



Voicing Concerns

Road Map and Strategic Document on
Advocacy and Campaigning

Developed by Sightsavers and CBM
in association with Leonard Cheshire Disability



Sightsavers



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MESSAGE

According to a 2007 World Bank report on disability, India has some 40 to 80 million persons with disability. Low literacy and widespread social stigma are making disabled people among the most excluded in the country. Children with disabilities are less likely to be in school, disabled adults are more likely to be unemployed, and families with a disabled member are often worse off than average. In the years to come, the number of disabled people in India is expected to rise sharply as age related disabilities grow and traffic accidents increase.

India has a growing disability rights movement and one of the more progressive policy frameworks in the developing world. It is among the first countries to have supported the UNCRPD, having ratified it in 2008. For the first time disability was part of the 11th five year plan in India. But a lot more needs to be done in implementation and getting the basics right. Newer thinking and better coordination of programmes is called for. People with disabilities need to be better integrated into society by overcoming stigma and should be encouraged to be active participants in the development process.

In this context, the role of disabled persons organisations (DPOs) is of great significance. As the great Helen Keller said, "Alone we can do so little, together we can do so much". Other than providing a voice of their own, these organisations encourage collective thinking and action in identifying needs, raising awareness, building leadership and advocating for transformational change for disabled communities. Hence it is imperative to encourage the development and strengthening of such organisations.

In view of this Sightsavers India and CBM South Asia Regional Office initiated a research to study DPOs in the country and their work with the purpose of better engaging with them towards positive practice, policy and legislation changes for persons with disabilities. The study was commissioned to the South Asia Regional Office of Leonard Cheshire Disability and is intended as a resource for policy makers, managers and practitioners in the disability sector and most importantly, for persons with disabilities.

We are grateful to Leonard Cheshire Disability and all those who contributed to this study, especially experts in the country, staff and partners.

Elizabeth Kurian
CEO Sightsavers India



MESSAGE

I am delighted that CBM and Sightsavers have brought out this publication on advocacy and campaigning in partnership with disabled people's organisations in India. Several organisations and individuals have worked on developing this document which promotes the rights of people with disabilities through engagement with disabled people's organisations.

Disabled peoples organisations play a vital role in achieving empowerment and participation of people with disabilities both in society and in all activities or programmes concerning them.

With more than 100 years of experience in the field of disability, CBM works to ensure that people with disabilities lead productive and fulfilling lives. CBM advocates for the inclusion of Persons with Disabilities in all aspects of society. It is in this context that CBM attaches great significance to the role of disabled people's organisations in India. CBM stresses the importance both of building the capacity of disabled peoples organisations and the need for all stake holders to actively engage with them.

CBM and Sightsavers commissioned this study to provide guidance and direction for further engagement with disabled people's organisations in terms of creation of livelihoods, leadership development among DPOs and capacity enhancement.

CBM is thankful to Leonard Cheshire Disability and all others who conducted the research and hopes that this study will be utilized by development practitioners, policy makers, and the public, non-governmental and private sector to plan their programmes.

Dr.Sara Varughese

Acting Regional Director

CBM South Asia Regional Office, Bangalore

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This is not just a formality but a sincere and humble attempt of acknowledging the significant contributions made by all the individuals and agencies both directly and indirectly in the process of developing this document for Sightsavers and CBM for deepening their understanding on engagement of DPOs in advocacy and campaigning towards promotion and protection of human rights, fundamental freedoms and dignity of persons with disabilities across the country.

It is our first and foremost duty to generously thank our primary stakeholders i.e. persons with disabilities, Self Advocacy Groups [SAGs] and federations, disabled people's organisations [DPOs] and their movements whose rich inputs and great value addition has lead this process and its outcome and whose participation has enlightened us about the various actions and processes which they have been facilitating since ages.

We acknowledge the tremendous contributions made by disability agencies [NGOs] to this process with at most humility and extend our heartiest thanks to all the representatives, heads and leaders of these organisations for their time, effort and support.

We are honoured to thank all the activists with and without disabilities, government representatives as well as leaders of disability & disabled peoples' movements for their great support and rich inputs to this document.

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Last but not the least, we appreciate the initiative taken by Ms. Elizabeth Kurian, CEO, SIGHTSAVERS, India; Ms. Gunawathy Fernandez, Regional Director CBM South; Ms. Silvana Mehra, Regional Director CBM North and all the team members of these organisations for their continued support and cooperation extended to us throughout the process and giving us an opportunity to enrich our learning on the issue.

Once again we are highly grateful and honestly express our gratitude to all those who have directly and indirectly made their significant contributions to this process and its final outcome.

Mr. K.R. Rajendra and Dr. Victor John Cordeiro,
Leonard Cheshire Disability
South Asia Regional Office



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EXECUTIVE SUMMARY

This exercise is in response to the request made by SIGHTSAVERS and CBM to LCD SARO to suggest the road map and strategic directions for strengthening the engagement of both of the above mentioned agencies with DPOs. This aim was to undertake the advocacy and campaigning initiatives through this study of the present status of DPOs and advocacy and campaigning efforts being carried out in the country. This section tries to capture the essential elements of this document which are summarized below:

CHAPTER - 1

This chapter elucidates the historical perspective of disability and disabled people's movement in India recording the paradigm shifts that took place as responses to deal with the emerging issues of persons with disabilities. They form a heterogeneous group unlike any other invisible minority groups of the country. The current available statistics such groups them does not depict the correct picture of their situation. Rehabilitation of persons with disabilities began in 19 century with institutions and centers for specific categories of impairments. The process has evolved in different phases as per the advancement and development in the sector both at national and international levels. Integration, inclusion, CBR, inclusive development, self advocacy and formation of DPOs and parent's organisations are the key developments of the sector.

This chapter makes an attempt to examine and explain the institutional and policy framework for the protection and promotion of rights of persons with disabilities. Both general and specific legal frameworks including references in constitution are discussed in the chapter.

CHAPTER - 2

This chapter begins with a brief introduction to Sight Savers and CBM and their work with persons with disabilities in the region. The main objective of this exercise is to study the situation of DPOs in India and to suggest a road map or strategic direction to these agencies in order to strengthen their engagement with DPOs, advocacy and campaigning. The specific objectives of the study include; to identify - key agencies and DPOs for future engagement, priority issues which require macro advocacy efforts, capacity building needs of agencies and DPOs and to suggest a road map or strategic direction to achieve the key objectives.

The key areas explored in this exercise include - advocacy needs of persons with disabilities, current advocacy efforts, capacity of DPOs in advocacy and the present need and capacity of CBM and Sightsavers in advocacy and campaigning.

The key methodology includes - consultations through workshops with agencies and DPOs separately, FGD with Self Advocacy Groups [SAGs], telephonic interview with activists with and without disabilities, state officials and practitioners and review of secondary literature. This process has involved 23 [15.03%] women/girls and 65 [42.48%] Men/Boys with disabilities, 17 [11.11%] women/girls and 48 [31.37%] Men/Boys without disabilities representing 72 Agencies/Federations/Groups/DPOs from 16 states and UTs.

CHAPTER - 3

This chapter attempts to present the primary data in tabular form in order to help the reader to refer back and relate the findings, analysis and suggestions with the primary data. It is a systematic attempt to capture and summarize the critical glimpses of discussions, interviews and feed back of respondents on the subject matter.

CHAPTER - 4

This chapter is divided into three sub-sections. The first section attempts to capture the key findings of the exercise which mainly state –

The understanding of DPOs of the concept of advocacy and campaigning is relatively advanced than NGOs. There is a difference in the understanding of DPOs and NGOs on the concept of DPOs due to lack of clarity of roles. Both respondents strongly feel that advocacy and campaigning is still in the initial stage and needs to be accelerated. Both strongly expressed the need for capacity building in the areas of – human rights instruments and framework, advocacy and campaigning, research and documentation, organisational development and management and resource mobilisation. DPOs strongly feel that they are very effective and active in advocacy but NGOs feel that they are in still the initial stage.

The second section makes a scientific attempt to analyze the findings as per the specific context, need and the future utility of the document. The key analysis includes;

- a. DPOs and NGOs have a slightly different understanding on the concept of DPO with regard to composition, membership, role, structure and functions which needs some consensus to be arrived at by convincing them about the specific roles and accountability of DPOs and NGOs in advocacy and campaigning processes.
- b. The understanding of NGOs about the concepts of advocacy and campaigning is very basic and remains limited to demonstrations, protests, rallies for accessing entitlements, facilities, services and reservations. There is a need therefore for NGOs to deepen and widen this understanding with a rights perspective based on the human rights framework, where as DPOs have already

deepened their understanding on the concept and are very clear about their vision and mission towards the creation of an inclusive society with no discrimination.

- c. Role conflict as a result of lack of role clarity among DPOs and NGOs has created antagonistic feelings among each other and this requires immediate attention. There is a great need to define specific roles in order to work in harmony with each other for the cause, to achieve convergence and to maximize impact with available resources, person power and infrastructure.
- d. The present model of advocacy and campaigning is largely limited to a block/district/regional level and is mainly focusing on accessing and enhancing the scope of entitlements, implementation of schemes, programmes and existing government orders in few pockets through negotiations, liaisoning and soft demonstrations. This is in contrast with the efforts of a few DPOs who have applied hard-line lobbying, strong demonstrations and protests, negotiations and other strategies at the state level in the process. This calls the attention of stakeholders to build alliances for macro and issue based advocacy and campaigning at state and national levels.
- e. Present advocacy attempts have not significantly contributed in change, amendment, enactment and implementation of existing or new laws and policies towards systemic, structural, institutional and functional changes, which should be the future agenda for advocacy and campaigning.
- f. Conceptual framework, clarity of issues, application of strategies and impact of advocacy and campaigning attempts clearly reveal the capacity building need of DPOs/NGOs. The focus should be on human rights frameworks and instruments, organisational development and management, research and documentation and advocacy and campaigning and should be backed with

adequate and appropriate resources dedicated towards advocacy and campaigning.

- g. Micro level, completely isolated and agency driven processes of advocacy clearly sets the agenda for the creation of a common force for advocacy and campaigning at different levels. This also helps us to bridge the distance between uni and cross disability DPOs, parent's associations and DPOs, DPOs and NGOs, international and national disability agencies, national and international development agencies and larger movements and networks for maximizing impact and reach.
- h. There is a strong demand from NGO and DPO representatives to change the identity and role of international agencies with specific focus on partnership, participation and involvement, consultation, freedom and choice for partner organisations while implementing initiatives supported by international agencies. International agencies should not interfere frequently in the implementation process by imposing ideas, strategies and approaches practiced in different contexts.
- i. There is also a strong demand from DPOs for international agencies to shift in paradigm from a welfare or charity approach to a human rights based approach by ensuring primary accountability towards primary stakeholders, transparency, active participation and involvement of DPOs in the decision making processes of the organisation which affects the lives of persons with disabilities.
- j. NGOs and DPOs also demand to shift the focus from a single disability to a pan disability approach through the inclusion of persons with all types of impairments in the community initiatives supported by international agencies in order to maximize the impact with existing resources.

