



Sightsavers

Drishti

a journey towards an inclusive society



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Shankarlal in front of his shop in Garhwala village. Rehabilitation has helped him to be independent; photo by Praveen Kumar/ Sightsavers



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Foreword

Everyone has the right to health, education a livelihood and a life lived with dignity. However the needs of disabled people have traditionally been treated as special and separate and this has kept them outside mainstream society. Poverty has been the most pressing issue for millions of disabled people due to which they face multiple discriminations. While the United Nations estimates that 10 percent of the world's population lives with a disability, the World Bank estimates that one in five of the world's poorest people are disabled or live in a household with a disabled member. In such scenario social inclusion of disabled people continue to be a major challenge.

Sightsavers is one of the first organisations to adopt CBR as an organisational strategy and programmes in India have been developed with this approach since 1983. During the last decade the external environment of the disability sector saw a lot of changes including the launch of United Nations Convention on Rights of Persons with Disabilities. Though the Union Government of India has various schemes and entitlements for disabled people, their accessibility is still a major challenge. In this context such programmes on CBR approach have important roles in reducing social exclusion of disabled people in the society.

Sightsavers along with partners - Urmul network initiated a district based intervention since 2007, adopting the CBR strategy to address issues faced by persons with disabilities

A group of young girls in school uniforms are standing outdoors, smiling and talking. The image is slightly blurred, giving it a soft, candid feel. The girls are wearing red and white uniforms. One girl in the foreground is wearing a yellow skirt. The background shows more people and trees, suggesting an outdoor school setting.

in Bikaner district of Rajasthan. One of the highlights of the project was the detailed household survey which mapped all persons with disabilities in the district; today Urmul network has a strong database on disability which is being used even by the District Administration. The project had strong focus on mobilizing persons with disabilities and brought them under one roof as part of their district level network. Today the network has over 1500 members and is recognized by all stakeholders in Bikaner. The network boasts of several success stories which make each member proud to be associated with it and taking up the issues of their rights and entitlements.

Sightsavers and Urmul network partners planned to come up with this document, we hope this document is useful for planners from government and non-government organisations in planning intervention on disability and mainstreaming disability as part of their programmes thereby ensuring wider social inclusion. I feel proud that I was involved in the planning phase of this project and am elated to see the outcomes it has achieved. My hearty congratulations to the Urmul network partners, the project team and the team of Sightsavers North West Area Office in Jaipur for the successful implementation of the project and coming up with this learning document.

Prasannakumar
Director – Programme Operations
Sightsavers India



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Preface

Persons with disabilities form a small part of the marginalized and most vulnerable section of the society. Social exclusion, lack of awareness, confined access to social and economic security schemes; financial exclusion and limited livelihood opportunities are the major issues of persons with disabilities (PWD). They are largely considered as unproductive and confined to their house, which increases their dependency on the family members for routine activities. In the year 1980 World Health Organisation (WHO) initiated Community based Rehabilitation (CBR), a multi-sectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services.

Sightsavers has been implementing CBR since two decades. Its programme in Rajasthan is one of the older ones in the country and has evolved over time through learning

in each phase of intervention. The first phase of the Bikaner district CBR project started in 2007 with focus on identification, mobilization, training on Orientation and Mobility, Daily Living Skills, Rights and Entitlements, Generation of Awareness and rehabilitation services of livelihood. During the first phase special focus was on persons with visual impairment. The second phase of the project named 'DRISHTI' has been a unique district based intervention in community development processes engaging communities, grassroots level development agencies (Urmul trust network) and the district administration covering all persons with disabilities. It has demonstrated the successful implementation of the CBR approach through a district-based intervention.

The project was made possible by the strong commitment and conviction shown by the team members of project DRISHTI who took



“People don’t go blind by the million.
Each of them, as a human being goes blind as a personal tragedy.”

Sir John Wilson (Founder- Sightsavers)

the challenge of bringing persons with disabilities closer to the society in the Bikaner district of Rajasthan. The team in identifying and mainstreaming PWD has put in tremendous efforts. The Urmul trust network is registered under the PWD Act and recognized by the district administration for its work in the area of disability. The district administration seeks support from the Urmul trust network and has been involving it in planning, implementing and monitoring the government programmes on disability. For five years of the project Sightsavers put in funds to the tune of INR 30.00 million during which INR 8.30 million was disbursed in the first phase and INR 21.70 million in the second.

The success achieved as a result of the project gave Sightsavers and the Urmul trust network an opportunity to document its experiences and results for wider dissemination and impact so that the efforts they made can be adopted as best practices and even improved upon. The documentation narrates the plight of the PWDs, their involvement in the project, the challenges they faced; the processes adopted during the project, major achievements, case studies, involvement of the various stakeholders and plans for a way forward. It gives an insight into how the PWDs were brought under one roof to form a pressure group of PWDs called DPO-Bikaner (Disable people organisation) that eventually led to changes in their life which otherwise they would have probably only dreamt off. The documentation also reflects the engagement of the wide range of stakeholders, viz: the district administration,

PRIs, community members, government and financial institution officials who worked in tandem to bridge the gap and bring in the desired social change.

One of the major challenges was the unavailability of data, which was addressed during the inception of the project. But today the Urmul Network has comprehensive data on disability, which is used by the district administration. The document captures several case studies of people with visual impairment or other disabilities pursuing various livelihood options and contributing to the increase in their family income, which in turn further led to significant attitudinal change at the community level, and even of the stakeholders concerned.

The information available in the document has been collected from the field through interviews with key informants, persons with disabilities themselves, discussions with the project team and Sightsavers North West Area office staff involved in the project from inception to its completion. The document attempts to reflect how a cost effective district based CBR intervention leads to social inclusion of persons with disabilities through enhanced accessibility to social and economic empowerment schemes. The journey has been tough but the result achieved has made each person associated with the project proud.

We hope that this document would serve as an insight into the genesis of the project; what went into transforming the lives of the persons with disabilities in Bikaner and how the desired results were achieved. This document can also be used as reference in the times to come.



Introduction

The current and first ever WHO-World Bank report on disability suggests that almost 15 per cent of the world's population (more than a billion people) experience some form of disability or impairment¹, with higher prevalence in low-income countries. According to it persons with disabilities have generally poorer health, lower education achievements, fewer economic opportunities and higher rates of poverty than people without disabilities, largely due to the lack of services available to them and the many obstacles they face in their everyday lives.

According to the 2001 Census of India, out of 1.2 billion people there were 21.9 million² persons with disabilities, which was 2.13 per cent of the entire population. The current census figures can only be left to the imagination.

Common to the third world countries, persons with disabilities in India too struggle to access basic human rights and justice in opportunities. People with disabilities persistently face challenges in accessing delivery systems across the country despite India ratifying the United Nations Convention on the Rights of Persons with Disabilities. In the rural areas where opportunities in general are already limited, their struggles are further complicated across the economic, social and even familial realms. Persons with disabilities suffer while attempting to access the basics of citizenry rights including education, food, employment extended up-to the dignity of their existence.

In India, though the government has various policies and schemes befitting persons with disabilities, the NSSO (National sample survey organisation) survey points out that

only 12 per cent of the people with disabilities above the age of five years have received some government aid or support. Sightsavers experience shows that about 50 per cent of persons with disabilities do not even have valid disability certificates, which enable them to avail the entitlements under these schemes. Most persons with disabilities and their families were not even aware of their rights and benefits as outlined by the law. Accessibility to information on disability, schemes and benefits of the government, lack of comprehensive data on disability, insensitivity of the communities, government officials and negligible implementation of the government schemes contributes to the social and economic exclusion of persons with disabilities.

Background:

The Bikaner district of Rajasthan continues to be one of the priority districts for any developmental work in the state because of poor social-economic indicators. It is predominantly a desolate region of shifting sand dunes with scanty rainfall and scrub vegetation. Extreme climatic conditions, difficult geographical terrain and recurrent drought make living a life very challenging.

As per the census 2001, there are over 1.4 million people with disabilities in Rajasthan. This is 2.5% of the State's population. The district of Bikaner alone has over 30,000. Disabilities ranging from locomotors, color blindness, blindness so many of them are children under the age of 19. Social exclusion, limited livelihood opportunities, lack of awareness and financial exclusion make persons with disabilities the most vulnerable section of the society. The area being a desert with limited accessibility to the schemes of the govern-

1 World Report on Disability, 2011
2 <http://www.ccdisabilities.nic.in>



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ment further adds to the vulnerability leading to poor social and economic development of persons with disabilities.

