

# Barriers to Healthcare Services for People with Disabilities in Developing Countries: A Literature Review

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## ABSTRACT

**Purpose:** *This literature review aimed to identify the main barriers in access to mainstream healthcare services for people with disabilities.*

**Method:** *Online databases were searched for relevant articles published after 2006. Preference was given to articles pertaining to developing countries. On the basis of pre-determined inclusion and exclusion criteria, 16 articles were selected for the review. Barriers noted in the articles were grouped thematically.*

**Results:** *There appeared to be 7 main barriers - 4 related to the demand side i.e., pertaining to the individual seeking healthcare services, and 3 barriers on the supply side i.e., pertaining to healthcare provision. These are: 1) Lack of information; 2) Additional costs of healthcare; 3) Limited mobility; and 4) Stigmatisation, on the demand side; while on the supply side, 5) Staff attitude; 6) Communication barriers; and, 7) Inaccessible facilities.*

**Conclusion:** *To ensure that people with disabilities can successfully access the necessary health services, the barriers on the demand side (the individuals requiring healthcare) as well as the barriers that are part of the healthcare system, should be attended to.*

**Key words:** *Disability, eye care, sexual and reproductive health, health*

## INTRODUCTION

Over the past decades, there has been considerable progress in making healthcare available and affordable. This has resulted in a decline in child and maternal mortality rates, as well as the decreased prevalence of diseases like HIV/AIDS and Tuberculosis. Healthcare needs of individuals are addressed through health promotions, preventative care such as immunisation, treatment of illnesses and referral to specialised services where needed (World Bank & WHO, 2011).

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Notwithstanding these achievements, there are people who have still not reaped the benefits of progress. Many of them live in Sub-Saharan Africa and many are people with disabilities.

Disability and health are quite often interrelated, with disability being associated with a wide range of primary health conditions (World Bank & WHO, 2011). Healthcare necessary for preventing and treating impairments is increasingly available: eye care for those with vision problems, auditory services for those with hearing impairments, and physical rehabilitation services for those with mobility impairments, among others. Important as these services are, the fact that people with disabilities are individuals who also need access to general healthcare – healthcare not specifically related to their impairment - is quite often forgotten or ignored. As a result, the figures are high for people with disabilities not receiving healthcare services as compared to people without disabilities, and particularly so in low-income countries (World Bank & WHO, 2011).

To rectify this unequal access to healthcare for people with disabilities, a starting point is needed: what should be addressed first to ensure equal access to health services for people with disabilities? There is little research on health and persons with disabilities, with most of it being focussed on high-income countries. The existing research on barriers to healthcare in low-income countries is limited and often on a small scale.

