Developing a disability inclusive model for low vision service

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The current practice for low vision management in India exclusively focuses on clinical aspects without much of the rehabilitation components. While making all efforts to improve independent living skills, daily living activities, and quality of life as a whole for people living visual disabilities, vision rehabilitation is an indispensable component. There is no single appropriate low vision and rehabilitation model implementable at health care institutions in the country to cover these fundamental aspects of a visually impaired individual. We did a literature review to know the existing practices of low vision and various disability models. The purpose of the review is to discern any pitfalls and shortcomings in managing visually disabled in India and to underpin the credibility and feasibility as well as suitability of the developed model. The review was done using search key terms low vision, current practices, visual disability, disability models, vision rehabilitation, and service delivery. Therefore, the article discusses the development of an inclusive low vision management model name as “Clinico-Social Model”, which we consider the most appropriate for the best management of people with vision loss. The primary aim of this model is to provide both clinical and vision rehabilitation components of management for people with visual disabilities. Such an approach is likely to have the potential to improve the quality of life of people with vision loss and can provide practical guide to eye care managers across India. Given the specific context in the current practices of low vision in India, it is desirable to design a similar model to care for the visually disabled.

Key words: Disability model, low vision service, person-centered approach, rehabilitation, visual disability

In the plethora of organized eye care facilities of the 21st century, low vision service is not given due importance in many of the developing countries, including India. It is a fact that the burden of visual disability; low vision and blindness, across the globe is significant although the true magnitude of it is not precisely known. The World Health Organization estimates that around 246 million people have moderate to severe low vision problem globally.\(^1\) When cataracts (43%) and refractive errors (33%), not a part of low vision per se, are excluded from the global estimate of visual impairment, more than 70 million people will have low vision problem.\(^1\) Around 90% of them are from low and middle-income countries.\(^1,2\) In India, the prevalence of low vision using functional definition is reported to be 1.05%; extrapolating this figure to the estimated 1.35 billion population more than 13 million people have functional low vision in the country.\(^3,4\) Nigeria National Blindness survey reported that nearly 1 million individuals have functional low vision problem in aged 40 years and above groups.\(^5\) A similar study in the Pakistan National Blindness survey has shown that the prevalence of functional low vision was 1.7% in adults.\(^6\)

Although many studies reveal that the prevalence of low vision in hospital amongst the older age groups is lower than younger age groups in developing countries, the incidence of low vision as a whole has been shown to increase with age.\(^7\) It is expected that low vision population will substantially increase in the next few decades due to continuous demographic transition resulting from an increase of population aging, particularly in low and middle-income countries as well as an epidemiological transition on account of the growing proportion of noncommunicable diseases like diabetes, macular degeneration, and glaucoma, etc. For example, in India, the life expectancy at birth is projected to increase to 73–77 years by 2020 from the current 69.1 years, and subsequently the proportion of the adult population will increase to 20% from the present 8.2%.\(^8,9\) This shows, hypothetically, that it is likely to have a dual surge in the context of low vision; the demand for the services as well as the need for strengthening of low vision services, in the country over the period of time.

Although low vision is an emerging significant public health concern in India, the current practices for low vision management, to a broader extent the management of people with a visual disability, focuses exclusively on clinical aspects or diseases without much of rehabilitation components, e.g., mobility, vocational training, and social welfare, etc.\(^2,10\) Indeed, the objective for managing people with visual disabilities is not to manage the diseases in so-called “patient-centered approach” where patients are passive recipients, being less involved in decisions and planning for their management.
rather it should be a “person-centered approach” where it calls for holistic approaches to manage the disabled persons\[\text{[3, 12]}\]. In a person-centered approach, patients, family or caregivers, community, and providers work together to plan for optimum care and management with high quality as per the need of the disabled people.\[\text{[13, 15]}\] Such an approach will have the potential of achieving the principles laid in The Rights of Persons with Disabilities Act, 2016, India and The United Nations Convention on the Rights of Persons with Disabilities.\[\text{[16, 17]}\]

