Control in all countries, as appropriate
11. Support the research and development of vaccines and medicines for the communicable and noncommunicable diseases that primarily affect developing countries, provide access to affordable essential medicines and vaccines, in accordance with the Doha Declaration on the TRIPS Agreement and Public Health, which affirms the right of developing countries to use to the full the provisions in the Agreement on Trade Related Aspects of Intellectual Property Rights regarding flexibilities to protect public health, and, in particular, provide access to medicines for all
12. Substantially increase health financing and the recruitment, development, training and retention of the health workforce in developing countries, especially in least developed countries and small island developing States
13. Strengthen the capacity of all countries, in particular developing countries, for early warning, risk reduction and management of national and global health risks

The following examples illustrate the potential difficulties or challenges in meeting some of the targets related to reducing mortality and prevalence of disease in SDG number 3, if the

needs of people with disabilities are not addressed:

- Target number 3 states: *by 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.*

Using AIDS as an example, it is now clear that people with disabilities are at least as vulnerable to infection with HIV as people without disabilities (Touko et al. 2010; Tarkang et al. 2015; De Beaudrap et al. 2017). This is partly because, contrary to popular belief, people with disabilities are often as sexually active as other people. Additionally, their vulnerability arises from their structural disadvantaged position in society, so that they experience on average many of the risk factors associated with high risk of HIV, including poverty, sex work, sexual violence, not to mention the barriers they face as people with disability to access to reproductive healthcare. Furthermore, as argued above, people with disabilities are often excluded from health promotion strategies and initiatives that address awareness and education on such diseases (Groce et al. 2007). This target will therefore not be met without including people with disabilities in programmes and strategies by using an inclusive approach.

An example of where this was attempted is the ‘Accessible AIDS Materials for PWD’ project in the North-West Region of Cameroon. This involved collaboration between an international funder and three local agencies in the region to develop communication tools to provide education and thereby reduce the prevalence of HIV and AIDS amongst people with disabilities. The initiative targeted people with disabilities and/or HIV/AIDS and their caregivers, their respective organizations, health care providers/institutions, related ministries such as the Ministry of Public Health and Social Affairs (Hashemi et al. 2011). Meetings and consultations were held with various stakeholders including people with disabilities, disabled people’s organisations, community workers and community leaders during pre and post-development of materials to ensure relevance and applicability in the context. The outcome was development and distribution of HIV/AIDS educational materials in accessible formats including Braille, American Sign Language DVDs, audio and print copies in English and a local dialect (Pidgin English). Topics covered in each format included ‘HIV testing’, ‘Living and coping with HIV/AIDS and Disability’, ‘Healthy living with HIV/AIDS and Disability’, and ‘Local Allusions’. In addition, a facilitators’ guide for hosting workshops and seminars on Disability and HIV/AIDS was also developed, trialled and disseminated to disability organisations, rehabilitation facilities and educational centers in the North-West Region, as well as radio announcements to further sensitize the community and increase awareness of the initiative and where to go for obtaining the accessible formats.

Another example is in the first ‘Voluntary Counselling and Testing services for the Deaf’ in Kenya where people with hearing impairments learned about HIV services, including

education and testing, through a peer education programme involving both hearing and deaf clients (Taegtmeier et al. 2009). The program initially took place in three densely urban centers in Kenya, but then developed a mobile outreach program to more rural contexts to increase awareness and reach those clients who were unable to access urban sites. While overall the program was a success and there was a significant increase in the number of clients being reached, the peer educators found working in the rural areas more challenging due to variations in the local sign language with differences in the signs used for relevant terminology and the need for increased repetition and education due to complete lack of exposure to AIDS related materials.

- Target number 4 states: *by 2030, reduce by one third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being.*

As discussed earlier, evidence shows that people with disabilities are more likely to have non-communicable diseases (Froehlich-Grobe et al. 2016; Kinne et al. 2004; Wilber et al. 2002; AIHW, 2010; Reichard et al. 2011) and so must be actively included in strategies to prevent and treat these conditions.

