Barriers to health care services for people with disabilities in developing countries: A literature review
ABSTRACT

**Purpose:** The aim of this literature review was to identify the main barriers in access to mainstream health care services for people with disabilities.

**Method:** Online databases were searched for relevant articles published after 2006. A preference was given to articles covering developing countries. Sixteen articles were selected for inclusion in the review on the basis of pre-determined inclusion and exclusion criteria. Barriers noted in the articles were grouped per theme.

**Results:** The review brought out that there are seven main barriers, four of which are related to the demand side i.e. the side of the individual seeking health care services, and barriers on the supply side i.e. the side of health care provision. These are 1. Lack of information; 2. Additional costs of health care; 3. Limited mobility and 4. Stigmatization on the demand side, and 5. Staff attitude; 6. communication barriers and 7. Inaccessible facilities on the supply side.

**Conclusion:** Ensuring that people with disabilities can successfully access the health services they need requires attending to both the barriers on the demand side (the individuals requiring health care), as well as the barriers that are part of the health care system itself.

**Key words:** disability, eye care, sexual and reproductive health, health.
Introduction

Over the past decades, considerable progress has been made in making health care available and affordable, resulting in a decline in child and maternal mortality rates, as well as decreased prevalence of diseases like HIV/AIDS and tuberculosis. Health care needs of individuals are addressed through health promotions, preventative care such as immunization, treatment of illnesses and referral to specialized services where needed (World Bank & WHO 2011). However, notwithstanding these achievements, there are people that have still not seen the benefits of these achievements. Many of these live in Sub Saharan Africa, and many of them 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). Health care 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, amongst others. Important as these services are, the fact that people with disabilities are individuals that also need access to general health care – health care not specifically related to their impairment - is quite often forgotten or ignored. As a result, people with disabilities show high rates of not receiving health care services as compared to people without disabilities, and particularly so in low-income countries (World Bank & WHO 2011).

In order to address this unequal access to health care for people with disabilities, a starting point is needed: what then needs to be addressed first to ensure equal access to health services for people with disabilities? Little research has been done on health and persons with disabilities, with the large part of it being focused in high-income countries. With existing research on
barriers to health care in low income countries being limited and often small-scale, our goal was to collate all existing information to understand what the current body of knowledge is when it comes to barriers to health care 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 focused on disability or (inclusive) health care were searched through. Search terms used included a varying combination of the terms “disab*”, “inclusi*”, “health”, “eye”, “cataract”, “sex*”, “maternal”, “family planning”, “reproductive”, “neglected tropical diseases”, “trachoma”, “barriers”, “health care” and “accessible”. The bibliography of included articles were also scanned for interesting references. Lastly, programme managers of three NGOs involved in inclusive health care (Light for the World, Ethiopian Center for Disability and Development, and UPHLS Rwanda) were interviewed and asked whether they knew of any studies or publications. The search was restricted to publications published 2006 and afterwards, as well as limited to texts written in English, for which full text was available. The initial aim was to limit to articles from East Africa, but this provided such limited results that the search was broadened to research carried out in similar countries. The flow chart below demonstrates the process used for article selection.
After a thorough selection process, sixteen articles were included in the review. The characteristics of the included publications are shown in Table 1.
<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Study design</th>
<th>Disability type</th>
<th>Health Care Type</th>
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</thead>
<tbody>
<tr>
<td>Ahumuza et al. (2014)</td>
<td>Uganda</td>
<td>50 interviews</td>
<td>Cross disability</td>
<td>Sexual and reproductive health services</td>
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<tr>
<td>Burke et al. (2017)</td>
<td>Senegal</td>
<td>144 young people, of which 128 in FGDs and 50 in in-depth interviews</td>
<td>Physical, visual and hearing impairments</td>
<td>Sexual and reproductive health services</td>
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<tr>
<td>Eide et al. (2015)</td>
<td>Sudan, Namibia, Malawi &amp; South Africa</td>
<td>Population based household survey among 9307 individuals</td>
<td>Cross disability</td>
<td>General health services</td>
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<tr>
<td>Gaihre et al. (2016)</td>
<td>Nepal</td>
<td>293 questionnaires</td>
<td>Physical, visual or hearing impairments</td>
<td>Sexual and reproductive health services</td>
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<tr>
<td>Ganle et al. (2016)</td>
<td>Ghana</td>
<td>72 interviews</td>
<td>Physical, visual or hearing impairments</td>
<td>Maternal healthcare</td>
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<tr>
<td>Gudlavalleti et al. (2014)</td>
<td>South India</td>
<td>839 people with disabilities age and sex matched with 1153 people without a disability</td>
<td>Cross disability</td>
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<tr>
<td>Jolley et al.</td>
<td>India and</td>
<td>Interviews and FGDs</td>
<td>Cross disability</td>
<td>Primary Eye</td>
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<td>Reference</td>
<td>Country</td>
<td>Methodology</td>
<td>Participants</td>
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<tr>
<td>Kritzinger et al. (2014)</td>
<td>Tanzania</td>
<td>Programme managers and data collectors</td>
<td>19 interviews</td>
<td>Care and NTD Elimination</td>
</tr>
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<td>Ledger (2016)</td>
<td>South Africa</td>
<td>29 participants for interviews and FGDs</td>
<td>Deaf</td>
<td>General health services</td>
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<tr>
<td>Mprah (2013)</td>
<td>Ghana</td>
<td>26 participants in 3 FGDs and 1 interview</td>
<td>Deaf</td>
<td>Sexual and reproductive health services</td>
</tr>
<tr>
<td>Molumba et al. (2014)</td>
<td>Uganda</td>
<td>FGD and interviews.</td>
<td>Cross disability</td>
<td>General health care</td>
</tr>
<tr>
<td>Ormsby et al. (2012)</td>
<td>Cambodia</td>
<td>KAP questionnaire among 599 people</td>
<td>Cross disability</td>
<td>Eye care</td>
</tr>
<tr>
<td>Tun et al. (2016)</td>
<td>Ghana, Uganda &amp; Zambia</td>
<td>FGDs with 76 people</td>
<td>Physical, visual or hearing impairments</td>
<td>HIV services</td>
</tr>
<tr>
<td>UPHLS (2015)</td>
<td>Uganda</td>
<td>Interviews, questionnaires and FGDs, including with 136 people with disabilities</td>
<td>Cross disability</td>
<td>HIV services</td>
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</table>

