Universal design and inclusive eye health: a pilot initiative in Bhopal (India).

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ABSTRACT

Sightsavers is an international organisation working with partners in over 30 countries to eliminate avoidable blindness and promote the rights of people with disabilities. The organisation is currently piloting an Inclusive Eye Health (IEH) initiative in Bhopal (India), involving a tertiary eye hospital and six primary vision centres located within urban informal settlements. The project aims to develop an IEH model inspired by principles of inclusion, accessibility, participation and universal design, and informed by a human rights-based approach to inclusive development. Ultimately, the goal of Sightsavers' IEH model is to ensure that sustainable and barrier-free eye health services are available to all; that people with disabilities, women and other marginalised groups are empowered to exercise their fundamental right to health; and that governments and other stakeholders implement inclusive health policies, in line with the principles expressed in international human rights treaties, Agenda 2030 and the Sustainable Development Goals (SDGs).

Keywords

INTRODUCTION

Sightsavers is an international organisation working with partners in over 30 countries of the Global South to eliminate avoidable blindness and promote the rights of people with disabilities. In January 2016 Sightsavers launched an Inclusive Eye Health (IEH) pilot initiative aimed at developing a more inclusive model of eye health programmes based on principle of universal design, participation and comprehensive accessibility. The project is currently being implemented as part of the Urban Eye Health Programme in Bhopal (India). This paper presents key features of the IEH model and explores how universal design can be applied to different components of a health programme.

Universal design and the right to health

The first definition of universal design is credited to Ron Mace, who described it as 'simply a way of designing a building or facility at little or no extra cost so it is both attractive and functional for all people disabled or not' (1985: 147). This initial definition was later

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reformulated in "The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (The Center for Universal Design, 1997). Starting from this idea, a group of architects, designers, engineers and researchers at The Center for Universal Design of the North Carolina State University collaborated to identify seven standard principles of universal design: equitable use; flexibility in use; simple and intuitive; perceptible information; tolerance for error; low physical effort; size and space for approach and use (ibid.).

While initial conceptualisations focused very much on physical environments and products, the notion of universal design evolved to encompass a wider realm of human experiences, as reflected in the European Institute for Design and Disability (EIDD)'s Stockholm Declaration:

> Design for All aims to enable all people to have equal opportunities to participate in every aspect of society. To achieve this, the built environment, everyday objects, services, culture and information – in short, everything that is designed and made by people to be used by people – must be accessible, convenient for everyone in society to use and responsive to evolving human diversity. (2004: 1)

This comprehensive understanding of universal design naturally includes health services, which must be accessible and affordable for each individual. The universal right to health, in fact, is proclaimed in numerous international treaties. The Universal Declaration of Human Rights states that 'Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family' (UN, 1948: Art. 25), and this principle is reiterated in the International Covenant on Economic, Social and Cultural Rights (ICESCR) (UN, 1966: Art. 12). The Convention on the Elimination of All Forms of Discrimination against Women (CEDAW) specifically addresses health rights from a gender perspective, stressing the need to 'eliminate discrimination against women in the field of health care' (UN, 79: Art.12), while the Convention on the Rights of the Child (CRC) affirms 'the right of the child to the enjoyment of the highest attainable standard of health' (UN, 1989: Art. 24). The Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006) was the he first human rights treaty of the twenty-first century, and represents a fundamental milestone on the path towards the full realisation of human rights for people with disabilities. The CRPD specifically refers to health, affirming that people with disabilities 'have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability' (ibid: Art. 25). Article 9 further stresses the importance of identifying and eliminating obstacles and barriers to accessibility, promoting principles of inclusion and universal design.

While these treaties represent crucial international achievements, health services are far from being universally accessed. In fact, the cost of health care, limited availability of accessible services, widespread infrastructural barriers, inadequate training of health care personnel, social stigma and discrimination still prevent people with disabilities, women and girls, as well as other marginalised groups from exercising their right to health in many regions, particularly in the Global South (UN DESA, 2015). It is relevant to note, for instance, that over a billion people worldwide live with some form of disability (WHO and World Bank, 2011), and 80% of people with disabilities live in Low and Middle Income Countries (LMICs) (WHO, 2015a). Literature clearly suggests the existence of a cyclical link between poverty and disability (Banks and Polack, 2014). On the one hand, poverty often implies poor health care, hazardous living conditions, and lack of proper nutrition, and these factors increase the likelihood of impairments; on the other hand, people with disabilities frequently face barriers in accessing education and employment, experiencing higher risks of poverty and lower standards of living (WHO, 2015a). Literacy is another relevant factor to consider in terms of universal design and accessibility. While 85% of the global population is literate, 76% of all the illiterate people worldwide live in sub-Saharan Africa and South and West Asia (UNESCO Institute for Statistics, 2015). Due to social and cultural reasons, women in LMICs

present lower rates of literacy compared to men, and women and girls with disabilities face even more layers of discrimination compared to women without disabilities or men and boys with disabilities (Leonard Cheshire Disability, 2014).