- k. It is evident from the discussions and interviews that people with a mild and moderate degree of mobility or visual impairment and urban based educated middle class disabled people are playing the key role in the management of cross disability DPOs and their movement. This demands that the stakeholders need to take appropriate steps and affirmative actions to ensure that women/girls with disabilities, people with hearing, intellectual, psychosocial, severe and profound impairments, rural poor and non-literate disabled become part of the movement making it more inclusive and vibrant.
- l. The sector strongly feels that international agencies should be flexible enough to support the initiatives of DPOs/NGOs implemented as per the demand of the sector.
- m. The sector is in a better position to negotiate with stakeholders and should focus on representation and negotiation strategies in advocacy and campaigning initiatives. The third section attempts to relate the first and second sections and suggests specific measures for CBM and Sightsavers to implement the outcomes of this exercise on the ground as per the organisational mandate. The key suggestions include -
- Appropriate amendments should be made to the statutory documents of the organisation such as organisational policies, strategic documents, guidelines, HR policy and procedures, organisational priorities and programme policies with the active participation and involvement of persons with disabilities and DPOs through extensive consultative processes in order to facilitate cross disability/Disabled people's movement through active engagement with DPOs, BPOs and NGOs.
 - Requires the organisation to make a paradigm shift from a welfare/Charity approach to a human rights based approach both at the organisational and the partners' level. This needs to be done with a clear understanding of disability as not merely a

rehabilitation issue but a development and human rights issue which requires multi-stakeholder, multi-dimensional and multi-sectoral action based on a human rights framework in phases with continuity and consistency in the long term process.

- There is a need for appropriate and adequate sensitisation, orientation, visioning and capacity building exercises for the organisational staff to deal with change management and transformation process of the organisation in order to actively engage with DPOs and advocacy/campaigning initiatives.
- There is need for initiating or strengthening of the advocacy and campaigning unit or wing with a well equipped team specifically dedicated to support and coordinate macro level advocacy and campaigning initiatives in partnership with the larger alliance of DPOs, NGOs, persons with disabilities and other appropriate groups and federations.
- There is a strong demand from DPOs/NGOs for the organisation to initiate critical engagement with all persons with disabilities of all types of impairments with specific focus on people with speech and hearing, intellectual, psychosocial, multiple, severe and profound impairments in all the actions and processes of the organisation particularly in community initiatives.
- Statutory changes need to be made in guidelines, monitoring tools and evaluation & assessment tools in order to ensure active participation and involvement of persons with disabilities and DPOs right from the planning process of any initiative approved by the organisation to be implemented by NGOs.
- There needs to be a specific mandate for the partner NGOs to ensure the active participation of persons with disabilities in different stages of disability initiatives. This ensures participation not only in the process of implementation but also in the planning, decision making, monitoring and evaluation processes.

- Massive capacity building programmes need to be organized on human rights framework and instruments, advocacy and campaigning, mobilisation and collective action for existing partner organisations in order to prepare them for changing approaches and strategies of the organisation.
- There is a strong demand from DPOs to initiative specific actions with them directly in order to strengthen their struggle for equity and justice by instituting fellowship programmes for disabled activists and undertaking direct initiatives with DPOs with monetary and technical support.
- A systematic and conscious endeavor needs to be made to build the organisational, management, campaigning and advocacy capacity of DPOs by supporting them in putting systems and structures in place to meet the demands of donor agencies either through partner organisations or directly.
- There is also a strong demand from DPOs and NGOs to change the role and identity of the organisation from merely that of a funding agency to a resource sharing and support agency in the change process.
- There is a great need for international agencies to understand and support the work of agencies/DPOs as per the priority and demand of the sector rather supply driven approach with the rigid programmatic framework of the organisation;

CHAPTER - 5

This chapter is the outcome of this entire exercise and makes a systematic and conscious attempt to put forth a strategic framework for the agencies in order to strengthen their critical engagement with DPOs in the process of advocacy and campaigning efforts. The framework has been divided into goal, objectives and strategic objectives. The strategic objectives include specific strategies and outcomes. The summary of the strategic framework is as follows –

1. HISTORICAL OVERVIEW OF DISABILITY AND DISABLED PEOPLE'S MOVEMENT

1.1 INTRODUCTION

Persons with disabilities form a heterogeneous group in India with a wide range of characteristics such as age, gender, religion, caste, ethnicity, language, category of impairment, degree of impairment and other socio, economic and cultural differences. Some of these identities resulted in further exclusion and deprivation of this invisible minority of the country. They account for 2.13% of the total population of the country, as per the decennial census of India 2001. However the vast majority of stakeholders in the sector feel that this is a huge and gross underestimate. A statistical analysis carried out in 2002 by CBR Network South Asia, a voluntary agency based in Bangalore revealed that persons with disabilities constitute 2.7% of our total population which seems to be little close to the ground reality. Many micro studies and surveys conducted by large and small NGOs in the different parts of the country for implementing disability interventions have demonstrated that the prevalence rate is somewhere between 5-6% of the total population.

1.2 HISTORY OF DISABILITY MOVEMENT

The history of disability movement in India can be traced back to 1887, when the first center for the visual impaired was established in Ludhiana, Punjab in order to rehabilitate visual impaired people who were affected by war casualties. In 1902, the Maharaja of Mysore established a school for people with visual and speech/

hearing impairment in Mysore. This trend continued for a long time and witnessed the setting up of residential care centers, special schools, vocational and rehabilitation centers for different category of impairments. Furthermore, the first known self help movement in the form of an organization called Blind Men's Association was initiated in 1947 in Ahmedabad. Since 1960, '80 and '90s many international agencies like CBM, Sightsavers, Action Aid, LCD etc. initiated projects for rehabilitation and rights of PWDs in the country.

1.3 DISABILITY REHABILITATION AND MEDICAL INTERVENTIONS

Disability agencies, professionals, rehabilitation practitioners and allied technical people controlled and managed rehabilitation of disabled people almost completely without sharing power with the primary stakeholders who were disabled persons themselves. The rehabilitation process for persons with disabilities was carried out by these agencies in bits and pieces and in isolation, more specifically in residential centers. Medical rehabilitation was the key element of all these processes along with a strong component of education. These isolated and centralized interventions were successful in providing some kind of relief to disabled people but did not result in the holistic development and empowerment of the primary stakeholders.

1.4 POLICY AND LEGISLATIVE FRAMEWORK

Equality, dignity, autonomy and liberty are the founding principles on which international human rights law is premised. These values have sufficiently influenced the fundamental law of democratic polity and are reflected in constitutions of most democratic States including India. The Preamble to the Constitution of India while giving a structure and philosophy of governance clearly proclaims to –

'...secure to all its citizens; justice, social, economic and political; liberty of thought, expression, belief, faith and worship; equality of status and of opportunity; and to promote among them all fraternity assuring the dignity of the individual and the unity and integrity of the Nation.. .'

Equality: Under right to equality the Constitution of India guarantees to all citizens equality before law and equal protection of law (Article 14); and it prohibits discrimination on grounds of 'religion, race, caste, sex, place of birth or any of them' (Articles 15 and 16). Further, to ensure equality in the outcome, it encourages the State, under Articles 16(3) and 16(4), to frame any law or make provision for the reservation of appointments or posts in favour of any backward class of citizens, which, in the opinion of the State, is not adequately represented in its services.

There has been a mixed response to the use of reservation as a means to achieve equality amongst unequals. The judiciary has had many occasions to examine not only the legality of such a concept but also its consistency with the right to equality. The most important judgment, which has set at rest all controversy, is the case of Indra Sawhney vs. Union of India. This case is of particular importance for persons with disability since the apex court also examined the legality of reservation in favour of the disabled who are not explicitly covered under Article 16 of the Constitution. The Court held:

'...mere formal declaration of the right would not make unequals equal. To enable all to compete with each other on equal plane, it is necessary to take positive measures to equip the disadvantaged and the handicapped to bring them to the level of the fortunate advantaged. Articles 14 and Article 16(1) no doubt would by themselves permit such positive measures in favour of the disadvantaged to make real the equality guaranteed by them...'

The legislature and judiciary in India have unequivocally promoted special positive measures as a means to achieve substantial equality. In *Dr. Jagadish Saran & Ors Vs. Union of India*, Justice Krishna Iyer held that even apart from Articles 15(3) and 15(4), equality is not degraded or neglected where special provisions are geared to the larger goal of the disabled getting over their disablement consistent with the general good and individual merit.

Non-Discrimination: The formal recognition of discrimination on grounds of disability is a recent phenomenon and laws enacted even twenty years ago generally did not include disability in the list of prohibited discriminations. For instance, the Constitution in Articles 15 and 16 prohibits discrimination in the matter of employment and access to public facilities on grounds of religion, race, caste, sex and place of birth, but is silent on disability. In fact, the service rules until 1995 prevented entry of persons with disabilities in higher grades of service. These rules gave the employer the authority to force premature retirement in public interest and often employees who acquired disability during service were either forced out of job or got their rank reduced. In most cases their opportunity for career enhancement was suspended forever.

The case of *Narendra Kumar Chandla* is one such example where an employee was reduced in rank on acquiring disability during service. Aggrieved by this arbitrary treatment he approached the Supreme Court, which at that stage refused to entertain his petition. He then approached the Punjab and Haryana High Court, which too dismissed his petition. Chandla again filed a Special Leave Petition in the Supreme Court., The Supreme Court justified his appointment in the lower rank as an L.D.C. (clerk), but ordered that his salary be retained at the higher scale which he was initially drawing. No doubt, to some degree the Supreme Court removed the injustice and protected his livelihood, but it did not outlaw discrimination in the matter of career enhancement against persons who acquire disability during service.

Article 41 of our constitution declares that,

'... (T)he State shall, within the limits of its economic capacity and development make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement.' action on the State '(T)o promote with special care the educational and economic interests of the weaker sections of the people, ... and ... protect them from social injustice and all forms of exploitation...'

That was the only reference about persons with disabilities that existed in our statutes till 1987, in which year "The mental health Act 1987" was amended through which persons with psycho-social impairments have got some kind of relief with regard to their treatment. "Rehabilitation Council of India Act 1992" was enacted to regulate training and service agencies along with development of appropriate human resource required for the rehabilitation of persons with disabilities. Indian disabled people had a landmark achievement, when the "Persons with disabilities, [equal opportunities, protection of rights and full participation Act 1995" was enacted which is a progressive legislation for promoting and protecting the human rights of persons with disabilities in the country. "National Trust for the welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities Act 1999" was enacted and came in to force to bridge the gap created by persons with disabilities act 1995 with regard to few category of impairments. National policy was formulated in the year 2006 which provided a broad guideline for interventions to promote the empowerment of persons with disabilities.

1.5 INTEGRATION AND INCLUSION

This so called specialized, technical, specific disability, isolated and medical rehabilitation trend continued for quite some time. The formulation of the new education policy in 1986 resulted in the paradigm shift in the approach and strategies for the development

of persons with disabilities in the country. The concept of integrated education was given adequate emphasis and this concept was promoted through the Integrated Education Scheme few years before the policy. The concept of integration was further challenged by persons with disabilities and organisations of and for persons with disabilities and this reaction gave rise to the concept of inclusion which has been extensively applied in facilitating right to education of children with disabilities. SSA specifically emphasized on inclusive education which significantly contributed to the increase in the enrolment rate of children with disabilities in regular schools.