Promoting ‘well-being’ for people experiencing non-communicable diseases must include provision of rehabilitation in order to reduce morbidity and mortality after an illness or for the aging population. The use of technology can provide much needed support and accessible information in this area, since human resources to deliver rehabilitation are often limited, particularly in resource poor settings. For instance, a smartphone-based app was successfully developed to deliver rehabilitation and support in daily activities at low cost to people post-stroke and their caregivers in India (see Sureshkumar et al. 2016). More evidence is needed as to how these types of intervention could be extended to the poorest and rural communities, where access to a smartphone and ‘airtime’ may be a barrier to this kind of support.

At a global context, the WHO has also made several attempts at bringing disability health and rehabilitation to the forefront of its agenda with developing strategies such as the ‘Disability Action Plan 2014-2021’ and ‘Rehabilitation 2030: A Call for Action’. It is important to note that it will be difficult to achieve these goals and objectives without including people with disabilities as part of these movements and recognizing the needs of people with disabilities living in diverse contexts and experiencing multiple barriers.

- Target number five states: *Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol*

Earlier in the paper it was reported that there is extensive literature showing that people with

disabilities, at least in high income countries, are more likely to abuse substances, specifically drugs or alcohol (NARIC, 2011; Slayter, 2010). While the mediating factors driving this link are unclear, prevention and treatment strategies are rarely actively inclusive enough to provide for people with disabilities on an equal basis. Where evidence is available, this focuses mostly on vulnerability to substance abuse by people with disabilities related to mental illness and again based out of urban research centers where specialty care is available. A review of the literature by Horsfall et al. (2009) identified that while the provision of psychosocial interventions for people with substance abuse disorders is effective, its effectiveness is less clear amongst those with severe mental health conditions or dual diagnosis due to the complexity and variations of their needs and presentations in addition to structural barriers. This further reinforces the need to ensure all prevention and treatment programmes are not only inclusive and barrier-free, in order to achieve this target, but also able to respond to variations in need and the heterogeneity of the clients they are serving.

- Target number 7 states: *by 2030, ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes*

While there appears to be limited quantitative data, there is clear qualitative evidence on the lack of inclusion of people with disabilities in sexual and reproductive health services (Smith et al. 2004; Kiani, 2009). Several organizations are working in low resource settings to ensure universal access to these services, including for people with disabilities. For example, the African Youth with Disabilities Network (AYWDN) is a programme that provides support for youth with different types of disabilities, their families, friends and supporters across the continent. One of the main components of the programme is to work with various stakeholders, including health educators and providers to ensure that youth with disabilities both receive sexual education and have access to quality and equitable sexual reproductive health services and support (AYWDN, 2017).

Such examples highlight how the lack of inclusion of people with disabilities in activities to meet these targets, means that it will be unlikely for SDG 3 to be met. At the same time, there are many ways in which inclusive health can be achieved, and all rely on a clear need to involve people with disabilities in developing these solutions. Currently, user-involvement, user-focused and even user-led research and consultation in health are common, particularly in high income settings. In a consumer-driven society this is seen to be a good way of making sure that services are responsive and matched to the needs of the population as expressed by these ‘expert patients’ or ambassadors. However, this kind of consultation about needs is in its infancy when it comes to asking people with disabilities about what they would like their health service to be. Both pure and action-orientated research needs to move towards a more inclusive and participatory research approach which would recognize the specific health needs of this diverse group, making up 15% of the world population.

*Disability and Universal Health Coverage (UHC)*

The other key focus of SDG 3 is to improve access to healthcare services for all through achievement of Universal Health Coverage. While this is alluded to in a number of the targets (e.g. 7, 11), target 8 specifically describes UHC and its key components:

