

Ensuring Universal Access to Eye Health in Urban Slums in the Global South: The Case of Bhopal (India)

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Abstract. Sightsavers is an international organisation working with partners in over 30 countries to eliminate avoidable blindness and help people with disabilities participate more fully in society. In the context of its Urban Eye Health Programme in Bhopal (India), the organisation launched a pilot approach aimed at developing an Inclusive Eye Health (IEH) model and IEH Minimum Standards. Accessibility audits were conducted in a tertiary eye hospital and four primary vision centres located within urban slums, addressing the accessibility of physical infrastructures, communication and service provision. The collection and analysis of disaggregated data inform the inclusion strategy and provide a baseline to measure the impact of service provision. Trainings of eye health staff and sensitisation of decision makers on accessibility, Universal Design, disability and gender inclusion are organised on a regular basis. A referral network is being built to ensure participation of women, people with disabilities and other marginalised groups, explore barriers at demand level, and guarantee wider access to eye care in the community. Finally, advocacy interventions will be developed to raise awareness in the community and mainstream disability and gender inclusion within the public health sector. Founded on principles of Universal Design, accessibility and participation, and in line with international human rights treaties, Agenda 2030 and the Sustainable Development Goals (SDGs), Sightsavers' IEH model ultimately aims to develop a sustainable, scalable and universally accessible system-strengthening approach, capable of ensuring more inclusive services to people with disabilities, women and other marginalised groups, and designed to more effectively meet the health needs of the entire population.

Keywords. Inclusive eye health, accessibility, disability data disaggregation

1. Introduction

Sightsavers is an international organisation working with partners in over 30 countries to eliminate avoidable blindness and help people with disabilities participate more fully in society. In the context of its Urban Eye Health Programme in Bhopal (India), the organisation launched a pilot approach aimed at developing an Inclusive Eye Health (IEH) model and IEH Minimum Standards. While the initiative is still a work in progress, this paper outlines the key features of this model and describes Sightsavers' human rights-based approach to inclusive development.

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The first section of the paper focuses on the interplay of disability, poverty and literacy, and the right to health proclaimed in international human rights treaties. Following an introduction to Sightsavers and its new social inclusion strategy, the second section describes the development of the IEH pilot initiative, and the key features, achievements and challenges of this model.

1.1. Disability, poverty, illiteracy

According to the World Health Organization (WHO) and the World Bank, over a billion people worldwide (or about 15% of the global population) live with some form of disability, and an estimated 80% of people with disabilities live in Low and Middle Income Countries (LMICs) [1][2]. About 285 million people worldwide are visually impaired, of which 39 million are blind [3]; however, about 90% of the world's visually impaired people live in LMICs, and 80% of all causes of visual impairment can be prevented or treated. Women are disproportionately affected, representing about two-thirds of the world's blind population [4], and research indicates that such a difference is primarily ascribable to 'gender (social constructs that define roles of men and women in society), rather than sex (biological differences between men and women)' [5].

It is relevant to highlight how disability and poverty are inextricably connected:

Poverty increases the likelihood of impairments through malnutrition, poor health care, and dangerous living, working and travelling conditions. Disability may lead to a lower standard of living and poverty through lack of access to education and employment, and through increased expenditure related to disability. [2]

The United Nations Department of Economic and Social Affairs (UN DESA) estimates that 54% of the global population, about 3.9 billion people, lives in urban areas [6]. India has the second largest urban population (758 million) and is projected to add '404 million urban dwellers, nearly doubling the size of its urban population between 2014 and 2050' [6]. One-third of urban residents in LMICs still live in slums or informal settlements [7], and the figure in some megacities of these regions reaches almost 80% of the population [8]. Due to a complex combination of demographic, socio-economic, governance and environmental issues, urban informal settlements located in the Global South are among the poorest, least accessible and most over-populated areas of the planet [9].

Alongside poverty, literacy is another important factor determining the exclusion of people with disability and women. The UNESCO Institute for Statistics [10] indicates that 85% of the global population is literate; however, 51% of the illiterate people in the world live in South and West Asia, while 25% of all illiterate adults live in sub-Saharan Africa. In these regions, 'women aged 15 years and older are 24% less likely to be literate than men in the same age group' [10], while an additional burden is incumbent on girls with disabilities, who are less likely to access quality education and have lower rates of literacy compared to girls without disabilities or boys with disabilities [11].