1.6 COMMUNITY BASED REHABILITATION [CBR]

The Alma Ata declaration in the year 1978 following the slogan of “health for all”, accepted CBR is an important strategy to deal with the issues concerning persons with disabilities. Voluntary agencies made tremendous amount of progress by introducing, implementing and popularizing the concept of Community Based Rehabilitation [CBR] in early 90s. CBM initiated its first CBR programme in 1977 and in 1979 and started supporting integrated education projects. Sightsavers has partnered with over 100 local NGOs for CBR programmes since 1983s in different parts of the country. Action Aid India, a development agency supported 16 agencies across the country to implement CBR initiatives in 1991. This strategy facilitated disabled people from rural areas to access various range of services at their door step. Initially the concept of CBR focused on the medical dimension of disability but during the phase of evolution the concept adopted the rights based approach to deal with the issues of persons with disabilities. Action on Disability and Development [ADD] India, a Bangalore based disability agency promoted the concept of self help among disabled people and facilitated them to organise in to Self Help Groups [SHGs] and federations in early 90s in some parts of South Indian states. This agency also started engaging with development agencies to facilitate inclusive development along with persons with disabilities.

1.7 SELF ADVOCACY AND UNI DISABILITY MOVEMENT

In contrast, the self-help organisations, though relatively small in number, are motivated by a rights-based development orientation. Obviously, the self-help movement is spearheaded by persons with disabilities themselves. The disability movement is an emerging agent of social transformation as it has challenged the society to be more accepting of diversity and differences. Self-help organisations have played a significant role in reshaping public opinion and their contributions in law and policy discourse have been noteworthy.

Any endeavor that seeks to promote the concept of development and human rights necessarily needs to take into account the perceptions of people themselves, as their real participation in the process of development alone can propel the process of change. This is not to suggest the involvement of concerned people in the design and delivery of policies as an end in itself. In fact, it is a means to greater participation in economic, social, cultural and political life.

The support to self-help organisations of the disabled and their parents for advocacy campaigns and for people-to-people empowerment does not come so easily since Indian society accords greater importance to welfare-oriented services.

Prior to the formation of the Disability Rights Group (DRG) in March 1994, the advocacy organization which made its presence felt at the national level was the NFB of India, founded in 1970, an organization inspired by but not directly related to the organization of the same name in the United States. In the 1980s NFB spearheaded a radical blind movement by resorting to methods such as picketing, rallies, hunger strikes, demonstrations, and the like. Therefore, when it came to advocacy for rights of the disabled, it was basically the advocacy movement of the blind led by the NFB for over two decades. In demanding their own rights, the blind often spoke for those of other disabled people as well. These efforts culminated in India's Persons

with Disabilities Act (equal opportunities, protection of rights and full participation), known as the PERSONS WITH DISABILITIES Act of 1995. This initiated a new phase in the history of disability in India, something that needs to be explored and carefully documented, as the following overview of the existing literature in the country is inadequate.

1.8 SELF ADVOCACY AND CROSS DISABILITY MOVEMENT

The publication of noted American journalist Joseph P. Shapiro's, 1993 book *No Pity: People with Disabilities Forging a New Civil Rights Movement* aroused great interest from disability rights activists and scholars of Disability Studies in the United States and India. Shortly after its publication, a discussion was held through video conferencing between some scholars and activists from both the countries. In addition to Shapiro, they included Judy Heumman and Justin Dart, both prominent disability rights activists from the United States, and some leading people involved in disability issues in Delhi in March of 1994.

Soon after that discussion, the Delhi-based group followed up by forming a cross-disability coalition to advocate for the passage of comprehensive legislation ensuring the rights of disabled people in India. The organization was named Disability Rights Group (DRG). A core committee was formed that consisted of people with different categories of disabilities: three blind people, four physically-impaired people, and a scholar interested in people with cognitive disabilities. It was not a highly comprehensive group, but it was a start.

1.9 ADVOCACY BY PARENTS

Learning from the self advocacy movement by uni-disability and cross disability groups, the parents of Persons/Children with intellectual, psychosocial, autism, cerebral palsy and multiple disabilities initiated

groups and parent's associations in order to advocate for the rights of their children. Parivar, a confederation of over 200 parent's associations from different parts of the country was instrumental in the enactment of National Trust Act 1999.

1.10 HARD LAW REGIME

International human rights regime exhibited the legacy of a soft law approach till the adoption of UN Convention on the rights of persons with disabilities -2006. Prior to this land mark development, there were soft instruments such Declaration on the rights of the mentally retarded -1971, Declaration on the rights of disabled-1975, Principles for the protections of mentally ill, World programme of Action, Standard rules for the equalization of opportunities for persons with disabilities-1993 and other regional instruments. These are soft in nature and do not have any legal binding on the states or parties. The adoption of the UNCRPD marked a distinct and definite history of hard law regime for persons with disabilities. India is a signatory and ratified the same. Accepting the obligation, a drafting committee was constituted to draft a brand new law for persons with disabilities in harmony with the spirit and purpose of CRPD.

1.11 ACHIEVEMENTS OF THE DISABILITY MOVEMENT TILL DATE

Disability movement in India refers to all the actions and process facilitated and led by persons with disabilities and their formal or informal groups and federations [DPOS]; all the agencies such as organisations and institutions having different approaches to deal with the issues and working with persons with disabilities; All the groups, federations and organisations of parents of persons with disabilities; disabled and nondisabled activists. These actions and process have made progress to varied extents which are summarised as achievements of the disability movement:

1. Enactment of persons with disabilities [Equal opportunities, protection of rights and full participation] Act 1995 is a landmark achievement which had gifted persons with disabilities of the country with a progressive law with rights framework.
2. Parent's associations, organisations and interest groups were successful in the enactment of "National Trust for the welfare of Persons with autism, cerebral palsy, mental retardation and multiple disabilities Act 1999 in order to deal with the specific issues of these categories of disabilities which were not addressed by Persons with Disabilities Act 1995.
3. Persons with disabilities were included in the decennial census of India 2001 as a distinct group along with other specific sections of the society in order to assess the situation of this most excluded and marginalised section.
4. Hon. Supreme Court of India in its interim and final judgment, directed the GOVT and chief election commissioner to ensure a barrier-free and completely accessible election process in the 2004 general elections of the country and then onward.
5. A specific section has been dedicated for persons with disabilities with enhanced budgetary provisions in the 11th five year plan of India through extensive consultations facilitated by sub-groups with primary and secondary stakeholders.
6. Ratification of UN Convention on the rights of persons with disabilities 2006 by India on 01/10/2007 without any reservations towards the fulfillment of international obligation arose out of signing the UNCRPD on 30/03/2007 as a result of the mounting pressure by the disability movement.
7. Successfully influenced the government to incorporate the specific section to address the specific issues of children with disabilities in the "Right to Education Act 2010".

8. Convinced the government to draft a new law on the rights of persons with disabilities in order to replace the existing Persons with Disabilities Act 1995 towards implementation of the provisions enshrined in UNCRPD. A drafting committee was constituted with adequate representation of persons with disabilities which prepared the working draft and put the same before disabled people of India for comments through extensive consultations across the country.
9. Many progressive court orders, Hon. Supreme and High courts judgments, orders passed by Chief and state Commissioners office, statutory circulars by various state agencies and institutions, policy changes and appropriate amendments to various statutes were the result of the sustained lobbying and advocacy by DPOs and disability movement of this country.



2. PROCESS AND METHODOLOGY

2.1 CONTEXT

Sightsavers International, earlier the Royal Commonwealth Society for the Blind, works to combat blindness in developing countries, restoring sight through specialist treatment and eye care. Sightsavers supports people who are irreversibly blind by providing education, counseling and training. Today, Sightsavers works with partners in over 30 countries and its mission has expanded to also provide services to the blind and campaign for the eradication of needless blindness.

Their programmes have been providing direct service delivery to the target group of eye care & social inclusion projects. The services thus have been mostly limited to what the implementing partner agencies could deliver directly. The emphasis of the programme has been on social inclusion and economic rehabilitation of the blind and low vision persons in the rehabilitation projects. The initiatives have been project based targeting the needs of limited number of beneficiaries.

The Sightsavers strategic plan for 2009-2013 has a one of the long term goals to ensure that “visually impaired people are equal members of society and governments implement obligations under international conventions for disabled people”. To achieve the long term goal Sightsavers wishes to develop programmes that will “Enable BPOs and DPOs to advocate effectively for their members rights”. Sightsavers has traditionally worked with general development organisations who now have also developed some understanding about the needs of visually impaired persons and

disability in general. Thus Sightsavers also wishes to include them in the process wherever possible.

CBM is an international development organisation, whose primary purpose is to improve the quality of life of the world's poorest persons with disabilities and those at risk of disability.

Working with persons with disabilities, CBM advocates for their inclusion in all aspects of society. As of 2012, CBM supports more than 800 projects in around 90 countries in Africa, Asia, Latin America, and Eastern Europe. Through its partner organisations, CBM currently reaches 25 million people and aims to reach many more in the coming years. CBM uses comprehensive, sustainable, and community-focused approaches, which contribute to poverty alleviation and self-reliance. CBM partners develop high-quality preventive, curative, educational, rehabilitative, livelihood, and advocacy programmes, which are designed to maximise the quality of life of persons with disabilities.

2.2 PURPOSE OF THE EXERCISE

To identify the best means for Sightsavers & CBM SARO(S) to advocate for the rights of persons with disabilities by working with BPOs, DPOs and general development organisations.

2.3 SPECIFIC OBJECTIVES

- To identify major organisations (BPOs, DPOs and NGOs) who are actively working for the rights of persons with disabilities.
- To understand the major issues related to rights of persons with disabilities on which advocacy work is going on or will have to be started for in India. To understand the strategies adopted, programmes implemented and learnings by organisations (NGO, BPO & DPO) for advocating for the rights of persons with disabilities.

- To identify the capacity building needs of the BPOs and DPOs and the strategy of the same.
- To develop a road map and a strategy for Sightsavers and CBM SARO(S) in order to develop and implement the advocacy programme in India.

2.4 KEY QUESTIONS ANSWERED

a) Advocacy needs of disabled people

- Identifying major issues related to rights of disabled people
- Enactment or reform of legislations, policies to ensure non-discrimination
- Effective monitoring and implementation of existing laws, policies, schemes (Persons with Disabilities Act, National Rural Employment Guarantee Act, Right to Information Act)
- Better grievance redressal mechanisms
- Improvement in legal and related services
- Facilitating change in attitudes

b) Current advocacy efforts

- Organisations, BPOs, DPOs currently undertaking disability advocacy
- Advocacy Strategy – Evidence based advocacy, issues, message, intended audiences, time period
- Advocacy channels used – public, direct advocacy
- Advocacy mode - events, letter campaigns, sit-in protests
- Advocacy with whom - policy makers, influential people etc
- Advocacy aimed at – general public, health workers, policy makers etc.

- Participation by - disabled people (gender and disability break-up), caregivers, NGOs
- Advocacy model – local, district, state, national level; federations, individuals, groups etc.
- Coalitions/partnerships developed
- Resources – mobilized and spent
- Advocacy Impact
- Lessons learnt and Best Practices

c) Advocacy capacity among BPOs/DPOs and development organisations

- Awareness on legal provisions, UNCRPD, advocacy needs of disabled people, rights
- Assessment of their advocacy skills (planning and executing an advocacy programme)
- Assessment of resources – staff, networks/partnerships, financial resources.

d) Sightsavers and CBM

- Current strategy on advocating for the rights of disabled people
- Assessment of resources - staff (number, skills), financial resources

2.5 METHODOLOGY

This document is the outcome of a culmination of views, responses, expressions and suggestions of a wide range of stakeholders through extensive consultations held across the country. The

key stakeholders who have actively participated in the process include; 23 [15.03%] women/girls and 65 [42.48%] Men/Boys with disabilities, 17 [11.11%] women/girls and 48 [31.37%] Men/Boys without disabilities representing 72 Agencies/Federations/Groups/DPOs from 16 states and UTs.