Sightsavers has been working in India on avoidable blindness and disability since the year 1966. Over the years it has evolved into an organisation recognized for its work in the field of eye care, Community Based Rehabilitation and Inclusive Education, which forms the core of Sightsavers, programme themes. In Rajasthan, India after over a decade long partnership of working on reducing the burden of avoidable blindness in western Rajasthan. Sightsavers India and Urmul trust-Rajasthan envisaged a wider programme intervention to work with especially the visually impaired.

After an initial two year pilot of activities related to primary prevention, treatment and rehabilitation of persons with disabilities since 2007, the Project DRISHTI was launched in

2009 in Bikaner district of western Rajasthan for addressing the issues faced by persons with disabilities including visually impaired in five blocks of Bikaner district, by Sightsavers in partnership with Urmul Trust network³.

Urmul Trust network is a grassroots level organisation, which has brought about positive changes in the lives of people of the harsh Thar Desert also known as The Great Indian Desert. The partnership with Urmul trust network to implement such a project was with an objective of embedding disability into wider development programmes of the government and bringing issues of persons with disabilities into the mainstream development agenda of the stakeholders of the region.

The project adopted CBR approach integrated with community development engaging communities and the district administra-

³ Urmul Trust, Urmul Setu, Urmul Seemant Samiti, Urmul Jyoti



tion to ensure that all persons with disabilities receive enhanced opportunities for social and economic empowerment.

- The project focused on primary prevention and treatment related aspects along with promotion of good practices in eye care to address the burden of reversible blindness in the district by establishing primary eye care centres at block levels and developing a primary to secondary level referral mechanism.
- The project connected people by sensitizing and educating various stakeholders about the inclusion, rights and spaces, in private and in public for persons with disabilities.
- It facilitated the formation of an association of persons with disabilities to ensure their rights and entitlement through advocacy. The group being of persons with disabilities will have better understanding of their issues and work on advocacy mechanism to address their matters.

- It facilitated the linkages with various social and economic empowerment schemes and also with financial institutions to engage them in livelihood options of their choice.

- The project facilitated the creation of an enabling environment for children with visual impairment to pursue their education in regular school with support from itinerant teachers, provision of aid-appliances, education materials and skill development camps. This helped children with visual impairment to acquire enhanced learning.

Based on a new strategy introduced in 2008 the project set its focus on overall social inclusion of persons with disabilities.

Hence, the project invested in developing grassroots level Disabled People's Organisations at the block as well as at the district levels. The support received from the community after the initial sensitization initiatives, collaboration and determination of persons with disabilities led the project to bring about lasting changes in the district in terms of quality in the lives of the people with disabilities.

This partnership and the strong engagement of the implementing organisations with the communities of the project area influenced the progress of the project and helped the strengthening of the network of disabled people. The goodwill and influence Urmul Network had with various government departments helped the project and the newly formed DPOs to infuse wider changes beyond what was planned. However, the journey was not so smooth...

Highlights of the project



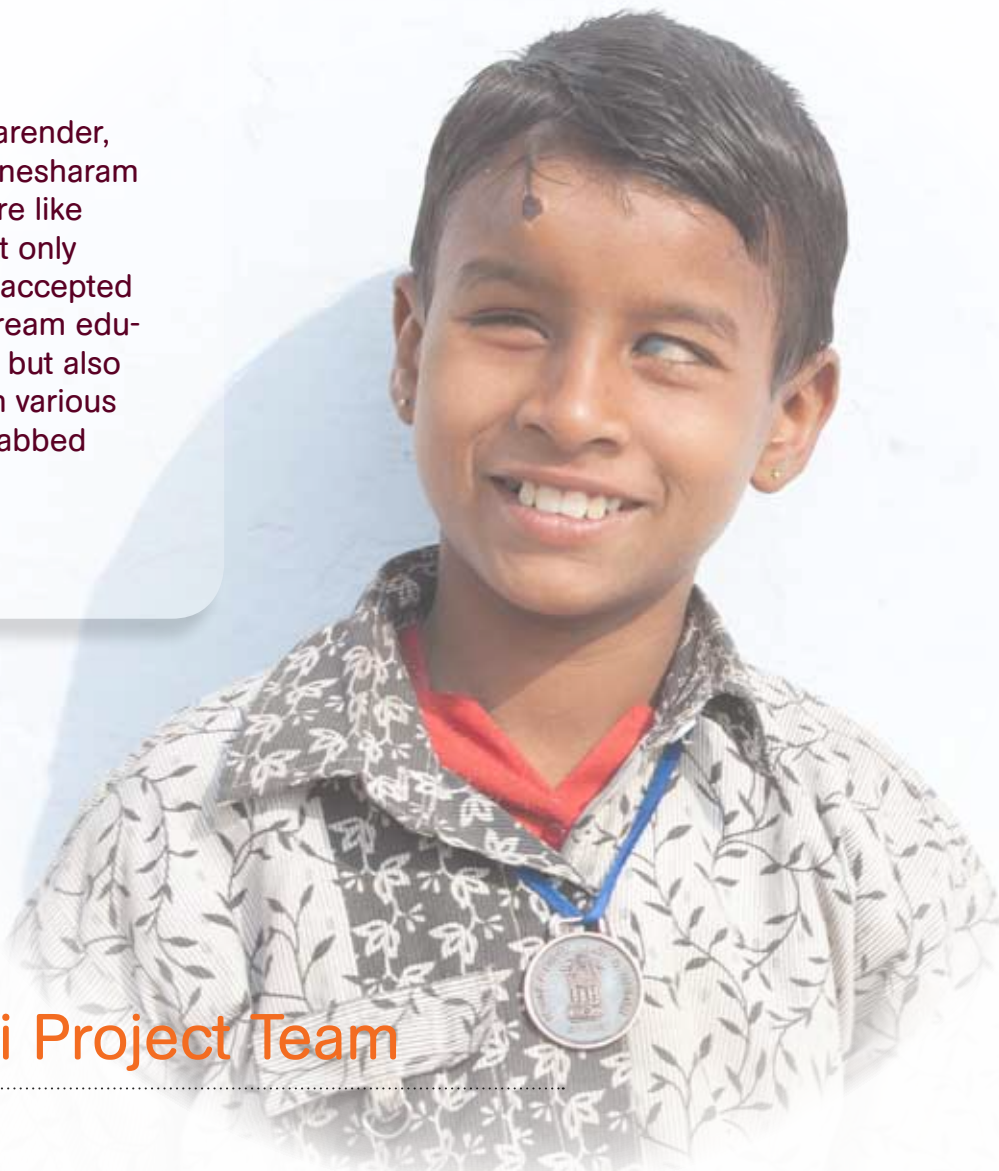
- 90 percent budget allocated by the government under various schemes has been utilized. In three years, the utilization of funds has gone up from 3-4% to 90%.
- Through the project over 4600 aid packages- loan, pensions, monthly stipends etc- were linked to as many people. This valuing the total of over 3.8 million.
- Through the project 80% of the identified BLV children are in school, have a bus pass, a rail pass and those eligible for a pension, get or have filed for a pension.
- Other disabled persons are linked with various schemes, pensions and loans; which otherwise until now was unavailable to them.
- DPOs have begun to add member and help people. There are already over 1500 members in the Bikaner district DPO.
- 683 eye camps in various villages and 1814 eye screening events organise in schools in which more than 1 lakh 20 thousand people were screened.
- 4250 people got their vision back through this project.
- 1680 Community Health Worker, 2865 School Teachers got primary eye care training under this project.
- All the school going children identified in the project now have Braille Kits, large print books and low-vision devices. They are now getting escort and transportation allowance under the Sarva Shiksha Abhiyan.