While efforts have been made to improve the quality of life, independence, and activities of daily living; rehabilitation, including community-based rehabilitation is an indispensable component. There is a need for filling the service gap if any in caring people with vision loss. An appropriate rehabilitation model aligned with the principles of a person-centered approach is needed to be designed to cover these fundamental aspects of a visually impaired individual. This article discusses the development of an inclusive low vision management model, which we consider the most appropriate and cost-effective for the best management of people with visual disability. To accomplish the development of this model, we conducted a narrative review of the literature and analyzed it to discern any pitfalls and shortcomings in the management of low vision or people with visual disability in the country, followed by the conceptualization of a model as “Clinico-Socio Model” for low vision service. We also described key steps to operationalize such a model in eye care institutions. Initial descriptions of a health care context, conducting a detailed literature review followed by critical analysis to identify the gaps are methods employed in the process of developing a model in other healthcare sectors.\[\text{[18-20]}\]

**Literature Review**

Electronic data using mainly, PubMed, Medline, Google Scholars, and the relevant Government of India and WHO websites were searched to retrieve relevant information using keywords “low vision”, “functional low vision”, “visual disability”, “model of disability”, “vision rehabilitation services”, “service delivery” and “current practices and low vision in India”, and “developing countries”. The search was conducted using MeSH (Medical Subject Headings) terms, Boolean Operators, Truncation symbols, Wildcard symbols, Phrase searching, etc.

Scrutiny of all abstracts was done, and the full text of publications was reviewed for selected papers. The majority of information collected was segregated with the Indian context and checked for any discrepancies and irrelevance before summarization. Various models of disability described in the International Classification of Functioning, Disability and Health (ICF), World Health organization were also reviewed. Furthermore, we retrieved the report of the national level workshop on preparation of an action plan for low vision and rehabilitation service conducted in an apex eye institute in India.\[\text{[21]}\]

**Current low vision services in India**

A global survey on low vision services reported that seven south east Asia countries, including India, had some form of low vision service with less than 10% coverage among people needing low vision services.\[\text{[22]}\] The same survey also revealed that most low vision services in these nations are mainly clinically oriented (monodisciplinary) in nature without much of rehabilitation components like education, social welfare services, orientation and mobility training, training on activities of daily living, vocational training, and sports and recreation. A national survey on low vision service in India reported that 48 of 701 eye care institutions have dedicated low vision service centers with predominant clinical orientation like prescribing near and distance optical magnifiers.\[\text{[23]}\] A similar nature of monodisciplinary services is reported in another study in India.\[\text{[24]}\]

Evidence shows that several factors attribute to low uptake, nonacceptance, and poor coverage of low vision services. For example, the common causes of low uptake and nonacceptance are a social stigma on devices, fear of losing employment, lack of felt need, and denial of the problems among patients. In addition to this, the absence of transportation and urban dominated distribution of facilities are also common reasons for poor utilization.\[\text{[25-27]}\] At the same time, lack of knowledge and training on low vision care among eye care professionals, nonavailability of devices in the hospital due to inadequate funding, less interested, and preoccupation with general ophthalmic care are additional factors for poor coverage of low vision services in the country.\[\text{[28]}\]

**Visual Disabilities: Low vision and blindness**

The International Classification of Impairments, Disabilities, and Handicaps (ICIDH-I), the World Health Organization in the 1980s defines disability as any restriction or lack of ability, resulting from an impairment, in performing any activity within the range considered normal for a human being.\[\text{[29]}\] This definition explains the very nature of the medical model of disability in which disability is considered as purely a medical problem or body impairment on account of disease. However, in 2001 the ICIDH –II, now name as ICF (The International Classification of Functioning, Disability, and Health) recommends that disability should no longer be viewed as merely the result of anatomical impairment or diseases rather viewed as the umbrella term with impairments, activity limitations, and participation restrictions, and as a consequence of negative interaction of these components within the individual’s socio-environment context.\[\text{[30]}\] This paradigm shift of disability is due to a constant movement and advocacy from many researchers, academicians, various societies for people with disabilities and clinicians as well as social scientists. They identified the role of the sociocultural and physical environment in leading to disability per se. Following this, there is a transition occurred from individuals and medical perspectives to a social perspective in caring for disabled, leading to shift from the “medical model” to the “social model” in which people are being disabled by society rather than by their impairment or disease. Indeed, the social model of disability reiterates that the socioenvironment factors like stigmatization, discriminatory attitudes, social barriers, ignorance, and negligence affect to a large extent the lives of disabled, more than an individual’s physical impairment. If these factors are removed from disabled people, then there is a high possibility that these people will live an equal or similar way of living alongside people without disability. Currently, the WHO considers disability as neither purely medical nor purely social, but to be viewed equally to address the issues.\[\text{[30]}\]