The key methodologies applied to this process include- consultative workshops, Focus Group Discussions, telephonic interviews, interactions and a review of secondary literature.

Consultative workshops – 5 workshops, 2 for DPOs and 3 for NGOs were facilitated at Bangalore, Bhopal, Hyderabad, and Delhi in order to facilitate the participants from different parts of the country. 19 [21.11%] Women/Girls and 71 [78.89%] Men/Boys with and without disabilities representing 68 voluntary organisations/DPOs took part in the discussion processes.

FGD with SHGs: FGDs were facilitated with the members of SHGs of persons with disabilities in which 12 [24.48%] Women/Girls and 18 [36.73%] Men/Boys with disabilities and 6 [12.24%] Women/Girls and 13 [26.53%] Men/Boys without disabilities as parents representing SHGs and members took part in the discussion process.

Telephonic interview was facilitated with 3 [21.42%] Women and 11 [78.58%] Men with and without disabilities who represented activists and professionals in the field.

Extensive literature review was carried on in order to collect information on the historical overview of disability and disabled people's movement in India.

Interactions with state officials – Women and men with and without disabilities were interacted with who represented the government from various departments.

2.6 LIMITATIONS OF THE STUDY

Limitations

- 153 respondents from 72 agencies from 16 states have participated in the process which may not be a true representative sample considering the total disabled population, diversities and geographical size of the country.
- Few key respondents were not able to participate in the research process due to unexpected incidents as a result of which few important views and opinions could not be captured by the research.
- Stratified sampling method was used in the selection process of final sampling and there are chances of missing key respondents who hold a unique and different view about the issues discussed in the study.
- The research did not have control over the primary respondents who were deputed by the head of agencies and organizations who may not have had updated information about their organization and their recent advocacy and campaigning activities.



3. DATA PRESENTATION

3.1 CONSULTATIVE WORKSHOPS FOR NGOS AND DPOS

5 consultative workshops were facilitated for the representatives of 68 Agencies/Federations/Groups/DPOs from 16 states and UTs involving **11 [12.22%]** women/girls and **40 [44.44%]** Men/Boys with disabilities and 8 [8.88%] women/girls and **31 [34.44%]** Men/Boys without disabilities. The summary of the outcomes of these workshops is stated in table-1:

Table-1 Experiences of NGOs and DPOs in advocacy and Campaigning

Questions	NGOs	DPOs
Issues	<ul style="list-style-type: none"> ● Accessing and enhancing the scope of entitlements ● Enrolment to regular schools ● Implementation of Quota and reservations ● Affirmative actions/preferential treatment ● Access to banking, mental health care, natural and built environment 	<ul style="list-style-type: none"> ● Access to entitlements, services & facilities ● Enhancing the scope [Increase in the amount of pension] and additions to entitlements (housing) ● Implementation of quota and reservations ● Admissions to education ● Employment issues

	<ul style="list-style-type: none"> ● Political participation and inclusion ● Corruption in accessing entitlements ● Violence against women/girls with disabilities ● Implementation of 3% reservation ● Implementation of PWD Act ● Barrier free environment 	<ul style="list-style-type: none"> ● Political participation ● Separate ministry ● Human rights violations ● Increasing resource allocation & utilization ● Participation of disabled people in Decision making process ● Access to natural & built environments ● Inclusion in Government schemes such as NREGS
Role	<p>DPO: Implementation, participation, Decision making.</p> <p>NGOS: Facilitation, Technical advice, Support to resources and infrastructure.</p> <p>Liaisoning with the government</p>	<p>NGO: Facilitation, information Sharing, solidarity.</p> <p>DPO: Planning, implementing, decision making, Monitoring and leadership.</p>
Strategies/ Methods	<ul style="list-style-type: none"> ● Mass Mobilisation ● Capacity building ● Demonstrations in various forms 	<ul style="list-style-type: none"> ● Mobilization ● Different types of campaigns (SMS, Letter, Signature, Post card, email campaigns etc)

	<ul style="list-style-type: none"> ● Use of IEC material ● Campaigning in different forms ● Negotiating with Government bodies & judiciary ● Setting up groups to advocate 	<ul style="list-style-type: none"> ● Demonstrations ● Judiciary (filing of PIL) ● Use of media ● Consultations & seminars ● Social audit & public hearings ● Negotiations and Liaisoning ● Use of judiciary and Filing petitions
Changes/ Impact	<ul style="list-style-type: none"> ● Systemic – Circulars, rules and procedures. ● Policy – GOs and amendment to GOs ● Process – achieved immediate remedy 	<ul style="list-style-type: none"> ● Policy [Issue of GO, amendment to old GOs] ● Systemic [Circulars, procedures, rules, functions] ● Increased participation in the decision making process ● Increased Budget allocation ● Increased Visibility of DPOs and disabled people's movement ● Attitudinal changes ● Institutional changes and Proactive actions of the state

Challenges	<ul style="list-style-type: none"> ● Resources ● Mobilisation of persons with disabilities ● Awareness on laws and policies ● Disunity among DPOs and individuals ● Lack of clarity of Objectives and issues among DPOs ● Huge turnover of sensitised and trained officials ● Lack of technical skills ● Lack of media support ● Lack of implementation of government policies, transfers of officers etc. 	<ul style="list-style-type: none"> ● Resource mobilisation ● Administrative capacity of DPO ● Differences of opinion between different groups ● Antagonistic attitude between NGOs & DPOs ● Vested interests of NGOs and remote controlling ● Lack of awareness about disability and violence on disabled
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Table-2 Concept and meaning of Advocacy

NGOs	DPOs
<ul style="list-style-type: none"> ● Fighting for equal opportunities and protection of rights of persons with disabilities ● Process of empowering, protecting rights and entitlements 	<ul style="list-style-type: none"> ● Sensitizing & empathizing process ● Giving voice to voiceless ● Raising voice against injustice

<ul style="list-style-type: none"> ● Mobilizing people around some common issue that affects their lives ● Influencing policies and activating the delivery mechanisms ● Fighting/Resisting against injustice and Changing policies and systems ● Influencing public opinion and media ● Facilitating social inclusion and Addressing issues ● Process to end injustice and discrimination ● Process of pressurizing and influencing stakeholders ● Convincing and changing mindset ● Balancing the power equations 	<ul style="list-style-type: none"> ● Addressing violation of human rights with involvement of oppressed ● Struggle for equal participation and rights ● Addressing need based issues through legal framework
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Table-3 Concept and Role of DPOs

Questions	NGOs	DPOs
Meaning	<ul style="list-style-type: none"> ● A group of persons with disabilities including family members to achieve common goal 	<ul style="list-style-type: none"> ● DPO is an organization of persons with disabilities only.

Active participation	<ul style="list-style-type: none"> ● Persons with mild and moderate degree from few category of impairments ● Literate and educated 	<ul style="list-style-type: none"> ● Persons with visual and mobility impairment ● Men/Boys with impairments ● Poor and middle class ● Rural disabled people participate ● Management lies with urban disabled people
Objectives	<ul style="list-style-type: none"> ● Empowerment, ● Inclusion and inclusive development, ● End discrimination and injustice, ● Accessing rights and entitlements, political representation and participation ● Creation of role models 	<ul style="list-style-type: none"> ● Mobilisation for fighting injustice, discrimination and exclusion ● Promote and protect rights ● Empowerment and holistic development ● Change attitudes, systems, policies
Role in Programme	<ul style="list-style-type: none"> ● DPO: Implementers, ● Facilitators, ● Resource persons, ● watch dogs, advocates, Deciding issues, Networking and linkage building 	<ul style="list-style-type: none"> ● NGO: Facilitation, Equal partner, Resource provider

Effectiveness	<ul style="list-style-type: none"> ● Quite effective ● Presence is relevant 	<ul style="list-style-type: none"> ● Very effective, Nothing about us without us
General feedback	<ul style="list-style-type: none"> ● Individual driven leadership ● Disunity and differences ● Antagonism and threatening ● Leadership crisis and effective functioning ● Dependency of NGOs and need capacity building ● Need for transparency ● Need for pan disability and inclusion of family perspectives 	<ul style="list-style-type: none"> ● Remote control ● Vested interest ● Threatening ● Lack of Accountability and Transparency

Table-4 Difference between Advocacy and Liaisoning

NGOs	DPOs
<ul style="list-style-type: none"> ● Advocacy is larger process while liaisoning is small part of the larger process ● Advocacy is systemic while liaisoning is ongoing ● Advocacy needs more people while Liaisoning can be done by one 	<ul style="list-style-type: none"> ● Advocacy is systematic and Liaisoning is on going ● Advocacy is mostly collective action and Liaisoning is one to one ● Aims at changing policy and institutional framework and aims at building rapport

<ul style="list-style-type: none"> ● Liaisoning is rapport building process while advocacy is influencing and lobbying ● Former is generic and the latter is specific 	<ul style="list-style-type: none"> ● Advocacy is fighting for rights, liaisoning is convincing ● Hard approach, Soft approach.
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Table-5 Priority issues for Advocacy and Campaigning

NGOs	DPOs
<ul style="list-style-type: none"> ● Inclusive Schemes, programmes and development ● Barrier free natural and built environment ● Access to services, schemes and entitlements ● Effective implementation of quota system and reservation policies ● Political participation and representation ● Access to Health care with particular reference to mental health ● Formation and strengthening of DPOs ● Inclusive curriculum with explicit focus on disabilities in teacher training and other study programmes ● Employment ● Building awareness about schemes 	<ul style="list-style-type: none"> ● Harmonizing laws & policies in line with UNCRPD (1) ● Accurate collection & utilization of data of persons with disabilities (2) ● Access to quality education under appropriate environment (3) ● Access to livelihoods (4) ● Effective implementation of policies (4 again) ● Access to Social protection or social security, reservations etc (5) ● Specific structure such as ministry for disabilities (6) ● Access to built & natural environment ● Protection against exploitation, injustice, abuse and human rights violation

<ul style="list-style-type: none"> ● Social & cultural activities ● Focus on rural development 	<ul style="list-style-type: none"> ● Effective and timely utilization of resources ● Political participation (reservation & separate ministry)
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Table-6 Perceived and Proposed role of International agencies

Questions	NGOs	DPOs
Current understanding	<ul style="list-style-type: none"> ● Sensitisation ● Funding ● Service delivery ● Capacity building ● Networking and resource mobilisation ● Advocacy and campaigning 	<ul style="list-style-type: none"> ● Support for services ● Support to build network of NGOs ● Lack information about DPOs ● Scared of hard core advocacy work and rights approach ● No clarity about certain aspects of the work ● Do not ensure sustainability ● They pitch at the micro-level and not about scaling up
Proposed role	<ul style="list-style-type: none"> ● Formation and Strengthening of DPOs ● Capacity building of DPOs and NGOs 	<ul style="list-style-type: none"> ● Directly engage with DPOs ● Ownership of program is with DPOs

	<ul style="list-style-type: none">● Networking and resource mobilisation● Advocacy and campaigning● Skills training for employment● Shift from charity (service delivery) to right based approach● They should support in improving the health system● Promoting inclusive strategies focused on disability● Sustainability policy● Disability must be included as one components in all the programmes supported by these INGOs● Creating platform● Enhancing the scope of development issues● Information sharing on best practices	<ul style="list-style-type: none">● Invest in capacity building of DPOs● Use human rights based approach not service delivery● Share info and publications with DPOs● Help DPOs build alliances at macro levels● Should have clarity on purpose of funding● Should build their capacity to engage with DPOs
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	<ul style="list-style-type: none"> ● Sensitizing the legal systems ● Building sustainable livelihood options 	
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Table-7 Areas of capacity building needs of DPOs