1.2. The Right to Health

People with disabilities have the same health care needs of the general population, and every human being is entitled to the fundamental, inalienable right to health, without distinction of sex, ethnicity, disability, language, religion, political or other opinion, national or social origin, property, birth or other status. This right is proclaimed in several international treaties. Article 25 of the Universal Declaration of Human Rights affirms that ‘Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family’ [12]. In a similar manner, Article 12 of the [International Covenant on Economic, Social and Cultural Rights \(ICESCR\)](#) recognises ‘the right of everyone to the enjoyment of the highest attainable standard of physical and mental health’ [13], while article 12 of the [Convention on the Elimination of All Forms of Discrimination against Women \(CEDAW\)](#) underlines the importance of taking ‘all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services’ [14]. Article 24 of the [Convention on the Rights of the Child \(CRC\)](#) declares ‘the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health’ [15]. Similarly, Article 25 of the [Convention on the Rights of Persons with Disabilities \(CRPD\)](#) boldly states that people with disabilities ‘have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability’ [16].

Despite these international treaties, however, people with disabilities, women and other marginalised groups worldwide still face relevant obstacles in accessing health care, such as prohibitive costs, limited availability of services, infrastructural barriers, inadequate skills and knowledge of health workers, social stigma, discrimination and lack of inclusive policies [6]. Furthermore, promoting health is a key precondition to empower all individuals to actively and meaningfully contribute to society.

In order to address these and other issues, the United Nations General Assembly recently adopted the new global development framework [Transforming our world: the 2030 Agenda for Sustainable Development](#) [17]. The 2030 Agenda includes 17 [Sustainable Development Goals \(SDGs\)](#) and 169 targets aimed at eradicating poverty, fighting inequality and tackling climate change over the next 15 years. The entire Agenda is based on the principle of ‘Leave No One Behind’, contains many references to people with disabilities and women and girls, and has a specific goal aimed to achieve universal health coverage by 2030, ensuring access for every individual to quality, and accessible and affordable health-care services.

2. Sightsavers’ Approach to Inclusive Eye Health

2.1. Sightsavers’ Social Inclusion Strategy

In 2015 Sightsavers adopted a new social inclusion strategy, *Empowerment and inclusion, Strategic framework 2015* [18], which defines the organisational approach to mainstreaming disability and gender throughout its programming and operations, and complements its global strategies on eye health, education and research [19]. Sightsavers’ strategy is informed by a rights-based approach to inclusive development [20], aimed to strengthen local systems by supporting governments and local

stakeholders in the provision of inclusive and sustainable services, and enable people with disabilities and other marginalised groups to claim their rights to health and other services, thus contributing to greater social inclusion. This process is based on a twin-track approach: on the one hand, the organisation commits to mainstream disability and gender inclusion within its existing portfolio and operations; on the other hand, targeted, strategic interventions are developed to contribute to the individual and collective empowerment of women and men with disabilities.

The first of seven key objectives of Sightsavers' social inclusion strategy is to mainstream disability inclusion in health programmes, which represent the organisation's largest portfolio and area of particular expertise [21]. The rationale behind this choice is that by embedding inclusion within existing eye health and Neglected Tropical Diseases (NTD) programmes, the organisation can reach a wider number of people with disabilities and deliver more inclusive, and therefore effective, interventions, and ensure that infrastructures are universally accessible, that quality and sustainable services are provided and that referrals to other services (e.g. rehabilitation) are systematised.

2.2. Inclusive Eye Health

In June 2014 Sightsavers launched a pilot project on Disability Data Disaggregation (DDD) in Bhopal (India) and Dar es Salaam (Tanzania), using the Washington Group Short Set of Questions (WGSS) [22] and national census questions for comparison. The WGSS is based on the International Classification of Functioning, Disability and Health (ICF), WHO's classification of health and health-related domains [23]. The aim of this pilot initiative was to understand how existing data collection processes in Sightsavers' programmes could be adapted to understand how health services are accessed by people with disabilities. In one year, in Bhopal, Sightsavers collected disaggregated data from over 20,000 patients accessing a tertiary eye hospital and four primary vision centres located within urban slums, and results indicated that eye health services were not equitably accessed by people with disabilities [24].

In light of these results, and as part of its social inclusion framework, Sightsavers launched a second pilot initiative in Bhopal, aimed at developing a standard model of Inclusive Eye Health (IEH) based on principles of Universal Design and comprehensive accessibility. The pilot, which began in January 2016 and will run for 18 months, is embedded within the existing Urban Eye Health Programme. The project is implemented in partnership with Sewa-Sadan Eye Hospital (SSEH) and the local development agency AARAMBH, and involves the tertiary eye hospital and four primary vision centres in the urban slums. This initial IEH pilot approach will be replicated in different regions and contexts (e.g. a rural eye health programme in Sierra Leone) to evaluate the applicability of the IEH model in different settings. At the end of this process, Sightsavers will produce a set of IEH Minimum Standards, which will eventually inform all future eye health programmes of the organisation, and will be available to other national and international stakeholders.