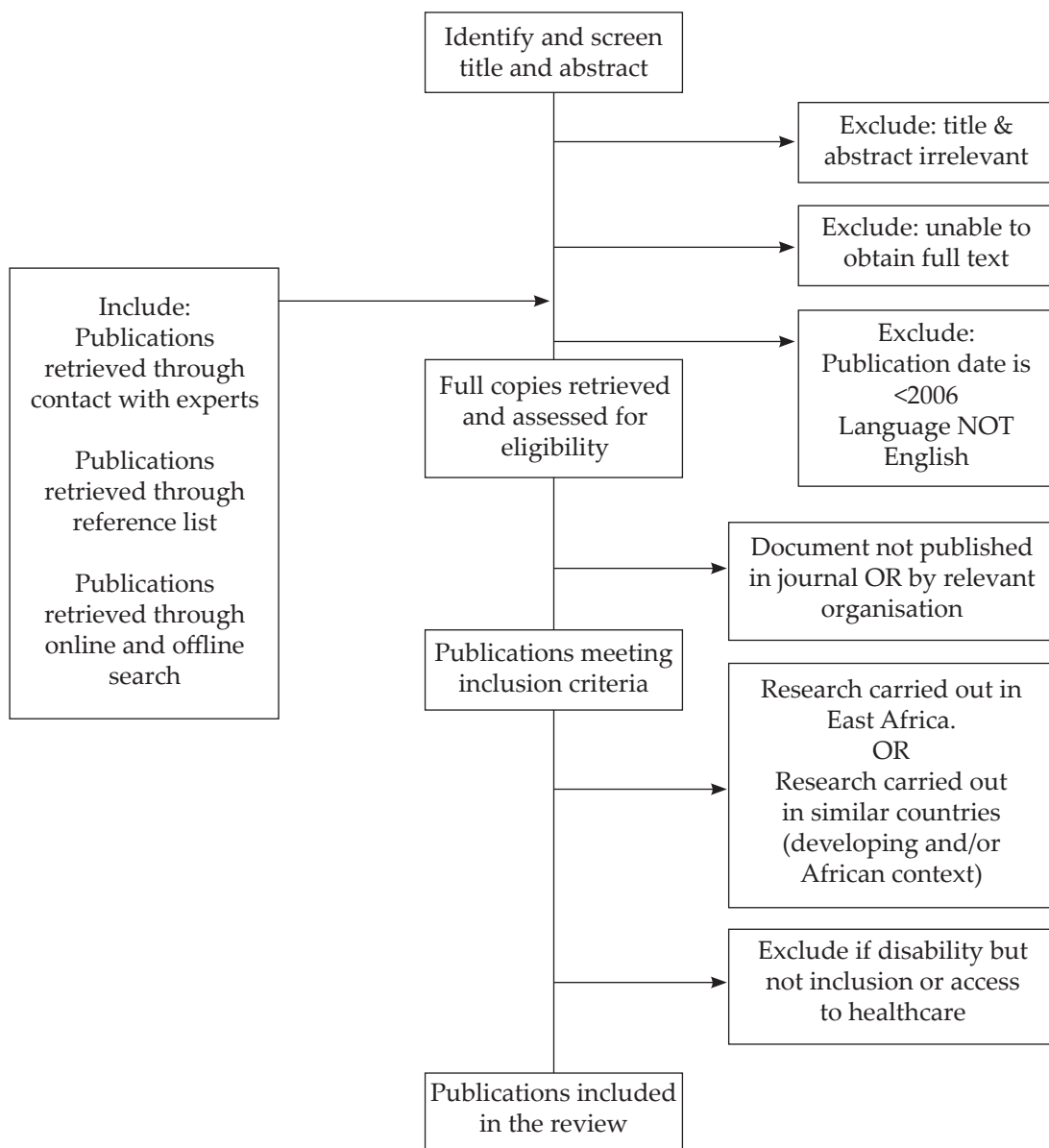
## **Aim**

The aim of this study was to collate all available information on barriers to healthcare for persons with disabilities in low-income countries.

## **METHOD**

An online search was done in the following databases: Google Scholar, Ask Source, Academia.edu, and Wageningen University digital library. In addition, the resource sections of websites of known (I)NGOs focussed on disability or (inclusive) healthcare were searched through. Search terms used included a varying combination of the terms “disab\*”, “includi\*”, “health”, “eye”, “cataract”, “sex\*”, “maternal”, “family planning”, “reproductive”, “neglected tropical diseases”, “trachoma”, “barriers”, “health care” and “accessible”. The bibliography of included articles was also scanned for interesting references. Lastly, programme managers of three NGOs involved in inclusive healthcare

(Light for the World, Ethiopian Centre for Disability and Development, and UPHLS Rwanda) were interviewed to find whether they knew of any studies or publications. The search was restricted to publications in 2006 and thereafter, as well as articles in English for which full text was available. Initially the aim was to keep to articles from East Africa, but this produced such limited results that the search was widened to include research carried out in similar countries. The flow chart below demonstrates the process used for article selection.



After a thorough selection process, 16 articles were included in the review. The characteristics of the included publications are shown in Table 1.

