**Access to health for persons with disabilities**

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# Introduction

This report was commissioned to provide a general overview of the health status of persons with disabilities, in order to inform the next report of the UN Special Rapporteur on the rights of persons with disabilities for the UN General Assembly. The purpose of this background document is to provide an overview of different topics related to the health of persons with disabilities, including:

* relationship between disability and health;
* health care needs of persons with disabilities;
* unmet health care needs of persons with disabilities;
* barriers in accessing to free or affordable general and disability-specific health care services;
* barriers in accessing to free or affordable health-related habilitation and rehabilitation goods and services, including early identification and intervention;
* human rights violations in the context of health care services.

Persons with disabilities have the same health needs as every other member of the population, including immunization, screening, sexual and reproductive health, and all other aspects of regular healthcare. They may also have additional or more complex health needs, because of impairment and the consequences of impairment. Persons with disabilities may face particular barriers in accessing needed healthcare. Not least of these is the increased likelihood of living in a situation of poverty and social exclusion, which increases both the likelihood of ill-health, and the likelihood of facing barriers to accessing healthcare. For all these reasons, health is a disability rights issue, which is why Article 25 of the Convention on the Rights of Persons with Disabilities sets out the normative framework which should govern disabled people’s access to healthcare.

Health is important in itself, because it enables a person to have a good life, and a full life expectancy. However, poor health or lack of access to needed healthcare also makes it more difficult for other rights to be realized. If an individual does not have access to needed medical or rehabilitation services, they may be unable to attend school, or access livelihood opportunities, or participate in society. For example, in a study carried out by the London School of Hygiene and Tropical Medicine in Nepal, a major reason why children with disabilities said they weren’t going to school was because of poor health.[1] Those who lack access to wheelchairs, prosthetic or orthotics are likely to face barriers to participation. So, achieving the right of access to health and rehabilitation underpins other social and economic rights.

The disability rights movement may sometimes have been reluctant to campaign on the issue of health and rehabilitation, because of concerns about medicalization of disability. Over many decades, the disability rights struggle has been to highlight the role of barriers and oppression in the lives of persons with disabilities, to reject inappropriate medicalization, and to challenge the power of professionals over the lives of persons with disabilities. Whilst persons with disabilities may usually have experienced health conditions and impairments, there has been greater focus on removing societal barriers through the social model of disability to avoid over medicalized views of disability. As a consequence, the role of needed healthcare has sometimes been minimized. However, talking about health and healthcare does not mean being defined by an impairment or health condition. Acknowledging that almost all impairments have a health component does not mean being defined as ‘unhealthy’ or seen as ‘invalid’. Like everyone else, persons with disabilities have health needs. By virtue of their health condition or impairment, they often – but not always – have additional health needs. These should not define them, because to have health needs is part of the human condition.

The issue of prevention is also controversial within the disability rights community. There is no difficulty with campaigning for access to health to ensure that persons with disabilities enjoy the right to health on an equal basis with others. Ensuring that persons with disability can access health promotion, prevention, screening, rehabilitation and other mainstream and specialist health services is unquestioned. However, there can be concerns about certain efforts to ensure that non-disabled people can take all available steps to avoid developing impairments themselves. First, health promotion should not use negative images of life with disability to encourage non-disabled people to live healthy or safe lives. Second, preventing existing people becoming disabled is different from preventing future disabled people. Actions around prenatal diagnosis can be particularly complex, and will be addressed in a later paper from the Special Rapporteur. Here it is important to stress that while prenatal sceening has an important role in healthcare, if it is conducted under conditions of informed consent and balanced information, screening messages should not stigmatise life with disability. Parents should be supported to make the choices about testing that are best for them and their family, and all choices should be supported, and all babies should be welcomed and included. Third, prevention of disability in the general population is not a disability rights issue, it is a health issue. Health promotion, immunization, screening and other efforts should be included under the right to health, not as part of efforts to promote, protect and ensure the rights of persons with disabilities.

## Disabled people can be healthy

Objectively, according to the International Classification of Functioning, Disability and Health, all people with disabilities have a health condition (Appendix 1). However, having an impairment does not mean being unhealthy.[2] Moreover, objective health is not the same as subjective health. As the 1948 WHO definition states, health is “a state of physical, mental and social well-being and not merely the absence of disease or infirmity”. Well-being relates to the subjective sense of being healthy. Many people have static impairments – for example, blindness or deafness or a missing limb – but report feeling healthy. Regardless of impairment or illness, people can be in good health, because they eat a good diet, take exercise, get enough sleep, are in a good emotional state, and pursue other healthy behaviours.

For example, the United Kingdom (UK) Office for National Statistics published analysis of 2011 Census data from England and Wales on the subject of disability and health[3]: the Census asked people to rate their own health on a five point Likert scale, and it also asked whether respondents’ day-to-day activities were limited because of a health problem or disability which had lasted, or was expected to last, at least 12 months. The results show that 4.3% of the private household population, or 2.4 million people had a disability, but still reported being in good health. There was an age gradient: over 50% of children with disability were in “good” health, whereas at the oldest ages, slightly less than 20% of people with disability were in good health. However, because disability is more common among older people, the overall population of people with good health despite disability was highest among older age people: around one in 6 people aged 85 and over were in good health despite a disability. This is important, because it suggests that some people may report feeling healthy but still have social care needs. A richer understanding of health and disability is required to capture the lived experience of people who have life limiting illnesses or impairments.

## Health care needs of persons with disabilities

There is good evidence that persons with disabilities are more likely to have poorer health than the general population, due to a variety of possible mechanisms, which may be different for people with different impairments.[4-9] First, by definition they have a *primary impairment*, which may or may not be a health condition which becomes progressively more significant, such as multiple sclerosis or muscular dystrophy. Some impairments do not directly affect health, they could be considered more as differences in functioning – such as Deafness or some aspects of neurodiversity.

Secondly, many disabled people are at greater risk of *secondary health conditions*, where there is a causal link to their primary diagnosis or impairment. For example, people with spinal cord injury are at increased risk of pressure sores and urinary tract infection.[10] People with Down’s syndrome are more likely to experience congenital heart disease, impaired hearing and early onset dementia.[11] People with blindness due to diabetes may also experience kidney disease. People with cerebral palsy may develop osteoporosis.[12] People with schizophrenia are at higher risk of diabetes.[13] Some of these secondary conditions may be iatrogenic, in other words, caused by the treatments they receive for the primary impairment.

Third, disabled people are also at higher risk of *co-morbidities*, where the cause is less direct. Often, a co-morbidity might result from the increased risk of poverty and social exclusion that persons with disability might face. Disabling barriers and isolation can impact persons with disabilities in diverse ways. For example, people with a long-term physical condition are 2-3 times more likely to have a mental health condition such as anxiety or depression.[14] Poor people have higher rates of long term illness, and disabled people are generally at risk of poverty, all of which means they are also more likely to experience other health risks associated with social disadvantage (e.g. poor housing and diet).[15, 16] People with disabilities are more likely to be women and are more likely to be older people, each of which may be associated with health risks.[17] People with mental health conditions are more likely to experience premature mortality due to higher levels of obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke.[18-20] Older people, for example those with dementia or stroke, are very likely to have more than one condition, which makes medical care more complicated, particularly if they are prescribed multiple drugs, leading to the problem of interactions, or polypharmacy. In general, disabled people have a *narrower margin of health*, for example they may be at increased risk of dying of influenza in an epidemic. [21]They also often have a greater vulnerability to age-related conditions than persons without disabilities.[4]

Considering health, structural factors are as important as risks associated with having a disabling health condition. Poor physical and social environments can make primary conditions worse; can exacerbate secondary consequences of primary conditions; and can lead to co-morbidities. For example, as well as poverty and social exclusion, persons with disabilities are also at higher risk of violence: adults have a 50% higher risk of experiencing violence in the past year, rising to 300% higher risk in adults with mental health conditions.[22] Children have a 300% risk of experiencing violence and abuse, as compared to non-disabled children.[22] Disabled people also tend to be at higher risk of some unintentional injuries, such as falls or road traffic injury.[23] Dangerous health behaviours may trigger health conditions associated with disability indirectly: e.g. drug or alcohol abuse may lead to disability as a result of road traffic injury. Above all, and as discussed below, lack of access to healthcare leads to poorer health outcomes. All of these processes can differentially affect different demographic groups: for example, women may experience multiple disadvantage, and migrants and people from minorty ethnic communities are at higher risk of poverty and exclusion, with negative implications for health. Equally, persons with psychosocial disabilities and persons with intellectual disabilities are often perceived to be at a higher risk of exclusion or negative treatment in healthcare.

