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Community participation in addressing the challenges of childhood blindness

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Introduction

India is home to the largest number of blind children in the world. Ironically, in 50% of these cases, blindness can either be prevented or treated. Among the rural population of the economically backward states of Central India, childhood blindness (CB) is alarmingly high. Childhood cataract, refractive error and vitamin A deficiency are the most common causes of childhood blindness in the region.

According to the National Blindness Survey of 2002, Madhya Pradesh is estimated to have 19,200 blind children (best corrected visual acuity <3/60) and a major proportion of these children need not have lost vision had early diagnosis and treatment been available. There also exist barriers that prevent the rural populace from accessing paediatric eye care services. In this article, we examine some of the community participation strategies that we have found to be of great value in addressing challenges of childhood blindness.

Methods

With the goal of eliminating CB from central India, Sadguru Netra Chikitsalaya (SNC), a state-of-the-art eye hospital in rural Central India took up an innovative community-based approach for its ORBIS supported Childhood Blindness Project. Focus Group Discussions (FGD) were conducted with multiple stakeholders from the community to determine their knowledge of eye care and diseases and their beliefs, customs, myths and traditional practices followed to deal with eye diseases.

Having assessed their knowledge, training and awareness building programmes were conducted to educate them about the preventive and curative measures that can be undertaken to prevent eye diseases in children.

Clear, simple messages were devised for various stakeholders in the community and pre-tested. Messages were further fine-tuned based on the feedback received from these stakeholders.

Schoolteachers were trained to identify vision defects in school children and to refer those with eye problems for early treatment. Parents were educated on how to prevent blindness amongst their wards and advised to seek immediate medical attention for control of CB, once the symptoms were noticed. Health workers, Traditional Birth Attendants (TBA's), and Community Leaders were sensitised to educate rural families about the social, economic and health-based repercussions of blindness on not only the patient but the entire family.

Results

During the project period (October 2002 - May 2003), FGDs were conducted with different stakeholders in the community and it was ascertained that traditional practices, home based medical treatment and poor economic conditions were the main barriers that prevented parents from accessing eye care services for their children. Armed with this background knowledge and with the key messages developed, 618 school teachers, 56 community leaders, 120 health workers,

2918 parents and 78 Traditional Birth Attendants (TBAs) were trained to identify common childhood eye diseases, understand preventive measures for childhood blindness, counseled to bring children with vision problems immediately to hospital for treatment and to conduct preliminary vision tests.

The trained schoolteachers screened 75,754 (50,571 boys and 25,183 girls) children for eye defects and visual impairment. Of the total children identified with eye problems, a total of 1,424 children were prescribed spectacles; 1,441 were given medical treatment and 241 children referred to SNC for surgical vision correction.

Discussion

FGDs for multiple stakeholders in the community highlighted the use of indigenous substances for eye medicine, gross prevalence of myths, traditional beliefs and practices, dependency on quacks, ignorance and unwillingness to access eye care from hospitals, the cumulative effect of which perpetuates and accentuates the impact of blindness on individuals, families and communities.

Of all the strategies implemented in the project, the School Eye Screening Programme and awareness programme proved to be effective in targeting children. School eye screening targeting school-aged

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children results in proper mobilization and better use of existing resources¹ resulting in better eye health of children. The programme conducted by SNC benefited more than 75,000 children; this would not have been possible without the teachers' support.

Creating awareness among various stakeholders in the community, especially the 2,918 parents is perhaps, the most important outcome of the project; since they are more perceptive to the medical needs of their children, being direct care givers. Even greater success was achieved in counseling women on the importance of eye care and where to access eye care services for their children, should the need arise. Traditionally, women are allowed only limited participation in decisions concerning their own or their family's health² and have no access to formal education, (only 51% of women in Madhya Pradesh are literate).

Government health care workers and TBAs were trained to identify eye diseases in children, counsel parents to access services at the hospital, collect relevant population based data and to motivate

women to attend the eye care health education sessions.

The community participation strategy increased outpatients' flow by 26% and pediatric surgeries doubled in volume, thereby showing improved health-seeking behavior (Figure 1).