अनमोल वचन
ध्या के समान कोई चक्षु नहीं है।
सत्य के समान कोई तप नहीं है।
ठके समान कोई पाप नहीं है।
त्याग के समान कोई सुख नहीं है।
भय के समान कोई दुख नहीं है।
पाप से दृष्टा करे पापी से नहीं।
कहे सौ कर, गुरु करे सौ न करे।

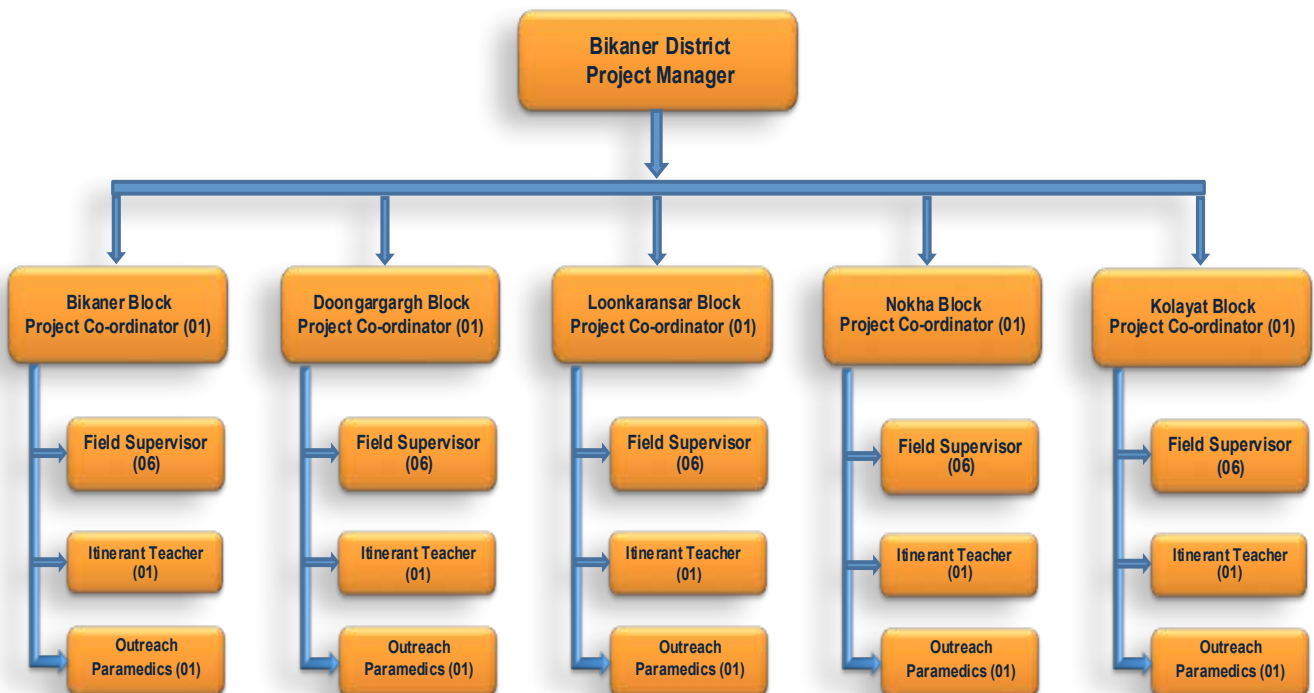
परान्त नहीं।



Raghuv eer, Narender, Purnaram, Ganesharam and many more like them were not only admitted and accepted by the mainstream education system but also participated in various events and grabbed many prizes.

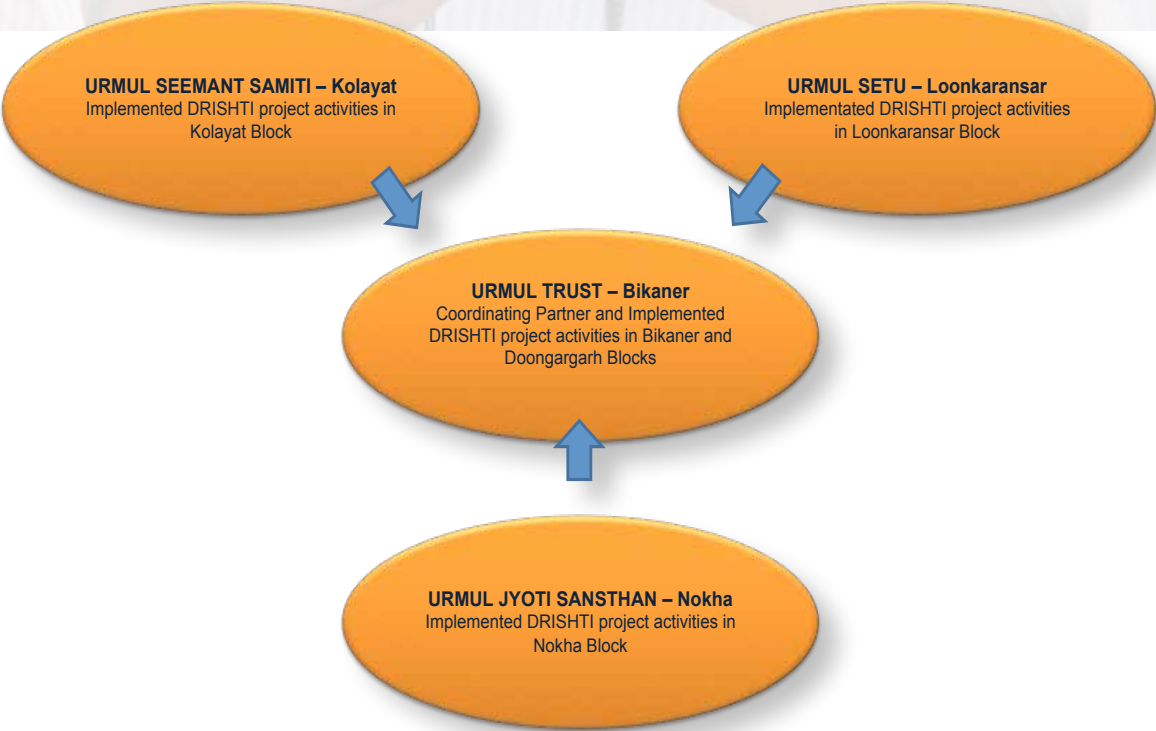


Drish ti Project Team



Shankarlal 12 years old boy from Indrapalsar, Sri Doongargarh underwent cataract surgery and today enjoys photography.

Urmul Network Partners





- Lack of proper data on disability
- Lack of Awareness
- Poor Health seeking behavior
- Social Exclusion of persons with disabilities
- Timely Diagnosis, Low Cost treatment & Provision of assistive devices
- Limited Livelihood
- Limited access to Social and Economic Security schemes of the government



Challenges

Disability and poverty are considered to be two sides of the same coin. Persons with disabilities face a higher risk of being excluded from the society. It has been observed that generally persons with disabilities are not identified by their ability but by their disability type. Social stigmas around disability lead to considering persons with disabilities as a burden on the society. The society withdraws itself from accepting persons with disabilities as a group of the society and a co-contributor to its development. The demography and geography of the desert further adds to the exclusion of the persons with disabilities. The exclusion of persons with disabilities in the family and the society plays a significant role and limits their opportunity to learn and be a part of the society at large.

Women and children with disabilities face multiple levels of discrimination including their inability to exercise their rights to education, employment and a dignified life. Chal-

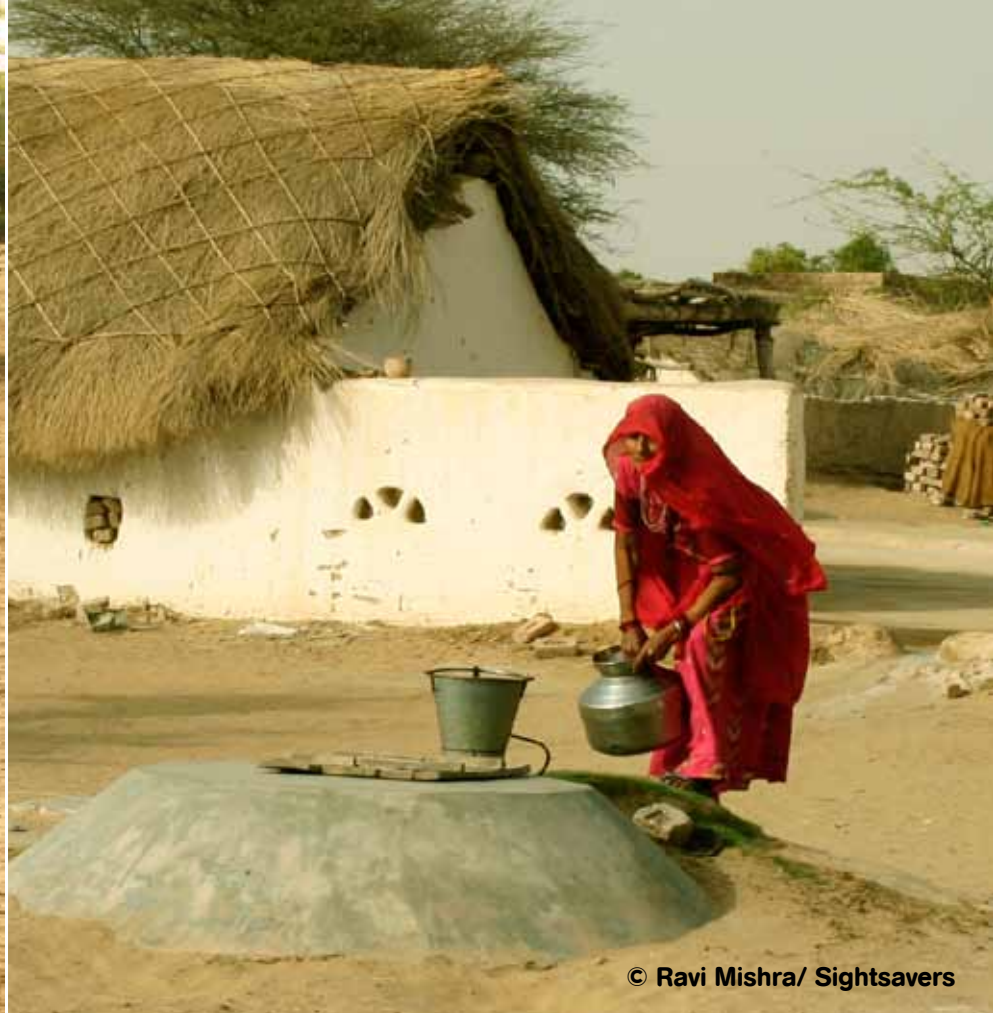
lenges vary from those related to awareness at the community level to the policy level issues which are not duly addressed due to lack of appropriate data on disability and the attached social stigma.