Because of all these processes, many of which originate in the social environment, persons with disabilities have a higher risk of ill-health, when compared to persons without disabilities.[4-7, 9] There is also evidence from a study in the United States 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%).[24] These trends are also apparent in poorer settings, although data here is more sparse. As examples, a study across 30 low and middle income countries found that both boys and girls with disabilities were significantly more likely to report a serious illness than children without disabilities.[25] A national survey in Guatemala showed that persons with disabilities were more than twice as likely to self-report that they had experienced a “serious health condition” in the last year (47% versus 23%, adjusted Odds Ratio[[1]](#footnote-1) [aOR] 2.8, 95% CI 2.2-3.7). People with disabilities were also three times more likely to report that they had one of 17 different health conditions than those without disabilities (aOR=2.9, 95% CI 2.2-3.8).[8] A South African study found that persons with disabilities were less than half as likely to report excellent or very good health as non-disabled pople; they were nearly four times as likely to report fair or poor health.[26] A study in Chile found that people without disabilities were more than twice as likely to report having good health (54%) as people with disabilities (20%).[27]

## Healthcare meeting the needs of persons with disabilities

Due to the higher vulnerability to health concerns discussed above, on average persons with disabilities are likely to require and use health services more than persons without disabilities. Persons with disabilities require the same general health services as persons without disabilities, from promotion, prevention, and treatment, to rehabilitation and palliative care. People with disabilities may also require different types of specialist services (e.g. rehabilitation or assistive devices) or adaptations in how services are offered (e.g. sign language communication). The *World Report on Disability* summarises results from the World Health Survey in 50 countries, reporting individuals’ care seeking behaviour by country income level. The analysis found that in low-income countries, a significantly higher proportion of both males and females with disabilities (>18 years) sought inpatient and outpatient care.[17]

A key consideration is whether there is equity in quality of health and healthcare between persons with and without disabilities. Health equity can be divided into vertical health equity – are different groups of people with the same needs treated the same – and horizontal health equity – are people with different needs treated differently according to their health needs. Because the needs of disabled and non-disabled people are not the same, the measure of health equity should not be parity of usage: it should be the extent to which health services meet complex medical and rehabilitation needs of persons with disabilities, i.e. horizontal health equity. For example, the analyses of the World Health Surveys in the *World Report on Disability* showed that both men and women with disabilities were significantly more likely to report needing healthcare services but not receiving them, then people without disabilities (women: 5.8% versus 3.7%; men: 5.8% versus 4.1%). A Canadian study found that adults with disabilities aged 20-64 had three times the level of unmet healthcare needs as adults without disabilities.[28] Health outcomes are likely to be worse for some persons with disabilities, because some impairments inevitably limit life expectancy, so that there is unlikely ever to be complete health equality. But steadily improving outcomes in terms of quality of life and life expectancy show that barriers are being removed, services are becoming more appropriate, and gaps are being minimized.

Discussion of health needs of persons with disabilities should take into account improved technologies, health and social care that are increasingly available to people with different impairments. Sometimes, this is about expensive health interventions which may not be available in resource-constrained settings. For example, life expectancy for people with Down syndrome has increased as they have access to better medical care – such as cardiac surgery, where the survival rate for infants with Down syndrome has been found to be better than that for ‘genetically typical’ infants.[29] But in other cases, interventions are comparatively cheap. For example, evidence shows that nocturnal home ventilation is a simple and highly effective intervention for people with Duchenne muscular dystrophy, and it has increased life expectancy from approximately 14 years to upwards of 25 years.[30]

While evidence-based interventions are generally to be welcomed, there can be concerns about other pioneering treatments for which efficacy may be uncertain, and ethical problems might arise, particularly regarding lack of consent obtained from child subjects of interventions. For example, experimental mercury detoxification treatments or harsh behavioural modification regimes for children with autism; or conductive education for children with cerebral palsy; or limb-lengthening for children with restricted growth.[31-34] In many of these cases, interventions reflect the urge of parents or clinicians to attempt correctivecures or normalization, whereas acceptance of difference and removal of societal barriers will often be a more effective and less damaging response.

Often improvements in mortality (life expectancy) and morbidity (experience of impairment) result from comparatively simple interventions which are as much to do with social support and inclusion as they are medicine itself: for example, Worf et al (2011) showed that life expectancy for children with spina bifida in Uganda improves with availability of Community-Based Rehabilitation (CBR).[35] CBR began as provision of rehabilitation interventions in the community provided by community heath workers, and has evolved into a multi-dimensions approach encompassing health, rehabilitation, education, livelihood, social and empowerment aspects: increasingly, it is known under the term ‘disabilty-inclusive development’. CBR has an important role to play, particularly in identifying children and adults with unmet needs; providing community heath and rehabilitation responses; and referring persons with disabilities to the mainstream health system when those needs cannot be addressed in community settings. CBR can thus contribute to overcoming barriers of access to health and health-related rehabilitation. CBR also works to promote inclusion in education, livelihood and social life, and thereby reduce poverty and discrimination, which are underlying drivers of poor health among people with disabilities. Figure 1 shows the CBR matrix. A systematic review of CBR found a beneficial effect in the lives of persons with physical disabilities and a modest beneficial effect in the lives of persons with mental health conditions or intellectual disabilities, but also found that more and better research was needed.[36]



**Figure 1:** CBR matrix [37]

To achieve health equity, access to health is a vital prerequisite. Access to health is not just about physical access to a healthcare facility but also covers factors such as[38]:

Quality

Geographical accessibility

Availability

Finanancial accessibility

Acceptability of services

In other words, having services available, being able to travel to services, being able to get into premises, and access information, and benefit from accessible facilities, being able to have free or reimbursed services, being treated with respect and being able to have high quality and acceptable services is all part of healthcare access, properly understood. However, evidence suggests that people with disabilities face a multitude of barriers to accessing health facilities. As an example, in Namibia, people with disabilities reported difficulties with transportation, having to travel long distances, and inability to afford treatment.[39] These types of barriers are expected to be very common in many low and middle income countries. Further, too often, examination couches or scanners or other equipment is not accessible to persons with mobility impairments, for example, and this results in lower quality of examination and treatment.

The concept of acceptability highlights how meeting human rights in the area of healthcare does not simply mean ensuring basic health needs are met. It also requires attention to how those healthcare needs are met. Major human rights violations will be discussed later in this paper. But there is also the basic matter of whether persons with disabilities are treated with respect and dignity when they encounter healthcare professionals. This raises several important questions. Are people supported to make decisions for themselves, on the basis of informed consent? Is communication appropriate and accessible? Do persons with disabilities experience ‘diagnostic over-shadowing’, when their general health needs are neglected because of the focus on the primary impairment? Are they supported to get appropriate referrals to address their specific healthcare needs?

## Access to healthcare: Universal Health Coverage and Disability

Access to healthcare is a development issue, as well as a question of realization of rights. A key focus of Sustainable Development Goal 3 “Good Health and Well-being” is to improve access to healthcare services for all through achievement of Universal Health Coverage (UHC). 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.[40] Figure 2 illustrates the three dimensions which can affect the achievement of UHC: coverage of (effective) health services, finance, and population.[40, 41] The smaller blue cube represents current circumstances while the larger cube represents the ideal coverage at which UHC is achieved.



**Figure 2:** The three dimensions to consider when moving towards universal coverage.[40]

People with disabilities may potentially be left behind across the three aspects of UHC:

* *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. People with disabilities may experience poorer access to healthcare services and consequently high unmet needs[17].
* *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, but may 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.[16] Furthermore, healthcare costs are often higher for people with disabilities (e.g. accessible transport, need for carer to accompany), which will increase the lack of affordability further.[17] The World Report on Disability also showed that 51-53% of people with disabilities cannot afford healthcare, compared to 32-33% of people without disabilities, and that persons with disabilities were 50% more likely to experience catastrophic health expenditure which pushed them into poverty.[17]
* *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, should be available in order to achieve truly UHC. Crucially, for people with disabilities, rehabilitation and assistive devices must be explicitly included within essential healthcare services and consideration of achievement of UHC. The WHO estimates in many low-income and middle-income countries, only 5-15% of people who require assistive devices and technologies have access to them.[42]

Coverage is not the same as effective coverage, and the aspect of *quality* needs to be considered within the UHC framework. Quality of healthcare provision may be a particular concern for people with disabilities, because of stigma and discrimination, presence of comorbidities and consequent need for complex coordinated care and due to inaccessible equipment or lack of skills of healthcare professionals.[43]

It is therefore important to consider healthcare access for people with disabilities, to assess whether their rights are being fulfilled and also whether they are being left behind on the path towards UHC.

## Healthcare coverage of persons with disabilities

A fundamental concern in discussing healthcare coverage of people with disabilities is that we do not have clear and consistent metric for how this concept can be measured. A lack of measurement tools is not merely an academic issue; different ways of measuring access will give us different answers as to whether or not people with disabilities are excluded from healthcare, and consequently what our policy and programme response should be. This issue is illustrated using the case study below from Guatemala.

Access to health was explored within the context of a national survey of disability in Guatemala.[8] This survey included 707 people with disabilities and 465 people without disabilities matched by age, sex and location. Different methods were used to measure access to health, and this fundamentally influenced our judgment as to whether people with disabilities received better, worse or no different access to healthcare than people without disabilities, as summarized in table 1.

**Table 1:** Healthcare access in relation to disability in Guatemala

|  |  |  |
| --- | --- | --- |
| Method for measurement of healthcare access | Main result | Interpretation: Access to healthcare by disability  |
| Sought care when had a “serious health condition” | 76% of people with disabilities had sought care versus 72% of people without disabilities (difference not statistically significant[[2]](#footnote-2)) | No difference |
| Receiving treatment if diagnosed with one of 17 health conditions | People with disabilities were more likely to be receiving treatment than people without disabilities (aOR 1.4, 1.0-1.9). | Better access among people with disabilities |
| Vaccination coverage | High coverage among children with disabilities (94%) and those without (88%) (difference not statistically significant).  | No difference |
| Receiving antenatal care | Women with disabilities were significantly less likely to seek antenatal care (aOR 0.4, 0.1-1.0). | Worse access among people with disabilities |
| Delivery assisted by doctor/nurse | Women with disabilities were more likely to have delivery assisted by a doctor/nurse rather than a non-medical professional (aOR 2.9, 1.0-8.2) | Better access among people with disabilities |
| Coverage of rehabilitation services | Very few people with disabilities had received these services | Poor access among people with disabilities  |

Quality, availability and affordability are crucial, as well as access or coverage. The Guatemala survey did not specifically measure affordability of care, but did find people with disabilities were more likely to report that availability of services was a big problem (table 2). They were also more likely to report being disrespected by health professionals and finding information difficult to understand during their most recent healthcare visit.