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, so little research has been done that disaggregation and contextualization was nearly impossible, and the choice was made to broaden the search to all countries in Asia and Africa, and 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 those who are deaf blind, were very rarely included or not included at all. This means that their specific concerns are also not included in this review. 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.

Results

This review revealed thematically similar barriers across the different countries. In this paper, we present barriers related to the demand side i.e. the side of the individual seeking health care services, and barriers on the supply side i.e. the side of health care 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 (UPHLS 2015; Mpah 2013; Gudlavalleti et
al. 2014; Jolley et al. 2014; Dadun et al. 2016; Ormsby et al. 2012; Tun et al. 2016; Kritzinger et al. 2014). As Gudlavalleti et al. (2014) report, despite the fact that people with disabilities have a higher need for health care as compared to people without a disability, there is also a significant difference between people with and without a disability in whether they know 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 have little to no literacy, 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 health care centres (Jolley et al. 2014). Because 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 health care
The cost associated with getting to and receiving health care were regularly named as one of the main obstacles to accessing healthcare services by people with different disabilities (Mavuso & Maharaj 2015; Gudlavalleti et al. 2014; Ahumuza et al. 2014; Mulumba et al. 2014; Eide et al. 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 health care costs (CBM 2016). Yet people with disabilities have higher health care needs due to their impairment, and therefore more costs than others may have.

In addition, people with disabilities are impeded by high (public) transportation costs to get to the health facility. This is because people with disabilities often have to also pay transport costs to have someone accompany them, may need to give a financial incentive to the person accompanying them, and/or have to hire specialized means of transport that can, for example, accommodate them and their wheel chairs (Mavuso & Maharaj 2015). Such costs are not incurred by people without disabilities, making cost a notable additional barrier to those with disabilities.

