Inclusive Eye Health – breaking down the barriers so all people benefit

Pakistan

CBM Learning Document 2016

Photo: Haseena at the DMRC Complex, Pakistan. All pictures: Courtesy of PCPSM Ltd

What is Inclusive eye health?

Around 15% of the world's population, or 1 billion people, live with disability. People with disabilities are the world's largest minority group and 80% live in low and middle income countries.[1] Furthermore they make up 20% of the world's poorest people.[2]

Inclusive eye health (IEH) means ensuring eye care services are accessible and welcoming to all members of the community, including people with sensory, physical and intellectual impairments, and those with mental health conditions; it also means proactively ensuring that people with long term vision impairment access their right to wider opportunities in rehabilitation, health, education, livelihoods and social inclusion. IEH is essential for reaching the poorest people.

Achieving IEH requires responding to attitudinal, physical, communication and policy related barriers at all levels: national, regional, community & individual.

CBM has been actively building and sharing approaches in inclusive eye health since 2009. This has included the establishment of pilots and the production of training resources co-branded with IAPB, Vision 2020 and 14 other key agencies.

In line with the strong evidence base being built, which shows the importance of inclusive practice, CBM wants to see all eye health programmes across the world strengthened to include and welcome not only people with disabilities, but also those from all marginalised groups. This is essential practice for poverty alleviation.

Key CBM intervention areas in Pakistan

Following the 2010 floods, CBM developed an inclusive eye health initiative through its local partner CHEF Intl in Charsadda district, Khyber Pakhtunkhwa (KPK) province. This was the first disability inclusive initiative at primary & secondary level in KPK Province.

1. Policy level

Creating an **inclusive eye health taskforce** as part of the National Committee for the Prevention of Blindness

2. Organisational level

Training CHEF field and headquarter staff in inclusive eye health

3. Service delivery level

Making **facilities accessible** & welcoming, including training of staff:

- in 4 Basic Health Units (BHUs)
- in 1 NGO unit, the District Medical and Rehabilitation Complex (DMRC)
- linked to **one inclusive education project** (26 schools)

4. Community level

Training Lady Health Workers (LHWs) who conduct outreach at household level

[1] World Health Organization / The World Bank, "World Report on Disability", Geneva, WHO, 2011.
[2] UN CRPD (World Bank estimate) https://www.un.org/disabilities/convention/facts.shtml

Study objectives and methodology

Objectives

1. To identify **policies and policy structures** related to inclusive eye health.
2. To generate **evidence of strengths and weaknesses** of CBM's inclusive eye health approach.
3. To identify the **impact** of inclusive eye health in Pakistan and its **outcomes** for the target groups.