**Table 2:** Quality of healthcare experience in relation to disability in Guatemala

|  |  |  |  |
| --- | --- | --- | --- |
| Measure of quality | Persons with disabilities | Persons without disabilities | aOR (95% CI) |
| Availability of health services a big problem | 88 (19%) | 88 (19%) | 1.9 (1.4-2.6) |
| Experience last time received health care |  |  |  |
| * Felt completely/mostly disrespected
 | 47 (9%) | 13 (4%) | 1.9 (1.0-3.7)\* |
| * Difficult to understand information
 | 121 (22%) | 42 (14%) | 1.6 (1.1-1.4)\* |
| * Difficult to be understood
 | 106 (20%) | 43 (14%) | 1.3 (0.8-1.9) |

This example from Guatemala therefore illustrates the complexity of measuring access to healthcare. It also shows that different results are obtained when different metrics are used.

Access to healthcare for people with disabilities is an important issue for achieving their human rights, and for achieving development targets such as the Sustainable Development Goals. Disaggregated data are needed to assess whether people with disabilities are being left behind in inclusion in healthcare. The complexity in measuring access and lack of standard measures that would allow comparability of findings must be kept in mind while assessing the findings from the literature.

# Systematic review of access to healthcare

Two of the current authors conducted a systematic review to assess access to healthcare among people with disabilities in low and middle income countries, to explore these questions in more detail and across the full spectrum of published literature available. The key methodological features of the review are summarized in Appendix 2. In brief, over 13,000 titles were screened for eligibility. The review assessed separately access of people with disabilities to general healthcare (49 studies included), and to specialist healthcare (80 studies included).

## **Access to general healthcare services among people with disabilities**

### Summary of findings

The review of access to general health for people with disabilities identified six main outcome types: utilisation, coverage, adherence, affordability, health insurance and quality. Comparisons were made between people with and without disabilities for each outcome. Results of each study were summarized in to higher, lower, mixed (e.g. if results were higher for one disability type and lower for another), and no difference. The results of the 49 included studies are summarised by outcome in Figure 3.

**Figure 3:** Results by outcome type

In summary, the results showed the following*:*

* **Utilisation** of healthcare services was measured using a range of outcomes in two main groups: use of primary or secondary health services, and use of tertiary services, and by different time periods of assessment. Examples include: number of visits to health centre or public health facility in past 12 months or 2-3 months; access to services in the past 6 months; home visits by a doctor in past 12 months; length of time since last consultation; hospital outpatient visit in the previous 6 or one month; hospitalisations (inpatient admission) in the past 12, 6, or 3 months. Overall, 33% of studies showed that utilisation of healthcare services was higher for people with disabilities compared to those without; 14% showed lower utilisation, 43% showed mixed results, and 10% found no difference.
* **Coverage** of healthcare services refers to receipt of treatment when needed, either in terms of need for routine services (e.g. vaccination) or need for services as a result of a health concern (e.g. care when ill). A wide variety of outcomes were used to measure coverage and these included: probability of not receiving care last time needed; help sought when ill in past 30 days, in the past 12 months, or over an unspecified time; and uptake of specific services, (e.g. HIV related, vaccination, dental visits, maternal health). Overall, 43% of studies measuring coverage (n=21) found lower coverage amongst people with disabilities in comparison to people without. A similar proportion found no difference (41%) and 23% found mixed results. Due to the range of outcome measures,it is difficult to compare data. The most consistent finding is among the studies that measured coverage of dental services among children with intellectual impairments; three found lower previous dental attendance for children with intellectual impairment in Nigeria, Egypt, and Jordan respectively, with one finding no difference in any dental treatment received amongst children with Down’s Syndrome in Malaysia.[44]
* **Adherence** to treatment is important since nonadherence leads to poor health outcomes. Good adherence indicates sustained and regular contact with health services.Adherence was measured in three studies – either to HIV treatment, fluid or diet restrictions for end stage renal disease, or medication. Of these studies, two found mixed results by impairment type, and one found adherence was lower than in people without disabilities.
* **Affordability** of services is a core component of access to healthcare. In total, six studies measured outcomes related to health expenditure in people with and without disabilities. Costs or expenditure outcomes included catastrophic health expenditure ; total out of pocket expenditure ; and health expenditure to income ratio. Three studies (50%) found higher expenditure among people with disabilities, one study (17%) found no difference, and two studies (33%) found mixed results by impairment type.
* **Health insurance** is a key mechanism by which the right to access healthcare can be realized, as it reduces financial constraints to seeking care. Four studies measured outcomes related to health insurance coverage. Access to health insurance was measured in two main ways – medical payment method or provider; or coverage. One study found lower coverage amongst people with disabilities, and three studies found no difference in coverage for people with or without disabilities.
* **Quality of services** was assessed in two studies through: ease of access, satisfaction, and overall accessibility. Trani et al. (2012) found no difference in satisfaction with public health facilities in Afghanistan for people aged >5 years with and without disabilities.[45] In Thailand, a study by Wongkongdech et al. (2014) found that 66% of people with physical impairment of all ages ranked their accessibility to health services at a moderate level (i.e. neither high nor low), taking in to account adequacy of health personnel, respect for rights and dignity, transport, service related aspects, personal factors and costs.[46]

The use of different metrics for measuring healthcare access may therefore produce inconsistent findings and makes assessment of trends across the literature difficult. Furthermore, there were big gaps in evidence. Health promotion and preventive services are crucial to maintain good health. However, we did not include health promotion in the review as we were concerned that it was difficult to determine whether knowledge was indicative of receipt of health promotion. Furthermore, few studies addressed whether preventive services were reaching people with disabilities. In addition, there was a gap in evidence around access to palliative care for people with disabilities.

### Data disaggregation and comparability of findings across studies

People with disabilities are not a homogenous group, and characteristics such as gender, age and impairment type are likely to impact on access to healthcare services. Very few of the individual studies included in the review disaggregated the data by these characteristics. For the majority of other studies, the numbers in each category became too small to make meaningful inferences about differences by these cross-cutting characteristics. It was also impossible to compare the findings across studies to identify consistent patterns, since there was too much variation in how healthcare access was measured, as well as the study designs, settings (e.g. clinical or population based) and so on. Developing common metrics for measuring healthcare access, and using these in large-scale studies, will improve the availability of high-quality, comparable data, so that the impact of these intersecting issues on healthcare access can be explored.

## **Access to specialist services among people with disabilities**

### Summary of findings

People with disabilities may benefit from specialist services as a result of their impairment, which includes physical therapty, assistive devices, speech and language therapy, psychiatry and more. Many of these services are usually known as “rehabilitation”: It should be noted that this is a complex concept to define. The same term is also used for vocational rehabilitation, rehabilitation of offenders, drug and alcohol rehabilitation. Article 26 of the Convention on the Rights of Persons with Disabilities uses an expansive conception of rehabilitation. In this paper, we refer to health-related rehabilitation only. WHO defines rehabilitation as a *“set of measures that assist individuals who experience or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments”*. Using this definition, a broad range of interventions that may be required to maximise functioning were included under “rehabilitation” for the review, including: access to medical rehabilitation, access to therapy, coverage of assistive devices, and adherence to medication. These interventions are mainly operating at the level of the individual child or adult with disability.

People with impairments that cannot be cured may have improved functioning through the provision of rehabilitation. Coverage of rehabilitation would therefore be the proportion of people needing rehabilitation who have received it. The reality of making this measure is more complex. Measuring coverage of rehabilitation and assistive devices requires a clinical assessment of whether curative treatment is possible (e.g. someone visually impaired from cataract will need surgery, not rehabilitation). Then, assessment of the rehabilitation or assistive device needed and whether this has been received. Estimation of the latter measure is challenging, since it must take into account, for instance that people who have been given an assistive device are still using it, or that the full therapy sessions are provided if needed. Self-report tools may therefore be inadequate to measures of the need for and coverage of rehabilitation. In the studies included in the review, all measured coverage of rehabilitation in terms of self-reported usage versus need. There are therefore serious concerns about the quality and accuracy of data on coverage of rehabilitation services obtained through the systematic review.

### Description of findings by impairment type

Results of the 80 included studies are presented below by access to services specific to the following disability domains: hearing, mental health, physical, and visual.

#### Coverage of rehabilitation for people with mental or behavioural conditions

36 studies measured access to specialist healthcare services for people with mental health and behavioural disorders in 18 countries across six World Bank regions. There was a wide variation in underlying condition for the study population (depression, CP, schizophrenia, epilepsy, intellectual disability, psychiatric disorders, general mental disorders). The majority of studies were conducted amongst adults (22 studies) and most studies sampled participants from the general population (28 studies). There was also a lot of variety in measures of access to rehabilitation used: 26 measured non-pharmaceutical rehabilitation, seven measured adherence to treatment, and four measured access to medication.

The broad range of conditions, source of participants, outcomes, and age groups mean that estimates within this group cannot be directly compared. Moreover, the way in which coverage was measured through self-reported usage versus need means that the estimates are of little meaning. However, it was clear that coverage of all coverage of rehabilitation was generally low across studies. As examples:

* Coverage of medical rehabilitation for depression ranged from 0% for males in Mexico to 53% in South Africa.
* Coverage of epilepsy treatments ranged from 0% for older adults in Zimbabwe, to 52% amongst people of all ages in The Gambia.
* For children with intellectual disabilities coverage of rehabilitation services was higher, between 73-87% in Ethiopia and India.
* For other less specific conditions, coverage of medical rehabilitation ranged from 1% in China (all ages) to 39% for adults in Georgia.

#### Coverage of rehabilitation for people with physical impairment

24 studies measured coverage of physical impairment specific services in 20 countries and five World Bank regions. The types of physical impairments varied, including rheumatoid or other arthritis (five studies), leprosy (two studies), difficulties walking (six studies), amputation (one study), and musculoskeletal impairment (three studies). Five studies were conducted amongst adults, 12 amongst people of all ages, four amongst children and in three studies the age group was not presented. Outcomes included coverage of physical therapy, assistive devices, medical rehabilitation, and adherence.