An initial definition of IEH was elaborated in October 2015, during the IEH inception workshop in Bhopal:

Eye health services that are provided within a barrier free environment, which are inclusive by design and are sustainable. [25]

This definition was developed through a participatory approach, involving Sightsavers’ Indian and global staff, representatives of SSEH and AARAMBH, and people with disabilities belonging to Disabled People’s Organisations (DPOs).

Following a similar iterative process, Sightsavers elaborated a Theory of Change (TOC) for IEH. TOCs are useful tools to identify early and intermediate changes required to achieve a long-term goal in a designated community, and to develop solutions to complex social problems [26]. Sightsavers’ IEH TOC aims to ensure that sustainable and inclusive eye health services are accessed by all, including people with disabilities and women. While the pilot initiative is still a work in progress, a number of key elements considered to be important pathways to achieving that change were identified in three main areas –supply, demand and policy– and will be discussed in the following sections.

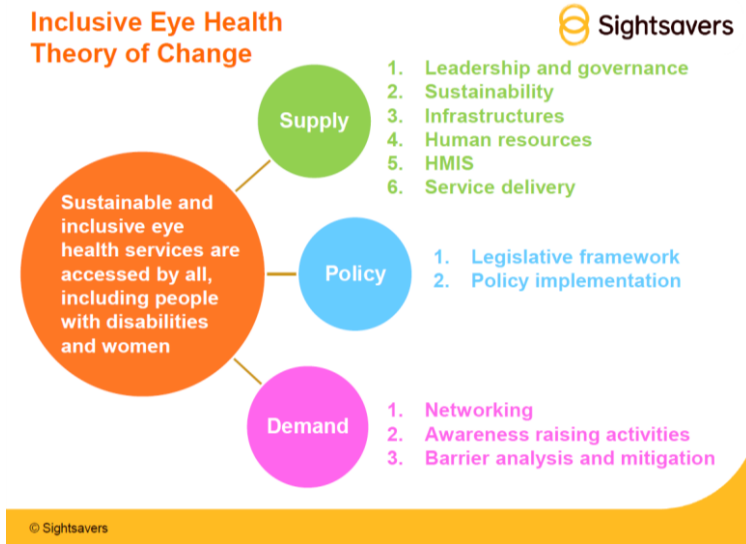


Figure 1. The overarching goal of Sightsavers’ Inclusive Eye Health Theory of Change is “Sustainable and inclusive eye health services are accessed by all, including people with disabilities and women”. Three areas of interventions are identified to achieving this goal:

- A. *Supply*: 1. Leadership and governance; 2. Sustainability; 3. Infrastructures; 4. Human resources; 5. Health Management Information Systems (HMIS); 6. Service delivery
- B. *Policy*: 1. Legislative framework; 2. Policy implementation
- C. *Demand*: 1. Networking; 2. Awareness raising activities; 3. Barrier analysis and mitigation

2.2.1. Supply level

Sightsavers’ IEH TOC at supply level is based on the WHO Health Systems Framework [27].

An integral aspect of Sightsavers’ approach is to promote sustainability of impact at local level. In order for this to happen in the context of the IEH initiative, it is crucial to promote ownership of the project with the senior management of the implementing partners. In this respect, the DDD pilot had unintended positive consequences, as the process of collecting and analysing data disaggregated by disability had a demonstrable transformative effect on the leadership of the partner organisations [28]. For instance, data showed that very few people with disabilities were accessing the hospital, and

because SSEH's mission is to serve the most marginalised, the hospital management realised the need to create more universally accessible infrastructures and services, and committed to be actively involved in the IEH initiative.

Senior management's long term commitment is also essential in relation to the financial aspects of sustainability and the end of the project cycle. On the one hand, in fact, a system strengthening approach involves rights holders and their entitlements: in this case, the right to health of every person, including people with disabilities, women and other marginalised individuals. On the other hand, it involves duty-bearers and their obligations: while governments are responsible for the creation of mandatory regulations and policies on universal accessibility, it is responsibility of the single institutions, including hospital trusts such as SSEH, to ensure that their services are inclusive and accessible to all. Sightsavers and its partners are therefore working to identify cost-effective and sustainable solutions to IEH, and to ensure the inclusion component of eye health will be embedded in the standard costs and activities of the health facilities.

