

Learning brief

Disability inclusion in the eye care sector

A case study from Pakistan



Sightsavers



Introduction and background

Pakistan is the sixth most populated country in the world, with over 220 million people. Under the constitution, Pakistan's health system is devolved and health service delivery is the prime responsibility of provincial governments. Provinces are autonomous in developing their own health policies and strategies in line with national policy. Service delivery is organised through preventive, promotive, curative and rehabilitative services. The curative and rehabilitative services are mainly being provided at secondary and tertiary care facilities. Preventive and promotive services, on the other hand, are mainly provided through various national programmes, and by community health workers interfacing with communities through primary health care facilities and outreach activities.

The second national survey on blindness and vision impairment conducted from 2002–2004 revealed that the most common causes of blindness were: cataract 51.5%, corneal opacity 11.8%, uncorrected aphakia 8.6%, and glaucoma 7.1%. Refractive error was the most common cause of moderate visual impairment at 43%¹.

During the last 20 years, incredible progress has been made to strengthen eye health systems in Pakistan through public-private partnerships. Working with international organisations, the national programme for the prevention and control of blindness has improved infrastructure, human resources and the outreach of eye care services to a great extent. A comprehensive eye care approach that identifies districts as a unit of implementation while establishing the link between primary and secondary health care, played a key role in this change. According to the cataract surgical rate (CSR) mapping study conducted jointly by the National Programme for Prevention and Control of Blindness and Sightsavers in 2019, Pakistan has improved its cataract surgical rate by 200 per cent in the last 18 years – from 2,254 (in 2002) to 5,203 (in 2019)², and getting a place among the countries with the highest CSR. However, despite all the good work, these services are not equitable for everyone, especially rural communities, the ultra-poor and people with disabilities.

Sightsavers, along with other international organisations, has been investing resources in strengthening eye health systems in Pakistan since 1998. This has been through advocacy, research, evidence-based programme implementation, the development of human resources for eye health, and improving eye health service delivery, infrastructure and management information systems.



A female health worker conducts a routine visit with a diabetes patient in Lahore.

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Women queue for their eye health appointments at LRBT Hospital in Quetta.

Universal health coverage and eye health in Pakistan



Two key global developments – the Sustainable Development Goals (SDGs) in 2015 and the World Health Organization’s (WHO) World Report on Vision in 2019 – have provided the basis for changes in eye health systems in many countries. The SDGs provided the strategic direction for the strengthening of health systems, especially under target 3.8 which is about universal health coverage (UHC). ‘Leave No One Behind’ (LNOB) is one of the major guiding principles that urges the inclusion of everyone, especially those with disabilities. The World Report on Vision indicated that the future strategy for eye health should be based on integrated people-centred eye care (IPEC), to ensure equitable access to eye health services for all.

Pakistan is moving towards an inclusive eye health approach that aligns with the frameworks of the WHO Vision 2020 Strategy; the Global Action Plan 2014–2019: Towards Universal Eye Health; the UN Convention on the Rights of Persons with Disabilities (UNCPRD); the Sustainable Development Goals (SDGs); and the WHO roadmap for neglected tropical diseases (NTDs). In addition, the

disability-related legislative framework is also improving in the country with the approval of one federal-level act and three provincial-level acts on the rights of people with disabilities during the last four years. The national health insurance scheme recently launched by the federal government aims to provide health insurance cards to 15 million poor families. The package of services includes cataract surgeries.



Inclusive eye health in Pakistan

The federal government of Pakistan adopted the SDGs as the national development agenda of Pakistan through a unanimous parliamentary resolution in 2016. In line with this strategic change, Sightsavers and other key stakeholders started discussions at the forum of the National Committee for Eye Health (NCEH) to shift from traditional eye health programme design and implementation, to inclusive eye health (IEH) programmes. The purpose of proposing this shift was to make sure that all marginalised groups, particularly people with disabilities, are able to access eye health services in an enabling environment. Sightsavers, supported by the UK Foreign, Commonwealth and Development Office (FCDO), designed and implemented an inclusive eye health project in four districts, demonstrating inclusive eye health approaches from 2018 to 2021. This IEH project has contributed significantly to paving the way for the inclusion of people with disabilities in eye health services. **Major outcomes include:**



Development of a sign language module for eye health professionals: During the project implementation, the need for a sign language module for eye health professionals was recognised, because health professionals were unable to communicate with people with hearing loss and hearing impairments when they visited health facilities. Sightsavers, with the support of key stakeholders, successfully developed the sign language module for eye health professionals and trained eye health professionals at partner hospitals to address the specific needs of people with hearing impairments. The sign language module was also integrated into the curriculum of the BSc in Vision Sciences (Optometry) at College of Ophthalmology and Allied Vision Sciences (COAVS) in Punjab province. It will also be replicated at other institutions under the leadership of the National Committee for Eye Health (NCEH).