Broad framework of challenges

One of the major challenges was the unavailability of comprehensive data on disability. Though India included all types of disabilities in its enumeration coverage of people with disabilities in 2011, the actual on disability is yet to be released. The United Nations estimate that of the 10 per cent population with disabilities in the world, about 120 million people live in India. The available data on disability was not comprehensive enough to affect the planning of an intervention, allocating budgets and setting up targets. In the absence of the data numerous brilliant schemes of the gov-



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ernment do not reach to its intended beneficiaries.

Communities across the world face the biggest challenge of awareness. Bikaner primarily being decertified results in communities having limited access to information leading to poor awareness on disability and its causes. Moreover, the poor implementation of health interventions also has resulted in lack of information. The communities due to poor awareness tend to ignore early signs of disability and often undergo treatment at the later stages. They have limited knowledge on the facilities and are unaware of the types of disabilities. Further, there is lack of awareness on the rights and entitlements and hence persons with disabilities do not have access to the provisions and benefits. The awareness on disability of various stakeholders like local administration and district administration authorities is also limited which adds to the misery of the persons with disabilities.

The communities of the district have poor health seeking behaviour, which attributes to poor awareness about facilities being located in distant places, pre-existing traditional beliefs and an under-trained health workforce. The communities mostly visit traditional healers and quacks and have a tendency to ignore early symptoms of diseases and visit doctors only when the conditions worsen. This also attributes to the poor reach of the community health workers to the vicinity of the population.

Persons with disabilities are socially excluded from the society and bridging this gap remains the biggest challenge. The communities consider them as a burden, always in need for support and their disability is considered a result of bad Karma of their past life or a curse from God and so PWDs remain confined to the houses with little or no participation in the family and community functions. The situation of women with disability is far worse than men as they are not even allowed to come



Identification of PWDs

Orientation of PWDs

Sensitisation of stakeholders

Provision of assistive devices

Involvement of stakeholders

Counselling

DPO formation

Development of Linkages

Advocacy

Project Drishti processes

“ In 2007, we started to systematically engage with People with Disability, in partnership with various agencies, government. We began with identifying the people to connect them to medical services. Integrating PWDs to the public welfare schemes meant they could get on paths of financial rehabilitation; and eventually, we wanted to use comprehensive advocacy to amplify the issue and the model-work done. And we had to start from the real scratch. Nobody even had a database of the people in the district with disabilities. So we actually went on developing one, which is now being used by government also.

Overall, we worked directly with over ten thousand people in district of Bikaner.

Arvind Ojha,
Secretary, Urmul Trust

out of their houses for fear of untoward physical abuses. Children with special need specially the blind and those with low vision are refrained from going to school. They suffer exclusion as other children make fun of them and even school authorities are not sensitized and trained to address their needs and are often denied admission. The society strongly believes that persons with disabilities cannot be definite contributors to the society. The adults often are not married, considered unproductive and hence can never be employed.

There is lack of availability of proper diagnostic facilities, low cost treatments, which can reduce the chances of people getting disabled. People thereby end up visiting private practitioners, traditional healers or quacks. Government facilities are often inaccessible, limited and cold attitude of the health care providers at the district hospitals discourages the communities resulting in the loss of hope of getting cured. Provisions for assistive devices like calipers, low vision aid, hearing aid, white cane, wheel chairs and similar other aids which can assist persons with disabilities to reduce their dependency on their families and the communities and help live life with dignity are limited. Children with visual impairment lack proper diagnosis, treatment and due to the absence of assistive devices refrain from pursuing their education. Lack of support systems keep the communities from accessing benefits and this

leads to poor utilization of the schemes of the government.

The district being desert offer limited livelihood options attributing to insufficient resources, industries and agricultural produces. Even if a person with disability takes initiative to engage in livelihood related activities and approaches financial institutions for financial support she/he is considered less credit worthy and often faces rejection. The support system to address the issues does not provide an enabling environment for persons with disabilities to make themselves employable.

The government has schemes like 'Vishwas' scheme; provision for bus and rail passes and DRI loans to name a few for persons with disabilities which can provide the desired platform for them to lead a dignified life. But all and most of this only possible if one has a disability certification. The major challenge for persons with disabilities is getting a disability certificate for which he has to make several visits. In the absence of proper assessment and after having faced rejections from the authorities one eventually gives up and is denied of the services actually due. The district lacked proper data on disability, which resulted in poor allocation of funds and the local administration officials' insensitivity towards persons with disabilities, constrict access to the schemes and benefits of the government.



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Action Response

Urmul has been working in the desert region of Western Rajasthan for over two decades. The specificity of challenges of the region has been deeply understood and dealt with using this extensive twenty-eight years of experience. Project DRISHTI was the first step taken in the direction of comprehensive response assisting persons with disabilities in the rural extremes of the area. As a part of the organisational culture, the project was discussed threadbare to clarify, precisely identify and design the programme and its envisioned outcomes.

The onus was on the awareness for the available facilities and bridging the gaps between the community and government on the issue of disability, to facilitate the existing systems and strengthen them. It was essential to design an initiative that would not only enhance awareness and service delivery but most importantly shall establish rehabilitation within the families and communities. The project although having strong focus on people with visual impairment also tried to address the needs of the peo-

ple living with other disabilities like locomotors, hearing, mental, speech impairment and the like covering people of all ages. To have a comprehensive reach and outcome, the program focused on close collaboration of three main stakeholders: the Government agencies, the local governance (Panchayats) and community based organisations and jointly they adopted the Community Based Rehabilitation approach. Keeping inclusion as an over-arching principle action objectives were planned in the broad categories of Medical, Education, Social Inclusion and Livelihood:

- Enhancement of accessibility to the services of eye care for proper diagnosis, treatment and counseling.
- Facilitation of children with visual impairment in receiving quality education.
- Assurance of access to sustainable social and economic rehabilitation services.



With the coming together of the Urmul, government agencies and banks - which was an exercise driven in Bikaner, We were able to achieve a huge increase in the number of beneficiaries. For instance up to 2011-12, we delivered loans to just about 20 people but through this partnership we could give loans to 201 Differently Abled People. This is massive increase in just about in a year and the main reason for this was that we managed to bring all the people, all the necessary agencies in one level

Aarti Dogra, District Magistrate, Bikaner

- Formation of a strong network of PWD to advocate their rights and entitlements.
- Capacity-building and engagement of stakeholders for social inclusion of PWD.

Inclusive Education

Enabling early rehabilitation plays a highly positive role in setting a person on positive pathways. This is significantly possible through inclusive education approach at the entry level. This operates at two levels-it ensures education to the child with disability and sensitizes the others on accommodating, welcoming and eventually not distinguishing based on disability. The impact on the person with disability is severe in the rural areas, the traditional sectorial categorizations construes into a highly complex divide based on disability and leads to marginalization. For instance a visually impaired Dalit child is not just another child but a Dalit and a visually impaired.