**Table 1: Studies included in the Literature Review**

Author (year)	Country	Study Design	Disability Type	Healthcare Type
Ahumuza et al. (2014)	Uganda	50 interviews	Cross disability	Sexual and reproductive health services
Burke et al. (2017)	Senegal	144 young people, of which 128 in FGDs and 50 in in-depth interviews	Physical, visual and hearing impairments	Sexual and reproductive health services
Eide et al. (2015)	Sudan, Namibia, Malawi & South Africa	Population-based household survey among 9307 individuals	Cross disability	General health services
Gaihre et al. (2016)	Nepal	293 questionnaires	Physical, visual or hearing impairments	Sexual and reproductive health services
Ganle et al. (2016)	Ghana	72 interviews	Physical, visual or hearing impairments	Maternal healthcare
Gudlavalleti et al. (2014)	South India	839 people with disabilities, age and sex matched with 1153 people without a disability	Cross disability	General health services
Jolley et al. (2014)	India and Tanzania	Interviews and FGDs with programme managers and data collectors	Cross disability	Primary Eye Care and NTD Elimination

Kritzinger et al. (2014)	South Africa	19 interviews	Deaf	General health services
Ledger (2016)	Timor-Leste	29 participants for interviews and FGDs	Cross disability	Maternal and new-born health services
Mavuso & Maharaj (2015)	South Africa	16 interviews	Cross disability	Sexual and reproductive health services
Mprah (2013)	Ghana	26 participants in 3 FGDs and 1 interview	Deaf	Sexual and reproductive health services
Mulumba et al. (2014)	Uganda	FGD and interviews	Cross disability	General healthcare
Ormsby et al. (2012)	Cambodia	KAP questionnaire among 599 people	Cross disability	Eye care
Tun et al. (2016)	Ghana, Uganda & Zambia	FGDs with 76 people	Physical, visual or hearing impairments	HIV services
UPHLS (2015)	Uganda	Interviews, questionnaires and FGDs, including with 136 people with disabilities	Cross disability	HIV services

## RESULTS

This review revealed thematically similar barriers across the different countries. This paper presents barriers related to the demand side i.e., the side of the individual seeking healthcare services, and barriers on the supply side i.e., the side of healthcare provision.

### Barriers on the Demand side

#### Lack of Information on the Availability of Services

Available research suggests that people with disabilities are often unaware that they can access healthcare services in the mainstream health centres (Ormsby

et al, 2012; Mprah, 2013; Gudlavalleti et al, 2014; Jolley et al, 2014; Kritzinger et al, 2014; UPHLS, 2015; Dadun et al, 2016; Tun et al, 2016). As Gudlavalleti et al (2014) report, despite the fact that people with disabilities have a higher need for healthcare as compared to people without disability, there is also a significant difference between people with and without a disability regarding their knowledge about where to go for treatment. For example, people with disabilities report that there is only a limited amount of information in accessible formats about HIV and the importance of testing, and that they therefore do not know that they can go for HIV testing and services (Tun et al, 2016). In Cambodia, a Knowledge, Attitudes and Practice (KAP) survey showed that only 18% of people with disabilities knew how best to treat cataract, as compared to over half of all other respondents (Ormsby et al, 2012). Dadun et al (2016) indicate that people with leprosy did not receive information about the cause, transmission and contagiousness of the disease, which has led to increased disabilities that could otherwise have been prevented or treated at an early stage.

Both UPHLS (2015) and Mprah (2013) report that the low literacy rate among people with disabilities, and particularly deaf people, hinders access to information. Illiteracy prevents access to commonly used print materials such as newspapers, magazines, leaflets, brochures, posters and billboards. Deaf people who are not very literate, for example, would find it difficult to understand information from sources other than sign language. This would be similar for people with visual impairments, who cannot access printed sources. Lack of awareness is also a barrier to attending healthcare services, as families or caretakers may not know that people with disabilities can be taken to general healthcare centres (Jolley et al, 2014). As people with disabilities are often not able to access information themselves, they are reliant on friends and family for health information, rather than on messages and information from health professionals (Ormsby et al, 2012).