In order to tackle these and other issues, in September 2015 the United Nations adopted the new global development framework *Transforming our world: the 2030 Agenda for Sustainable Development* (UN, 2015). The 2030 Agenda is rooted on the principle of 'Leave No One Behind' and presents 17 Sustainable Development Goals (SDGs), including *Goal 3: Good health and well-being*, which aims to achieving universal health coverage by 2030.

Sightsavers' approach to Inclusive Eye Health

In line with the principles proclaimed by international treaties and Agenda 2030, Sightsavers is committed to reach the most marginalised individuals within each area of intervention. This commitment is enshrined in Sightsavers' social inclusion strategy, *Empowerment and inclusion, Strategic framework 2015* (Sightsavers, 2015), which defines the organisational approach to mainstreaming disability and gender throughout its programming and operations.

The first of seven key objectives defined by the strategy is to mainstream disability inclusion within health programmes. In fact, with 142 million treatments given for Neglected Tropical Diseases (NTD), such as trachoma and river blindness, and 334,000 eye operations performed in 2015, health programmes represent Sightsavers' largest portfolio and area of expertise (Sightsavers, 2016a), and present an opportunity to reach a larger number of people and deliver more inclusive and effective interventions. The pledge to leave no one behind, however, raises a fundamental question: how can health programmes in LMICs be designed so that they are universally accessible and reach the most marginalised individuals?

To answer this question, in January 2016 Sightsavers launched its first pilot initiative on Inclusive Eye Health (IEH). The project is currently being implemented as part of the Urban Eye Health Programme in Bhopal (India), in partnership with Sewa-Sadan Eye Hospital (SSEH) and the local development agency AARAMBH, and involves the tertiary eye hospital and six primary vision centres located within urban informal settlements. The IEH initiative follows a previous Disability Data Disaggregation (DDD) pilot project launched by Sightsavers in Bhopal in 2014 to understand how health services are accessed by people with disabilities living in poor urban areas. The DDD pilot used the Washington Group Short Set of Questions (WGSS) (United Nations Statistics Division, 2016), a questionnaire modelled on the International Classification of Functioning, Disability and Health (ICF) (WHO, 2015b). Over the course of 16 months, disaggregated data was collected from more than 24,000 patients, and results indicated that eye health services were not equitably accessed by people with disabilities in the hospital and vision centres (Sightsavers, 2016b). The DDD pilot provided a useful baseline for the IEH initiative, which was then launched to design a standard model of IEH based on principles of participation, comprehensive accessibility and universal design, and that could be replicated in all future programmes of the organisation.

Sightsavers' commitment to inclusive development is based on a system strengthening approach, which involves duty bearers and rights holders (United Nations Development Programme, 2016). In the context of IEH, Sightsavers aims to support duty bearers, such as the hospital and ultimately the government, in the provision of universally accessible services. At the same time, the organisation also aims to promote the right to health of each individual in the community, and in particular of those exposed to higher risks of vulnerability, such as people with disabilities and women.

The pilot initiative was designed with a participatory approach in mind, and a definition of IEH was elaborated involving Sightsavers' Indian and global staff, representatives of SSEH and AARAMBH, and people with disabilities belonging to Disabled People's Organisations (DPOs):

> Eye health services are provided within a barrier free environment, are inclusive by design and are sustainable. (Sightsavers, 2016c)

Adopting a similar collaborative procedure, Sightsavers drafted a Theory of Change (TOC) to define the IEH theoretical model. TOCs are instruments used to map early and intermediate changes needed to reach a long-term goal, and to elaborate solutions to complex social problems (Anderson, 2012). The overarching goal of Sightsavers' IEH TOC is to ensure that sustainable, barrier-free and inclusive eye health services are accessed by all, including people with disabilities and women. This model is currently being tested in Bhopal, and will eventually inform all future eye health programmes of the organisation. The IEH TOC is built on principles of inclusion and universal design in the context of health care, and the following sections of this paper will summarise some of the key features of the IEH theoretical model.