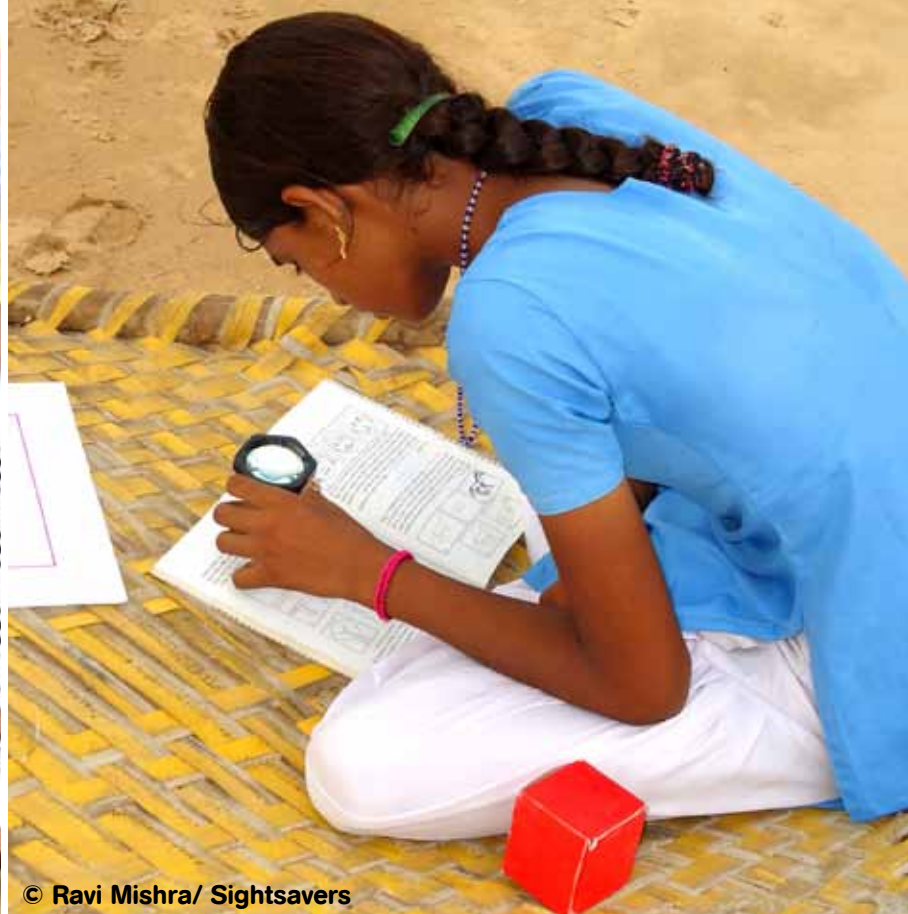
A detailed assessment of children with any form of causal disability was undertaken by a

qualified professional doctor to issue certification stating their level of disability. This provided a platform for these children to access the services of grant-in-aid, escort allowance and bus-rail passes which facilitated accessibility to regular education. In the preparatory education specially trained Inclusive Education teachers were appointed and trained to address the educational needs of the children with visual impairment. This was a highly specialized job and needed the greatest possible state of perseverance and patience with long distances to travel by the teachers. The IE teachers prepared and developed Individual Education & Development Plan (IEDP) for all identified visually impaired children for their easy and adaptive learning. These teachers prepared them for formal education, mobility as well as social conduct in schools.

Once the child was ready with basics, s/he was admitted into a school. There have been several occasions where the school headmasters or teachers refused admission to a child with disability due to sheer ignorance and in order to avoid the extra burden. Itinerant teachers ensured that most of the chil-



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children identified were admitted into local regular schools and pursued their education there.

Various teaching aids, Braille books, Braille kits and similar were provided to impart early Braille skills to the children. Large print and pictorial aids were also made available, through Sarva Shiksha Abhiyan (SSA) in schools for LV (low vision) children. Training and counselling with teachers resulted in nurturing a support system for these children.

As a core strategy, intensive skill development camps were undertaken for the visually impaired children assisting them in sharpening their skills on reading and writing in Braille and also developing advanced daily living skills (ADSL).

The programme ensured that identified children with visual impairment admitted into regular schools and continued to receive equitable and quality education. This has led to a greater acceptance of the project and its field staff in the community. Parents of children with other disabilities, who had been previously reluctant to allow their children to attend school, now insist to be part of it and grew keen to send their children to school.

Provision of Aids and appliances:

The project facilitated an enabling environment through provisions of assistive devices for the children with visual impairment and adults to assist them in pursuing their education. Further, the advocacy efforts with the Department of Social Justice and Empowerment (SJE) helped to increase budgetary provisions for assistive devices. The compiled data on disability under the project is now being used by the district administration in planning and conducting the assessment camps. The SJE department now seeks support of the project team and the DPO in successfully conducting these camps where-from several persons with disabilities have benefited with disability certifications and assistive devices. The assistive devices, which were available from the market at higher price are now distributed by SJE and SSA free of cost. The project thus supported in strengthening the government systems and bridging the gap between the beneficiaries and the government. It has enhanced the accessibility of the schemes of the government to the person with disability located in the far-flung areas of the district.



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“THOUGH IT APPEARS THAT I AM NOT EVER GOING TO TRAVEL IN A TRAIN BUT THE SHEER FEELING OF HAVING A RAIL PASS THRILLS ME.”

Chataram has spent his entire 43 years of his life being blind. He was born in a poor family in Barasalpur village located on the Indo-Pak border. He lives with his five brothers and mother; poverty struck the family so hard that none of the brothers could even marry.

It was in 2009 when he was identified in the survey and was brought under the project. During the initial days the project team assisted him in linking with disability pension, accessing provisions of bus-rail pass and 100 days of employment with NREGA. He underwent training on livelihood and went on to set up his own grocery store in village using the funds received in form of pension and grant amount of rupees five thousand received from the government.

Gradually, he started having substantial increase in the income. He did not limit

himself to running grocery shop but expanded his work and traded earthen pots for which he received INR 100,000.00 financial support from the Vishwas Yojna with the help of project staff and made a handsome profit after getting loan from the bank. He did not stop here and traded in metal utensils. He purchased and stock piled diesel and sold it to local farmers and vehicle owners. The community members praised him for being able to purchase fuel locally as they had to travel long distances to buy it.

He stabilized with all the support, returned his loan amount on time and recently supported his brother Rajaram with an amount of INR 10, 000 from his savings to open a shop. In this remote village almost everyone buys their requirements from Chataram and his brother Rajaram's shop.

Medicinal and Surgical support:

One of the major components of the project was to address the curable disabilities in the region with special focus on visual impairment. The communities of the district faced a major non-availability of primary level services of eye care, which was addressed through establishing vision centres in five blocks of Bikaner district with referral services at the base eye hospital at Urmul Jyoti Sansthan- Nokha. Medical camps, school screenings and community screenings were organized in the project blocks where hundreds of people were treated or referred to next stage for surgeries. The establishment of vision centres brought the services of eye care to the door-steps of the communities of the desert district.

Following the camp referrals, quality treatment for identified candidates for eye surgery (Cataract, Glaucoma, Refractive Error and other eye deformities) were initiated at the Urmul Jyoti run eye hospital at a Nokha block headquarters. For other tertiary level surgical ser-

vices, patients were sent to other places like Gujarat, Jaipur and other states. All the surgeries were done free of cost for those who were not position to pay for the fee for the surgeries. This way confidence that was humbly build encouraged the people to access more surgical options. This triggered a ray of hope to those who had given up or had accepted their disability as their fate. Till November 2013, the Project had reached out to 1, 20,654 people. 4250 people get successfully eye restoration through this project.

After consolidating the work on ground and having gained the confidence and trust of the community, the team now also advocates on personal issues of eye or organ donation in the rural areas. This includes providing the people with necessary information about the possibilities of eye treatments in the case of eye donations. The teams during the trainings also conducted sessions for PRI members, Anganwadi Workers, ANMs and CBOs informing and encouraging them to donate their eyes and other organs after their death.



© Andy Weekes/ Sightsavers

Four year old Ali Shah was identified with cataract and successfully operated at Drashti Netralaya and Dahod Tribal Community Eye Care Center (A Sightsavers partner hospital) Ophthalmic Mission Trust, Dahod, Gujarat, India.



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14 year old Sumitra has passion for photography and she feels great to be seen on the Sightsavers 2013 calendar along with her best photograph. She frequently goes out to photograph the beautiful morning and evening surrounding her village. She studies in class 9 and wants to be doctor and. In a programme a dignitary appreciated her saying, "I have seen a girl photographing in a function for the first time ever." The story may sound ordinary but the labour behind this is worth appreciating.

Sumitra lives in a small desert village of Thukriasar of Bikaner. After she was admitted in school she started losing her eye sight. Her father failed to understand anything but got her examined at the nearby clinic but due of lack of understanding could not have solution to the problem. Disappointed from all ends after some days of frustration, scolding and fail-

ures at school, Sumitra began to stay at home. The corner of her house became her life.

In a 2009 survey under the project, Sumitra was identified and diagnosed with cataract in her eyes. She was operated in Nokha based Urmul run eye hospital. She was able to see with the help of spectacles after the surgery. Her father says, when she lost her vision we were totally disappointed. We tried our level best but then thought that perhaps this was written in her destiny. But now the entire world seems different as Suman shares she can recognize colour, which she was unable to see, and she feels great to see this colourful world. Her father says it's a big contribution of Urmul and Sightsavers behind this miracle. Earlier I used to only think how would she get married, but now I am determined to educate her properly.