As with rehabilitation for mental health conditions, the wide variety in range of conditions, source of participants, outcomes, and age groups mean that estimates within this group cannot be directly compared and coverage varied widely across studies. Again, the method for measuring coverage casts serious concerns on the validity of the results. As examples:

* Coverage results for arthritis were varied, with the highest coverage seen in Jordan (76%) and lowest in India (4%).
* Results were also varied for less specific physical impairments such as “difficulties walking”, musculoskeletal impairment, and physical impairment – with particularly low coverage of assistive devices found in Tanzania (0-4%) and rehabilitation in Brazil (18%), and high coverage found in Rwanda (87%) for physical therapy.

#### Coverage of rehabilitation for people with vision impairment

In total, 16 studies measured access to health for people with visual impairment across 13 countries in four World Bank regions. Eleven studies measured medical rehabilitation, six studies measured access to assistive devices, and one study measured adherence. All but two studies used a population-based sample.

Coverage of medical rehabilitation was varied – from 5% amongst people of all ages in Brazil to 82% amongst people of all ages in Nigeria. Similarly, results for assistive device coverage were very variable, but typically quite low across studies. There were some outliers, however, with a Nigerian study finding a coverage of 82%. As in the previous examples, the validity of the measures used for coverage is questionable, and so results are not reliable: for example, it is most likely that in practice, coverage of medical rehabilitation is better in Brazil than in Nigeria due its more extensive healthcare system.

#### Coverage of rehabilitation for people with hearing impairment

In total 13 studies measured access to hearing specific services in 12 countries, and four World Bank regions. Of these, nine studies measured coverage of assistive devices (hearing aids), five studies measured access to medical rehabilitation, and one measured adherence. Coverage of assistive devices ranged from 0-66% across studies. General rehabilitation coverage was between 3-62%, while one study reported adherence at 34%.

#### Coverage of rehabilitation for people with any disability

Overall, 25 studies did not disaggregate results by impairment type, or reported overall coverage in addition to impairment specific coverage, and thus were grouped together under access to any specialist treatment for disabilities, which included access to assistive devices (16 studies), general rehabilitation (22 studies), and adherence (one study). These studies were conducted in 23 countries in 6 regions – the majority in sub-Saharan Africa (12 studies). Ten studies sampled participants from the population. 21 used self-reported tools, including 14 used the Washington Group questions[[3]](#footnote-3), two used the Rapid Assessment of Disability[[4]](#footnote-4), and the remaining using bespoke tools. Only two studies out of 25 used a clinical examination, and so it is not possible to infer from this information what the true coverage was of rehabilitation services.

Coverage of general rehabilitation was very varied across studies ranging from 3-80%. Coverage was particularly low in India and Turkey at 3 and 5% respectively (both low-middle income). In contrast studies in the Philippines, South Africa, Malaysia, and Brazil found much higher coverage at 70%, 71%, 76%, and 80%. Substantial variation was also found for access to assistive devices – but generally coverage was low.

### Data disaggregation and comparability of findings across studies

The coverage results for rehabilitation are hard to compare across studies – different types of impairment are considered, as well as varying measures of coverage, age groups, selection of sample (e.g. population-based versus clinic-based). Individual studies attempted to disaggregate by variables such as age and gender, but the numbers often became small and the inconsistency in methods used makes it impossible to compare disaggregated data across studies.

Better metrics are needed to measure need for and coverage of rehabilitation. Self-reported measures are inadequate, as individuals are unlikely to be able to determine which services they require. The Washington Group questions are also insufficient to measure need for rehabilitation, as they do not assess which conditions would benefit from assistive devices or rehabilitation services. For instance, a recent survey in Cameroon found that the most common cause of hearing loss was impacted ear wax, which requires simple removal and not a hearing aid.[48] Furthermore, the Washington Group questions are inconsistent in whether they take consideration of the presence of assistive devices in terms of whether difficulties in functioning are experienced: difficulties in hearing and vision are asked “even if” spectacles or a hearing aid are available, but difficulties in mobility do not consider the presence of assistive devices. Another important issue is that most people will not know that they could benefit from a type of assistive device or rehabilitation service unless they had been offered it in the past. Consequently, measuring coverage in terms of usage of services that the person perceived he/she needed will over-estimate the coverage and not give a meaningful measure of the true need or the true coverage in the population.

Clinical assessment of impairments is optimal for determining the need for rehabilitation, but can be costly and take time, and often requires the expertise of health professionals. The more widespread availability of mobile tools to measure visual and hearing impairment and their cause may make clinical assessments more feasible in the future (e.g. Portable Eye Examination Kit (PEEK), hearScreen).[49, 50]

### Summary of results of the literature review

There is limited evidence that persons with disabilities have worse access to general healthcare services than people without disabilities. We can propose different reasons for this conclusion, but it requires further research. There is a lack of high quality data capturing coverage fully, rather than utilization alone. Use of such crude indicators may mean that we are not able to discern differences in access to healthcare between people with and without disabilities. Another possibility is that if people have a real need for treatment they will attend for services, even if people with disabilities may face more difficulties in achieving access. For instance, in the Guatemala survey the majority of people sought treatment for a “serious health condition” whether disabled or not, and similarly, almost all children were immunized, regardless of disability. As a consequence, these broad measures will not allow us to distinguish access to healthcare in different groups. A related point is that in poor settings there may be general widespread lack of access to healthcare services, and so it may be difficult to identify a difference between persons with and without disabilities. People with disabilities may be more linked in with the healthcare system, because of their impairment and various health conditions, and that helps to overcome some of the barriers they experience in accessing healthcare.

There is some evidence from the systematic review that the cost of seeking treatment is higher, and that quality of services/healthcare experience may be worse for persons with disabilities. There is also some evidence that access to rehabilitation is low among persons with disabilities – so that they are not receiving the care they need and have the right to.

This review has highlighted that further research is needed to understand how people with disabilities are accessing health services, not just in terms of utilisation, but also coverage of preventive services, affordability of health services, and the quality of care received. In particular, there is a need to define a broader range of metrics to allow collecting more meaningful data and greater comparability of outcomes across countries. Utilisation alone is not an appropriate indicator for people with disabilities, given that people with disability generally experience greater health needs. Coverage of rehabilitation services was highly variable and poorly measured within the studies in the review, but generally shown to be low. Far better metrics are needed, including through clinical assessment, before we have a true appreciation of the population level need for and coverage of these services.

People with disabilities are not a homogenous group, but include people with different impairment types, age, level of poverty, gender, ethnicity and so on. All of these factors can influence the relationship between disability and healthcare access. As mentioned, it was not possible to draw out broad patterns of access by these intersecting issues due to the lack of consistency in how data was collected. There are also specific groups that may be particularly hidden and/or under-represented in the data, such as people with autism, those with psychosocial disabilities or rare diseases, who may face even more exclusion and discrimination within healthcare settings and so may have particularly poor levels of coverage. Another concern is that not all settings are the same. As an example, humanitarian crises can result in people developing impairments, but may also make it more difficult for people with disabilities to seek healthcare and rehabilitation. Yet evidence on the inclusion of people with disabilities in healthcare in these settings is extremely limited. UHC strives to achieve health for all, leaving no one behind, and without more inclusive indicators, we will not be able to monitor progress towards this end. This review found evidence that UHC is not being met for people with disabilities, as they may be falling behind in terms of coverage of general healthcare services, as well as rehabilitation, and services are not affordable or of sufficient quality.

# Barriers in accessing healthcare

This section will explore barriers which persons with disabilities experience to free or affordable general and disability-specific health care services, including health-related habilitation and rehabilitation goods and services, including early identification and intervention

Persons with disabilities are faced with a range of barriers when they seek healthcare. Strategies are required to overcome these different barriers in order to achieve UHC and the fulfilment of rights. People with disabilities are a diverse group, and people withdifferent impairment types may be particularly vulnerable to certain types of barriers to accessing services. Barriers will also vary in different geographic and cultural settings and in different policy environments.

A barrier that is perhaps conceptually straightforward arises from limited physical access to healthcare facilities. Obstacles can make it difficult to gain entry into the facility, but also to move through elevators or doorways into treatment rooms, or use the bathrooms. Having accessible/adaptable furniture or equipment is also an important consideration. 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.

Other types of barriers may be less well recognised and understood. For example, for people who are deaf or have other communication difficulties (e.g. cognitive or psychosocial impairments) may miss out on information or on being informed about their options if there is a lack of sign language or other adapted communication tools (easy read information, pictures, symbols). People with visual impairment may not be able to read letters from health professionals or instructions regarding medication.

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 may discourage people from attending for healthcare services. This experience can be even further complicated by the person with a disability belonging to a certain racial or ethnic minority group, exemplifying the intersectional aspects of disadvantage.[51] 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 not to be sexually active and may not receive education and care regarding sexual and reproductive health needs.[52, 53] 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. In Argentina, barriers to accessing reproductive health interventions for women with disabilities - such as contraception, voluntary sterilization, abortion after rape - included long delays, unnecessary referrals, downright denial, need for husband’s permission, were reported by Human Rights Watch.[54]

Cost are another major hurdle to accessing healthcare. This barrier arise because people with disabilities are on average poorer, yet face higher healthcare costs, for instance, through needing accessible transport, a companion for the visit, or more expensive treatments.

The systematic review included assessment of barriers to accessing general healthcare and rehabilitation among the included studies. Eight studies measured barriers to accessing general healthcare services. The most commonly reported barriers across studies were transport difficulties, financial difficulties and attitudes of staff. These results are shown in Table 3.