Participation

Along with universal accessibility, participation is a fundamental principle underpinning Sightsavers' IEH model. The historic motto of the Disability Movement, "Nothing about us without us", can easily apply to other social groups, and underlines the importance of involving the beneficiaries in any process or decision that may affect them. In the context of Sightsavers' IEH pilot initiative, this means involving at every stage of the project cycle women and men with and without disabilities, as well as children, people with HIV/AIDS, and other individuals living in urban informal settlements. This process is crucial to ensure that their voices are heard, but also represents a great opportunity to identify barriers at supply, demand, and policy levels. A number of important recommendations, for instance, were collected during Focus Group Discussions (FGDs) held with people with disabilities, individuals with HIV/AIDS, vulnerable women and members of different non-governmental organisations (NGOs) working in Bhopal. After being invited to identify key barriers preventing them from accessing health care in the district, most participants lamented lack of accessible infrastructures, unsympathetic health personnel, and persisting stigma in the community. These testimonies provided precious insights and informed the inclusion strategy of Sightsavers and its partners in the IEH initiative.

Governance and sustainability

A cornerstone of Sightsavers' system strengthening approach is to seek sustainability of impact at local level by promoting ownership of the interventions with the implementing partners. In this respect, the IEH project benefits from strong collaborations consolidated through the DDD pilot, and both SSEH and AARAMBH demonstrated high level of commitment, enthusiasm and responsibility in making eye health services in Bhopal more accessible and inclusive. This is a crucial aspect for the long-term sustainability of the IEH initiative. In fact, while the main goal of the pilot is to develop an IEH model that could be replicated across different programmes of the organisation, it is fundamental to ensure that inclusive and accessible services will continue to be provided in Bhopal following the end of the project cycle. For this reason, regular sensitisation meetings are scheduled throughout the whole duration of the project, and Sightsavers and its partners are collaborating to elaborate cost-effective interventions and embed inclusion in the standard eye health budget and procedures.

Infrastructure

In line with principles of universal design, and as highlighted in the FGDs held in Bhopal, the provision of comprehensive accessible infrastructure must be a key consideration in any health service. However, it is relatively rare to find universally accessible buildings in most LMICs. This was the case of SSEH and the six vision centres in Bhopal where Sightsavers is running the IEH pilot initiative.

Figure 1. The enquiry counter at CHC Kolar Road vision centre is not accessible, being at a height of 1120 mm, with a communication opening at 1550 mm.

Figure 2. At the entrance of the Chandbarh vision centre there are two steps with uneven risers, and no handrails and ramps are provided.

In order to tackle these issues, soon after the beginning of the project a certified Indian agency led by people with disabilities was hired to conduct accessibility audits in the hospital and the vision centres. The audits identified a number of key obstacles, such as lack of ramps, braille signage and tactile pavers, poor visual contrast in several rooms, and inaccessible toilets. Subsequently, following the submission of the audit reports, Sightsavers and its partners elaborated a plan to make the health facilities more accessible, and works are due to be completed by spring 2017.

Human resources

As emerged in the FGDs, one of the biggest barriers preventing people with disabilities, vulnerable women and other groups of people from accessing health care is often the attitude of health staff. For this reason, building capacity of health personnel on inclusion and accessibility is a key aspect of the IEH TOC. After the beginning of the pilot initiative, an initial training on gender and disability inclusion was organised for senior management and technical staff of the hospital and vision centres. Subsequently, several Indian organisations and people with different disabilities were consulted by Sightsavers to elaborate a training module for health care personnel through a participatory process. The training targets both health staff working in the facilities and Community Health Workers (CHWs) active in the community. The module focuses on general principles, such as inclusion and universal design; contextual elements, such as cultural issues and local legislations; and practical and context-specific recommendations for staff, such as how to interact with a deaf person.

Data disaggregation

The collection and analysis of disaggregated data constitutes a key element of the IEH model, and it is crucial to survey the percentage of people with disabilities accessing eye care services compared to rest of the population, as well as to monitor the level of inclusivity and accessibility of the IEH interventions. Following the completion of the DDD pilot, the collection and analysis of data disaggregated by disability was therefore integrated in the IEH model. During the course of the DDD pilot, specially trained data collectors manually registered the answers to the WGSS on paper and transferred them to Microsoft Excel, while data analysis was conducted by data analysts at Sightsavers International. With the start of the IEH pilot, however, a transition strategy was devised to train eye health staff to collect DDD as part of their standard data collection procedures, to conduct data analysis at country office level, and to embed the whole procedure into an electronic Health Management Information Systems (eHMIS). Data disaggregated by sex, age and disability is now analysed on a monthly basis by local staff to assess the progress of the project and inform the inclusion strategy.