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Action towards Economic Self-reliance

The project facilitated economic empowerment of persons with disabilities by building their capacities and linking them with economic empowerment schemes of the government. It supported persons with disabilities in building their capacities through exposure visits to TATA BADI (Gujarat) and need based trainings on various income generation activities which-after they approached financial institutions for assistance. The financial institutions considered the persons with disabilities to be less credit worthy and rejected several applications. The project sensitized the financial institutions and ensured that PWDs have enhanced accessibility to the schemes and financial institutions.

The project resulted in bridging the gap between the beneficiaries and government, which ensured enhanced accessibility of economic security schemes of the government. Schemes like Vishwas Yojna, Anugrah Rashi provided opportunities to start ups like petty shops, mobile recharge points and similar other vocations. A number of people with visual impairment operate their own shop and are earning INR 2000-3000 per month thus contributing to the family income. The economic

empowerment of these people has set examples for others in the village and has facilitated their inclusion in the society.

Sensitization of the various stakeholders:

The major step of social rehabilitation of persons with disabilities was providing a congenial environment in which they can overcome the complexes and the feeling of exclusion from the society. One of the main reasons is the insensitivity of the society towards persons with disabilities. The project through regular counselling of the family members, PWDs and sensitization of various stakeholders like PRI members, SJE, SSA, Government Officials, community leaders, officials of Financial Institutions and educators facilitated in the creation of an environment where all have equal opportunity to participate and express themselves. The result being, persons with disabilities reported increase in their confidence level and decrease in dependency on their families in particular and the society in general. They now actively participate in the regular familial and community affairs. This indicates their acceptance in the social sphere.



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I hated it when people called me Andha (blind). I had no friends. I stayed at home always and never attended any social functions. Always excluded!

Maggaram is a teenager empowered enough to make choice on where he would like to pursue his education. He got admitted in a blind school at Jodhpur for higher education but later declined owing to the poor quality and joined the blind school in Sri Ganganagar district of Rajasthan. A gifted singer with a melodious voice, he energizes the ambience each time he sings. He often gets invitations to jagrans (prayer nights) during festivals where he spends the night singing.

Life was never easy for him three years ago. His family would often leave him alone at home to attend jagrans and festivities He always used to wonder what jagrans and festivals were actually like. Hearing the sounds of singing and chanting he would always want to be there and participate. His parents found it difficult to take care of him in the crowd as they felt he could not manage himself. He recalls and shares his stories, whispering how people and children used to taunt him and scorn him away. His parents were unsure and worried about his future. They did not know there was facilities available for education and Maggaram can manage with a little training.

The first male born child after six daughters was the reason his life was spared.

Maggaram was identified in the project during the survey and was immediately supported with home-based education by the Itinerant teacher. Being a fast learner he quickly picked up the Daily living skills and started learning Braille. With a little support, a petition to the SSA and support of the teachers he easily managed an admission into school. Continuous support from the teachers on pursuing his learning and his zeal to continue his education helped him in clearing primary education and was mainstreamed into secondary level. He travels on his own, even to Bikaner city or Lunkaransar town. He showed tremendous growth, gained confidence as days passed and now has bigger aspirations to accomplish. Journeying from dependency to self-dependence, Maggaram has already come a long way. Now he says, "Now, I don't mind when the people call me blind, or laugh or taunt at me. I know I can do so many things, just like them. They are the one who can't see." Maggaram now pursues his education in Sri Ganganagar in class 9th.



A district level workshop focused on life skills development and capacity building of PWDs.

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Linkages and Close Cooperation with Government

The programme received great cooperation of the various governmental agencies that readily lent their complete support at the district and respective block levels. Successful linkages to various schemes, facilities and aids; immediate redressal of complaints and effective coordination in implementing programmes of various departments has led to a remarkable achievement. The Department of Social Justice and Empowerment, the Department of Social Welfare, the Sarva Shiksha Abhiyan, the offices of CMHO (chief medical health officer) and the other government medical facilities extended their full cooperation, each time needed.

An exemplary partnership with the government has been that the district magistrate of Bikaner having realized the non-friendly PWD infrastructure at the Magistrate's Office not only got the building renovated but also developed a special conference room, where-from PWDs can appraise their issues directly to the Magistrate's Office. The conference room is equipped with all modern communication and access facilities for the disabled.

District level network of persons with disabilities

The project facilitated the mobilization of persons with disabilities and creation of a network of persons with disabilities (DPO- Bikaner) in the district to advocate for their rights and entitlements. The Viklang Adhikar Manch- Bikaner was formed and its members trained on group formation, rights and entitlements of PWDs and development of future plans to strengthen the DPOs and take up their issues with various stakeholders. The DPO- Bikaner is working continuously to increase its membership base so that all the PWDs in the district are aware of the forum and contribute to its objectives by being a part of it. As of May 2013 more than 1500 PWDs have registered with the DPO and many more are in the process. The forum has a strong presence and is well recognized in the district among government officials for its activities.

Major Achievements of DPO

- A district level network with a membership base of more than 1500 is active and pursues



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Narendra is a star at home and in the village with several medals to his credit, which he won in various sports, meets at block and district level. He enjoys playing but what makes him happier is the change in the attitude of his parents, siblings and villagers when they praise him and speak high of him.

He grew as a disoriented child with no schooling and hardly any friends. His siblings, though many- two brothers and five sisters were his only social world. His family dependent on agriculture still tried best to treat his blindness. Despite several efforts and surgery his eye sight could not be restored and the family gave up hope feeling it to be his ill fate and curse of his past life. They were dejected about his future and this had crept into his siblings' behaviour too.

And just then, they happened to meet project DRISHTI project team and his case was studied thoroughly. Analysing the situation Narendra was immediately supported with home based learning to mainstream him in regular school. ADLS (Advanced Daily Living Skills) and Braille was taught to him which he picked up very fast and today he is studying in class 2. He carries on with his daily chores like bathing, dressing and eating on his own. His parent's doubts about the possibilities and his future are diminishing as they watch him learn and grow. His quick adaptation and learning has reassured them. At seven, he knows his numbers, alphabets, symbols and works easily on Braille and abacus. He even knows the English synonyms for words, by-heart. Today, Narendra finds little time to ponder at his shortcomings.



After observing the success of project other agencies came forward to support and salute the confidence of PWDs. Tri-cycles were presented by Bhagwan Mahavir Viklang Sahayta Samiti at a function at Sri Doongarharh.

© Ravi Mishra/ Sight Savers

the rights and entitlement issues of persons with disabilities across district of Bikaner. The network has established itself and is well recognized across and certain members are well known to the key officials of the district administration.

- Significant attitudinal change- within the communities, the officials of the district administration, and financial institutions towards disability and persons with disabilities has been noticed. The Office of the District Collector made special provisions for audio-visual communication enabling persons with disabilities to access key officials. Officials of financial institutions now give priority to the requests of persons with disabilities and consider them credit worthy.
- There has been a significant increase in the financial outlay and utilization of the schemes of the Department of Social Justice and Empowerment. Vishwas Yojna in the year 2012 reached to 200 people against 20 in the year previous. Assessment camps, through which various benefits for persons with disabilities have been delivered, too have increased.
- The project facilitated leverage of funds worth INR 38.02 million in the form of Disability Pension, Vishwas Yojna, Escort Allowance, Swarna Jayanti Swarojgar Yojna, MNREGA, Anugrah Grant Yojna, Indira Awaas Yojna and related schemes of the government and made sure that persons with disabilities benefited directly from it.
- As a result of the intervention the district administration involves Urmul trust network and DPO-Bikaner in the planning and implementation of its programmes, which speak well of the response received from the government.

The Team

“From one village to another, from one mind-set to another and from one person to another- our team has been working ardently to re-establish dignity and honour, to help people access all benefits available and to enable self-efficacy and independence among in them. Hours turned into days and days into years, and even today each one of us work with the same enthusiasm, we started off with.



DPO members raised their voice during a protest in front of District authority demanding of equal rights and entitlements.

© DPO Urmul/ Sightsavers



जिला विकलांग अधिकार मंच

Zila Viklang Adhikar Manch

Secretary, DPO Bikaner and all other members have taken an oath to ensure the rights and entitlements of all persons with disabilities. He shares we have a membership base of more than 1500 and we are hopeful all persons with disabilities of Bikaner district will soon be member of the DPO-Bikaner and would have one voice. He strongly believes that all deserve respect and have the right to dignified life. "We are a force today and people across recognize us and do give us priority which was earlier missing."