- *Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all*

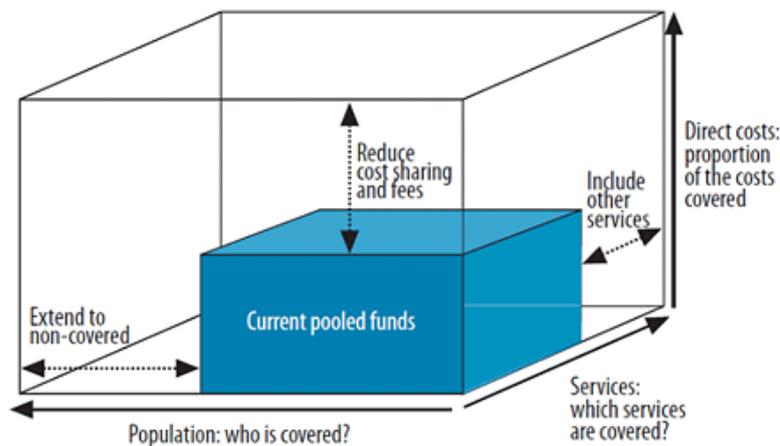
The WHO suggests that:

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 (2015: 7).

This means that to achieve UHC, it is important to consider the proportion of the population covered, the availability of essential good-quality health service coverage and the existence of financial coverage (WHO, 2015). Financial coverage relates to the extent to which the healthcare cost may be either catastrophic, exceeding a given fraction of the total household expenditure, or impoverishing, that is pushing the households below or further below the poverty line (ibid, 2015). This is displayed in figure 1 below with the use of three axes, demonstrating the three dimensions which can affect the achievement of universal health coverage: – (effective) health services, finance, and population (WHO 2015). The smaller blue cube represents current circumstances while the larger cube represents the ideal coverage at which UHC is achieved.

We will explore the three dimensions of UHC and how they relate to healthcare access for people with disabilities.

Figure 1: The three dimensions to consider when moving towards universal coverage (WHO, 2015)



**Population coverage:** The population coverage axis of UHC focuses on access to health for all, aiming for health care that is available to the entire population. Unfortunately, however, there are many people who are unable to access healthcare services, can only access certain services, or have inadequate levels of access at different stages of their lives.

People with disabilities are likely to be an important group who experience poor access to healthcare services. As an example, the World Health Surveys showed that across 51 countries, people with disabilities were significantly more likely to express needing inpatient or outpatient care, but experienced difficulties in accessing the care (WHO and World Bank, 2011). Yet, overall, there is a lack of quantitative data on access to healthcare among people with disabilities in poor settings. One challenge for filling these evidence gaps is to find a way of measuring health coverage among people with disabilities. Research has shown that almost all people, including those with disabilities, do seek health during instances of ‘serious illness’ (Kuper et al. 2014; Mactaggart et al. 2015) so that these questions cannot differentiate varying levels of access among different population groups. In contrast, if data on perceptions of health and health seeking is sought by asking about any illness in the recent past, then many people will not have sought care, and this is often appropriate in the case of mild self-limiting conditions. There is a need for scales that not only measure access to health, but also compare this access between people with and without disabilities to understand any inequalities in access to healthcare and to reveal how these could be equalised. Changes in patterns of health and illness across the life course will also complicate the picture and need

to be captured in data collection, in analysis, and subsequent planning of inclusive services.

Nevertheless, it is likely that people with disabilities as a group are less likely to have access to health. In order to achieve full health coverage for people with disabilities, it will be necessary to consider the different types of barriers described above: physical, communication, attitudinal, cultural and power-based ones that confront people with disabilities seeking healthcare. Following this, strategies can be put in place to overcome these barriers. People with disabilities are not a homogenous group and people with different impairment types may be particularly vulnerable to certain types of barriers, and these will also vary in different cultural settings and policy environments. In order to address many of these barriers, people with disabilities need to be more actively recognized as representing a large minority of the world population, and this needs to be actively taken into account in all efforts to make healthcare inclusive. As discussed earlier, it is crucial to include people with disabilities while working to remove barriers, and more nuanced and sensitive qualitative research is also important in developing solutions. Achieving health coverage will require educating health care providers, as well as designing inclusive barrier-free healthcare services and tackling the structural factors underlying poor access to healthcare among people with disabilities (e.g. poverty). Making healthcare services inclusive and barrier-free and thus accessible to people with disabilities, will make them more accessible for all, and thereby improve healthcare coverage overall.