Community approach to eye care has resulted in

- More acceptable community based paediatric eye care services
- Empowerment of individuals through increased knowledge³, awareness and a proportional increase in eye health seeking behavior.
- An attitude change amongst the rural populace that will encourage eye health and prevent eye disease⁴.
- Identification of vision problems among both school and non-school going children.
- Vision restoration/improvement of children by treatment/surgeries/spectacle prescription at an early stage preventing loss of opportunities in life that would have been unavoidable had blindness become irreversible.
- Community ownership and participation in outreach eye camps.

Setbacks faced in adopting the community approach to eye care

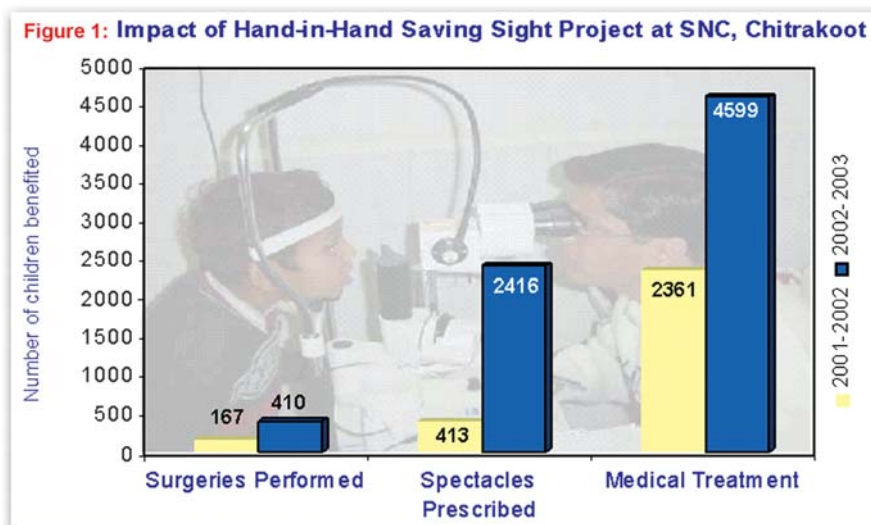
- Faulty screening by some teachers and thereafter rectification of the mistake by hospital authorities resulted in delayed treatment of some children.
- Community support tapers off unless a well-planned public relations strategy is adopted to ensure continuous community support.
- It was difficult to find dedicated persons from within the community who would take the onus of organizing screening/education programmes. Moreover, community participation did not always result in contribution in cash or kind.

Conclusion

Most of the causes of childhood blindness are exacerbated by lack of community awareness. "Ignorance and harmful traditional practices" can unwittingly lead to blindness. Strategies adopted by SNC for its education, training as well as screening programmes helped in preventing unnecessary blindness in children and also in appropriate utilization of available resources in the community leading to better eye health.

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Training of grassroot workers for the community eye health (CEH) programme in Southern Gujarat

By Sewa Rural Team*

There are more than a million people in India who are incurably blind, amounting to about 0.1% of total population. But the rehabilitation coverage is a meagre 4% nationwide (Personal Communication - Rehabilitation Council of India, Govt. of India). The more unfortunate fact is that

80% of the people need live in rural areas where there is hardly any opportunity to become reasonably socially self dependent and financially self-sufficient. The scenario is worse if we add the fact that there are not enough trained human resources in the country.

SEWA Rural has had the experience of implementing traditional Community Based Rehabilitation (CBR) programmes in four tribal blocks around Jhagadia Taluka in Gujarat state. In an effort to achieve VISION 2020 objectives in the rural areas and to find out how much eye care can be delivered through the grass root level

workers, SEWA Rural undertook a Community Eye Health (CEH) programme in a tribal block covering a population of 200,000.

SEWA-Rural is a voluntary organisation engaged in overall development of the community around Jhagadia for the past 25 years. The organisation's activities include running a 100-bedded general hospital, a Comprehensive Eye Care Programme including CBR and integrated education, a Community health project, the Vivekananda Gramin Tekniki Kendra, and several women's development programmes. CBR has more recently been taken up as an integral part of the comprehensive eye care programme.

The first round of CBR activities in Jhagadia block was completed in 1998. When the second block in Valia Taluka was nearing completion, the funding agency suggested that all the components of primary eye care be introduced, as an innovation, into new CBR programme. The new idea was challenging and appealing but the two blocks were very remote, totally tribal, devoid of most facilities and located 100 kms from the headquarters. It was not easy to undertake extra responsibilities in



(Courtesy - Sewa Rural)

such an experimental setting. After much deliberation, however, the project was undertaken. It included the following additional primary eye care tasks.