NGOs	DPOs
<ul style="list-style-type: none"> ● Human rights framework and instruments ● Capacity building in Research ● Managerial/management capacity ● Building DPOs of all category of impairments ● CBR training 	<ul style="list-style-type: none"> ● Research, development & documentation ● human rights instruments and frameworks, ● leadership development & training of trainers, ● organizational development and management, ● advocacy & campaigning

Table-8 Expected support for capacity building from international agencies:

NGOs	DPOs
<ul style="list-style-type: none"> ● Financial support ● Exposure visits ● Building alliances ● Providing financial support for administration of DPOs ● Technical Expertise ● Review and monitoring 	<ul style="list-style-type: none"> ● Direct engagement with DPOs ● Resources and infrastructure ● Fellowship and sponsorship ● Alliance of cross disability organisations ● Technical support and expertise

3.2 TELEPHONIC INTERVIEW WITH INDIVIDUAL ACTIVISTS WITH AND WITHOUT DISABILITIES

Telephonic interviews were facilitated with activists, professionals and state authorities in order to have their views on advocacy, campaigning and engagement with DPOs. 14 [70%] out of 20 respondents responded to the request which included 3 [21.42%] Non-disabled women, 4 [28.57%] non-disabled men, 7 [50%] men with disabilities representing various arenas of disability and development, geography and sectors. The summary of the interview has stated in the following table –

Table-9 Summary of telephonic interviews

Questions	Responses
Concept of Advocacy	Tool for Influencing public policies in favour of disabled people; Critical engagement with state, civil society and other actors; Tool to secure rights and fundamental freedoms; Way of application of rights based approach; Speaking, writing and Acting for a cause; Enabling people to exercise their rights;
Present situation of Advocacy	Divided between uni and cross disability organisations; Sporadic and not consistent; No synergy between players; Advanced, well informed with greater awareness; Regionalized; single disability focused; Awareness raising; Isolated and micro level efforts; Limited to accessing entitlements; No impact in rural part of India;
Effectiveness of Advocacy so far	Not very strong; Effective in enactment and amendment of legislations; Few systemic and structural changes;

Suggested strategies for enhancing effectiveness	Rotational leadership of cross disability movement; Synergy between uni and cross disability groups and general human rights movement; Specific focus on rural poor disabled; Facts and data through research; Active involvement of parents; Material development; Engagement with academia and general development agencies; Socializing disability issues; addressing root causes; Unity of persons with disabilities and DPOs on common minimum agenda; Specific issue with clear and measurable outcomes;
Priorities for advocacy in future	Implementation of UNCRPD, existing policies and laws; Harmonizing domestic laws and policies with CRPD; Ensuring state accountability; Gender equity and justice; Quality education; Rural employment; Protection and justice; Inclusive development; Access to entitlements and information; Increase resource allocation; inclusive programmes and internationally agreed goals and targets; Health care; Capacity building of DPOs; Disparity between rural & urban; Social security; companionship and care giving; assistive technology;
Scope for collective action by INGOs and NGOs	Partnering local agencies; Specific focus on advocacy; Synergy between service providers and advocacy organisations; Only through active engagement with DPOs; Alliance building;
Role of INGOs in Advocacy	Funding, Capacity building, empowering, alliance building with key players of strategic importance; influencing DPOs to include all types of impairments; Building replicable models; building expertise;

Experience with DPOs	Urban centric, individual dominated, limited progress; Articulate and vocal; Narrow minded and outdated; Not completely inclusive; Egoistic; multiple issues at a time;
List of DPOs	NFB, DPI, AICB, DRG, Kerala Federation of Blind, Karnataka Federation of Blind, All India Federation of Deaf, NFD, Society for physically handicap, Mandya Federation, Ramanagara Federation,
Role of DPOs in Advocacy	Leadership, Management, Control; Changing language; developing guidelines and reports;
How effective DPOs are?	Slow progress; Very effective and vibrant; Isolated;
Position and Role of INGOs in Advocacy in future	Facilitating, Capacity building, Engagement with DPOs; Advocacy should be a cross cutting theme; Formation of united front advocacy unit; Material development; creation of knowledge base; National advocacy and campaigning; setting better monitoring standards;
Remarks/ Comments	Multi-prong strategy, multiple stakeholder engagement; Collaborations with local agencies; Advocacy should be based on the core principles of UNCRPD;

3.3 FGD WITH THE MEMBERS OF SHG OF DISABLED PEOPLE

FGDs were facilitated with the representatives of SHG/Federation of persons with disabilities in which 12 [24.48%] Women/Girls and 18 [36.73%] Men/Boys with disabilities, 6 [12.24%] Women/Girls and 13 [24.53%] Men/Boys without disabilities actively took part in the meeting. Representatives without disabilities are largely the parents or family members of persons with disabilities who represent their disabled member in the group meetings. The FGD was facilitated with a semi structured interview guide which was conducted by the

partner organisations of Sightsavers and CBM. The summary of the FGD is as stated below:

Q1. Group Details:

Particulars	Details
Location-No. of districts/States	Districts: 4 States: 3
Total members with gender and impairment break up	Male: $707+400+12+228+ 16+19 = 1382$ Female: $83+320+2+140 = 545$ Total: 1927 Data without break up is taken as all male.
Duration of functioning in Years	0-1:0 1-3: [2] 4-6: [2] 7-10:[1] 10-Above:
Key Achievements	<ul style="list-style-type: none"> ● Accessed entitlements such as bus passes, BPL cards, NREGS job cards, housing schemes, livelihoods ● Advocated and successfully restored PWD pension of 2500 people that had been stopped by the government at the mandal and district level ● Conducted study on behaviour of government officials with PWDs and submitted the same to the district magistrate
Total Savings	$6500+100000+4000+19000= 129500$
General Activities	Accessing entitlements, schemes, programmes, mobilization of local resources, referral services, regular review meetings, participation in mandal & district level meetings,

	Monitoring to ICDS program and Immunization, participating in Pallisabha, Counseling to families with CWDs for their education at formal school, village sanitation work with Gaon Kalyan Samiti, information sharing among members
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Q2. Discussion outcomes:

Questions	Responses
2. Objectives of the group	Generate awareness on rights, entitlements, facilities and Services
	Fight for rights, Promote integrity among disabled people, Promote social inclusion and Development & empowerment, welfare of PWDs Collective action to ensure human rights & dignity of PWDs
3. Extent of Achievement of objectives	60% in accessing entitlements; have organized themselves and accessed rights, villagers are now involving PWDs in regular activities and meetings, formed an identity among major stakeholders at block & district levels.
4. Understanding on the concept of Advocacy	Fighting for rights, entitlements, schemes and fight against discrimination and exclusion; Voicing issues and concerns to stakeholders; demanding rights at all levels; remain within legal framework, collaborative efforts
5. Advocacy initiatives taken up	Micro level initiatives to access entitlements and schemes, restored pension entitlements for 2500 PWDs, bank linkages

6. Rate of success in advocacy	Significant success in accessing entitlements and schemes; protecting rights of PWDs; bank linkages provided after long debates and sensitization of bank employees
7A. Examples of achievements	Accessed compensation for death; accessed bus pass with escort facility; restored pension scheme for 2500 people at the local level, linked PWD groups with DRDA banks and finance sources through advocacy, some members have been elected at local government positions, upheld the right of a PWD to stand for elections and matter is under district disability commissioner's jurisdiction
7B. Examples of unsuccessful actions	Could not fight against corruption and had to pay the demanded amount for issuing pension; group dynamics within the PWD group
8. Need for formation and strengthening of groups/ Federations	Strongly felt; Strengthen mobilization and unity; better information on acts & UNCRPD, financial sustainability, economic rehabilitation, PWDs issues are not in public view due to lack of visible and organized efforts, PWDs need to be interconnected, look into geographical spread and difficulty of terrain
9. Need for advocacy	Strongly felt, to implement acts & schemes, to achieve a barrier free environment; policy needs to be changed, to educate PWDs about their rights
10. Who advocated , Who partnered	Advocated: DPOs; members of PWD forums at local & district levels; group leaders Partnered: NGOs, media, public, CBOs

11. Role of Agencies/ Organisations in mobilization and advocacy	Mobilization and Strengthening; Capacity building with exposure; Resource mobilization; Sensitization; information & facilitation; support in highlighting issues at media level, provide a platform and promote group formation
12. Priority issues for advocacy	Right to employment; Education; Livelihood development; implementation of UNCRPD; access & availability of resources; social inclusion; vocational training, financial support for self employment; providing BPL status to all families with PWDs; 10% reservation in livelihoods etc, single window delivery system for entitlements,
13. Awareness about international agencies	Majority are not aware about international agencies
14. Proposed Role of international agencies	Capacity building; funding; direct engagement; facilitation; advocacy
15. Expected role of international agencies	Exposure, Capacity building; Direct engagement; information update, legal support; promotion of livelihoods; linkage for skill building and livelihoods
16. Proposed ways of partnership with international agencies	Improving systems and Functions; Alliance and linkage building at macro level; membership in rights based groups at all levels, Involvement of NGO as advisory; acquiring memberships in PWD forums of NGOs.

4. FINDINGS AND ANALYSIS

4.1 FINDINGS

These findings are largely derived from the responses of those who have actively participated in the process during consultative workshops, telephonic interviews, FGDs and interactions for the purpose of this study. Kindly refer Chapter-3 for more details about the findings.

- A. Majority of DPO representatives strongly feel that a DPO is the group of persons with disabilities alone and should not include non-disabled people regardless of parents and care givers since persons with any type of impairment is in the best position to raise and address the issues of all disabled people. Inclusion of non-disabled people into DPOs, even the parents of children with disabilities, will dilute the focus and may ignore the best interest of persons with disabilities.
- B. Majority of NGO representatives strongly feel that DPOs should be inclusive of persons with all types of impairments including parents for representing their children with disabilities and adults with disabilities who have difficulties in expressing their feelings, thoughts and needs. Few NGO representatives strongly feel that DPOs should not be inclusive of parents since the role and organisations of parents differ from that of DPOs but both can support each other in the larger advocacy processes.
- C. Majority of NGO representatives strongly feel that DPOs are in the initiation stage and have not been quite effective in advocacy and campaigning due to disunity, individual differences, leadership

crisis, inadequate management/technical capacity and limited reach.

- D. Both the representatives strongly feel that presently persons with visual and mobility impairment- men, urban based, literate, middle class and disabled people from the upper strata of society are playing a key role at the macro level in DPOs and advocacy initiatives but rural poor disabled are actively participating in the group activities at the micro level. Management and leadership of DPOs lies with urban based middle class persons with disabilities and rural poor disabled people are playing only a support role in the management and organisational development of DPOs.
- E. Majority of DPO and NGO representatives strongly feel that both entities are antagonistic and threatened by each other's presence due to lack of role clarity amongst them. NGOs feel that the empowerment of persons with disabilities and DPOs are a potential threat to their own existence since limited resources will get distributed among NGOs and DPOs and hence DPOs should completely be managed by NGOs. DPO representatives strongly feel that DPOs are created by NGOs for their own benefit and NGOs want to have a remote control over DPOs to mobilise resources.
- F. Majority of the respondents strongly feel that they have taken up advocacy and campaigning activities largely on the issues with regard to access to entitlements, enhancing the scope of entitlements, school admissions, inclusive and accessible election process, effective implementation of reservation and quota system, implementation of legal commitments of the state, issues of discrimination and exclusion, violence and abuse against women/girls with disabilities etc.
- G. Key strategies adopted by these agencies include mobilisation of persons with disabilities, various forms of campaigns,

demonstrations and protest rallies, filing petitions, use of media and extensive use of the right to information act.