### **Additional Expenses to Access Healthcare**

The cost associated with getting to and receiving healthcare was regularly mentioned as one of the main obstacles to accessing healthcare services by people with different disabilities (Ahumuza et al, 2014; Gudlavalleti et al, 2014; Mulumba et al, 2014; Eide et al, 2015; Mavuso & Maharaj, 2015; Ledger, 2016). People with disabilities and their caretakers often struggle with poverty due to limited access to employment, and are also less likely to access subsidies and insurance programmes which can mitigate healthcare costs (CBM, 2016). Yet

people with disabilities have higher healthcare needs due to their impairments, and consequently more costs than others.

In addition, people with disabilities are impeded by high (public) transportation costs to get to the health facility. The reasons are: they often have to pay additional transport costs to have someone accompany them; they may need to give financial incentives to their escort; and/or have to hire specialised means of transport that can, for example, accommodate them and their wheelchairs (Mavuso & Maharaj, 2015). Such costs are not incurred by people without disabilities. Thus expense is a notable additional barrier to those with disabilities.

### **Limited Mobility**

Transportation and other mobility issues are mentioned as a barrier to healthcare in at least 8 of the 16 articles reviewed (Ormsby et al, 2012; Ahumuza et al, 2014; Eide et al, 2015; Mavuso & Maharaj, 2015; UPHLS, 2015; Ganle et al, 2016; Ledger 2016; Tun et al, 2016; Burke et al, 2017). Mobility-related barriers that fall on the demand side revolve around lack of support from family members to go to health facilities and services. Specifically, people with visual and physical disabilities are vulnerable as they often have difficulty to access a health centre if unaccompanied (Ganle et al, 2016; Tun et al, 2016). This situation is an extra worry for women seeking antenatal or maternal healthcare services, as they are additionally vulnerable due to both their femininity and their pregnant condition. In Uganda, it is reported that persons with disabilities are rejected or made fun of by taxi drivers or other passengers in public transport (Ahumuza et al, 2014). A study by Tun et al (2016) in three countries (Uganda, Zambia and Ghana) highlights that people with disabilities often need to travel with an assistant to help them manoeuvre around obstacles they encounter on the way. This brings additional complications due to the difficulty of finding someone prepared to give up not only time but also to be seen in public with a person with disability. In addition, accompaniment comes with additional transport costs, as mentioned earlier (Ormsby et al, 2012; Ganle et al, 2016; Tun et al, 2016). Health centres are often a long distance from where people with disabilities live, and public transport is sometimes inaccessible as well, meaning alternative modes of transportation need to be found and budgeted for (Mavuso & Maharaj, 2015; Ganle et al, 2016). Similarly, there may be poor roads and sidewalks, ramps could be missing, the terrain may be mountainous or flooded, thus making it difficult for people with disabilities to navigate the path on foot (Ledger, 2016; Tun et al, 2016).

## **Stigmatisation and Marginalisation**

Stigmatisation and marginalisation are significant barriers in accessing healthcare services. These are largely embedded in negative family and community attitudes towards people with disabilities, leading to feelings of rejection, shyness and lack of confidence (Ahumuza et al, 2014; Jolley et al, 2014; Kritzinger et al, 2014; Mulumba et al, 2014; UPHLS, 2015; Dadun et al, 2016; Ledger, 2016; Tun et al, 2016). This in turn translates to negative health outcomes, not only because people with disabilities report increased levels of stress and anxiety (Mulumba et al, 2014) but also because, in some cases, people with disabilities are seen as worthless, and therefore are not taken to the hospital by their family or caretakers. Marginalisation is manifested through feelings of shame by families who tend to hide family members with disabilities within their homes. Negative family attitudes also manifest in a lack of practical support for their relative with disabilities. This is particularly so when it comes to sexual and reproductive health, as people with disabilities are often seen as asexual beings (Ahumuza et al, 2014; Ledger, 2016).