Table 3: Quantitative barriers to general healthcare reported in included studies

|  |  |
| --- | --- |
|  |  Reference |
| Geographic accessibility |  |
| Transport difficulties | [17, 55-58]  |
| Location of services |  [59] |
| Affordability |  |
| Financial |  [17, 55-57, 60] |
| No accommodation at health facility |  [57] |
| Acceptability |  |
| Lack of perceived need |  [17, 57] |
| Other commitments |  [17, 57] |
| Lack of awareness or information |  [17, 55, 60] |
| Did not know where to go |  [57, 58] |
| Fear  |  [55, 57] |
| Faith/belief |  [57] |
| Physical access to facility |   [57, 58] |
| Availability |  |
| Services not available |    [57] |
| Lack of equipment |  [17, 57, 58] |
| Tried but denied |  [17, 57] |
| Difficulty finding doctor |  [44] |
| Quality |  |
| Discrimination or lack of awareness amongst health workers |  [17, 57-59] |
| Previous bad experience |   [57] |
| Health care providers skills inadequate |  [17]  [57] |
| Standard of facility |   [57] |

22 studies evaluated barriers to accessing rehabilitation. Commonly reported barriers included, geographic accessibility (distance to service, lack or cost of transport), affordability (of services, treatment, lack of insurance), availability of services, and acceptability-related factors (including perceived need, fear, and lack of awareness about the service) and quality of services. These results are shown in Table 4.

Table 4: Quantitative barriers to rehabilitation reported in included studies

|  |  |
| --- | --- |
|  | Reference |
| Geographic accessibility |  |
| Distance to service | [61-70] [71] |
| Transport problems | [25, 56, 60, 61, 63, 65, 66, 69-73]  |
| Nobody to accompany | [64, 65, 67, 69, 72] [70, 71] |
| Affordability |   |
| Unable to afford services | [56, 60-66, 68, 69, 72-79] |
| Unable to afford treatment | [62, 63, 67, 80-82] |
| No insurance | [62] |
| Acceptability |   |
| Do not know where to go for treatment | [61, 62, 64, 65, 67, 69-71, 77, 83] |
| Have not heard about service | [82] |
| Thought nothing could be done | [61, 64, 65, 69, 80, 83] [70] |
| Lack of perceived need | [64, 65, 67, 69, 74, 80] [70] [61, 62, 83] [61, 65, 69, 80] [63] [57, 61] |
| Family do not perceive need | [64] |
| Fear of seeking care | [61, 64, 65, 69, 80] [70] |
| No time/other priorities | [62, 64, 65, 67, 69-71, 73, 80] |
| Other medical problems | [64] [81] |
| Shame | [57, 61] |
| I did not trust that the health care staff would keep my problem confidential | [61] |
| Availability  |   |
| Waiting time at the clinic | [61, 69, 72] |
| Not availability of drugs, services | [66, 67, 73, 81, 82] [71] |
| Quality |   |
| Discrimination/poor treatment from health provider | [63] [71] [66] [61, 62] [70] |
| Poor relationship with provider | [80] [57, 64] |
| Provider refused care | [73] |
| Communication barrier | [66] [71] |
| Provider lacks skills | [78] [71] |

The review identified some particular barriers to which people with disabilities may be particularly vulnerable, including discrimination from the health provider, provider lacking skills, and communication barriers. However other barriers like cost and distance may be experienced among both disabled and non-disabled populations. It is questionable whether barriers can be assessed through quantitative questionnaires, as included in this review. The reasons why people choose to attend healthcare services, or not, are complex and inter-related and often cannot be reduced to simple answers. People may say that cost is the main barrier, whereas in fact this may mean that not enough priority within the family is given to the person with disability to support spending money, so that discrimination and neglect is the true barrier.

As an example of the difficulties in measuring barriers, a study was undertaken on cataract in Kenya, the Philippines and Bangladesh.[84] People visually impaired from cataract were identified in the three settings and asked whey they had not attended for surgery (acknowledging that cataract surgery is not a form of rehabilitation). In each place, “cost” and “lack of awareness of the availability of services” were reported as the main barriers. All people were counselled about the need for surgery, and offered free surgery, and often free transport. After one year, only half of cases in each setting had gone for surgery, even though the main reported barriers had been removed. Now, other reported barriers emerged, such as "surgical services inaccessible" and "fear". The study concluded that although cost is often reported as a barrier, this explanation may conceal more complicated underlying barriers which need to be explored through in-depth qualitative research. However, qualitative data are more time consuming to collect and analyse, and are often not easy to compare across studies to identify whether consistent patterns exist.

Single reported barriers are also often insufficient, as barriers and exclusions are reinforcing. For instance, a study in Kenya showed that many children with disabilities were not attending school, and so were not receiving school-based health interventions such as feeding programmes.[85] Barriers in accessing school were therefore more pertinent than barriers to healthcare when considering why children did not receive this health intervention.

# Human rights violations in the context of health care services

Access to healthcare is a human right, expressed in the International Convenant on Economic, Social and Cultural Rights, and reiterated from a disability perspective in the Convention on the Rights of Persons with Disabilities. Therefore the most extensive human rights violation in the context of health services is the failure to meet health needs, or to meet those health needs in appropriate ways, as discussed throughout this paper. Furthermore, the rights of people with disabilities may be violated in instances where they are denied health care because of their disability. This was raised as a key barrier to accessing services in the systematic review.

However, there are also a range of specific human rights issues that arise in the area of health care. Space prevents extensive discussion, but this section highlights rights violations in terms of violence and abuse, frequently conceptualized as a public health issue in itself, but also with very significant physical and mental health consequences; violations in the area of sexual and reproductive health, such as forced or coerced sterilization and long-term contraception; particular violations in the delivery of psychiatric treatments; and violations arising from failure to respect decision-making capacity, promote informed consent, or provide support decision making.

Women and girls with disabilities are at particular risk of violence and abuse, but it should be noted that men and boys with disabilities are also at risk.[86] Children with disabilities are up to three times as likely to have experienced violence than children without disabilities.[87] Adults with disabilities are 50% more likely to have experienced violence in the last year than adults without disabilities; this raises to three times as likely for adults with mental health conditions.[87] Violence against people with disabilities, whether it arises from child maltreatment[88], intimate partner violence, elder abuse, or community violence, is increasingly conceptualized as a public health issue, with serious mental and physical health implications for victims. There is increasing research on what can be done to reduce exposure to these different forms of violence experienced by persons with disabilities.[89, 90]

In the area of sexual and reproductive rights, persons with disabilities often face discrimination, and as discussed, may lack access to the full range of sexual and reproductive health services.[91, 92] In particular, persons with disabilities may also be at risk of forced sterilization or involuntary long term contraception, particularly women (and some men) with HIV, or with intellectual disabilities, or sometimes with mental health conditions.[93, 94] Those individuals with intellectual disabilities who do reproduce, run the risk of having their children taken away by the state.[95] or by their families.

Many human rights violations are incurred by people with mental health conditions. For example, Drew et al (2011) chart violations such as physical or sexual abuse or violence, arbitrary detention, lack of opportunities for marriage and family life, and financial abuse.[96] Some violations consist of involuntary treatment, or imposing cruel, inhuman or degrading treatments, in contravention of Article 12 of the Convention on the Rights of Persons with Disabilities. Proposals to address this include the ‘Fusion Law’, where involuntary treatment is not based on distinctions of status – as a person with mental health condition – but is about anyone with impaired capacity from any cause.[97]

A wider area of concern for all people with mental health conditions or intellectual disabilities is the issue of legal capacity. The CRPD proposes that disabled people have legal capacity on an equal basis with others; rejects substitute decision making (guardianship etc) and proposes supported decision making. Instead, the CRPD favours the provision of supported decision making, where people have access to a range of supports to enable them to exercise their right of legal capacity. Another dimension of this drive to give weight to the wishes and preferences of the individual themselves is the notion of advanced decision making, where someone who is symptom-free draws up a statement about how they wish to be treated in a future situation where they are experiencing, for example, symptoms of mental illness. For those who cannot make decisions for themselves, or with the aid of supporters, or who is expressing a wish which is known to conflict with their previously expressed values and wishes, the third option is ‘facilitated decision making’: this means appointing someone to work with the individual, and their family and close friends, to gauge what action or decision best coincides with their previously expressed will and preference. Non-consensual treatment remains possible, under this approach, but in strictly limited circumstances, and not simply on the basis of a status as someone with mental health condition or intellectual disability.[97]

Finally, more subtle violations of human rights commonly occur where there is a failure by medical services to obtain full informed consent, or where decision-making is dominated by parents and carers or where there is a failure to provide reasonable adjustments.[98] For example, persons with intellectual disabilities may not be given appropriate reasonable adjustments in healthcare, particularly where they come from a minority ethnic community.[99] Disabled children may not have their abilities respected, whether this concerns assent (for children under the legal age of capacity) or consent for those young people who should be given the right to make choices in the area of healthcare.[100] As a correlary point, removing barriers to healthcare may reduce barriers to accessing education, and vice versa.

# Overcoming barriers to accessing health care services

Measures to ensure the implementation of disability-inclusive health systems, including mainstreaming, participation, financing, accountability and awareness raising. Efforts are needed to remove barriers so that access to healthcare services is made equitable for people with disabilities. Evidence is currently lacking on which interventions work to achieve these changes, as shown in the recently produced Evidence Gap Map.[101, 102] A recent overview of systematic reviews also identified very limited data addressing disability within delivery, financial or governance arrangements for health systems in low-income countries, or for implementation strategies.[104-107] More evidence is needed taking a health system approach to addressing the issues and identifying solutions, and this must focus on quality of care as well as access to healthcare services. [108] Guidance documents are also very limited. However, a toolkit from UN Division for Social Policy and Development (DSPD) and Department of Economic and Social Affairs (DESA), highlights some measures to be taken at country-level to create inclusive health services, specifically for the African context.[103] CBM has guidance on how to make eye health programmes inclusive.[109]

In order to remove barriers and achieve UHC three key dimensions must be considered: the proportion of the population covered, financial coverage, and which services are covered. Laws and policies already exist in many countries. More efforts are therefore needed to make changes at the levels of services and programmes, rather than at the policy level. The “twin track” approach promotes inclusion of people with disabilities across a range of services – including health. This involves specific programmes targeting people with disabilities, and ensuring general development programmes include and are accessible for people with disabilities. To ensure equal access to health services, actions are needed at multiple levels. These actions must be supported through governmental budgetary allocations.