*Financial coverage:* The second component of UHC is that healthcare needs to be affordable even for the poorest in the community. Financial barriers to accessing healthcare are widespread for many people. However, these are likely to be exacerbated among persons with disabilities as they are often marginalized, less likely to be employed, and on average are poorer than those without disabilities (Banks and Polack, 2014). Furthermore, healthcare costs are often higher for people with disabilities which will exacerbate the lack of affordability further (WHO and World Bank, 2011). Examples of such extra costs facing people with disabilities include the costs of accessible transportation and opportunity costs such as loss of employment or wages because of the need for a family member to accompany them to seek healthcare (Grech, 2015). It is not surprising that research has found that persons with disabilities are up to 50% more likely to have catastrophic health expenditures compared to their non-disabled counterparts (Shakespeare and Kleine, 2013). The World Health Surveys also showed that 51-53% of people with disabilities cannot afford healthcare, compared to 32-33% of people without disabilities (WHO and World Bank, 2011).

Health insurance is frequently promoted as a means to provide financial protection and achieve UHC, and is being rolled out in many countries such as Ghana, Indonesia, and Rwanda. However, and once again, people with disabilities may be at a disadvantage. They on average can less easily afford to join health insurance schemes or benefit from work-related health insurance schemes (Banks and Polack, 2014). In addition, people with

disabilities are more likely to be excluded from health insurance schemes, if they do not participate in the formal labour market and/or on the basis of underlying health conditions, as was the case in the US, until the signing of the Affordable Care Act into law in 2010. This is also true in Guatemala, where many people with disabilities living in rural areas depend on informal sources of income such as small scale farming (Grech, 2015).

Lack of insurance can mean that people with disabilities may delay or forego medical care. Moreover, health insurance schemes often do not cover all the services that people with disabilities may require, most notably access to rehabilitation and assistive devices.

Achievement of UHC which should include people with disabilities, will therefore necessitate consideration of how to make healthcare affordable for all. Positive examples do exist. For instance, in Vietnam, people registered with disabilities are enrolled in health insurance schemes, although there is inconclusive data on their effectiveness (Palmer and Nguyen, 2012; Palmer et al. 2015). However, in many countries, issues around gaining a form of registration which recognises a person as having a disability is itself problematic, bureaucratic and possibly stigmatizing. In turn, this reduces one's incentives to pursue this status or to go through the processes necessary to get onto health insurance schemes.

*Service coverage:* The service axis of the UHC model focuses on the type of services available. The full range of healthcare services that people with disabilities may need, both general and specialized, must therefore be available in order to achieve truly Universal Health Coverage. To address service coverage, stakeholders need to ensure that services are not only open to all, but are actually designed to be inclusive and take into consideration the varying impairment-related and other health needs people have, tackling the range of barriers which currently prevent access. Crucially, for people with disabilities, rehabilitation and assistive devices must be explicitly included within essential healthcare services and consideration of achievement of UHC.

There have been a number of global initiatives to encourage increased service coverage and access to healthcare services for people with impairments and activity limitations due to a health condition. One example is the implementation of the GATE (Global Cooperation on Assistive Technology) global initiative in 2011. The GATE initiative aims to improve access to high quality and affordable assistive devices to those who are in need to enable individuals in need of such devices to lead a healthy, dignified and productive life (WHO, 2017). This project focuses on aids and appliances of various sorts, but with a predominant focus on impairment-related equipment such as walking aids, wheelchairs, white canes, and hearing aids. More recently, in early 2017, during the WHO's Rehabilitation 2030, a call for action event, world rehabilitation experts pledged to support governments to enhance rehabilitation services by incorporating them into UHC. This move recognizes that greater access to rehabilitation is a requirement to achieving SDG 3 on health (WHO, 2017b) and will benefit

the entire population, not only people with disabilities. The hitch in this seemingly encouraging development, however, is that the WHO strategy is only advisory, so Ministries of Health at a country level, still have to be convinced to show commitment to increasing resources to incorporate rehabilitation and provision of assistive technologies into their health plans.