Low self-esteem, shyness and shame can lead to people with disabilities excluding themselves from health services. The impact of internalised negative feelings about themselves and their disability is that many are too ashamed to leave the house to attend health services (Ledger, 2016). People with disabilities reported not visiting the health centre or asking questions, for fear of appearing ignorant about their own health conditions (Kritzinger et al, 2014; Ledger, 2016). Deaf women reported not utilising health services when needed because they felt ashamed about not being able to ask simple questions (Kritzinger et al, 2014).

## **Barriers on the Supply side/ Healthcare Service Provision**

### **Staff Attitude**

The negative attitude of healthcare staff and service providers has been extensively reported, with all studies save Ormsby et al (2012) reporting negative attitudes as a barrier (Mprah, 2013; Ahumuza et al, 2014; Gudlavalleti et al, 2014; Jolley et al, 2014; Kritzinger et al, 2014; Mulumba et al, 2014; Eide et al, 2015; Mavuso & Maharaj, 2015; UPHLS, 2015; Dadun et al, 2016; Gaihre et al, 2016; Ganle et al, 2016; Ledger, 2016; Tun et al, 2016; Burke et al, 2017). Healthcare providers appear to be insensitive, whether on purpose or because of a lack of knowledge about the needs of people with disabilities (Kritzinger et al, 2014; Gaihre et al, 2016).



Verbal, physical and mental abuse characterise the negative attitudes reported. Dadun et al (2016), for example, report that there are health workers who refuse to shake hands with or treat a person affected by leprosy; and Mulumba et al (2014) report about blind people being ridiculed by health workers for requesting HIV/AIDS testing. Some service providers' negative attitudes related to women with disabilities are also implicit in practices such as forced sterilisation, the use of physical restraint during labour, and the use of derogatory terms such as 'crazy' to describe women with psychosocial impairments (Ahumuza et al, 2014; Ledger, 2016). Consequently, as reported by Ganle et al (2016), this hugely undermines the morale and desire to access and use skilled healthcare services.

The negative attitude has been associated with the healthcare staff's lack of understanding of the needs of people with disabilities (Gaihre et al, 2016). One study with deaf people indicated that negative attitudes were a result of frustration, as healthcare staff and deaf people were not able to communicate with each other, and deaf people were not given enough time to explain their situation. Other studies mentioned that healthcare providers would ignore clients with disabilities and give priority to others, in anticipation of communication problems (Mprah, 2013; Kritzinger et al, 2014; Tun et al, 2016). The negative attitude is also related to the mind-set that service providers have towards people with disabilities in general. For example, the popular assumption is that people with disabilities are asexual, or are simply seen as clients who are incapable of marriage and giving birth. People with disabilities report that health providers need to acknowledge and accept that people with disabilities are sexual human beings and therefore they need sexual and reproductive health services (Ahumuza et al, 2014; Mavuso & Maharaj, 2015; UPHLS, 2015).

### **Communication Barriers**

Communication barriers between health centre staff and clients with disabilities are a big challenge. This is especially noted for people who have speech and hearing impairments (Mprah, 2013; Kritzinger et al, 2014; Mulumba et al, 2014; UPHLS, 2015; Gaihre et al, 2016; Ganle et al, 2016; Ledger, 2016; Tun et al, 2016; Burke et al, 2017), and is expected to be similar for persons with intellectual or psychosocial impairments (though this is not proven as they were hardly included in any of the studies). Many healthcare providers at health facilities neither understand nor appropriately communicate in sign language, and no sign language interpreters are available to help out (Gaihre et al, 2016; Ganle