In 2009 during the inception of Project DRISHTI few gathered with support from the project team in which we got together and formed our network, Zila Viklang Adhikar Manch- Bikaner. We underwent several trainings on group formation, group management and vision building. It was the continuous support of the Urmul team and Sightsavers guidance that we have come this far and today has strong recognition in the government. Earlier very few used

to turn up in meetings but as we achieved success in various advocacy efforts and gradually we started having more participation. Today we have maximum participation from all blocks and across disabilities. We have staged several dharnas and peaceful protests against the Institutions and officials who have not entertained the requests of PWDs involving their rights and entitlements. One of the major advocacy successes we had been with the Social Justice and Empowerment for increasing the allocations for number of PWDs. The earlier sanctioned limit was only for only 20 people and after several meetings and discussions the allocation was increased to 200 and from next year onwards the same has been planned for 400. Tasting this success the members now feel empowered and this has resulted in more coming forward to join our movement.

Bhagirath, Secretary-
Zila Viklang Adhikar Manch, Bikaner



A SSA official reviewing a life skills development camp at Loonkaransar.

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Standing by each other in support, sharing ideas, innovating newer plans, drawing newer possibility, has been our greatest strength”. Madan Bishnoi

Rampal Bishnoi, Project Manager DRISHTI recalls the initial phase of the programme- “Everybody was doubtful, leaders of the different organisations and even Sightsavers. We were worried that without the requisite skill and experience in working with PWDs, we would not be able to bring about any change. But very soon we realized that we are bringing a sizeable change, which is quantifiable, and immediately visible. We have so far identified 80-90 per cent individuals with disabilities in the entire rural areas of the district. Now if any department needs any data, we are the one to be contacted. Earlier we used to go to the Welfare Department of the Government, but today, they contact us for any of their programs and its execution. We have ensured that all the welfare schemes and benefits of the government are availed by the people. For the last two years 85 per cent of the funds allocated by the government for social rehabilitation of the PWDs have been utilized.”

Adding to this, Chenaram, Project Coordinator of the Bikaner block highlights, “During

the initial days the communities were unaware and we found it difficult to convince them. They only started trusting us, when they received their Disability Certificates with our support. That’s when they joined hands and today when we have our monthly meetings of the Disabled Persons Organisation, we only need to make a call and more than 90 per cent of them turn up. The DPO has filed petitions with the government ranging from the SDM to the Chief Minister enlisting their grievances, concerns and requirements. One of the major achievements has been the increase in the budgetary allocations of Vishwas Yojna from 20 to 200 in 2013.

Rewat Ram- Project Coordinator of the Doongargarh Block further endorses the teams efforts and illustrates, “Our only concern is to help them find a place to live with dignity and respect in their families and with their communities. The first step to this is to make them the financial contributors to their families. The pensions and loans suddenly change the attitude of the family towards them. They are not looked down upon as burdens thereafter. Everything like training in orientation and mobility and daily living skills are only secondary. We have made a start towards helping these special people live their special lives with dignity. This has been our greatest motivation.”



Prunaram, a 10 year old boy of Palana village is blind since birth. He was identified in a survey and now studies at the government school of his village with support of Sightsavers and Urmul.

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Geeta receiving large print book set at an event organised on World Sight Day in a government school.

© Urmul/ Sightsavers



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The way forward...

The state that has the second highest number of disabled population in India stands tall in having been able to change the fable perceptions regarding persons with disabilities among the abled in the society with the coming together of Project DRISHTI, Sightsavers and the Urmul Network. They have collectively helped pull several persons with disabilities out of the clutches of poverty onto the safe-ways of livelihood and self-determination. This aligned with immediate relevance to the Million Development Goals which specifically call for cross-sectional change in attitudes and environmental-barriers, across areas such as education, access to health care, food, clean water, basic sanitation and economic empowerment to improve the lives of the world's poor.

In the district of Bikaner, Project DRISHTI addressed the human rights instrument with a

holistic, social development dimension in accordance with the United Nations Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities and its Optional Protocol. It developed relevant human resources and training methods applicable to the region. The project infused confidence in persons with disabilities as a result they themselves are now efficient as change-makers and their own District Disability Rights Forum augments the advocacy of their rights and needs in a collective manner and thereby become a part of the system challenging stereotypes.

Project DRISHTI bears appropriate parameters that can be accounted for as a best practice model. The endeavour has rightly put forward an approach that targeted families, teachers, and community provided opportunities for learning, enhanced capacities and

It was sheer delight to see how well inclusion takes place in far-off, unreached villages of Bikaner with support of Urmul. If we can do it here, we can do it anywhere and I think we really need to replicate the efforts in others parts of Rajasthan so that many more children can also get mainstream.

Deepak Kalra, Chairperson
Rajasthan state commission of protection of child rights (RCPCR)

ensured platforms for livelihood, and doing so in active partnerships with numerous stakeholders including the government and PRIs.

There are many areas that need specific attention at policy, implementation and capacity building level. The interventions and practices under this programme collate a wide and valuable repository of experiences. These are important to learn from and share amongst the peers for effectiveness, success and experience mapping.

Learning of equitable access to social-enablers such as education, employment, health care and the socio-legal support system can be necessarily experimented with by the Government, NGOs, INGOs, Bilateral Agencies and the development sector at large, and the communities concerned in other states of India and outside.

The course of the programme has brought afore a few prerequisites in the area for effective implementation of designs to strengthen inclusive education, service delivery and rehabilitation both social and economic. Some of them is be summed in following:

- There is an immediate and paramount need for working with adolescent girls. At present this area remains more or less left out due to lack of female team members. The barriers become difficult to be broken in such scenarios and women especially adolescent girls find it difficult to voice their grievances and concerns.
- Prioritization of the gender in the interventions needs to be augmented, as women with disability are likely to be more marginal-

ized and vulnerable than men. With limited access, taboos and social barrier women have limited possibilities to pick from the livelihood options available and therefore remain financially dependent on their families. There still exist a number of women who need to come out of their closet and live their life with dignity.

- Mining is predominant option to livelihood in the region and is also a major cause of blindness. Traditional smoke chulhas are a major area to look into to address the high incidences of blindness and low vision in the region.
- Far more effort needs to be made to address education and other rehabilitation needs for children below six years. Though this role is entrusted to the Anganwadi worker, they are unable to handle children requiring multi-disciplinary rehabilitation needs.
- Due to lack of resources and effective training, Inclusive Education teachers have to confine to work only with the school going children barring out children under the age of 6 years and over 15 years.
- Despite the achievement in procuring aids for BLV children, Braille school books are still required. Children located in far flung areas still do not receive books in Braille. Large Print books too are completely missing. The only large Print books that were available were those that had been developed by the Itinerant teachers.
- Intense counselling is needed, as barefoot counselling techniques are not effective in dealing with the psychosocial issues in various situation. This is necessary for both BLV persons as well as family members.

गाढ़वाला



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- The number of Self Help Groups is limited in the villages. The teams faced great difficulties despite twenty years of institutional knowledge in forming SHGs to bring together five disabled persons to form an SHG. As a result the potential of financing a significant economic rehabilitation is at stake.

- Trainings of the PRIs, VHSC and SMC members must be intensified, to raise their awareness extensively and at an exponential pace. This is essential for a committed coordinated impact.

- PRIs are responsible for the functioning of local governance. Benefits like pensions, loans and employment options like MNREGA are available at the village level but the lack of in depth understanding fails to make available such benefits to the PWDs.

- Intense capacity building of DPOs on organisational management and vision building is required for them to understand and take ownership of their network. It is of utmost importance to make them understand the advantage and power of the DPO.



Annexure

1. Data Of Blind And Low Vision Children Identified Through The Project

S.no	Details	Block			Block			Block	
		Bikaner			Doongargrah			Loonkara	
		M	F	T	M	F	T	M	F
1	Blind	7	6	13	6	1	7	11	10
2	Low Vision	14	3	17	12	9	21	7	1
Total Childrens		21	9	30	18	10	28	18	11
3	Enrolled in School	18	8	16	17	10	27	9	6
4	Enrolled in Aganwari Center	2	1	3	0	0	0	3	2
5	Home based Education	1	0	1	1	0	1	6	3
Total Enrollments		21	9	30	18	10	28	18	11
6	Certification of Blind	7	6	13	6	1	7	11	10
7	Certification Low Vision	14	3	17	11	9	20	5	1
Total Certifications		21	9	30	17	10	27	16	11
8	Pension	14	5	19	15	10	25	9	5
9	Bus Concession Pass	17	8	25	15	10	25	15	10
10	Railway Concession Pass	19	9	28	15	10	25	15	10

Source: Project DRISHTI reports of Urmul Network partners.