**Limited mobility**

Transportation and other mobility issues are named as a barrier to health care in at least eight of the sixteen articles reviewed (Mavuso & Maharaj 2015; UPHLS 2015; Ormsby et al. 2012; Ganle et al. 2016; Tun et al. 2016; Eide et al. 2015; Ledger 2016; Ahumuza et al. 2014; 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 unaccompanied (Ganle et al. 2016; Tun et al. 2016), a situation which is extra worrying for women seeking antenatal or maternal health care services, as they are additionally vulnerable due to both their femininity and pregnant status. 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 their time, but also prepared to be publicly seen with a disabled person. In addition, accompaniment comes with additional transport costs, as mentioned earlier (Ganle et al. 2016; Ormsby et al. 2012; Tun et al. 2016). Health centres are often a long distance from where people with disabilities live, and public transport is often inaccessible for them as well, meaning alternative modes of transportation need to be found – and costed (Mavuso & Maharaj 2015; Ganle et al. 2016). Similarly, roads may be poor and sidewalks and ramps missing, terrains may be mountainous or flooded and thus make it difficult for people with disabilities to navigate the road by foot (Tun et al. 2016; Ledger 2016).

**Stigmatization and marginalization:**

Stigmatization and marginalization are significant barriers in accessing healthcare services. In particular, these are largely imbedded in negative family and community attitudes towards people with disabilities, leading to feelings of rejection, shyness and lack of confidence (UPHLS 2015; Kritzinger et al. 2014; Mulumba et al. 2014; Ledger 2016; Jolley et al. 2014; Dadun et al. 2016; Tun et al. 2016; Ahumuza et al. 2014). 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 people with disabilities are seen as worthless, and therefore are not taken to the hospital by family or caretakers. Marginalization is manifested through feelings of shame by families who tend to hide family members with disabilities within the homes. Negative family attitudes also manifests 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 (Ledger 2016; Ahumuza et al. 2014).
Low self-esteem, shyness and shame can lead to people with disabilities excluding themselves from health services. The impact of internalized 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 attending 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 utilizing health services when needed because they felt ashamed for 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 (Gaihre et al. 2016; Mavuso & Maharaj 2015; UPHLS 2015; Mphah 2013; Ledger 2016; Ahumuza et al. 2014; Gudlavalleti et al. 2014; Dadun et al. 2016; Mulumba et al. 2014; Ganle et al. 2016; Tun et al. 2016; Jolley et al. 2014; Kritzinger et al. 2014; Eide et al. 2015; Burke et al. 2017). Health care providers appear to be insensitive, whether on purpose or because of a lack of knowledge about the needs of people with disabilities (Gaihre et al. 2016; Kritzinger et al. 2014). Verbal, physical and mental abuses characterize the negative attitudes reported. Dadun et al. (2016), for example, report health workers who refuse to shake hands with or treat a person affected by leprosy; (Mulumba et al. 2014) reports blind people being ridiculed by health workers for requesting HIV/AIDS testing. Some service provider's negative attitudes related to women with disabilities are also implied through practices such as forced sterilization, the use of physical restraint during labour and the use of derogatory terms such as 'crazy' to describe women with psychosocial disability (Ledger 2016; Ahumuza et al. 2014). Consequently, as (Ganle et al. 2016)
report, this hugely undermines the morale and desire to access and use skilled healthcare services.

The negative attitude has been associated with the healthcare staffs’ lack of understanding of the needs of people with disabilities (Gaihre et al. 2016). One study with deaf people indicated negative attitudes were a result of frustration, as health care staff and deaf people were not able to communicate with each other, and staff did not give deaf people enough time to explain their situation. Other studies mentioned that healthcare providers would ignore patients with disabilities and give priority to other patients, 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 a-sexual, or simply seen as patients that are not capable of marriage and birthing. 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 (UPHLS 2015; Ahumuza et al. 2014; Mavuso & Maharaj 2015).