With the end of the DDD pilot project, the collection on disaggregated data became an integral element of the IEH model. As the Washington Group does not offer official translations, a Hindi version of the questionnaire was commissioned to professional translators while Sightsavers and its partners are currently working to integrate DDD into an electronic Health Management Information Systems (eHMIS), in order to simplify the processes of data collection and analysis. Experience from the pilot shows that using the WGSS presents a number of challenges. Following a training of data collectors, the questionnaire was initially tested in the hospital and the vision centres; however, the hospital tends to be very crowded, and asking the WGSS at the registration desk proved to be unfeasible, while the vision centres have small rooms and presented issues of confidentiality. Data collectors also realised that asking questions raises expectations, as several patients sought support to overcome their hearing problems or other physical difficulties. This highlighted the importance of establishing a solid referral network, which will be discussed in the next section.

Ensuring that eye health facilities are universally accessible is a key element of the IEH TOC. Following a training session on barriers to healthcare for people with disabilities, men and women, children and older people, an initial audit of the hospital and vision centre was conducted through a participatory approach during the IEH inception meeting, involving all partners and people with disabilities themselves. This process had once again a transformative effect, as it raised awareness in senior management and staff on the importance of addressing the identified barriers at structural, communication and service provision levels [28]. After the official beginning of the IEH initiative, comprehensive accessibility audits of the hospital and vision centres were conducted by Samarthya, the Indian National Centre for Accessible Environments. The audits highlighted a number of barriers that need to be addressed, including lack of tactile pavers, poor visual contrast, and obstructing walls and stairs. The audits were conducted using a participatory approach, involving various stakeholders and policy makers from four Indian states, and included a training-of-trainers to build capacity on accessibility and inclusion, and ensure sustainability and replicability of the auditing process.



Figure 2. SSEH – Handrails are provided on one side only and there are no contrast colour edges on the step.



Figure 3. Anand Nagar vision centre – Steps mark the entrance to the centre and step risers are unequal. No handrails are provided. A ramp with gliders is provided in the adjacent building, which has a side entrance to the centre.



Figure 4. Gandhinagar vision centre – The channel of the iron gate creates a gap between the ramp and the flooring, and is potentially hazardous for people using mobility aids, such as wheelchairs and white canes.

Following the audits, Samarthyam submitted a report, and Sightsavers and its partners worked with an engineer to evaluate the cost of the interventions required to make the health facilities universally accessible. A plan was subsequently elaborated to identify short-, medium- and long-term priorities, and works are scheduled to begin in July 2016.

The endeavour of making health facilities universally accessible cannot be limited to infrastructures, but must entail human resources, too. Sightsavers provided an initial training on disability inclusion, Universal Design and gender mainstreaming to the senior management of its partner organisations and data collectors. However, in order to guarantee accessible services to all patients and create more inclusive environments within the health facilities, it is crucial to build the capacity of all staff members. For this purpose, Sightsavers India and global offices are collaborating to finalise a training module which includes elements of Universal Design, disability inclusion and gender mainstreaming, but also local policies and regulations, as well as practical guidelines aimed to support health staff to interact with people with different types of disabilities.

According to the IEH TOC, if managers of health facilities are sensitised and committed, infrastructures universally accessible, human resources duly trained, and disaggregated data properly collected and analysed, the assumption is that service delivery will be inclusive and accessible to all, including people with disabilities, women, illiterate people and other marginalised group. While this is still an ongoing learning process, Sightsavers is planning to work with its partners in the second half of the pilot initiative to consolidate these procedures, and to develop clinical and non-clinical internal protocols on inclusion, accessibility and Universal Design.

2.2.2. Demand level

Accessibility, affordability and participation are key principles underpinning the IEH TOC. In order to promote a community development approach and the likelihood of a higher impact at local level, Sightsavers is working to establish a network in Bhopal with a number of different stakeholders, including women's rights organisations

(WROs), community based organisations (CBOs), educational institutions, self-help groups (SHGs), a wide range of disability-focused organisations, and representatives of DPOs. The purpose of establishing these linkages is twofold. On the one hand, these agencies will ideally become part of a referral network for the eye health facilities: whenever patients will require services not directly related to eye health, they will be referred to those organisations which may be able to support them. On the other hand, it is anticipated that this stakeholder network may have an important role in analysing and addressing barriers at community level.