Awareness and barriers mitigation

Literature suggests that lack of accessible transportation and financial power are some of the recurrent issues influencing health seeking behaviours among urban and rural poor (WHO and World Bank, 2011). The IEH model suggests that, while these issues may be widespread in different regions, it is important to adopt participatory approaches to understand barriers and develop solutions which are relevant for the local context of intervention. Cultural and social barriers at community level often pose insurmountable obstacles preventing vulnerable groups of people from exercising their right to health, as highlighted by the participants of the FGDs. Women with disabilities or with HIV/AIDS living in LMICs, for instance, are exposed to multiple forms of stigma and discrimination, and are often segregated from the rest of their community (WHO & World Bank, 2011). In every

health programme run by Sightsavers it is a standard procedure to conduct activities aimed at raising awareness at community level on the importance of eye care. However, the IEH model suggests that this may not be enough. On the one hand, in fact, it is crucial to ensure that these activities are inclusive, and in particular that Information Education and Communication (IEC) materials on eye health are accessible to people with various types of impairments, as well as to individuals who are illiterate. On the other hand, unless certain stereotypes and cultural barriers are addressed, some of the most marginalised groups in society will continue to be excluded from the health care system. For this reason, Sightsavers and its partners are committed to adopt a twin-track approach, by mainstreaming inclusion and accessibility in all awareness raising interventions, and by addressing stigma and discrimination at community level in partnership with local stakeholders by devising targeted interventions aimed at promoting the rights of the most marginalised. As a result of this commitment, a new communication strategy was developed through a specialised local agency to produce a variety of accessible communication channels and materials. Additionally, an awareness raising strategy was elaborated to foster community engagement and reduce stigma towards marginalised groups living in urban informal settlements, and implemented in collaboration with local stakeholders.

Policy and advocacy

Advocacy is an intrinsic element of Sightsavers' programme planning. While the prime goal of the IEH pilot is to develop a model that will eventually be scaled up in all future Sightsavers' programmes, the IEH model also aims to support governments and other stakeholders in the provision of more inclusive health services. This is a key factor to ensure long-term sustainability of inclusion in health care in the regions where Sightsavers works.

India ratified the CRPD in October 2007 and the government recently launched the *Accessible India Campaign* (Department of Empowerment of Persons with Disabilities, 2016), aimed at achieving universal accessibility for people with disabilities. The Indian government further released programmatic documents such as the *Inclusiveness and Accessibility Index* (Department of Empowerment of Persons with Disabilities, 2015) and the *Harmonised Guidelines and Space Standards on Barrier Free Built Environment for Persons with Disability and Elderly Persons* (Ministry of Urban Development, 2016). In the context of the IEH pilot in Bhopal, therefore, it is a strategic priority for Sightsavers to cooperate with the government to support the provision of more inclusive health services. For this reason, three out of six of the vision centres involved in the project have been established within government facilities. This represents a unique opportunity to showcase simple and cost-effect solutions based on principles of inclusion and universal design that could be replicated and scaled up by the government in the following years. An advocacy strategy was also developed to promote dialogue and collaboration with district, regional and national policy and decision-makers, and Sightsavers is working to support the government in carrying out accessibility audits and infrastructural interventions in public health facilities.

CONCLUSION

Health is a fundamental human right, yet not all individuals have equitable access to health services. Widespread poverty, lack of accessible infrastructures, and stigma and discrimination are some of the key barriers preventing women and men with disabilities, as well as other marginalised groups from accessing health care in LMICs. Sightsavers is currently implementing an IEH pilot initiative in Bhopal (India), targeting some of the most vulnerable people living in urban informal settlements. The pilot initiative also serves as a test for a model that will eventually be used in all future Sightsavers' programmes, and made available to other health stakeholders, such as governments and local and international NGOs.

Several interventions were carried out in the first ten months of the pilot initiative to embed principles of inclusion, participation and universal design within the existing eye health programme, and contributed to the development of an IEH theoretical model. Focusing on leadership and sustainability, accessible infrastructure, human resources, data disaggregation by sex, age and disability, awareness raising on eye health, gender mainstreaming and disability inclusion, and a systematic engagement with relevant policy and decision-makers, Sightsavers' IEH model ultimately aims to ensure the provision of inclusive services, to empower people with disabilities, women and other groups at risk of marginalisation to exercise their right to health, and to support governments and other stakeholders in the implementation of inclusive health policies.

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