**Communication barriers**

Communication barriers between health centre staff and patients with disabilities are a big challenge. This is especially noted for people who have speech and hearing impairments (Gaihre et al. 2016; UPHLS 2015; Mprah 2013; Mulumba et al. 2014; Ganle et al. 2016; Ledger 2016; Tun et al. 2016; Kritzinger et al. 2014; Burke et al. 2017), and is expected to be similar for persons with intellectual or psychosocial impairments (but 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, nor are sign language interpreters available to interpret (Gaihre et al. 2016; Ganle et al. 2016). For expectant women with disabilities, these 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 doctor’s inability to take patients’ medical history. The doctors end up making estimations of what patients say and hence give wrong prescriptions (Mulumba et al. 2014). Also, Mprah (2013), Ganle et al. (2016) and Ledger (2016) report that health providers do not understand the explanations of deaf people’s health conditions, which has resulted in wrong prescription of medicines. A woman with this experience, for example, reported having received just paracetamol for a very complicated situation 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, who they perceive as giving them wrong information on their health status, or feel uncomfortable with the violation of privacy, particularly when it comes to sensitive information regarding to 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 health care staff and patients, 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). (Prevention) messages 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 seems to be one of the biggest barriers to access healthcare, and is mentioned in eleven of the sixteen articles (Gaihre et al. 2016; Mavuso & Maharaj 2015; UPHLS 2015; Gudlavalleti et al. 2014; Mulumba et al. 2014; Ganle et al. 2016; Tun et al. 2016; Ahumuza et al. 2014; Jolley et al. 2014; Ledger 2016; Eide et al. 2015; Burke et al. 2017). This is particularly so for people with physical and visual impairments. Specific
barriers cited under this category include the fact that health centre buildings have no ramps, toilets or latrines are inaccessible, there is a lack of sidewalks, and elevators are non-existent or non-functional (Gaihre et al. 2016; Mulumba et al. 2014; 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 with inconveniences, especially if they are unaccompanied – for example they have to get off their wheelchairs and move on the ground. A woman in Ghana reports how she almost fell off staircases during one of the hospital visits she made without being accompanied by her husband (Ganle et al. 2016). In Uganda, Ahumunza et al. (2014) highlights the experience of a physically impaired women who could not access the delivery ward of a major referral hospital, as it was located on the 6th floor. In as far as sexual and reproductive health services and maternal healthcare is concerned, the same sources highlight insufficient or absence of equipment such as adjustable delivery beds for women giving birth, wheelchairs and personnel to assist women to climb delivery beds and examination tables.

**Discussion**

This review was carried out to understand the barriers to health care 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 sixteen studies included in the review demonstrate that there are seven main barriers to health care for people with disabilities. Four of these barriers are found at the demand side of the person seeking health care (unawareness that they can access mainstream health services, additional expenses in accessing services, limited mobility and (self)stigmatization). Three of these barriers are found at the level of the health service provider (negative attitudes of health care staff, inability to communicate with patients and inaccessible facilities). This implies that for interventions aimed at increasing the accessibility of health services for persons with disabilities to work, both the demand as well as the supply side of health care need to be addressed.
In going through the literature, barriers to health services were found to be similar no matter what the 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 focused on health care in general. The exception seems to be sexual and reproductive health care, where much more research has been done, and with 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 people with disabilities do not need sexual and reproductive health services (Gaihre et al. 2016; UPHLS 2015; Ganle et al. 2016; Tun et al. 2016; Ledger 2016). Moreover, although communication and information is a barrier in general, this is additionally so in the situation of sexual health services as people may not feel comfortable discussing the issue in the presence of a sign language interpreter or accompanying family member, or asking for information which other people might learn about through radio or billboards.

In all studies save Ormsby et al. (2012) the negative attitude of health centre staff was stated as a significant barrier to health care – varying from frustration in not being able to communicate, to outright verbal and physical abuse. Combined with the fact that marginalization by family, caretakers and communities, as well as negative attitudes towards one’s own disability, is another oft-mentioned barrier, seems to indicate that tackling attitude change – at individual, community and health centre level – would be a necessary challenge.

In the majority of the studies, physical accessibility of the health facility was named as a problem. The exception was mainly articles focusing on deaf people, for whom physical accessibility is generally less of an issue. This indicates the importance of physically accessible buildings as an important step to health care 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 health care, and negative staff attitudes will not even be noticed. For many people with disabilities, the challenge of actually getting into the facility is already so large, that it already discourages many from even attempting to seek health care (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 was articles focused on access to maternal care, which targeted women specifically (Ganje 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 (Dadun et al. 2016; Mprah 2013; Kritzinger et al. 2014). The expectation would be that barriers would be different or increased for women as compared to men, as well as that the most important barriers would be different for people with different types of impairments (physical accessibility for those with mobility impairments, for example, or communication barriers for those with hearing impairments). The studies included, however, did not include enough information to explore such differences and commonalities more deeply.

Results throughout the different studies, in the various contexts, are similar enough to make broad conclusions about which are significant barriers for people with disabilities to access mainstream health services. Acknowledging however that there is a large variation in 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.

Conclusion

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

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