Across all these approaches, it is crucial to include people with disabilities and disabled people’s organisations (DPOs) while working to remove barriers, and more nuanced and sensitive qualitative research is also important in developing solutions. One effective approach is recommended by the UK Medical Research Council for the development of complex interventions.[110] This process involves conducting a systematic review of potential interventions and conduct of qualitative research with the target group (in this instance, people with disabilities and healthcare providers) to identify issues. Next, a participatory workshop is held with key stakeholders to agree potential solutions, which are then pilot tested for feasibility and acceptability, and then trialed for impact. A multisectoral approach is needed for improving coverage of healthcare services, integrating health care provision with education, employment and other interventions. Ideally, these interventions should tackle the underlying drivers of exclusion from healthcare from people with disabilities, such as poverty, exclusion and discrimination, as well as offering short term solutions, such as ensuring that services are physically accessible.

Some examples of good practice for achieving improvements in the different components of UHC for people with disabilities exist from LMIC and are presented below.

## Improving policy response

The rights of people with disabilities to healthcare are enshrined in the Convention on the Rights of Persons with Disabilities, in particular article 25 (Health) and 26 (Habilitation and rehabilitation).[111] Many countries have made specific provisions to preserve the right to healthcare for people with disabilities, but not all, and these efforts are not always specific about access to rehabilitation services.

The WHO Global Disability Action Plan has a target to “Develop and/or reform health and disability laws, policies, strategies and plans for consistency with the principles of the Convention on the Rights of Persons with Disabilities”.[112] It encourages countries to review and revise existing policies and eliminate discriminatory provision to ensure better access for and includion access for and inclusion of persons with disabilities in health and other sectors. One mechanism proposed is for each country to establish a multisectoral national disability strategy and action plan that ensures clear lines of responsibility and mechanisms for coordination, monitoring and reporting. Another is to identify focal points for disability within Health Ministries to work on this issue. Countries will need support in changing their health system to be more inclusive, and this could include technical support to develop laws, policies, strategies and plans. Opportunities need to be provided for learning and capacity development (e.g. workshops) and exchange of knowledge between different interested groups. Participation of people with disabilities is, of course, critical in achieving an inclusive health system.

Brazil provides a good case study of a country with a good policy environment supporting the inclusion of people with disabilities in the healthcare system. Brazil is a signatory to the CPRD.[111] Beyond the CRPD, there are a range of laws in place in Brazil, protecting the right to healthcare among people with disabilities, including:

* *The Brazilian Constitution* (1988) establishes the responsibility of government at different levels to protect and ensure the health of people with disabilities.
* *The National Policy for the Inclusion of Persons with Disabilities* (1989, 1999) guarantees access of people with disabilities to a wide range of healthcare services.
* *The National Health Policy for Persons with Disabilities* (2002) reiterates these rights, but also emphasizes extending and strengthening health information systems, capacity building, the planning and functioning of integrated health services networks, and its liaison with other sectors (e.g., welfare).
* *The National Plan on the Rights of Persons with Disabilities* (2011) allocates resources to building the capacity of a range of services, including primary health and rehabilitation.
* *The Brazilian Law for Inclusion of People with Disabilities* (2015), reinforces the rights of people with disabilities for priority access to healthcare and rehabilitation.

These laws are also reflected in policies in Brazil:

* In 2002, the Ordinance of the Ministry of Health was published, which established the *National Policy on the Health of Persons with Disabilities*.
* In 2008, the Family Health Support Centres (NASF) were created, whereby a multi-professional team (e.g. physiotherapist, speech therapist, occupational therapist) are available to complement the Primary Health Policy.
* In 2012, a further Ordinance established the Health Care Network for Persons with Disabilities within the Unified Health System.

Laws and policies therefore promote access to comprehensive healthcare for people with disabilities within Brazil. Yet, there is a large gap between policy/laws and practice.

## Improving coverage of services

Improving coverage of healthcare services to include people with disabilities will require interventions at the supply side (i.e. from the healthcare services) and the demand side (i.e. for people with disabilities).

Ensuring that services are physically accessible is important, and this should consider accessibility within the building, of toilets and of equipment. Accommodations are also needed so that information can be provided in varying formats to meet the needs of people with different impairments, such as visual (e.g. braille), hearing (e.g. sign language) and intellectual (e.g. simplified texts). It will be cheapest and most efficient if plans are made for these aspects of accessibility in the design of services. Delivery of services at or closer to home may also be helpful to improve access, particularly for people with physical or multiple impairments.

Improved coverage can also be achieved by promoting the inclusion of persons with disabilities within healthcare system decision making or delivery, whether at the central or local level. An example is in Kenya where people with hearing loss were trained as HIV counsellors in order to improve coverage of HIV health promotion services to include people with hearing impairment.[113] Sensitization of healthcare professionals may help to improve inclusion. Examples include training of healthcare professionals about disability awareness and the rights of persons with disabilities, whether through periodic online or other courses, or ideally, as a component of the medical curriculum.

Individual changes will be insufficient to ensure coverage of all people with disabilities. Good examples of inclusive health services exist which targeted different aspects of inclusion, such as the inclusive eye health programmes developed by CBM in Pakistan and Sightsavers in India. {CBM, Undated #205} Both programmes focused on a range of service level improvements, such as making the service physically accessible, including costs for accessibility in the programme budgets, offering outreach services, and training healthcare providers about disability.

Interventions can also aim to improve demand for healthcare services among people with disabilities. Two previous reviews have been conducted on interventions to increase access to health services for children in LMIC (not specifically with disabilities).[114, 115] Evidence was limited for many intervention types, however text message reminders, delivery of services at or close to home, and incentive programmes show promising results at improving uptake of healthcare services. These types of interventions could be used to help improve uptake of services by people with disabilities, whether as a targeted or inclusive programme. However, evidence on the effectiveness of interventions to increase demand for healthcare among people with disabilities in order to improve coverage is needed. Some examples do exist. For instance, a programme in Brazil for the carers of children with congenital Zika syndrome provides information about their rights to healthcare, and about how they can realise those rights, such as techniques to improve their interaction with healthcare professionals. The motivation is that this approach will help ensure that the child’s healthcare needs are met more fully and with better quality, to achieve better coverage.

## Improving health promotion

Health promotions can focus on encouraging health behaviours, such as exercise and a good diet, and taking part in preventive programmes like vaccination and screening. Health promotion activities must be inclusive of people with disabilities, so that they are available in appropriate formats, include illustrations of people with disabilities and address particular health conditions facing people with disabilities. However, these activities alone may fail to improve health for people with disabilities, as they do not address some of the underlying drivers causing their poor health – poverty, exclusion and discrimination.[116] Health promotion programmes should be more holistic, and also address these issues, and here CBR programmes may provide good examples. For instance, the Kwale District Eye Centre (KDEC) in Kenya has a CBR programme which focuses on alleviating discrimination and stigmatization towards children with albinism in their homes, schools and community environments.{Eyes for East Africa, undated #211} The programme tries to promote health directly through activities like educating parents on the importance of the child using sunscreen and protective clothing, as well as attending screening for visual problems. The programme is also more ambitious, and works to sensitise communities about albinism to improve attitudes, and reduce discrimination, in order to achieve more long-term and sustainable improvements in living conditions and health.

## Improving early identification and intervention

Delayed identification of children with disabilities means that opportunities are lost for early intervention, as a result of which the development of the child may not be maximized. High income countries routinely screen for impairments at different stages in childhood. For instance, in the UK, there is newborn screening for hearing and for hip dysplasia, and there are development review at around 9 months and 2 years to identify children at high risk of developmental concerns, and refer them for diagnosis and treatment. Some LMICs are working to implement early identification screening strategies in order to allow earlier interventions. For instance, hospital-based neonatal hearing screening pilot projects have been implemented in Nigeria, South Africa, India, Pakistan, Jordan, China, Malaysia, Philippines, Brazil and Mexico.[117] Vision screening occurs routinely in schools across the world. Identification of children with more “hidden” conditions, such as autism, ADHD and other behavioural conditions are lagging behind, and good models for how this should be achieved are currently not available.[118] However, evidence from India shows that if these children can be identified then non-clinician led interventions can help children with autism and their families.[119] Improving affordability of services

Improving affordability of services for people with disabilities is a critical step in improving coverage. 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, people with disabilities may be at a disadvantage as they may be less able to afford to join health insurance schemes or benefit from work- related health insurance schemes.[120] In addition, people with disabilities are more likely to be excluded from health insurance schemes on the basis of underlying health conditions. 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. One potential solution is to include health insurance as a linked benefit of the Disability Allowance or other social protection schemes offered to people with disabilities in many countries. For instance, in Vietnam there is free health insurance offered to some groups of recipients of the Disability Allowance. In Nepal, limited healthcare provisions are also made for people who receive the Disability Allowance.

More broadly, efforts to reduce poverty among people with disabilities may reap benefits in terms of improved access to and affordability of healthcare services. Examples here include social protection schemes, livelihood promotion or skills development.

## Improving access to rehabilitation

There have been a number of global initiatives to encourage increased service coverage and access to rehabilitation services. One example is the implementation of the GATE (Global Cooperation on Assistive Technology) global initiative in 2011. This initative 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.[121] 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.