### **Quality healthcare**

Finally, it is important to note that coverage is not the same as effective coverage. People with disabilities may face stigma and discrimination when accessing healthcare services, and this results in their receiving poorer quality care (Shakespeare and Kleine, 2013). People with disabilities may also have comorbidities that require complex coordinated care between different health professionals and flexible arrangements, which is often not provided.

These concerns are backed by data. An analysis of the 2006 US Medical Expenditure Panel Survey revealed that people with disabilities were more likely than nondisabled people to think that their doctor had not listened to them, treated them with respect, taken enough time, involved them in treatment decisions, or explained treatments properly (Shakespeare and Kleine, 2013). In the UK, the Formal Investigation into Inequalities in Health found that people with mental illness and people with intellectual impairments received a worse service from health professionals, which may have contributed to the poorer outcomes they experienced (Disability Rights Commission, 2006). These concerns are also apparent in resource-poor settings. A recent study from Chile provides a clear link between disability and socio-economic status in relation to access to quality healthcare. The study demonstrated that health status was mediated by the type of health service provider used, and this in turn is mediated by income, meaning that those with higher income could either pay for better insurance, or pay out of pocket for private care and access better care as a result (Rotarou and Sakellariou, 2017).

Many of these issues are due to lack of training of healthcare workers around impairment and disability, on inclusive practice and reasonable accommodations, and on how to communicate effectively in multimodal ways with people with disabilities. It may also be important for health professionals to give additional time for consultations with people with disabilities, to allow these to be conducted at high quality. Many clinicians are less likely to accommodate the needs of persons with disabilities because these require flexible practices. This may be closely related to financial coverage, since healthcare professionals may be more willing to coordinate care or be more flexible when they feel that they receive enough resources and/or greater compensation for their efforts.

## **Conclusion**

To summarize, even though people with disabilities are not explicitly mentioned in SDG 3 ‘to ensure healthy lives and promote well-being for all at all ages’, this goal will not be met without moving towards a truly inclusive approach to the provision of Universal Health Care. People with disabilities are a very large minority group who have greater health needs, both general and specialized, and who have lower health for a variety of reasons. Thus, a proactive approach towards removing barriers and adapting services to suit their needs is required, including greater participatory research to provide information on general and specific needs.

Just as the SDGs are interlinked and mutually reinforcing (e.g. both reducing poverty and increasing education will help support health improvements), for people with disabilities, improving their health and access to good quality healthcare will improve their overall participation and inclusion in society. This will facilitate their net contributions and will increase their overall wellbeing.

To address the barriers to provision of a genuinely inclusive healthcare system, especially for people with disabilities, there needs to be a greater understanding of how we measure health coverage, what is meant by access to health and quality, and how we know if it has been achieved. The concept of UHC aims to address the barriers, however as the WHO (2015) report on tracking UHC identifies, there are two main challenges to achieving UHC: the lack of reliable data; and difficulties in measuring effective coverage.

The lack of reliable data is great in the area of disability, particularly from low and middle income settings (WHO, 2015), and this is a major barrier in achieving equitable access. In addition, the lack of awareness and attention to the health of this neglected group could be argued to reflect their more general exclusion and lack of visibility within the larger population. For example, while the development of new health technologies could greatly improve access to healthcare and health education for people with disabilities, the WHO report on e-health in 2016 failed to mention disability and the role of e-health for this population in the entire report (WHO, 2016).

Very noticeably, the SDG on Health does not specifically mention inclusion or people with disabilities, although the aim of UHC implies their inclusion. However, the goal is unlikely to be achieved without specific strategies focusing on the one billion people with disabilities, who face both greater vulnerability to poor health and more difficulties accessing affordable and good quality services. The UNCRPD reiterates the fundamental right to healthcare and rehabilitation for people with disabilities, and the recent WHO Disability Action Plan (2014) and WHO Rehabilitation (2017) strategies focus on fulfilling these rights. Put together, there is now a groundswell of support for working towards universal, inclusive health coverage for people with disabilities, thereby contributing to their overall wellbeing, to equity and to the

achievement of SDG 3.

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