Literature suggests that discrimination, poorly accessible or often completely unavailable transportation systems, and lack of financial resources are typical obstacles in urban areas of LMICs preventing people with disabilities, women and other marginalised groups from fully participating in society [1]. Due to widespread stigma, in particular towards children and women with disabilities, these individuals are often secluded from the rest of the community, kept at home and unable to move independently. Sightsavers' commitment is to test these assumptions by analysing relevant barriers at local level through participatory approaches, and to develop context-specific and sustainable mitigating interventions. While this strategy still needs to be finalised, it is argued that collaborating with other stakeholders will allow Sightsavers to identify individuals with disabilities living in the slums, reach a wider number of people, develop more effective interventions, and raise more awareness on inclusion and accessibility in the community.

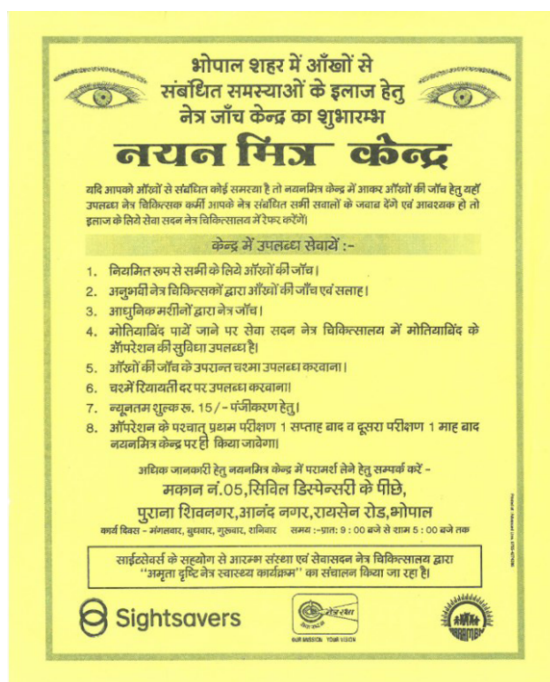


Figure 5. Information leaflet distributed within urban slums to provide directions to the nearest vision centre and promote health seeking behaviours. The leaflet contains only written language and may not be accessible to people with specific learning and intellectual disabilities, vision impairments and low levels of literacy.

Awareness raising activities in the community on eye health are a standard element of Sightsavers' strategy, and new interventions specifically focused on disability and gender will be developed in the second part of the IEH pilot. However, a key aspect that needs to be addressed is the level of accessibility of these actions. Information leaflets, for instance, are distributed within urban slums to provide directions to the nearest vision centre and promote health seeking behaviours. However, these leaflets often rely exclusively on written language and may not be accessible to people with specific learning and intellectual disabilities, vision impairments and low levels of literacy. For this reason, Sightsavers is now planning to liaise with a specialised communication agency, and a more inclusive communication strategy will be developed to raise awareness at community level.

2.2.3. Policy level

As part of a strategic organisational commitment, Sightsavers is increasingly integrating advocacy as an intrinsic aspect of programme planning. While monitoring policy at national level is beyond the scope of IEH, this pilot initiative can arguably have a role in influencing the government and other stakeholders, by showcasing a universally accessible, sustainable and scalable model of health care provision.

India is a signatory of the CRPD, and in recent times there have been consultations to update the 1995 Persons with Disability Act [29][30][31]. In December 2016, the Indian Government launched the *Accessible India Campaign*, with specific targets and timeframe aimed at improving accessibility for people with disabilities [32]. Additionally, the Government released several documents based on Universal Design principles, such as the *Inclusiveness and Accessibility Index* [33] and the *Harmonised Guidelines and Space Standards on Barrier Free Built Environment for Persons with Disability and Elderly Persons* [34]. As universal accessibility appears to be a clear priority at national level, Sightsavers is planning to closely engage with the Indian Government in the second phase of the pilot, in order to identify common areas of work and possible strategies to embed IEH within the existing health system.

3. Conclusion

The right to health for all individuals, including people with disabilities, women, and other marginalised groups, is a priority expressed in several international human rights treaties, and is a crucial aspect of the SDGs. Sightsavers' IEH pilot initiative is an attempt to integrate an inclusive approach within an existing eye health programme in the urban slums of Bhopal (India). This IEH model, underpinned by principles of Universal Design, accessibility, and participation, will eventually be scaled up to all future eye health programmes of the organisation. While the pilot is still ongoing, important work has already been done to improve the accessibility of health infrastructures, integrate disaggregated data collection systems, build capacity of health staff, and establish a stakeholder network, and significant developments in different areas are expected in the coming months, including barrier analyses and awareness raising activities at community level. Ultimately, Sightsavers' goal through the IEH approach is to empower people with disabilities and women to make informed decisions and prioritise their health, and to support governments and other decision-makers in the provision of more inclusive and sustainable services.

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