- H. The major achievements of these actions and initiatives are limited to issue of government orders, circulars, increase in pension, inclusion of excluded groups in the scope of entitlements, change of institutional and structural functions and unmet assurances. There is a great need to take up key issues such as systemic, structural and functional changes, ensuring the representation and participation of persons with disabilities in the decision making process, inclusive development, schemes, programmes, policies, actions and processes.
- I. Both the representatives strongly feel that there is a great need to build the capacity of DPOs in organisational development and management, advocacy and campaigning, human rights framework and instruments, research and documentation, resource mobilisation and leadership development.
- J. Representatives of autonomous DPOs strongly feel that they have been playing a leading role in advocacy and campaigning but NGOs and NGO supported DPO representatives strongly feel that DPOs have been just participants, implementers and facilitators in disability initiatives and advocacy and campaigning initiatives.
- K. The key challenges faced by both DPOs and NGOs in advocacy and campaigning actions largely include – resources, mobilizing people, disunity among DPOs, vested interests, statutory obstacles, effective leadership among DPOs etc.
- L. Both the representatives strongly feel that INGOs have been supporting NGOs with monetary resources, capacity building, and technical expertise to carry forward advocacy initiatives and strongly feel that INGOs should be equal partners, facilitators, resource sharing and capacity building agencies, macro players and alliance building catalysts.

- M. DPO representatives strongly feel that INGOs should have direct engagement with DPOs through various ways such as support fellowship, directive initiatives, capacity building, exposure and alliance building process with a conscious attempt towards building the organisational capacity and systems to meet the requirements of INGOs to receive monetary resources.
- N. Majority of the respondents strongly feel that advocacy and campaigning is in the initial stages in India. INGOs should have a specific focus on advocacy and campaigning as a cross cutting theme or issue in any of the organisational initiatives with adequate budget allocation and clear measurable outcomes.
- O. Majority of the respondents strongly feel that INGOs should have a dedicated person for advocacy and campaigning in order to liaison with, facilitate, network, develop partnerships, engage in capacity and alliance building, leverage, linkage building and coordinate national level campaigning initiatives in partnership with other NGOs and INGOs.
- P. Both the representatives strongly propose following issues as priority agendas for advocacy and campaigning for coming years. However DPO representatives strongly feel that political representation, participation, increased resource allocation, atrocities, violence, physical, mental and sexual abuse against persons with disabilities particularly women/girls with disabilities should be on the top of the priority list. The issues of common interest are as follows:
- i. Harmonizing the domestic laws in line with UNCRPD and its effective implementation;
 - ii. Speedy and effective implementation of existing statutes, quota system, laws, policies, schemes, programmes and related GOs;

- iii. Access to quality education, health care, recreation, livelihoods, entitlements and services;
 - iv. Active representation and participation in decision and policy formulation processes;
 - v. Demand for exclusive structure and institutional arrangement such as ministry, secretariat, offices at district and block levels;
 - vi. Reservation for Political representation and participation;
 - vii. Accurate data collection and utilisation;
 - viii. Access to mental health care and services;
 - ix. Enhanced resource allocation, utilisation and inclusive development;
- Q. Both the respondents strongly feel that the sector is powerful with appropriate and adequate human rights instruments in order to negotiate with the concerned stakeholders rather only through confrontation/

Few respondents with and without disabilities strongly feel that DPOs should be lead and managed by persons with disabilities and should not isolate from nondisabled community but work together for strategic advantages;

4.2 ANALYSIS

- DPOs and NGOs have a slightly different understanding about the concept of a DPO with regard to composition, membership, role, structure and functions which needs consensus through convincing them about the specific roles and accountability of DPOs and NGOs in the advocacy and campaigning process.
- The understanding of NGOs on the concept of advocacy and campaigning is different and limited to demonstrations, protest,

and rallies for accessing entitlements, facilities, services and reservations. There is a need to deepen and widen this understanding with a rights perspective based on the human rights framework, where as DPOs have deepened their understanding on the concept and are very clear about their vision and mission towards the creation of an inclusive society with no discrimination.

- There is a role conflict as a result of lack of role clarity among DPOs and NGOs which has created antagonistic feelings among each other. This requires immediate attention so that one can define specific roles for each in order to work in harmony with each other for the cause and achieve convergence and maximum impact with available resources, person power and infrastructure.
- The present model of advocacy and campaigning is largely limited to block/district/regional level and is mainly focused towards accessing and enhancing the scope of entitlements, implementation of schemes, programmes and existing GOs in few pockets through negotiations, liaisoning and soft demonstrations. This is in contrast to DPOs who have applied hard-line lobbying tactics, strong demonstrations and protests, negotiations and other strategies at the state level in the process. There is need to therefore call the attention of stakeholders to build alliance for macro and issue based advocacy and campaigning at state and national level.
- Present advocacy attempts have not significantly contributed in change, amendment, enactment and implementation of existing or new laws and policies towards systemic, structural, institutional and functional changes, which should be the future agenda for advocacy and campaigning.
- Conceptual framework, clarity of issues, application of strategies and impact of advocacy and campaigning attempts clearly reveal the capacity building need of DPOs/NGOs on human

rights framework and instruments, organisational development and management, research and documentation, and advocacy and campaigning which should be backed with adequate and appropriate resources dedicated towards advocacy and campaigning.

- Micro level, completely isolated and agency driven processes of advocacy clearly set the platform for the creation of a common force for advocacy and campaigning at different levels by bridging the distance between uni and cross disability DPOs, parent's associations and DPOs, DPOs and NGOs, international and national disability agencies, national and international development agencies, larger movements and networks for maximizing impact and reach.

There is a strong demand from NGO and DPO representatives to change the identity and role of international agencies with specific focus on partnership, participation and involvement, consultation, freedom and choice for partner organisations while implementing initiatives supported by international agencies. International agencies should not interfere frequently in the implementation process by imposing new ideas, strategies and approaches practiced in different contexts.

- There is also a strong demand from DPOs for international agencies to shift in paradigm from a welfare or charity approach to a human rights based approach by ensuring primary accountability towards primary stakeholders, transparency, active participation and involvement of DPOs in the decision making processes of the organisation which affects the lives of persons with disabilities.
- NGOs and DPOs also demand to shift the focus from a single disability to a pan disability approach through the inclusion of persons with all types of impairments in the community initiatives supported by international agencies in order to maximize the impact with existing resources.

- It is evident from the discussions and interviews that people with a mild and moderate degree of mobility or visual impairment and urban based educated middle class disabled people are playing the key role in the management of cross disability DPOs and their movement. This demands that the stakeholders need to take appropriate steps and affirmative actions to ensure that women/girls with disabilities, people with hearing, intellectual, psychosocial, severe and profound impairments, rural poor and non-literate disabled become part of the movement making it more inclusive and vibrant.
- The key role of NGOs and agencies is to ensure the provision of services for persons with disabilities, implementing micro projects, building successful models and facilitating the formation and strengthening of DPOs since NGOs have statutory limitations in getting into hard line advocacy and campaigning. The key role of DPOs is to mobilise persons with disabilities in to groups and federations, building and strengthening structure of the movement, hard line advocacy and campaigning with the state and other key stakeholders since they do not have statutory limitations.
- Sector strongly feels that international agencies should be flexible enough to support the initiatives of DPOs/NGOs implemented as per the demand of the sector.
- The sector is in the better position to negotiate with stakeholders and should focus on representation and negotiation strategies in advocacy and campaigning initiatives

4.3 SUGGESTIONS AND ROAD MAP

- These suggestions are largely based on the study findings, which have systematically and consciously attempted to explore and examine various issues and aspects of disability and development with specific reference to engagement with DPOs

and BPOs towards facilitating self advocacy and macro level advocacy issues through the larger alliance.

- Responses, views, concerns and opinions expressed by primary, secondary and tertiary stakeholders and their organisations form the strong basis for these suggestions. They are well informed by material collected through the extensive review of secondary literature, current approaches, perspectives and trends in disability and disabled people's movement. The essence and spirit of suggestions are stated below:
- Appropriate amendments should be made to the statutory documents of the organisation such as organisational policies, strategic documents, guidelines, HR policy and procedures, organisational priorities and programme policies with the active participation and involvement of persons with disabilities and DPOs through extensive consultative processes in order to facilitate cross disability/Disabled people's movement through active engagement with DPOs, BPOs and NGOs.
- The need of the hour is for the organisation to make a paradigm shift from a welfare/charity approach to human rights based approach both at the organisational and the partners' level. This needs to be done with a clear understanding of disability as not merely a rehabilitation issue but a development and human rights issue which requires multi-stakeholder, multi-dimensional and multi-sectoral action based on a human rights framework in phases with continuity and consistency in the long term process.
- There is a need for appropriate and adequate sensitisation, orientation, visioning and capacity building exercises for the organisational staff to deal with change management and transformation process of the organisation in order to actively engage with DPOs and advocacy/campaigning initiatives.
- There is need for initiating or strengthening of the advocacy and

campaigning unit or wing with a well equipped team specifically dedicated to support and coordinate macro level advocacy and campaigning initiatives in partnership with the larger alliance of DPOs, NGOs, persons with disabilities and other appropriate groups and federations.

- There is a strong demand from DPOs/NGOs for the organisation to initiate critical engagement with all persons with disabilities of all types of impairments with specific focus on people with speech and hearing, intellectual, psychosocial, multiple, severe and profound impairments in all the actions and processes of the organisation particularly in community initiatives.
- Statutory changes need to be made in guidelines, monitoring tools and evaluation & assessment tools in order to ensure active participation and involvement of persons with disabilities and DPOs right from the planning process of any initiative approved by the organisation to be implemented by NGOs.
- There needs to be a specific mandate for the partner NGOs to ensure the active participation of persons with disabilities in different stages of disability initiatives. This ensures participation not only in the process of implementation but also in the planning, decision making, monitoring and evaluation processes.
- There is a need to look at the formulation and execution of clear and specific proposal review guidelines in order to mandate the partner agencies to expand their engagement with all types of impairments, advocacy and campaigning as a cross cutting issue, formation and strengthening of DPOs with the allocation of specific budget line item and a dedicated personnel to carry out the task.
- Massive capacity building programmes need to be organized on human rights framework and instruments, advocacy and campaigning, mobilisation and collective action for existing partner organisations in order to prepare them for changing approaches and strategies of the organisation.

- There is a strong demand from DPOs to initiative specific actions with them directly in order to strengthen their struggle for equity and justice by instituting fellowship programmes for disabled activists and undertaking direct initiatives with DPOs with monetary and technical support.
- A systematic and conscious endeavor needs to be made to build the organisational, management, campaigning and advocacy capacity of DPOs by supporting them in putting systems and structures in place to meet the demands of donor agencies either through partner organisations or directly.
- There is also a strong demand from DPOs and NGOs to change the role and identity of the organisation from merely that of a funding agency to a resource sharing and support agency in the change process.
- There is a great need for international agencies to understand and support the work of agencies/DPOs as per the priority and demand of the sector rather supply driven approach with the rigid programmatic framework of the organisation;



5. WAY FORWARD

5.1 GOAL

Persons with disabilities are able to effectively claim their rights and entitlements through the active engagement of Sightsavers with DPOs, BPOs and voluntary agencies.