1. Cataract detection, referral and follow up.
2. Vitamin A distribution
3. Follow up of measles vaccination
4. School eye check up
5. Primary treatment of eye and minor ailments
6. Health Education of community
7. Provision of presbyopic glasses (added subsequently)

SEWA Rural had the experience of training both the grass root level workers in primary health and in primary eye care in their own training centre. So a special module was developed to provide primary eye care and primary health care training to the CBR workers. The manual developed for the purpose contained a lot of pictorial information for easier understanding. The module was planned to run for two weeks. Similar modules developed at Aravind Eye Hospital (Madurai) were used as references. Both theory and practicals were included and the training team included their own Ophthalmologists, paramedics and Community Health Project team members as resource persons. Pre-and post-tests were used to assess the level of understanding of the workers. Using the experience of this project, regular CMEs were introduced at quarterly intervals for the workers.

The blocks were divided into 14 clusters with each worker assigned responsibility for a population of 15,000. The duration of the project was extended to three years from the conventional two years. Their scheduling was done in such a way that they were able to combine primary eye care tasks along with rehabilitation tasks to save time and get more output. All the workers were found to be sincere, which made this task much easier.

The following table shows our achievements over the three-year period of the project.

CBR activities				Primary eye care activities		
Detail	M	F	TOTAL	Detail	Total	
Blind clients trained	67	64	131	Vitamin-A distribution – Anganwadi	56,957	
Blindness certificate issued	04	66	111	School eye screening	23,148	
O&M & ADL training	15	64	131	Spectacle distribution	144	
Bus pass issued	10	44	108	Ensuring measles vaccination	8,831	
Sant Surdas Scheme	12	16	28	Primary treatment	7,141	
Integrated education Programme	8	12	20	Govt. hospital operative work	197	
Enrolled in blind school	02	03	04	Diagnostic eye camps	76	
Economic rehabilitation	–	23	23	Cataract operations	1,372	
Started economic activities	–	14	14	Health education sessions – total attendance	19,597	
Loan from SEWA Rural	–	14	14	Field H.Ed. sessions at night	39	
Sent to TATAWADI fansa for agricultural training	–	06	6	School H.Ed. sessions	28	

O&M – Orientation & Mobility; ADL – Activities of Daily Living; H.Ed. – Health Education

It is evident that it is possible to combine primary eye care activities with traditional CBR activities with some extra training, a few additional workers and some extra time. It was found that 70% of the eye care components could be taken care of by these workers and prevention is totally taken care of. The satisfaction of providing prevention, promotion along with rehabilitation activities is another advantage, making the whole activity a much more powerful mode through which to deliver eye care services. The funding agency now proposes to extend the activity to other partners as well. Though the coverage of CBR is only 4% countrywide, it is a good idea for all those involved in CBR to provide primary eye care also as an integral component using the experience described.



(Courtesy - Sewa Rural)

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VISION 2020: The Right to Sight India Forum (Oct '05 - Feb '06)

The activities of the VISION 2020: The Right to Sight – INDIA Forum accelerated during the last five months, from October 2005 to February 2006. In keeping with its close working relationship with the National Program for Control of Blindness in India and the VISION 2020: The Right to Sight India plan of action, it strategically shifted its National Secretariat from Madurai, Tamil Nadu to New Delhi, to be in the thick of action.

Prominently during the period it played a -very strong networking role with the Government (Particularly with the Ministry of Health and Family Welfare) to strengthen and streamline the National Programme for Control of Blindness (NPCB) and to take the movement to various states of the country through the development of state plans.

During this period World Sight Day (WSD) was celebrated on 13th October 2005 (Fig. 1) in Hyderabad which saw participation from all the strong advocates like the President of India, Union Health Minister and the Minister for State, Government of India, Union Minister for Information & Broadcasting as well as representatives of various international and national non-governmental organisations and civil society. The Andhra Pradesh chapter of the VISION 2020: The Right to Sight and Lions Club International

Foundation along with the VISION 2020: The Right to Sight India Forum were the main organizers of the event.

During the event, felicitations and awards were given to the best performing partners in VISION 2020: The Right to Sight India. Two new projects on the elimination of Childhood Blindness and Diabetic Retinopathy were launched.