Low vision and unavoidable blindness are visual disability in the context of ocular health. While managing persons with visual
disabilities, various social and environmental factors should also be taken into consideration in addition to clinical aspects. For instance, treating visual impairment and prescribing low vision devices to a low vision individual means managing the medical problems, whereas making an accessible environment and treating with dignity, respect, and positive attitudes towards disabled means managing the social problems. This shows that the philosophy of low vision care services should be multidisciplinary in approach. It should address not only the medical issues, i.e., vision problems but also the social and psychosocial, cultural, economic, emotional, and functional components of the individual who has low vision or is blind.

**Rational for the proposed Low Vision Service Model**

Simply diagnosing and dispensing low vision aids are not sufficient to manage low vision or people with visual disabilities. An approach consisting of clinical services for vision impairment along with vision rehabilitation, including community-based rehabilitation to a large extent should be considered in managing people with visual disabilities. Such an approach needs a multidisciplinary team consisting of low vision-oriented ophthalmologists, optometrists—mainly for clinical components, special educators, occupational therapists, orientation and mobility trainers, social workers and counselors, and orthoptists for rehabilitation components. Such a multidisciplinary team approach requires a significant amount of resources like manpower, financial support, well-equipped infrastructure, multiple aids; with training as well as time. A country with limited resources, like India, such a resource-intensive approach is unlikely possible within an institution. It is essential to seek some alternative and cost-effective strategy to care for people with visual disabilities without compromising the rehabilitation services. Anecdotal evidence shows that most low vision services are predominantly clinical and provided in tertiary eye care institutes in India. They conform solely with the provision of optical and nonoptical aids without giving much attention to vision rehabilitation, including community aspects. This nature of practice is highly suboptimal in managing individuals with visual disabilities.

Indeed, developing a model for management of disability should be based on the principles furnished in “person-centered approach” in which health care provider, the disabled individual as an active partner, caregivers, and family members develop a good partnership and make a consensus decision to understand what matters most to the disabled individual, thereby formulate the management plan accordingly.\[^{[11]}\] The Right of Persons with Disabilities Act 2016, India and The UN Convention on the Rights of Person with Disabilities reiterates the right of persons with disabilities to achieve the highest possible standard of health care, improving access to inclusive education and vocational training, and respect their dignity, needs and choices without any form of discrimination based on disabilities.\[^{[16,17]}\]

The present low vision model, to the best possible, tries services in the line with the principles of person-centered care by working together with hospital and community-based organizations [Fig. 1]. It is developed after identifying the gaps in the current practices, based on a literature review (narrative) and critical analysis. We also take into consideration the report of the national action plan on low vision and rehabilitation services conducted in a tertiary eye care center in which many providers or trainers and stakeholders were involved. The very purpose of networking with various NGOs (Nongovernmental Organizations) is to optimize the services components towards the principles of a person-centered approach. To the best of our
knowledge and community experiences, these NGOs provide many rehabilitation services and vocational training to meet the choice or preference made by disabled persons.

The Proposed Model: A Clinico Social Model

Given the widespread lack of low vision along with vision rehabilitation services in the country, particularly in public sector institutions, we suggest four important key steps, which are feasible to implement. These steps can provide practical guide to eye care managers and health care planners. However, more steps, not limited to these four, can be considered while setting up such a service based on local priorities, context, and influencing factors.

1. Mapping and networking with the existing facilities
2. Identifying manpower and capacity building
3. Supplying equipment and assistive devices
4. Monitoring and follow-up.

Mapping and networking with the existing facilities

Mapping of the existing organizations working for visual disability is the first step to start with. An extensive online search for all organizations, including schools for the blind, using relevant websites of Ministry, Government of India, various newsletters received from various organizations and also information from key informants (local sarpanch, pradhan, health workers) should be performed. Each facility should be visited by a team to know about disability services being provided. Visiting these community-based organizations and schools is an important activity to develop a good partnership through networking. Developing a good networking system with existing community-based organizations is of utmost importance to ensure the continuum of care for individuals living with visual disabilities. In the absence of such a networking system, low vision or service for disabled people is highly incomplete.