As a complementary approach, 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.[122] This move recognizes that greater access to rehabilitation is a requirement to achieving Sustainable Development Goal 3 on health and will benefit the entire population, not only people with disabilities. Approaches to improve access include training more rehabilitation professionals, considering approaches to task-sharing, and ensuring that rehabilitation is included within healthcare budgets. 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.

## Improving quality of healthcare services

Alongside improving coverage, improving quality of services is paramount. Many of issues around poor quality services for people with disabilities are due to lack of training of healthcare workers. They therefore lack knowledge around impairment and disability, on inclusive practice and reasonable accommodations, and on how to communicate effectively in multimodal ways with people with disabilities. Allowing health professionals the flexibility to give additional time for consultations with people with disabilities could allow these interactions 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.

## Monitoring inclusion of people with disabilities in healthcare

Underlying all of these approaches is the need for more evidence to document difficulties in access to healthcare, as accountability is crucial for ensuring that the healthcare services are inclusive. One option is the routine auditing of the accessibility of health care units, looking beyond physical accessibility alone. Monitoring the inclusion of persons with disabilities in healthcare system may also reveal where there are gaps in provision. This monitoring has been undertaken by Sightsavers as part of its inclusive eye health services and trachoma programmes, by including the Washington Group questions for service users to assess whether people with disabilities are appropriately represented. Some attempts have been made for more routine collection of data on access of healthcare for people with disabilities, such as in the WHO’s Model Disability Survey or through efforts to disaggregate health data by Washington Group measures. Yet, more work is needed to establish common metrics on access to healthcare.

# Conclusions

Achieving CRPD Articles 25 and 26, by making healthcare services inclusive, respectful and barrier-free, will improve access for other vulnerable groups, as well as improve healthcare coverage overall. Strengthening rehabilitation services will have similar population benefits, as these are also needed by people with short-term impairments. Improving healthcare services will likely be cost-saving, reducing future healthcare costs, promoting inclusion and improving economic productivity. Overall, these changes will help in achievement of UHC and Sustainable Development Goals, by ensuring that healthcare services reach the whole population, so that they can experience better health, better productivity, and less poverty.

Above all, providing better access to inclusive and non-discriminatory healthcare for people with disabilities will help ensure that their rights are met, and help persons with disabilities to achieve better health and a good quality of life. . Improving health of people with disabilities will reap benefits in terms of reduced morbidity and mortality. Better health will also help people to realise their other rights, to education, employment, and social inclusion, and so will improve well-being, social inclusion and reduce poverty. As Amartya Sen has stated: *“there is … plenty of evidence that not only does universal healthcare powerfully enhance the health of people, its rewards go well beyond health”*.

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# Appendices

## Appendix 1: ICF Model of Disability



## Appendix 2: Systematic review methodology

|  |
| --- |
| Key features of systematic review* Topic: Access to health services (general and rehabilitation/specialist) for people with disabilities in Low and Middle Income Countries (LMICs)
* Eligibility criteria: quantitative studies, of people with disabilities in LMICs
* Measures of healthcare access included: utilization, coverage, adherence, expenditure, quality of care, barriers to access
* Disability measures included: functional status, self-reported disability, impairments, specific health conditions
* Information sources: Six databases (EMBASE, Global Health, CINAHL, Web of Science, MEDLINE, and PSYCINFO) were searched.
* Identification of eligible studies: Titles, abstracts and full texts were screened for eligibility by two authors (TB and HK).
* Data extraction: Data extracted by TB into an Excel database, with checking by HK for accuracy.
* Risk of bias assessment: Quality assessments of all eligible studies were carried out independently by two reviewers (TB and HK).
 |

## Appendix 3: Description of studies included in systematic review of access to general healthcare among people with disabilities

A total of 13,045 studies were initially identified by the electronic searches, of which 49 studies were selected for inclusion in the review on access to general healthcare. The features of the included studies are described in Table 5. Overall, the studies included provided data for 1,510,959 people across 75 countries. Most of the studies were conducted after 2010. Studies were widely distributed across geographic region, type of disability and age group of participant. Most of the studies were cross-sectional studies (73%) or case-control studies (27%), and no intervention studies were identified. Most of the studies used utilization or coverage as their measure of healthcare access. Of the included studies, 55% were judged to have low risk of bias, 35% medium, and 10% high risk of bias.

**Table 5:** Characteristics of included studies

|  |  |  |  |
| --- | --- | --- | --- |
| Variable |  | Number | % |
| Region | Latin America/Caribbean  | 10 | 20 |
|   | East Asia/Pacific  | 8 | 16 |
|   | Sub-Saharan Africa  | 17 | 35 |
|   | Middle east  | 3 | 6 |
|   | South Asia  | 5 | 10 |
|   | Europe/Central Asia  | 1 | 2 |
|   | Various | 5 | 10 |
| Decade of publication | 1990 | 1 | 2 |
|   | 2000 | 8 | 16 |
|   | 2010 | 40 | 82 |
| Study design | Cross sectional | 36 | 73 |
|   | Case control study | 13 | 27 |
| Age group | All ages (includes >5 years; > 4 years) | 10 | 20 |
|   | Adults only (>18 years) | 15 | 31 |
|   | Older adults (> 40 years; > 50 years; > 60 years) | 11 | 22 |
|   | Children only (0-18 years) | 10 | 20 |
|   | Unclear age/not presented | 3 | 6 |
| Disability domain | Visual impairment  | 12 | 24 |
|   | Hearing impairment  | 15 | 31 |
|   | Physical impairment  | 16 | 33 |
|   | Psychological functioning  | 25 | 51 |
|   | Functional difficulties\* | 20 | 41 |
|   | Participation (IADL) | 2 | 4 |
|   | Other (communication, sensory, albinism) | 6 | 12 |
|   | Multiple domains | 20 | 41 |
| Outcome measured | Utilisation | 28 | 57 |
|   | Coverage | 22 | 45 |
|   | Expenditure | 6 | 12 |
|   | Insurance | 4 | 8 |
|   | Adherence | 3 | 6 |
|   | Barriers  | 11 | 22 |
|   | Other | 4 | 8 |
| \* typically includes difficulties with hearing, vision, walking, self-care, communicating, and remembering or concentrating  |

## Appendix 4: Description of studies included in systematic review of access to specialist healthcare among people with disabilities

A total of 13,045 studies were identified by the electronic searches, of which 80 studies were selected for inclusion in the review of access to rehabilitation for people with disabilities. These studies provided data for 121,416 people with disabilities across 61 countries. Key features of the included studies are shown in Table 6. The studies included good representation of different geographic regions, and age groups. Over half of studies were conducted in 2010 or later (54%). The vast majority of studies were cross-sectional surveys (83%) and no intervention studies were identified. Considering disability domain, a large proportion of studies measured access outcomes related to mental and behavioural conditions (45%) which included the categories of mental health conditions, cognitive/intellectual impairment, and cerebral palsy. Types of rehabilitation outcomes included coverage of: medical rehabilitation (non-pharmaceutical), medical rehabilitation (pharmaceutical), assistive devices, adherence, and therapy.

**Table 6:** Characteristics of included studies

|  |  |  |
| --- | --- | --- |
| **Variable** | **Number** | **%** |
| ***Region*** |   |   |
| Latin America/Caribbean  | 12 | 15 |
| East Asia/Pacific  | 13 | 16 |
| Sub-Saharan Africa  | 26 | 33 |
| Middle east  | 7 | 9 |
| South Asia  | 14 | 18 |
| Europe/Central Asia  | 2 | 3 |
| Various | 6 | 8 |
| ***Decade of publication*** |   |   |
| 1990 | 11 | 14 |
| 2000 | 26 | 33 |
| 2010 | 43 | 54 |
| Age of participants |   |   |
| All ages (includes >5 years; > 4 years; >11 years) | 31 | 39 |
| Adults only (>18 years and >15 years) | 23 | 29 |
| Older adults (> 40 years; > 50 years; > 60 years) | 7 | 9 |
| Children only (0-18 years) | 13 | 16 |
| Unclear age/not presented | 6 | 8 |
| ***Study design*** |   |   |
| Cross sectional | 66 | 83 |
| Retrospective | 2 | 3 |
| Case control study | 8 | 10 |
| Cohort | 4 | 5 |
| ***Source of participants*** |  |  |
| Population | 60 | 75 |
| Clinic | 9 | 11 |
| Register | 3 | 4 |
| School | 2 | 3 |
| Other | 6 | 8 |
| **Disability domain** |   |   |
| Hearing | 13 | 16 |
| Vision | 16 | 20 |
| Physical | 25 | 31 |
| Mental  | 36 | 45 |
| Any disability | 25 | 31 |
| Multiple domains | 16 | 20 |
| **Outcome measured** |   |   |
| Medical rehabilitation | 55 | 69 |
| Medication | 3 | 4 |
| Assistive devices | 27 | 34 |
| Adherence | 27 | 34 |
| Therapy | 4 | 5 |
| Barriers  | 23 | 29 |