Methodology

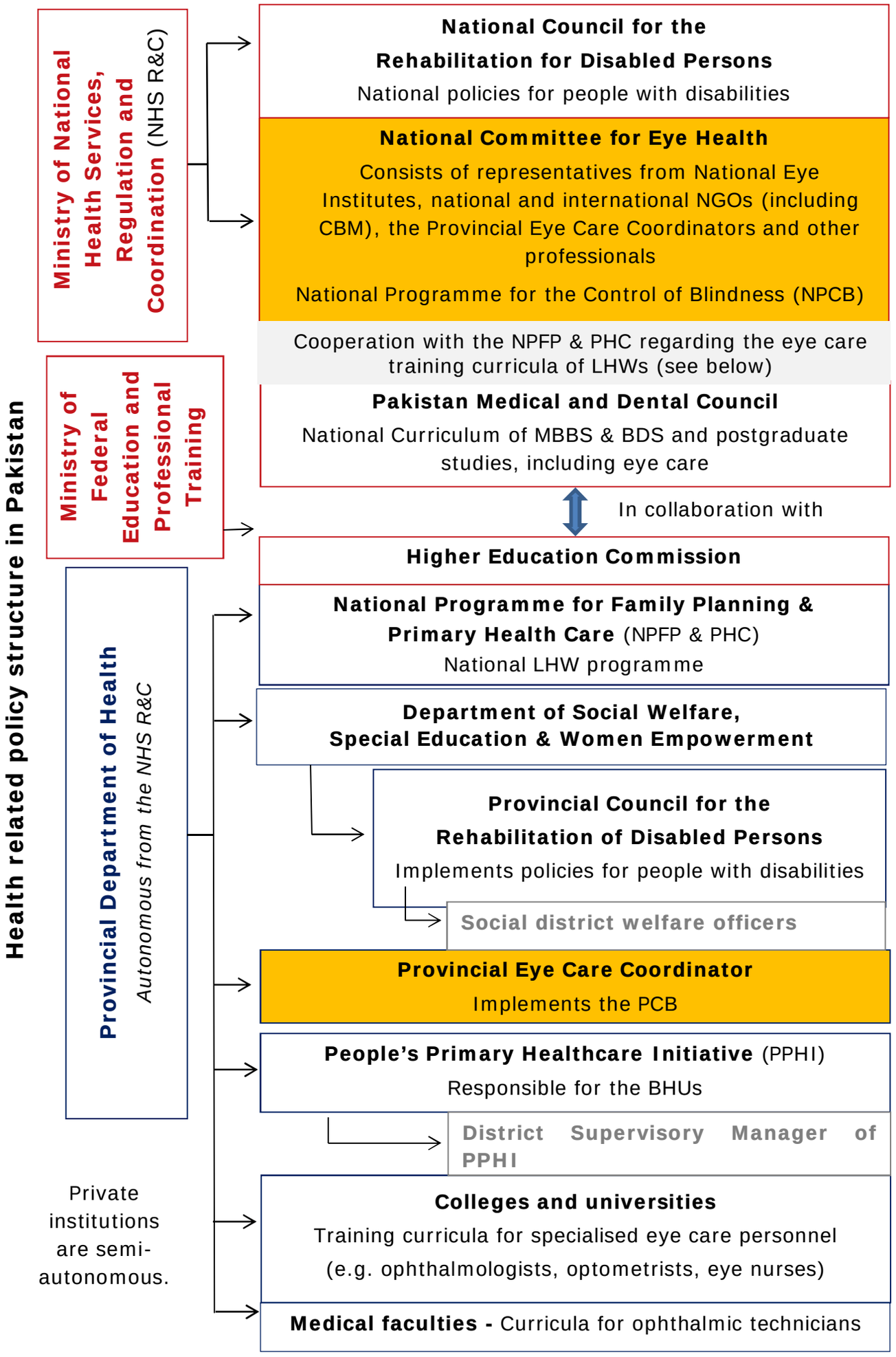
1. Review of relevant programme monitoring documents, evaluations, surveys, national plans and CBM publications.
2. Field visits to two BHUs, DMRC, DPOs, and one school in Charsadda (focus group discussions and semi-structured interviews).
3. Interviews with the People's Primary Healthcare Initiative (in charge of the BHUs), CHEF Intl and the National Eye Care Coordinator.

Key resources

1. CBM "Inclusion made easy - a quick programme guide to disability in development": http://www.cbm.org/Inclusion-Made-Easy-329091.php
2. CBM "Inclusion made easy in eye health programs - Disability inclusive practices for strengthening comprehensive eye care": http://www.cbm.org/article/downloads/54741/Inclusion_in_Eye_Health_Guide.pdf

Policies and policy structures

- The UN Convention on the Rights of Persons with Disabilities was ratified by the Federal Government of Pakistan in July 2011.
- Respective policies still need to be transferred into legislation at the provincial level and implemented at the district level.
- Separate departments and programmes are responsible for people with disabilities and not integrated into mainstream government initiatives, creating barriers to inclusive approaches, e.g. the provincial Departments of Social Welfare, Special Education & Women Empowerment are responsible for the education of people with disabilities; and the Department of Elementary & Secondary Education and the Department of Higher Education, Archives and Libraries are responsible for all other education.
- The health related policy structure includes a number of stakeholders at national, provincial and district levels (see next page).