Manpower and capacity building

In the context of limited resources, it is hardly possible to have all cadres of personnel required for such a Clinico-Social Model of low vision service. Therefore, we suggest a minimum of two eye care personnel; one optometrist and one medical social worker to start the service. These staff can be recruited with external funding projects or task shifting from existing human resources. The aim is to utilize existing human resources effectively. It may also be mentioned that the Deendayal Disabled Rehabilitation Scheme (DDRS), Ministry of Social Justice and Empowerment, and Government of India, provide financial assistance to organizations willing to start necessary rehabilitation services for persons with disabilities.[32] The

| Table 1: Role of Medical Social Worker for the model |
|-----------------------------------------------------|
| In Hospital                                         | In Community                                      |
| Working with patients, caregivers, or family members actively to understand the needs, values, and preferences of the disabled persons and formulate a plan for optimum management what they need for their care (Person-centered Approach). Deciding a place or organization where the concerned cares are provided in the networks. | Supporting a person-centered approach at the community level through networking with NGOs or schools for the blind. The community and family members are important for a successful implementation of person-centered approach. |
| Providing education, information about the eye disease causing low vision or blindness at the first meeting, e.g., retinitis pigmentosa, glaucoma. | Assisting in planning a roadmap for disabled. Creating enabling environment for disabled and family members to be able to participate actively in planning the roadmap. |
| Counselling and education about safety at home environment, e.g., need of spacing and spatial orientation, measures to reduce falls, lighting modification etc. | Creating supportive and safety environment in the family and community with talking and counselling while visiting home or community. |
| Providing education and information about daily living activities, e.g., personal care, hygiene, brushing, clothing, cleaning, financial management, and initial training if feasible. | Visiting community-based organizations and involving in co-designing of welfare, health promotion or prevention and safety programs. Creating a person-centered approach culture. |
| Counselling and information about vocational training and other livelihood activities. | Assisting removal of any physical or attitudinal barriers in family or in community. |
| Facilitating to avail various schemes under The Government of India, e.g., ADIP scheme, DISHA for early intervention and school readiness scheme, Scholarships etc. | Facilitating applications to the government schemes or issuance of disability certificate e.g., filling out the application forms. |
| Providing initial training about use of various assistive devices and their maintenance and safe keeping, e.g., reading stand, optical magnifiers. | Visiting to schools for the blind, inclusive or integrated schools and assisting students for issuance of visual disability certificate if required. Providing supports for person-centred approach environment. |
| Initial training on Orientation and Mobility (self-independent, Human, or sighted guide, mobility using walking cane). | Community awareness programs and sensitization of other community level health workers or community leaders. |
| Providing all information about initial reading and writing rehabilitation, e.g., different media used in special education like Braille, audio materials. | Assisting to access healthcare services. People with disability have generally a higher risk of health problems than people without disabled. They may require more frequent visits to the hospital. |
| Training on use of smartphone mobile application for communications and other daily living activities, e.g., SUPERSENSE application use for object or obstacle identification, Application for financial management. | Training of family members or caretakers via Tele-health for people with visual disability during emergency lockdown, e.g., during lockdown due to COVID 19 disease pandemic in India. |
| Training about tactile stimulation for preacademic learning in children. | Promoting inclusive education for children with visual disabilities. |
primary role of an optometrist is the assessment and clinical examination of patients with low vision, on the other hand, the medical social workers will ensure vision rehabilitation in the hospital as well as community through a networking system.

Additionally, the medical social worker should work as a link worker between hospitals and various community organizations. A training program on orientation for the model can be organized. Since the majority of tertiary eye care institutes run clinically oriented low vision services, there is hardly any need for clinical training of the optometrist; however, a refresher training can be done with external resource persons if feasible. In contrast to this, the medical social worker will require orientation and training for visual rehabilitation services to be provided in the hospital, knowledge about community-based rehabilitation and social welfare programs for the disabled under the government scheme, and counseling for education and vocational training, mobility training, and games for disabled, etc., [Table 1]. The medical social worker should acquire a thorough knowledge of each community organization, for example, what are activities or training facilities available in these organizations for disabled people? To be able to implement, the medical social worker can undergo training from a nearby leading organization. The duration of training can be decided by the concerned institute. There can be induction as well as refresher training over time.