## Appendix 5: Primary health service utilisation

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Study** | **Country** | **Age group** | **Disability domain** | **Time period (months)** | **Outcome** | **Result** | **Summary** |
| 12 | 6 | 2-3 | 1 | NS |
| Trani et al (2010), Trani et al (2012)[45, 123] | Afghanistan | > 4 years | Multiple: Physical impairment, sensory, psychological functioning (mental illness/intellectual impairment) |  |   |   |   |   | Health centre utilisation | PWD 82%; No disability 84% (p<0.001)PWD: mild/moderate 74.58%, severe/very severe 74.6%; No disability 74.96% (p=0.988) | NS |
| Liu et al (2009)[124] | China | >=65 years | Multiple: Psychological functioning (dementia), hearing impairment, physical impairment (limb or arthritis), visual impairment (eye problem) |   |   |  |  |   | Use of community services | Dementia: urban aOR=0.94 (0.73, 1.20); rural aOR=1.54 (0.82, 3.06); Physical illness: urban aOR=2.26 (1.79, 2.87), rural aOR=3.82 (2.12, 6.85); aOR=3.74(2.94-4.75); rural aOR=8.31(4.06-17.0) | Mixed: NS dementia; + physical illness |
| Marella et al. (2014) [47] | Bangladesh, Fiji | >=18 years | Functional difficulties |   |  |   |   |   | Access to health services | Bangladesh: PWD 69%; No disability 66% (p<0.001); Fiji: PWD 82%; No disability 82% (p<0.001) | - |
| Marella et al. (2016) [60] | Philippines | >=18 years | Multiple: Visual impairment, hearing impairment, communication, physical impairment, psychological functioning (cognitive, appearance, psychological distress) |   |  |   |   |   | Met need for general health services | aOR= 0.5 (0.3, 0.7) | - |
| Rodrigues et al. (2009) [125] | Brazil | >65 years | Functional difficulties |   |  |   |   |   | Medical visit at the primary health care unit | PR=1.31 (1.15;1.49) | + |
| Fujii et al. (2012) [126] | Brazil | >18 years | Psychological functioning (mental health) |   |  |   |   |   | Number of visits to traditional health care provider | PWD Treated 14.4+/-20.6, Untreated 8.4 +/-10.5; No disability 3.3+/-5.6 (p<0.05) | + |
| Fialho et al. (2014) [127] | Brazil | >=60 years | Participation |  |   |   |   |   | Number of appointments in past 12 months (0-1; 2-4; 5 or more); home visits by doctor in past 12 months | IADL aPR= 1.07 (0.94, 1.21), ADL aPR=1.12 (0.99,1.27)IADL aPR=1.67 95%CI=0.69,4.07, ADL aPR = 8.54; 95%CI: 4.22-17.27 | NSMixed: NS IADL; + ADL |
| Freire et al. (2009) [128] | Brazil | >15 years | Hearing impairment |   |   |  |  |   | Medical consultation | PR=1.3; 95%CI=1.10-1.51; p=0.007  | + |
| Andrade et al. (2002) [129] | Brazil | >18 years | Psychological functioning (mental disorders) |   |   |   |  |   | General health service utilisation in the past month | Any 12 month disorder 38.3% (SE=2.8) | + |
| Danquah et al. (2015) [56] | Haiti | >=5 years | Functional difficulties |   |   |  |  |   | Number of visits to health centre (No visits (base); 1 to 2 visits; >=3 visits) | Adults: OR=1.0 (0.5, 2.0); OR= 2.1 (1.0, 4.3) Children: OR=0.4 (0.2, 0.9); OR=1.3 (0.5, 2.9) | Mixed (adults: NS 1-2 visits vs none; + >=3 visits vs none; children: NS) |
| Groce et al. (2006) [130] | Swaziland | >=18 years | Hearing impairment |   |   |   |   |  | Clinic attendance | PWD 69%; No disability 87% (p<0.05) | - |
| Moodley et al. (2015) [26] | South Africa | Adults | Functional difficulties |   |   |   |   |  | Length of time since last consultation (last 30 days; 1-5 months ago; 6-12 months ago; >1 and <2 years ago; 2-4 years ago; 5-10 years ago; >10 years ago; never | PWD 44%; 15%; 8%; 16%; 5%; 2%;2%;10%No disability 20%; 14%; 8%; 29%; 10%; 4%; 2%; 13%p<0.001; p=0.1660; p=1.00; p<0.001; p<0.001; p<0.001; p=1.00; p<0.001 | Mixed by length of time |
| Twomey et al. (2015) [131] | China, Cuba, Dominican Republic, India, Mexico, Nigeria, Peru, Puerto Rico, Venezuela | >=65 years | Psychological functioning (Dementia, depression), concentrating/remembering, self-care, physical, communication, participation |   |   |  |  |   | Previous health service utilisation | Depression severity adjusted prevalence ratio=1.02 (1.01, 1.03); Functioning: aPR=1.01 (1.00, 1.03) | + |
| Albanese et al. (2011) [132] | Mexico, Peru, Cuba, Dominican Republic, Puerto Rico, Venezuela, China, India, Nigeria | > 65 years | Multiple: Psychological functioning (Dementia, depression), physical impairments, mobility restriction |  |   |   |   |   | Community health service use | Meta analytical pooled effect (all countries): Depression 1.21 (1.07, 1.38) ; Dementia 0.93 (0.90, 0.97); Physical impairment 1.37 (1.26, 1.49); Mobility restriction 1.02 (0.96, 1.09)  | Mixed (+ depression; - dementia; + physical; NS mobility) |

*+ higher; - lower; NS null*

## Appendix 6: Utilisation of hospitals

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Study | Country | Age | Impairment type(s) | Time period (months) | Summary of results | Hospitalisation | Outpatient visit |
| 12 | 6 | 3 | 1 | NS |
| Trani et al. (2010, 2012) [45, 133] | Afghanistan | > 4 years | Multiple: Physical impairment, sensory, psychological functioning (mental illness/intellectual impairment) |  |   |   |   |   | Hospital (12 months) PWD 80%; No disability 90%; p<0.001 | - |   |
| Palmer et al. (2011 & 2012) [134, 135] | Vietnam | > 5 years | Multiple: Physical impairment, hearing impairment, speaking, visual impairment, psychological functional difficulties (intellectual impairment, mental illness) |  |   |   |  |   | Inpatient (past 12 months) OR=1.69 (0.11)Outpatient (past month) OR=1.09 (0.06)  | + | NS |
| Palmer et al (2014) [136] | Vietnam | > 5 years | Functional difficulties |  |   |   |  |   | Propensity score matchingInpatient visit in last 12 months 0.093 (0.026) p<0.001Outpatient visit in the past month: NS | + | NS |
| Murthy et al (2014) [137] | India | >18 years | Multiple: Physical impairments, visual impairment, hearing impairment, psychological functioning (intellectual impairment) |  |   |   |   |   | Need to visit hospital (past year) aOR 1.58 (0.99, 2.48) p=0.05 | + |   |
| Castro et al. (2013) [138] | Brazil | > 11 years | Multiple: Visual impairment, hearing impairment, physical impairment |  |   |   |   |   | Adjusted prevalence ratios (aPR) for hospitalisation No disability aPR: 1.00 (base) Visual: aPR: 0.85 (95% CI: 0.45-1.60); NS Hearing: aPR: 1.59 (CI 95%: 0.88-2.86); NS Physical: aPR:3.77(95% CI: 2.00-7.11) Multiple: aPR:3.26(95% CI:1.62-6.55)  | Mixed (vision and hearing NS; + multiple impairments. + physical) |   |
| Fialho et al. (2014) [127] | Brazil | >=60 years | Participation |  |   |   |   |   | Prevalence ratio for hospitalisationAIVD aPR=1.62; 95% CI: 1.16-2.26; ABVD aPR = 1.73, 95% CI: 1.24-2.42 | + |   |
| Freire et al. (2009) [128] | Brazil | >15 years | Hearing impairment |  |   |   |   |   | Hospitalization PR=2.1; 95%CI=1.42-3.14 | + |   |
| Blay et al. (2008) [139] | Brazil | >60 years | Multiple: Physical impairment, psychological functioning (mental health condition) |  |  |   |   |   | Hospitalisations (12 months)Rheumatism OR=0.95 (0.82, 1.09)Psychiatric morbidity OR= 1.44 (1.09, 1.90)Outpatient visit (6 months)Rheumatism OR= 1.12 (0.98, 1.28)Psychiatric morbidity OR=1.07 (0.93, 1.23) | Mixed (NS rheumatism; + psychiatric morbidity) | NS |
| Fujii et al. (2012) [126] | Brazil | >18 years | Psychological functioning (mental health) |   |  |   |   |   | Hospitalisations (6 months): Treated 23.7%; Untreated: 17.1%; Control 7.7%; p<0.05 | + |   |
| Devendra et al. (2013) [63] | Malawi | 2-9 years | Functional difficulties |   |   |  |   |  | Overnight hospital admission aOR=2.7 (1.2, 6.2) | + |   |
| Twomey et al. (2015) [131] | Various | >65 years | Multiple: Functional difficulties |   |   |  |   |   | Hospital admission (past 3 months)Depression severity adjusted prevalence ratio=1.11 (0.95, 1.26)Functioning: aPR=1.14 (1.02, 1.26) | + |   |

*+ higher; - lower; NS null*

1. An odds ratio (OR) is a measure of association between an exposure (in this case, disability) and an outcome (in this case, self-reported health condition). The OR represents the odds that an outcome will occur given a particular exposure, compared to the odds of the outcome occurring in the absence of that exposure. An Adjusted Odds Ratio shows the association between the outcome and exposure, after adjustment for other key differences (often age and sex). [↑](#footnote-ref-1)
2. Statistical significance is when a test rejects the null hypothesis. This is usually determined by the p-value calculated by the statistical test being less than 0.05. If the difference is not statistically significant, then there is no evidence that two groups are truly different. [↑](#footnote-ref-2)
3. The Washington Group disability questions are a set of questions designed to identify people with disabilities, according to self-reported participation restrictions across six core domains of functioning (seeing, hearing, walking, remembering or concentrating, self-care, and communication). An extended set also assesses additional domains.17. World Bank and World Health Organization. *The World Report on Disability*. 2011 [cited 2018 13/04]; Available from: http://www.who.int/disabilities/world\_report/2011/en/ [↑](#footnote-ref-3)
4. The rapid assessment of disability questionnaire was designed to measure the magnitude and impact of disability and has five key sections: 1) demographics; 2) functioning; 3) rights awareness; 4) well-being; 5) access to the community47. Marella, M., et al., *Field-testing of the rapid assessment of disability questionnaire.* BMC public health, 2014. **14**: p. 900. [↑](#footnote-ref-4)