Development of an inclusive eye health module for optometrists: The national programme for the prevention and control of blindness introduced an additional module on IEH into the BSc in Vision Sciences at COAVS to make sure that the optometrists are well prepared on inclusive approaches in eye health services. All other institutes offering courses for optometrists in the country were also invited to consultation workshops on the IEH module, to make sure the module is replicated in other areas as well. OPDs and people with disabilities remain an integral part of the module development and training of staff and faculty, as well as other institutions offering the BSc in Vision Sciences. People with disabilities also participated in the capacity-building workshops as resource persons.



Disability access audits by OPD partners:

Under the IEH project, accessibility audits at all partner hospitals were conducted by the Special Talent Exchange Programme (STEP), an OPD. Based on the recommendations of the audit report, infrastructure adaptations at eye health facilities were made to make them accessible for people with disabilities. LRBT, the largest charity sector organisation in the eye health sector in Pakistan, which performs a sixth of the total cataract surgeries, is the partner for the IEH project. The impact of the IEH project is so significant that LRBT is constructing a new hospital building, which has considered accessibility for people with disabilities right from the start.



Inclusive data: Under the inclusive eye health project, Sightsavers piloted the disability disaggregated data collection at partner hospitals. The Washington Group Short Set of Questions (WG-SS) questionnaire was used for data collection after being translated into national and regional languages, as well as having a cognitive testing to make sure that the translation is as accurate as possible. All the project staff involved in DDD collection were provided with extensive training on the administration of the WG-SS questionnaire.

Outcome of inclusive eye health interventions

Two of the strategic outcomes of inclusive eye health pilots are;

- Formation of inclusive eye health task force
- Development of Integrated People Centred Eye Care (IPEC) plans



Formation of an inclusive eye health task force:

The IEH project provided the basis and a strong push for the development of an inclusive eye health task force under the umbrella of the National Eye Health Committee (NEHC) – an apex body to provide strategic direction to eye health in the country under the federal ministry of health where Sightsavers is a pioneer member. The inclusive eye health task force was notified in 2018 with the aim that it will provide direction on inclusive programming to ensure the inclusion of people with disabilities in eye health services. The task force is comprised of representatives from federal and provincial governments, as well as national and international NGOs working in eye health, the Directorate General of Special Education, OPDs and disability rights activists. Sightsavers is one of the key founding members of the task force. The major responsibilities of the task force were to develop inclusive policies and formulate IPEC plans, and advocate with federal and provincial governments for the allocation of technical and financial resources for the implementation of IPEC plans.



Development of IPEC plans: One of the most strategic tasks for the IEH taskforce was the development of IPEC plans for provinces and at a federal level. As a first step, Sightsavers in collaboration with NEHC carried out a policy analysis on disability, health and social protection in the context of the UNCRPD and the SDGs. The report identified existing gaps and provided key recommendations for policy and planning, as well as for operationalising these changes at the service delivery level. Furthermore, the report sets a policy context for the future planning of national and provincial-level inclusive eye health plans. The report was presented to the members of NCEH and the Special Advisor to the Prime Minister of Pakistan on health services for their endorsement. There was a unanimous consensus from all stakeholders for the proposed approaches and strategies within the IPEC plans.

Some of the key recommendations from the policy analysis on disability, health and social protection:



Conduct policy research to determine the health status of persons with disabilities and their relative risk compared to others in order to establish the rationale for integrated health and rehabilitation interventions and resource allocation.



Conduct joint curricular reviews of the medical, nursing and other health professional undergraduate and postgraduate training programmes with relevant authorities and stakeholders to incorporate disability inclusion and train faculty.



Undertake a contextual and operational review of the new provincial health sector strategies to identify opportunities for disability inclusion that can be integrated in specified objectives, actions and implementation plans in the respective health sector strategies.