5.2 OBJECTIVES

- To build the capacity of partners and organisational staff to equip them with appropriate attitudes, knowledge and skills necessary for implementing change process both at organisational and project level.
- To intensify the active engagement with DPOs and BPOs in order to enable them for advocating the rights of persons with disabilities effectively.
- To facilitate appropriate changes and amendments to policy, institutional and system related framework of the organisation.

5.3 STRATEGIC OBJECTIVES

S/O-1 Partnering the alliance of persons with all categories of impairments:

The organisation shall make systematic and conscious attempts to engage with persons with disabilities of all types of impairments with equal focus on each type of impairment and shall have specific focus and attention on the most excluded and densely marginalized sections of persons with disabilities. The organisation

is committed to facilitate, build and strengthen the organisations of persons with disabilities and initiate actions to build the alliance to strengthen larger disabled people's movement to combat exclusion and discrimination effectively.

Specific strategies:

- Facilitating shift of paradigm from welfare to human rights based approach;
- Massive capacity building programmes for staff and partner agencies;
- Strategic engagement with DPOs;
- Policy shift from single disability focus to cross disability engagement;
- Facilitating alliance building process with larger disabled people's movement;

Outcomes:

- Organisation is transformed into a rights based agency with a deep understanding on the approach;
- Partners and organisational staff are equipped to carry forward the mandate of changing situation;
- DPOs and persons with disabilities have increased say and involvement in all the actions and processes;
- Greater visibility of DPOs and the larger alliance in fighting exclusion and injustice;
- Increased involvement and key role of alliance in the decision making process which affect the lives of persons with disabilities;

S/O-2 Facilitating and practicing fair and just governance:

We consciously make attempts to promote just and fair governance both at the organisational and partner agency level in order to

apply the values and principles of human rights based approach to deal with issues concerning persons with disabilities. We believe in practicing the value of transparency and accountability and our primary accountability lies with primary stakeholders.

Specific strategies:

- Building the capacity of DPOs and partner agencies to undertake systemic and structural changes;
- Facilitating partner agencies to evolve appropriate policies, systems and structures for the organisations;
- Facilitating partners to initiate appropriate grievance redressal mechanism in the organisation;
- Facilitating DPOs and partners to lobby with the state departments for transparency and accountability;
- Undertaking advocacy and campaigning initiatives through DPOs and partners for enactment, amendment and effective implementation of statutes;

Outcomes:

- Partner agencies shall have appropriate policies, systems and structures in place;
- Increased transparency and accountability of partners towards primary stakeholders;
- Improved governance at organisational and partner agency level;
- Implementation of statutes on the ground towards grounding of rights;
- Improved transparency and accountability of the state;

S/O-3 Promoting gender equity and justice:

We are committed to promote the rights of women/girls with disabilities by acknowledging the existence of dense and multiple

deprivation and marginalisation which they suffer and embrace the value of gender equity and justice at the organisational level through specific focus and initiatives for addressing the issues concerning women/girls in all spheres and at all levels. The specific strategies include;

Specific strategies:

- Sensitisation, orientation and capacity building programmes for staff and partner agencies on gender equity and justice;
- Inclusive monitoring tools and methods to track the allocation and utilisation of resources on gender equity and justice;
- Gender segregated data on women/girls with disabilities in all reports and statutory documents of the organisation;
- Facilitating the representation and participation of women/girls with disabilities in all actions and processes;
- Priority engagement with organisations of or headed by women/girls with disabilities;

Outcomes:

- Increased sensitivity of staff and partner agencies towards women/girls with disabilities;
- Increased allocation and utilisation of resources on women/girls with disabilities;
- Increased involvement, participation of women/girls with disabilities in actions and processes;
- Appropriate systems, policies and mechanism is in place to address gender inequity and injustice;

S/O-4 Advocating pro-disabled and inclusive policies in praxis mode:

We are convinced and have courage of conviction to facilitate people centric advocacy in which persons with disabilities shall play the central and key role. We advocate for pro-disabled and inclusive

policies and practices with the active engagement with primary stakeholders. We believe in a bottom-up approach and ensure every policy and statute of the organisation shall be informed by lived expertise and experiences of primary stakeholders and without their involvement no statute is progressive.

Specific strategies:

- Massive capacity building programmes for persons with disabilities, DPOs and partner agencies;
- Facilitating the legal literacy of persons with disabilities;
- Partnering the struggle of disabled people;
- Facilitating larger alliance of persons with disabilities;
- Supporting advocacy and Campaigning initiatives of DPOs;
- Facilitating policy analysis and pushing for progressive and inclusive policies;

Outcomes:

- Advocacy, Campaigning and policy unit shall be in place;
- Increased allocation and utilisation of resources on policy analysis and change;
- Increased capacity and voice of persons with disabilities and DPOs;
- Increased capacity of partner agencies;
- Effective implementation of UNCRPD and other relevant statutes;
- Inclusive and progressive statutes shall be in place

S/O-5 Strengthening inclusive development processes and approaches:

We believe that disability is not merely a rehabilitation issue but a development and human rights issue, which should be dealt

with in a human rights framework. We are committed to facilitate inclusive development actions and process both at organisational and partner agency level in order to promote holistic development and empowerment of persons with disabilities.

Specific strategies:

- Initiating actions and process which focus equally on all persons with all types of impairments;
- Promoting actions which facilitate inclusive development;
- Advocating for inclusive development actions rather exclusive rehabilitation initiatives;
- Facilitating cross learning between partner agencies and other development agencies;
- Creating the knowledge base on inclusive development approach;

Outcomes:

- Partner agencies shall practice the approach of inclusive development;
- Appropriate tools and strategies on inclusive development shall be in place;
- A rich knowledge base shall be in place and used widely;
- Inclusive development shall be one of the criteria to judge proposals;



6. Case studies

6.1 AMARA JYOTHI ANGAVIKALARA KSHEMABIVRUDHI SANGHA

Amara Jyothi Angavikalara Kshemabivruddi Sangha [Amarajyothi Disabled Persons Association ADPA] is the federation of persons with disabilities promoted by Sourabha CBR project to trigger a disability movement across the region. The federation was established in the year 1996 with a view to promote and protect the human rights and dignity of persons with disabilities in the region. One of the outcomes of the midterm review in 1993 of the project strongly observed that sustainability of the project was questionable. Community organisation sector was introduced to organise persons with disabilities and their caregivers into groups so that they can take up their own issues and address them. Attempts were made to organise persons with disabilities into SHAGs at village level but initial efforts did not yield expected results thus efforts were made to identify leaders of persons with disabilities who were motivated to form a federation at the taluk level. 60 motivated disabled people met on 22nd June 1996 and discussed about the issues of persons with disabilities in the region and decided to form a federation of disabled to address the issues. The federation was named as Amara Jyothi Disabled Persons Association. An executive body was elected with 21 members representing all categories of disabilities, gender, hoblis and the project. Regular meetings were held to frame a constitution of the federation. Series of capacity building exercises enabled them to develop leadership skills and qualities along with technical and managerial skills to address the issues. When people realised that the concept of the federation is clear along with the vision and

mission of the federation they decided to register the same under Society Registration Act of 1860. Finally on 7th October 1997 the federation was registered in the District Registrar Office of Bangalore Rural District located in Bangalore. Federation conducted its monthly management board meetings to review the progress of the project. Federation joined hands with Sourabha CBR project to address the issues. It actively involved in the planning and implementation process. It took keen interest in the perspective document of 1996-1999 and ensured that its vision was incorporated into the document. Federation increased its members from 60 to 300 within a year. Many programmes were conducted with the support of the CBR project. Intensive interventions were under taken for the development of persons with disabilities across the taluk. Issues were addressed through advocacy initiatives to promote and protect the rights and dignity of persons with disabilities across the region. Attempts were made to establish clear linkages with SHAGs of persons with disabilities at village by ensuring flow of communication both up and down words in order to sustain the interest and motivation of members and strengthen disability movement at block and district levels. Linkages were established with state and national level disability networks, rights groups, movements, campaigns and struggles. Alliances were built with other human rights movements, rights groups, campaigns and networks. Solidarity was expressed with other marginalised sections by supporting their struggle.

Few case studies of advocacy efforts are worth mention. A girl with disability was studying in degree first year. She had mobility impairment, which compelled her to talk to her Principal and student welfare officer to shift the classroom to ground floor because of her inconvenience. The request was turned down in spite of her parents talking to the Principal and student welfare officer. ADPA took up the issue and met the Principal and persuaded him to shift the classroom to ground floor.

One of the members was selected for self-employment loan under PMRY scheme. He was asked to go to a local bank to get the loan. The bank manager concerned refused to give him loan on the ground of his disability. Federation took up the issue and finally he

was given the loan.

A corrupt officer of Sathnur Nada Kacheri insulted a group of persons with disabilities and asked bribe to sanction disability pension. The matter was brought to the notice of the federation and a rally was organised against the officer in front of the office. The senior official heard the federation and warned the officer and assured them that any application with the stamp of the federation will be approved without any delay.

Teachers were refusing children with disabilities to be admitted into the regular schools of the state. Issue was brought to the notice of the block education officer who sent a circular saying that it is mandatory to admit them and no child with disability will be denied admission. There are many such interesting instances of advocacy.

The accountability, transparency and democratic process attracted many disabled people to join the federation. After three years of establishment of the federation the member's number went up to 600. ADPA made a serious attempt to raise resources. Many initiatives were under taken to enhance the financial status of the federation. ADPA lent about Rs. 3,00,000/- as loan to its members. The recovery was satisfactory. Federation organised a series of training programmes, leadership camps, exposure visits, workshops, brainstorming sessions and visioning exercises to build the capacity of its members and give them a conceptual clarity. After the withdrawal of the Sourabha CBR project federation started managing the programmes independently with a little technical support of the parent organisation. Today federation has five-development workers to move around and provide services to needy persons with disabilities. Federation is looking for resources to expand its programmes to neighbouring taluks and Districts. ADPA is a unique model for the sustainability of the CBR programme by the same community in general and persons with disabilities themselves in particular.

6.2 JHARKAND VIKLANG MANCH

The Country Strategy Paper III of ActionAid India places emphases on organising poor and excluded communities and building alliances of these organized communities to challenge injustice, discrimination and exclusion. The Strategic Objective of CSP III categorically mandates us to build the organisations of poor and excluded and build their alliances to collectively address issues concerning them.

One of the key Result Area of Disability Unit of ActionAid is to “facilitate a strong, vibrant and active national organisation of People With Disabilities federated with Self-Help and Advocacy Groups of People With Disabilities at grass root level and federate them at block, district, state and national level to challenge blatant discrimination and sheer exclusion”

The Unit has initiated the processes to facilitate the organizing of disabled people at various levels. This process is on in the states of

- Jharkand,
- Madhya Pradesh,
- Gujarat,
- Orissa
- Karnataka.

We have also started working with the existing federations through building their perspective and capacity. The process followed in the state of Jharkand (the state has 22 districts) is mentioned below as a case study.

1. An advertisement was given in local news papers in order to get disabled activists for I Regional leadership Training Course (RLTC). We also approached both disability and development

organisations to send potential candidates for the training who are motivated and committed.