K	Block			Block			Total Bikaner District		
	Nokha			Kolayat					
ansar	M	F	T	M	F	T	M	F	T
21	10	10	20	6	7	13	40	34	74
8	6	4	10	10	11	21	49	28	77
29	16	14	30	16	18	34	89	62	151
15	14	9	23	11	16	27	69	49	108
5	2	2	4	3	1	4	10	6	16
9	0	3	3	1	0	1	9	6	15
29	16	14	30	15	17	32	88	61	149
21	10	9	19	6	7	13	40	33	73
6	6	4	10	5	6	11	41	23	64
27	16	13	29	11	13	24	81	56	137
14	15	12	27	8	7	15	61	39	100
25	16	13	29	10	12	22	73	53	126
25	16	13	29	10	12	22	75	54	129

2. Medical Aid And Allied Received

Sl. No.	Description of Aids/Activity	Place of Activity	No. Of Beneficiarie
1	Tri cycle	Block 5	568
2	Wheel chair	Block 5	120
3	Crutch	Block 5	435
4	Hearing Aid	Block 5	83
5	Braille Kit	Block 5	52
7	C.D. Player	Block 5	15
8	Laptop	Block 5	7

3. Vision Centres

Description of Activity	Place of Activity	No. Of Beneficiaries
Vision Centers	Block 5	7 (Vision Centers)
People screened in Vision Centers	683 Eye Camp & 1814 School Screening	1,20,654
Successful eye treatment	Block 5	4250
Training on Primary eye care	Block 5	15,980

4. Beneficiaries form various schemes in the project

Sl. No.	Description	Beneficiaries				Total
		Year 2010	Year 2011	Year 2012	Year 2013	
1	Medical Certificate on Disability	4555	793	589	886	6823
2	Train Pass (For free travel)	460	737	233	55	1485
3	Bus Pass (For free travel)	815	927	700	954	3396
4	Govt. Pension scheme for PWD's	1332	887	538	1738	4495
5	Vishwas Scheme	0	29	63	138	230
6	Govt. grants for various activities	50	133	0	0	183
7	Supporting aid	120	222	290	166	798
8	Escorts and transportation	91	136	312	36	575
9	Braille book	0	45	40	0	95
10	Large print books	0	0	32	0	32
11	Palanhar scheme	12	3	6	341	362
12	Astha Card for ration	151	96	52	66	365
13	NREGA	468	422	128	14	1032
14	SHG	4	11	11	14	40
15	Swarn Jyanti Scheme	0	33	20	60	113
16	Indira Awas Scheme	20	68	44	18	150
17	Marriage grant for PWD	6	15	11	2	34

5. Visually Impaired Directly Benefitted

Description of Aids/Activity	Place of Activity/No. Of Trainings	No. Of Beneficiaries
No. Of visually impairment directly benefit from the project	1125	985
No. Of PWD's trained through this project	80	2680
No. Of PWD's who become entrepreneurs	Block 5	1120

4. Trainings Conducted And Number Of People Reached

Activity	No. Of Trainings	No. Of Beneficiaries
No. Of government and private school teachers trained during the project	850	2865
No. Of training conducted during the project	336	74,168
General capacity building and awareness training	189	3780
Sector training of Community health worker (ASHA, ANM)	60	1680
Enterprise training	10	370
Capacity building training of Disabled People's Organisation	13	458
Skill Development training	10	240
Training to PWD's families of awareness	24	630
Meetings with other department	10	180
Number of people who participated in various awareness programmes	Block 5	65,980

A teacher monitoring a child learning to walk with the help of cane in life skill development camp at Loonkransar.



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Children in a joyful activity at a learning camp

© Ravi Mishra/ Sightsavers



Suman overcomes all the obstacles from her home to school, climbing step by step.

Vision testing is a regular activity at camps supported by Urmul and government schools.

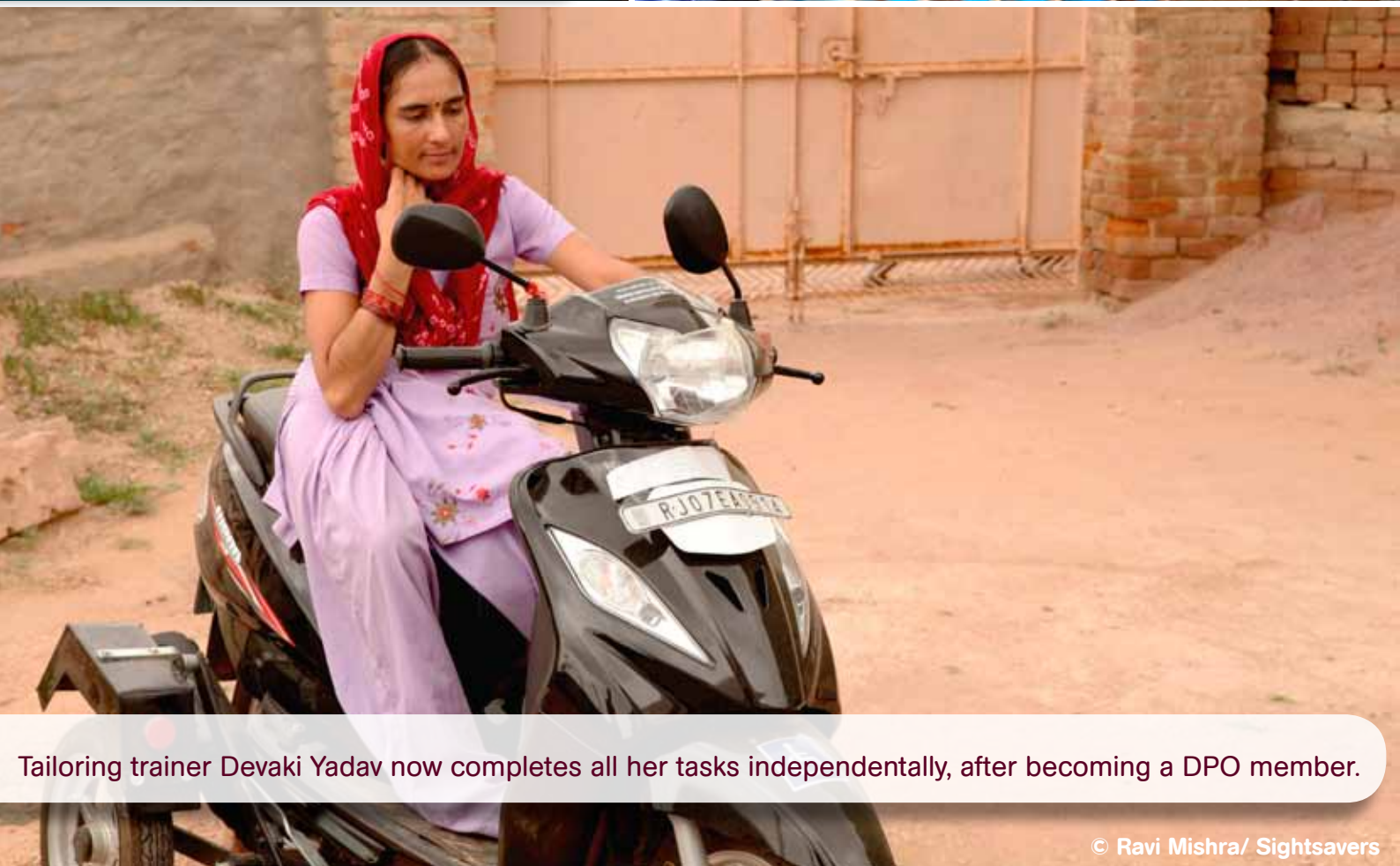




Magharam operating a Braille.



Children with Visual impairment learning DLS and ADLS.



Tailoring trainer Devaki Yadav now completes all her tasks independently, after becoming a DPO member.



DPO members staging protest against an incident where a doctor misbehaved with a PWD in Sri Doongargarh.







Changing
perspectives,
Bridging the worlds
between
me and you.

A scene of life skill development camp in Loonkransar

Millions of people, worldwide, live with disabilities...
The majority of these disabilities are preventable or curable
but is the pain, the agony and the anguish people feel curable?

Our insensitivity costs their chances to live.
May be its our time to see...

Our Office in India

Registered office

A-3, Shivdham, New Link Road,
Kanchpada, Malad (west)
Mumbai – 400 064
Phone: 91 22 28820808/ 1919

Head Office

45, Okhla Industrial Estate, Phase III
New Delhi – 110 020
Phone: 91 11 65955511/ 33

Other Offices

GC 104, Sector III, Salt Lake
Kolkata – 700 106
Phone: 91 33 40086225

E-8/78, Basant Kunj, Arera Colony
Bhopal – 462 039
Phone: 91 755 4292807

Flat no 104, Parth Kristal, No. 41
Devaraj Mudaliar Road
Off St. John's Road
Bangalore – 560042

Photo taken by Sumitra from Thukariyasar village in Rajasthan.
Sumitra was visually impaired before her eye treatment under the project