Develop a pilot district approach to develop and test the use of the checklist to conduct an accessibility audit of health facilities, collection and reporting from health facilities of a test set of disability indicators for district health information systems and the identification of persons with disabilities at union council level (smallest administrative unit) for disability assessment and support for getting a special national identity card.



Develop and roll out a customised disability equality orientation and training module for health planners, health administrators and managers, provincial and district health officials, and duty bearers. Extend the scope of disability equality orientation to doctors, nurses and allied health professionals as an in-service capacity-building initiative.



Hold a national consultation workshop in collaboration with the federal and provincial health authorities, Ministry of Social Protection and Poverty Alleviation Coordination, national and provincial councils for rehabilitation of disabled persons, trust for the welfare of the disabled and other stakeholders, to develop a roadmap for the adoption and adaptation of the WHO's assistive products list (APL), and mechanism for assessment, access to assistive products, procurement, provision and replacement, and its integration with social protection processes.



A meeting led by women with disabilities at the Equal World campaign launch in Islamabad in 2019.

Following the agreement of stakeholders on the development of IPEC plans for provinces and national level, the development process for IPEC plans started in early 2020. The IEH task force under NCEH took the lead on the process of IPEC plan development, with support from Sightsavers and other key stakeholders including OPDs. **The following key steps were taken in this regard:**

- Development of programme policies for inclusive eye health and safeguarding.
- Development of a 'Companion to planning: package of services for integrated people-centred eye care'. This contains the following:
 1. Province-wise online consultations with key stakeholders, including government officials, officials from NGOs, INGOs and OPDs.
 2. Used the 'companion' report to conduct a gap analysis of eye care services at health facility level.
 3. Development of an integrated people-centred eye care framework – to guide the development of provincial and national IPEC plans.
 4. Development of a 10-year perspective on eye care services.

The IPEC plans make very strong reference to disability inclusion in eye health services and devise actions to make the inclusion of people with disabilities a reality. The implementation of IPEC plans lies with the provincial comprehensive eye care (CEC) cells under health departments. The proposed actions include:

1. Ensure that integrated people-centred eye care services are comprehensive and include health promotion, disease prevention, curative medical and surgical services, and rehabilitative services (including access to low vision care).
2. Promote strategies for the inclusion of all potentially excluded groups, including people with disabilities, and recognising that there may be specific needs for women and children, in all phases of the programme cycle when developing eye health and integrated people-centred eye care programmes.
3. Identify both internal and external barriers to access (e.g. attitudinal, environmental, physical, social, communication and financial), especially for people with disabilities, in approaching health facilities and seeking eye care services, noting options that may be relatively easy or more difficult to fix. Develop and implement a plan of action to address these barriers.
4. Locate people (through engagement with OPDs) who are likely to be excluded in eye health and integrated people-centred eye care programmes that involve the communities and ensure that they receive access to quality eye care services.
5. Develop and ensure the use of accessible information, education and communication (IEC) and social behavioural change (SCC) materials in integrated people-centred eye care programmes.
6. Ensure eye health services and integrated people-centred eye care programmes incorporate counselling, linkages and referral to rehabilitation and education services for people who have untreatable eye conditions that result in irremediable vision loss.
7. Advocate for and incorporate disability inclusion modules in training programmes and curricula for human resources for eye health (such as: ophthalmologists, optometrists, orthoptists, ophthalmic technologists, ophthalmic technicians, ophthalmic nurses, opticians, primary health care workers and other related roles).
8. Incorporate a mandatory component of disability inclusion in epidemic and disaster preparedness and action plans for emergency eye care services.
9. Adaptations in the infrastructure of health facilities to create a reasonable accommodation/accessibility for people with disabilities.
10. Capacity building of health staff on disability inclusion, disability equality and inclusive approaches so that they feel confident when working with people with disabilities.
11. Collection and reporting of inclusive data at all eye health facilities.
12. Reorientation of eye health services to bring them closer to communities at primary level, to make them more accessible to people living in difficult circumstances, especially people with disabilities.



The way forward

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A man with disabilities leaves LRBT Hospital in Quetta after receiving free cataract surgery.