Health related policy structure in Pakistan
Ministry of National Health Services, Regulation and Coordination (NHS R&C)
National Council for the Rehabilitation for Disabled Persons
National policies for people with disabilities
National Committee for Eye Health
Consists of representatives from National Eye Institutes, national and international NGOs (including CBM), the Provincial Eye Care Coordinators and other professionals
National Programme for the Control of Blindness (NPCB)
Cooperation with the NPFP & PHC regarding the eye care training curricula of LHWs (see below)
Ministry of Federal Education and Professional Training
Pakistan Medical and Dental Council
National Curriculum of MBBS & BDS and postgraduate studies, including eye care
In collaboration with
Higher Education Commission
Provincial Department of Health
Autonomous from the NHS R&C
National Programme for Family Planning & Primary Health Care (NPFP & PHC)
National LHW programme
Department of Social Welfare, Special Education & Women Empowerment
Provincial Council for the Rehabilitation of Disabled Persons
Implements policies for people with disabilities
Social district welfare officers
Provincial Eye Care Coordinator
Implements the PCB
People's Primary Healthcare Initiative (PPHI)
Responsible for the BHUs
District Supervisory Manager of PPHI
Private institutions are semi-autonomous.
Colleges and universities
Training curricula for specialised eye care personnel (e.g. ophthalmologists, optometrists, eye nurses)
Medical faculties - Curricula for ophthalmic technicians

CBM supported inclusive projects, Charsadda (2011-2014)

'District Medical and Rehabilitation Complex (DMRC)'

A new district hospital was built to provide inclusive health care and disability services. This is the only provider of services for people with disabilities in Charsadda including eye health, low vision and assistive devices for people with visual impairments. The DMRC is the main referral hospital for the four BHUs above and continues to be run by CHEF Intl. CHEF Intl provided free transport for patients to DMRC which helped increase attendance, particularly by women and girls.

'Accessible health services for people with disabilities'

With the aim of establishing a functioning inclusive primary health care system, the "Accessible health services for people with disability" project was implemented in two districts, making four existing Basic Health Units (BHUs) more inclusive. This included making infrastructure accessible; disability training for hospital staff and for Lady Health Workers (LHWs), who are attached to each BHU and are responsible for community outreach and referral. Disabled People's Organisations (DPOs) were also set up in each local area.

'School renovation project'

A school renovation project was implemented with the objective of converting 26 schools into inclusive education providers. In addition to improving accessibility of infrastructure, the project also included awareness creation workshops about disability and inclusive education for district authorities, community leaders and teachers. Handbooks dealing with inclusive education were designed for teachers. School children and members of the wider community were screened for eye and ear conditions and a number of teachers were trained in vision and hearing screening, as well as in community based rehabilitation and mobility.

Key Strengths

1. **National focus on inclusive eye health**

   Recent recommendations of the National Committee of Eye Health state that “National and Provincial Eye Care Cells should strengthen and expand existing capacities for human resource development in eye health in an inclusive manner and make it part of the national and provincial eye care plans”.

2. **Health / eye care services accessible**

   CBM supported project buildings are accessible and welcoming for all people with disabilities, especially for those with physical disabilities. CBM is supporting the training of LHWs in primary eye care and in disability, bringing inclusive practices and services close to the community and integrating them within primary health care.

3. **Integration into government system and government ownership**

   The inclusive projects successfully cooperated with existing government structures such as the LHWs, BHUs, district eye care providers, and schools. The government took responsibility for the primary health care project at the end of the project period.

4. **Replicable best practice model for the Pakistani context**

   Inclusive health services at the district level not only benefit people with disabilities, but also women and girls who have limited travel opportunities due to cultural barriers. By offering gender inclusive and sensitive services including free transport, the number of women and girls who participated increased.

5. **Community awareness increased and perceptions changed**

   In some communities, people with disabilities are considered a burden and cursed by God for sins committed by the family. In communities witnessing the positive change that rehabilitation, assistive devices and empowerment have made to the lives of people with disabilities, there has been some change in perception. Training at school level has also strengthened understanding among school principals and teachers.