et al, 2016). For expectant women with disabilities, the same sources note that these barriers have resulted in life-threatening situations for both the mothers and unborn babies, with reports stating that deaf women have lost their babies because of their inability to understand the instructions of midwives. Other women experienced challenges with doctors' inability to understand clients' medical history. The doctors end up making estimations of what clients say and hence give wrong prescriptions (Mulumba et al, 2014). Mprah (2013), Ganle et al (2016) and Ledger (2016) also report that health providers do not understand deaf people's explanations about their health conditions, which has resulted in wrong prescription of medicines. A woman who experienced this, for example, reported having received only paracetamol for a very complicated condition of her pregnancy that the midwife could not understand (Ganle et al, 2016). In situations where people with disabilities do have access to a sign language interpreter, an additional challenge is that they may mistrust the interpreter and perceive that wrong information is being given on their health status, or they may feel uncomfortable with the violation of privacy, particularly when it comes to sensitive information regarding sexual and reproductive health, such as HIV status (UPHLS, 2015; Ledger, 2016). Similarly, those who come to the health centre with the support of an assistant or family member, report difficulty in maintaining confidentiality (Tun et al, 2016).

Barriers are not only found in the direct communication between healthcare staff and clients, but also in the indirect communication such as brochures and prevention or awareness campaigns. People with visual impairments are, for example, unable to comprehend information embedded in pictures and on flip charts (UPHLS, 2015; Ledger, 2016). Messages (on prevention) given on the radio, likewise, are inaccessible for people with hearing impairments (UPHLS, 2015).

### **Inaccessible Buildings and Equipment**

Inaccessible health facilities and equipment at the health centres seem to be some of the biggest barriers to access healthcare, and is mentioned in 11 of the 16 articles (Ahumuza et al, 2014; Gudlavalleti et al, 2014; Jolley et al, 2014; Mulumba et al, 2014; Eide et al, 2015; Mavuso & Maharaj, 2015; UPHLS, 2015; Gaihre et al, 2016; Ganle et al, 2016; Ledger, 2016; Tun et al, 2016; Burke et al, 2017). This is particularly so for people with physical and visual impairments. Specific barriers cited under this category include: health centre buildings have no ramps; toilets or latrines are inaccessible; lack of sidewalks; and, elevators are non-existent or non-functional

(Mulumba et al, 2014; Gaihre et al, 2016; Ganle et al, 2016; Ledger, 2016). As a result, people with physical disabilities who use wheelchairs are denied access to such buildings or access them at great inconvenience, especially if they are unaccompanied – for example, they have to get off their wheelchairs and move on the ground. A woman in Ghana reported that she almost fell off staircases during one of the hospital visits she made without her husband accompanying her (Ganle et al, 2016). In Uganda, Ahumuza et al (2014) highlight the experience of a physically impaired woman who could not access the delivery ward of a major referral hospital, as it was located on the sixth floor. In as far as sexual and reproductive health services and maternal healthcare are concerned the same sources highlight the insufficiency or absence of equipment such as adjustable delivery beds for women in labour, and lack of wheelchairs and personnel to assist women to climb on to delivery beds and examination tables.

## DISCUSSION

This review was carried out to understand the barriers to healthcare for people with disabilities, in order to inform health services and development programmes on where to start to address these barriers, and to understand where knowledge gaps still exist. The 16 studies included in the review demonstrate that there are 7 main barriers to healthcare for people with disabilities. Four of these barriers are found on the demand side - persons seeking healthcare are unaware that they can access mainstream health services, have additional expenses in accessing services, limited mobility and self-created stigmatisation. Three of these barriers are found on the supply side - the health service provider is afflicted by negative attitudes of healthcare staff, inability to communicate with clients and inaccessible facilities. This implies that both the demand and the supply sides of healthcare need to be addressed to increase the accessibility of health services for persons with disabilities.