The Union Health Minister released a Global report titled “State of the World’s Sight VISION 2020: The Right to Sight 1999-2005” as well as the Revised Guidelines for District Blindness Control Society and the Revised Scheme for Participation of Voluntary Organizations for 2000 – 2007, under the 10th Five-year plan of the central government.

Other activities during the period included the following:

I. Advocacy and Networking

Participation by the Executive Director at the 32 All India Optometric Conference at Khajuraho from 23rd to 25th December and the First National Conclave of Lions NGO Eye Hospitals from 26th December to 28th December at Ahmedabad respectively.

The VISION 2020-India forum had a discussion with the State Minister for Health and Family Welfare on 4th January 2006 in Delhi. The meeting covered areas

such as the strengthening of NPCB, facilitation for development of the state plan and the 11th five year plan.

A meeting was held with the Joint Secretary, Ministry of Health and Family Welfare and his team of officials on 20th January 2006 in his chambers in Delhi for discussions on strengthening the VISION 2020 initiatives in the North East Region, strengthening NPCB, developing the 11th Five Year Plan and state plans and for the next World Sight Day Celebration in North East.

The Task Force Committee Meeting for the 11th Five Year Plan was organised on 8th February 2006 at the VISION 2020-India premises in New Delhi under the chairmanship of Joint Secretary, Ministry of Health and Family Welfare, Government of India. Other representatives from Government, Founder INGOs of VISION 2020-India Forum, Representatives from the World Health Organization and representatives from other leading Eye Care Institutions participated in the meeting. The meeting was called to review the performance of NPCB in 10th Five Year Plan and to give strategic inputs for developing the 11th Five Year Plan. The group discussed a variety of relevant issues during the meeting and came up with suggestions that are to be incorporated in the 11th plan.

II. Membership

Two NGOs KK Eye Institutes, Pune, Maharashtra state and KG Hospital Coimbatore, Tamil Nadu state became members.

III. Workshops

- National Consultation on Refraction Error, sponsored by Sight Savers International
- National consultation on Eye Banking and Corneal Blindness, organized by ORBIS International.

c) With the overall objective of prevention and reducing blindness resulting from Diabetic Retinopathy (emerging priority disease in VISION 2020 initiatives), VISION 2020-India had organized the National Workshop on Diabetic Retinopathy in association with Vivekananda Mission Ashram, Chaitanyapur, West Bengal.

IV. Meetings

The Board of Management met twice during this period to give proper shape, direction and inputs to the VISION 2020 India.

Dr. Anbumani Ramadoss
Hon'ble Union Minister of Health & Family Welfare

Smt. Panabaka Lakshmi
Hon'ble Union Minister of State for Health & Family Welfare

VISION 2020
THE RIGHT TO SIGHT
INDIA

WORLD SIGHT DAY 2005
Theme "Sight for Kids"

Childhood Blindness: Childhood blindness refers to a group of diseases and conditions occurring in childhood or early adolescence, which, if left untreated, result in blindness or severe visual impairment that are likely to be untreatable later in life.

Prevention: Six Important Do's & Don'ts

- Give all vaccinations to children as per schedule.
- Give Vitamin 'A' rich food to children.
- Keep sharp-edged and pointed objects out of their reach.
- In case of any eye problem, consult a doctor immediately.
- Do not treat the child yourself.
- Spectacles can correct visual problems.

Common Causes

- a. Injuries through accidents, bows & arrows, gully danda, use of chemicals in Holi and crackers in Diwali etc.
- b. Vitamin A deficiency.
- c. Congenital causes i.e present since birth.
- d. Refractive Errors

Government action undertaken to address the problems

- a. School Eye Screening Programme for detection and correction of Refractive Errors.
- b. Eye donation for treatment of Corneal blindness.
- c. Annual check-up of children in blind schools initiated.
- d. Vitamin 'A' prophylaxis programme.

Inauguration of World Sight Day celebrations by
Hon'ble Union Minister of Health & Family Welfare
Dr. Anbumani Ramadoss
Venue: JNTU Auditorium, Masab Tank, Hyderabad
On 13th October 2005 at 3:30 p.m.

National Programme for Control of Blindness, Directorate General of Health Services, Ministry of Health & Family Welfare, Government of India.

(Courtesy - VISION 2020 India)



Supported by ORBIS International
India Country Office



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Hyderabad, India