Comprehensive eye care (CEC) cell Sindh is the first province to get the provincial IPEC plan formally endorsed by the Directorate General of Health. The plan was presented at the Sindh Provincial Eye Health Committee annual meeting, where it was approved and endorsed by the Secretary Sindh (the highest rank in health bureaucracy).

Furthermore, Sightsavers and the Sindh health department signed a memorandum of understanding (MOU) which requires that all future eye health projects will be completely aligned with the IPEC plan and will therefore be inclusive for all. To demonstrate the inclusive eye health approach, Sightsavers has initiated two projects on primary eye care and diabetic retinopathy in Sindh. They will generate evidence for advocacy, with the provincial government asking for the technical and financial support of the government for the implementation on IPEC plan. However, the strategy will be applicable to all such projects in Sindh, not only those that are supported by Sightsavers.

Key learnings from this initiative

During this journey, we have learned many things about the inclusion of people with disabilities in health services, through policy changes, capacity building, awareness raising and remodelling service delivery approaches. A few of the key learnings are:

- If advocacy initiatives are supported and based on evidence, data, research, best practices and learning, it becomes easier to achieve advocacy goals. Moreover, joined-up advocacy plays an important role for desired changes within public sector policies and plans.
- The advocacy initiatives cannot be stopped with the development of national and provincial eye health plans. Continuous engagement and advocacy is required to ensure that these plans are properly implemented, monitored and modified according to changing needs.
- Promote strategies for the inclusion of all potentially excluded groups, including persons with disabilities, recognising that there may be specific needs for them in all phases of the programme cycle when developing eye health and integrated people-centred eye care programmes.
- There is always more value and usefulness in face-to-face consultation, but we learned during the COVID-19 lockdown that virtual consultation processes can be efficient and cost-effective if participants are well informed and motivated enough about the objectives of consultation. The virtual consultation also provided us an opportunity to engage more stakeholders than in an in-person consultation process, particularly people with disabilities as they face many barriers when travelling.
- Embedding inclusive and equitable approaches in the design and deliver of eye care programmes is an effective way to ensure inclusion of people with disabilities in health care services.
- The IEH initiatives have the potential to ensure eye health programmes gradually become comprehensive in terms of promotion, prevention, curative interventions, and rehabilitation at the primary, secondary and tertiary level of service delivery.
- Inclusive eye health programmes' investment into working with national and provincial governments and other key players, such as district health offices, as well as disability networks and alliances, can embed long-term systemic change for inclusion and equity within existing policies and systems.
- We have learned that the translation of WG-SS questions into local languages and its cognitive testing is really helpful in the administration of the tool. It also needs continuous monitoring of the staff involved in disability disaggregated data collection.
- Increasing awareness, understanding and commitment to inclusion among all partners and at national and provincial government level is a necessary foundation to stimulate action.
- The involvement and leadership of people with disabilities, playing key roles in designing and implementing inclusive development (conducting sensitisation training, leading accessibility audits etc), is a highly influential factor in breaking down stereotypes and stigma, and raising awareness of inclusion issues.
- Building wider stakeholder networks and outreach with like-minded organisations strongly increases capacity for inclusive work by reaching out to marginalised groups.

Potential impact on the lives of people with disabilities



The overall improvement in the legislative framework related to disabilities, the evidence generated through implementing inclusive eye health projects, and the development of IEH and sign language modules, as well as IPEC plans, will have an impact on the lives of people with disabilities with reference to eye health services. All these interventions collectively make sure that both the demand and supply side of eye health services are moving from a traditional approach to an inclusive eye health approach.

The disability disaggregated data will be helpful in monitoring the number of people with disabilities that are able to access eye health facilities for services. This will also help the government and other stakeholders to have an informed planning, decision making and programme development process.

The successful inclusion of people with disabilities into eye health services will pave the way for people with disabilities to demand the same in other areas of health. This will ultimately lead to achieving universal health coverage (UHC) and SDG 3, while ensuring that people with disabilities are not left behind.



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Kousar, who has dwarfism, has an eye examination at an eye camp in Shahpur Sargodha.

References

1. <https://tinyurl.com/iovjournal>
2. <https://tinyurl.com/dawnpaper>

Cover image:

A child from the Brick Kiln community, near Shahpur Mandra, where a free eye camp was held.

We work with partners in low and middle income countries to eliminate avoidable blindness and promote equal opportunities for people with disabilities

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