Perusal of the literature revealed that barriers to health services were similar in every country, and it can thus be assumed that disaggregation by location would not have made a significant difference. The intention had also been to disaggregate by type of health service, but most studies focussed on healthcare in general. The exception seems to be sexual and reproductive healthcare, a subject on which more research has been done - with good reason - as barriers are compounded due to the intimate and sensitive nature of sexual health. People with disabilities are denied access because of the strong belief that such people do not need sexual and reproductive health services (UPHLS, 2015; Gaihre et

al, 2016; Ganle et al, 2016; Ledger, 2016; Tun et al, 2016). Moreover, although communication and information is a barrier in general, this is even more so in the case of sexual health services. People may not feel comfortable with discussing these issues in the presence of a sign language interpreter or an accompanying family member, or about asking for information which others learn about through radio or billboards.

In all studies save that of Ormsby et al (2012), the negative attitude of health centre staff was stated as a significant barrier to healthcare – varying from frustration at not being able to communicate, to outright verbal and physical abuse. Apart from marginalisation by family, caretakers and communities, the negative attitudes towards the individuals' own disability is another oft-mentioned barrier. This seems to indicate that tackling attitude change – at individual, community and health centre levels – would be a necessary challenge.

In the majority of the studies, physical accessibility of the health facility was cited as a problem. The exception was mainly articles focussing on deaf people, for whom physical accessibility is generally less of an issue. This indicates the importance of constructing physically accessible buildings as an important step towards improving healthcare for many people with disabilities. Indeed, if an individual cannot even enter the facility as a first step, then barriers such as inability to communicate, costs of healthcare and negative staff attitudes will not be noticed. For many people with disabilities, the challenge of actually getting into the facility is already so large, that it immediately discourages many from even attempting to seek healthcare (Tun et al, 2016).

Lastly, despite the fact that people with disabilities are not a homogenous group, very few of the studies disaggregated results by type of disability or gender. The exception were articles focussed on access to maternal care, which targeted women specifically (Ganle et al, 2016; Ledger, 2016), as well as the few articles that chose to focus on only one type of impairment, such as deafness or leprosy (Mprah, 2013; Kritzinger et al, 2014; Dadun et al, 2016). The expectation is that barriers would be different or more for women as compared to men, as well as that the most important barriers would differ for people with different types of impairments (for example, physical accessibility for those with mobility impairments, or communication barriers for those with hearing impairments). The studies included, however, did not provide enough information to explore such differences and commonalities in greater depth.

Results throughout the different studies, in the various contexts, are sufficiently similar to make broad conclusions about the significant barriers for people with disabilities to access mainstream health services. Acknowledging however that there is a large variation among people with disabilities, further research is needed to dive deeper and understand which barriers are crucial when disaggregated by context, type of impairment, and gender.

### **Limitations**

The initial aim had been to disaggregate the research per country of interest (Mozambique, Rwanda and Ethiopia), type of disability and/or type of health service (eye health, NTD care and sexual and reproductive health). However, research was so scarce that disaggregation and contextualisation were near impossible, and it was decided to extend the search to all countries in Asia and Africa, and to all types of health services. This meant that disaggregation at a more local level (e.g., whether there would be different barriers in different countries) was not possible.

In each of the studies, people with intellectual disabilities, mental health conditions, and the deaf and blind were very rarely, if ever, included. It means that their specific concerns are also not included in this review; hence more research is needed in this regard.

Lastly, the search for articles was limited to those for which full text was available, as well as to those available in the English language.

## **CONCLUSION**

Despite the fact that people with disabilities, like people without disabilities, have general healthcare needs – ranging from prevention, treatment of illnesses and referral where needed - there are still many barriers that prevent them from gaining access to mainstream healthcare services. To ensure that they can successfully access the health services they need requires attending to both the barriers on the demand side (the individuals requiring healthcare), as well as the barriers that are part of the healthcare system itself.

The studies included in the review seem to reach a consensus on these barriers to healthcare. However, more research is needed in order to disaggregate the barriers for persons with different types of impairments, as well as to understand the barriers to healthcare (and therefore access needs) of persons with other impairments such as psychosocial or intellectual disability.

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