6. **Sustainable referral system**

   Through coordination with the different stakeholders, a sustainable referral system for people with disabilities and other poor people was established using existing transport hubs, which ensures referrals from community level up to primary and district level services.

7. **Systems strengthened**

   Capacity has been built where participation of people with disability was lacking, e.g. DPOs have helped strengthen the management committees of BHUs to promote inclusive practices in planning, implementation, monitoring and advocacy.

Haseena's story

Haseena being examined in DMRC.

Haseena is a 17 year old girl living with her parents and siblings in a small village in Charsadda. From birth Haseena has had hemiplegia, a paralysis of one side of her body, usually caused by a brain lesion.

Taking Haseena to the doctor when she fell ill was very difficult for her parents, so usually they would buy medicine from their local pharmacist based on his advice. Sometimes the medicine helped Haseena, but often it made her condition even worse.

In 2014, Haseena's parents heard about DMRC and took her for a consultation, where she was provided with a wheelchair. "Suddenly, I was able to move on my own", Haseena says: "It gave me a reason to get up in the morning. It was liberating."

Recently Haseena discovered problems with her vision and returned to DMRC. She was amazed to find how easily she could move around the whole complex and the eye department, thanks to ramps built in almost every wing, wide doors, inclusive washrooms with rails, and a welcoming attitude of all the staff.

Haseena never believed that a hospital visit could be so easy for someone with a disability.

Key areas for improvement

1. **Improve data analysis**

   Routinely analyse disability data captured in the health and education information systems and use this for planning purposes. Continue to lobby for the inclusion of disability data in the national Health Management and Information System (HMIS).

2. **Improve referrals and school inclusion for blind and visually impaired children**

   Create a district model for a two-way referral system from health services to rehabilitation services and schools, and from schools to health services. This should involve all stakeholders, including government officials of all relevant departments.

3. **Further increase accessibility**

   Accessibility measures such as handrails, adequate lighting, colour line systems, large contrasting signage, and other aspects of universal design could be explored to further enhance the accessibility of buildings.

4. **Increase awareness of policies and referral services for people with disabilities among staff, patients, carers and volunteers**

   Regular awareness raising and training is required especially at the primary level, which is characterised by considerable staff turnover rates.

5. **Increase the cooperation with the Council for the Rehabilitation of Disabled Persons**

   Policies are needed to ensure sustainable free transport for people with disabilities, and proactive approaches which encourage two way referrals.

Recommendations for Inclusive Eye Health programmes

1. Conduct a stakeholder and situational analysis, which considers the relevant policy structures in the given country and the complexity of dealing with a range of different stakeholders. Discuss approaches with the relevant government and non-government bodies.
2. Identify & address the barriers for service uptake by people with disabilities and other marginalised groups, especially financial and transport, but also cultural, gender and access barriers.
3. Create linkages and strong two way referral pathways to primary/secondary health facilities and between health and education facilities, both within the government structure, but also in the NGO and private sector. Conduct regular meetings with local DPOs for two-way information about people with disabilities.
4. Ensure advocacy for disability inclusion is carried out at all levels of government – national, provincial, and local – to encourage commitment and effective collaboration.
5. Involve people with disabilities and DPOs in project planning, implementation, monitoring and advocacy, providing support where necessary.
6. At project level or appropriate levels of government, introduce a disability inclusion committee and policy, with clear guidelines and an action plan.
7. Designate a project budget to strengthen disability inclusive practice, with a clear exit strategy designed to ensure inclusive practice is embedded. This should include a budget for assistive devices.
8. Conduct comprehensive training & refreshers for personnel and communities, involving local DPOs.
9. Capture disability data in health and education information systems and use it to create an evidence base for future planning and advocacy.
10. Develop accessible infrastructure for people with all kinds of disabilities, which will also benefit other vulnerable groups such as older and very ill people.
11. Set up accessible, welcoming and sustainable screening programmes, within the community and in schools. Establish sustainable follow up systems of treated/ referred patients, and record patient satisfaction.
12. Ensure NGO interventions last long enough for sustainable services to be established and integrated into the government system.

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