Proposed roles and responsibilities of the staff for the model
The optometrist should perform all clinical examination, like the functional assessment of the vision, low vision evaluation, contrast and glare sensitivity, binocularity status, evaluation of various optical and nonoptical aids, whereas the medical social worker should have the following roles and at the same time all efforts to be made to ensure person-centered care of the individual from the very beginning in the hospital:

Equipment and assistive devices
One of the critical elements for the implementation of the present model is the procurement of low vision equipment and assistive devices for rehabilitation. To start with, the prescribed list of equipment and assistive devices for tertiary eye care centers, which were recommended by the national workshop on preparation of action plan for low vision rehabilitation service for Regional Institutes of Ophthalmology, India, can be procured. These equipment and devices can be requested either from an external funder or the hospital resources. Additionally, assistive devices under the Government of India scheme, though limited, can be also demanded. For example, Assistance to Disabled Persons (ADIP) scheme, Department of Disability Affairs, Ministry of Social Justice and Empowerment enlists 51 assistive devices for people with visual disability to be provided either free of cost or at subsidized rates.[16]

Monitoring and follow-up
This step is frequently neglected in many of the health care programs. The monitoring activities should be an integral part of the model. A record on paper and electronic formats with appropriate indicators (daily, monthly, other outputs) can be developed to monitor services. To review the services and performances, a monthly meeting of the staff can be conducted. In the meeting, discussion about the outputs as well as the placement of disabled individuals either in community-based organizations or vocational training centers or schools for the blind can be shared. The team can visit these facilities or make a contact telephonically to know whereabouts of the individuals or improvements in their lives.

Sustainability of the model
If there is a lack of external funding for human resources, alternative methods like task shifting from existing human resources is another viable option to sustain the service as highlighted earlier. Moreover, as the model involves the existing community-based organizations through a networking system, there is a good chance for the sustainability of the model in the long run.

Limitations
Although the model was developed based on the review of literature and the report of low vision rehabilitation workshops, it has not directly incorporated the views and needs from individuals with visual disabilities and caregivers. To improve the model in terms of person-centered approach and acceptance, qualitative studies using focus group discussions or interviews of individuals with visual disabilities or caregivers or family members will be required to know their choices, values, preferences, and thereby assist in planning to meet the needs. The model relies on NGOs for continuing care of the people with visual disabilities, therefore, the success of the model is partly dependent on these NGOs. It is unethical to monitor NGOs’ activities, which are beyond the hospital jurisdiction.

Future directions
A similar model is already being implemented in a tertiary eye care institute of Delhi. Over time, the performances and effectiveness of the improvement of quality of life of people having visual disabilities will be assessed. Further, working on advocacy using evidence generated will be key activities to scale up the model to other eye care facilities especially in the government sector, for example, Regional Institutes of Ophthalmology of the country. Efforts via advocacy will be done to bring more attention to services for people with visual disabilities under the health care delivery system of The Ministry of Health and Family Welfare, Government of India. Promotion of inclusive education rather than special education for children with visual disabilities is essential as indicated in The Right of Persons with Disabilities Act 2016, India, and article 24 of The United National Convention on the Rights of People with Disabilities. Therefore, emphasis on advocacy to address the need for inclusive education for children with visual disabilities will be given by making alliances and partnerships with various organizations and institutions.

Conclusion
In summary, for the first time, the article provides insights for the development of a model on low vision and rehabilitation services named as a “Clinico-Social Model”. The model intends to ensure clinical and rehabilitation intervention, including community-based components via networking with various community-based facilities. The model developed here can be a helpful tool for eye care managers and planners in setting up low vision and vision rehabilitation services. The main aim of the model is that it draws attention the various need-based
services for people with visually disability in the line of person-centered approach in collaboration with the hospitals and community-based organizations. Therefore, this model would be the most appropriate and cost-effective for the best management of people with vision loss in the country. Since, NGOs, which provide various disability orientated services to persons with visual disabilities, the acceptance of services is likely to be high. For a country, where resource constraints are barriers in providing multidisciplinary services to the disabled, such a model is recommended for the management of people with visual disabilities.

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