2. A development organisation helped us in coordinating with the applicants and organising logistics.
3. The I RLTC was conducted in March 2006 with 30 participants representing 12 districts.
4. Training covered issues such as; perspectives, attitudes, root causes, communication, personality development, rights and entitlements.
5. At the end of the training programme an action plan was prepared by each candidate and finally a common minimum programme was drawn which included,
 - Finding representatives for remaining districts,
 - Formation of district federation with the representation of all blocks
 - Formation of few block federation,
 - Advocacy on NREGP and other issues.
6. In the same training a decision was taken to form a State federation with the present members and once every three months
7. After three months a two day meeting was organized and on the first day a sensitization was done with new members and on the second day a review of the common minimum programme was done. The review revealed that 50% of the agreed work was completed. There was drop out of few trained members due various factors.
8. The third meeting had over 40 activists representing 18 districts. Again a common minimum programme was agreed the action

points were more or less same except few specific issues.

9. This quarterly meeting had over 50 members with few drop outs and few new additions. The same process was followed.
10. The fourth meeting had 20 district representatives out of 22 districts. That is all districts of the State. The review revealed that thousands of people had accessed certificates; entitlements addressed issues of discrimination and exclusion.
11. After the first meeting coordination and logistics was done by the members of the federation themselves. A constitution was framed with the active participation of the members.
12. An executive body with 22 members representing each districts and general body representing 2 each members representing their districts was formed.
13. The State federation was formed first and the members took the responsibility of forming district federations. The district members form the block federation and its members in turn form the grass root federation.
14. This approach brings many people together to work hand in hand at a time so that scaling up is easier.
15. Finally the national federation will be formed with the representatives of state federations considering various diversities such, gender, disability, and others.
16. The trained activists are presently working voluntarily with out any financial gain. They have their own business/job/daily wages and at the same time they use their free time for this.
17. Achievements:
 - Large number of people accessed entitlements along with medical certificate.

- Convinced DC to conduct monthly single window camps in few districts.
- Commissioner's office was shifted from the 1st to the ground floor..
- Jubilee park of Jamshedpur was made accessible.
- Many children with disabilities were enrolled in to regular schools.
- Hundreds of Self Help and Advocacy Groups were formed.
- Super fast express was stopped
- This is just in less than a year's time.

6.3 NETWORK OF PERSONS WITH DISABILITIES ORGANISATIONS-NPDO

A group of persons with different categories of disability, formed into a group to initiate intervention for the development of the persons with disabilities across the state of Andhra Pradesh under the leadership of Mr. Srinivasulu who is with locomotor disability. He hailed from a marginal background and served as a journalist in a vernacular newspaper. The initial concept of the group was initiated through a monthly magazine called 'Vaartha Teja' in the year 1996. This magazine reflected various issues of persons with disabilities across the state and had gained popularity as a magazine emphasizing on disability issues and rights. In this process a platform emerged for persons with disabilities to share and express their concerns which evolved into an organization called 'Network of Persons with disability Organization' (NPDO) and was registered in the year 2003 with a strong objective – to stand for the rights of persons with disabilities.

Over a period of time NPDO emerged as strong rights based advocacy group with a membership of 70,000 persons with disabilities across Andhra Pradesh. The organization provided a platform for persons to raise their voices for their rights. Its network had take forth

various interventions across the state of Andhra Pradesh ensuring coverage of all disability groups, through facilitating frequent training and awareness generation activities on various provisions and entitlements.

Organization Structure: NPDO has a general body, executive council, office bearers/ governing body represented by persons with disabilities. As per the organization's by laws the general body and the executive council should have 50% women with disabilities as members. NPDO has a total of 70000 individual members consisting of persons with disabilities, caregivers and more than 500 community based organizations (CBO's).

It has a state wide network and the general body consists of 98 members. These members are elected at the district level and two men and women are elected from 23 districts with 4 guardian members and two co opted members.

The Executive committee is elected from this general body with 50% women representation. NPDO had divided the state into six regions and from each region two men and women members are selected for the executive committee with 4 guardian members and two co-opted members making it a total strength of thirty. The Council elects the governing body/office bearers for a period of 5 years.

The organization has an advisory board of eminent persons from various fields that assist in functioning of the organization.

Core Beliefs: Transparency; Accountability; Democratic opinions to ensure effective networking at all levels

Vision: One world and inclusion of persons with disabilities in the mainstream and empower them at all levels – social, economical, political, cultural etc.

Mission: To strengthen and rehabilitate every person with disability

through capacity building and supporting them achieve their entitlements and to live life of dignity.

Value Statement: 'Nothing about us without us'

Believes: Independent living; Barrier free environment; Human rights; Advocacy; Inclusion of women with disability

Achievements: 70,000 persons with disabilities as members; trained above 1000 grass root activists; working in 20 districts of Andhra Pradesh; Active participation of cross section of disability; Strong linkages and wide dissemination of information at the grass roots.



7. APPENDIX

7.1 ACRONYMS

AA	:	Action Aid.
ADD	:	Action on Disability and Development.
AICB	:	All India Confederation of Blind.
BPA	:	Blind People's Association.
BPO	:	Blind People's Organisation.
CBR	:	Community Based Rehabilitation.
CRPD	:	Convention on the Rights of Persons with Disabilities.
DPO	:	Disabled People's Organisation.
DRG	:	Disabled Rights Group.
FGD	:	Focused Group Discussion.
GOs	:	GOVT Orders.
ICDS	:	Integrated Child Development Scheme.
IEC	:	Information Education and Communication materials.
LCD SARO	:	Leonard Cheshire Disability South Asia Regional Office.
NFB	:	National Federation of the Blind.
NGOs	:	Non Governmental Organisations.

NREGS	:	National Rural Employment Guarantee Scheme.
PIL	:	Public Interest Litigation.
PWDs	:	Persons with disabilities.
RTI	:	Right To Information Act.
SAG	:	Self Advocacy Groups.
SHG	:	Self Help Groups.
SMS	:	Short Message Service.
SSA	:	Sarva Shiksha Abhiyan.
UNCRPD	:	United Nations Convention on the Rights of Persons with Disabilities.
UTs	:	Union Territories.

7.2 GLOSSARY

Advocacy: A Latin term derived from “Ad” and “Voca” which means amplifying the voices of voiceless. It is a process of resisting unequal and unjust power relations in a just manner.

Campaign: It includes various actions and processes through different tactics and strategies using a wide range of communication methods to influence the targeted stakeholders.

Blind People’s Organisation [BPA]: A formal or informal organisation constituted and managed by blind/ visually impaired people who constitute the majority in the decision making body.

Disabled people’s Organisation [DPO]: A formal or informal organisation constituted and managed by disabled people who constitute the majority in the decision making body [DPI]. As per the majority of the respondents of this study, it is a formal or informal

organisation completely constituted and managed by persons with disabilities alone.

Federation: A form of formal or informal membership based organisation constituted by the representatives from different groups, networks or federations from different levels of geographical division or hierarchy.

Human rights: Rights enshrined or derived from the International Bill of Rights which includes UDHR, ICCPR and ICESCR.

Human rights instruments: Any statute or a combination of statutes or laws or declaration or convention or policy or charter which is enforceable either at the country or at the international level in order to enjoy human rights of human beings.

Human rights framework: A conceptual framework of a combination of statutes designed to ensure effective application of the rights based approach.

Rights Based Approach [RBA]: A conceptual framework for development normatively based on international standards of human rights and operationally directed towards human growth and development. Application of RBA has nothing to do with service delivery which is one of the key strategies and is still relevant.

Self Advocacy Group [SAG]: A group constituted by persons with disabilities at village or panchayat level to advocate for themselves.

Self Help Groups [SHG]: A group of persons with disabilities and the parents of children with disabilities constituted to help themselves. Credit and savings is one of the key activities this group.

Service delivery: A structure or mechanism or an approach

designed to facilitate people to access services through referral or to directly provide services to primary stakeholders.

Welfare approach: An approach to development where the fundamental assumption of people is based on the perspective that people are poor or helpless due to their fate and helping them in different ways gives righteousness to providers. Primary stakeholders are passive recipients and agencies or institutions are providers. It is also called the charity approach.

7.3 LIST OF DPOS AND NGOS

LIST OF NGOS AND REPRESENTATIVES

SL	NGO/Address	Representatives
1.	AIFO India, # 58, 4th Cross, Kavery layout, Tavarekere main road, Dharmaram College post, Bangalore – 560029 Ph: 080 25531264 M: 9742690162 E mail: mptcbr@gmail.com parthipan@aifoindia.org	Mr. Jayanth Kumar Mr. Parthipan Ramasamy
2.	Amty Amachy Proghysathi, Kurkheda, Dist-Gadchirali, Maharastra-441209 M: 09420146049	Mr. Manoj.P. Hanmalwar,
3.	Arakavathy disabled person's association, Sampoorna project, Manjunatha Nagar, Ramnagara M- 9739692703	Mr. Dhoddaputtaiah
4.	B-131, Patel Nagar, Dusherabagh Barabanki-225001 M: 09936642894 ashishsingh.bbk@sify.com	Ashish Kumar Singh

5.	Blind People's Organisation Jagdish Patel Chowk, Vastrapur, Ahmedabad Ph: 26305383, M:09825294057 luhartarak@gmail.com	Mr. Tarak Luhar
6.	Cadre India, Kurumathoor, Kuzhithurai PO K K District Tamil Nadu Pin – 629163 M: 09442636211 E mail: cadreindia@gmail.com	Mr. Mohan Kumar E.
7.	CBM SARO (South) 5th Main, Puttannachetty Road, Chamrajpet Bangalore Ph : 080-2667 356 shivamohan@cbmsaros.org	Mr.Shiva Mohan Rao
8.	CBM SARO (North) 5th Main, Puttannachetty Road, Chamrajpet. Bangalore M: 09663301136 prateep@cbmsaron.org	Mr.Prateep Chakraborty
9.	Cheshire Homes India Coorg, Pollibetta, P.B No. 93, Pin-571215, M-9880139575	Ms. Vidhya K.M.
10.	Cheshire Homes India Jamshedpur Project Maxvince Villa-Ave Maria, H.No.Nil, Coke Depot- 'A' Block, Sonary (E)Jamshedpur-831011 Ph: 0657-6574663, M:09279361902 shakticbrjsr@gmail.com	Mr.Vincent.R.A
11.	CTRD Trust, ctrdtrust@gmail.com	RS. Ranganathen

12.	Dalit Sangh, Sohapur-Hoshangabad (MP)-461771 Ph: 278336, M: 09329793363 dalitsangh@sify.com	Mr. Sunil
13.	Deafway 302/8, Sagavi Co-op Group, Housing Society, LTD GH-85 Sector-55, Gurgaon, Haryana M: 09810467412 hpdeafway@gmail.com	Ms. Harpriti Reddy Ms.Amita Reddy
14.	Grameena Asyudaya Seva Samsthe, Doddaballpur, Bengaluru rural Dist. M: 9916726575 E mail: ravikumarmgass@gmail.com	Mr. Ravi Kumar Ms. Sukhanya S.
15.	Grihini, Ultra Track Cement Corporation Hirmi-493114 Ph: 07726-281749, M: 09926179604	Mr. Hemendra Dewangan
16.	Kalyan Sewa Santhan, Kurebhar, Sultanpur-UP-228181 Ph:05362-266336, M: 09415183976 yvdks@gmail.com	Mr. Sant Ram Shukla
17.	KPAMRC 18, 1st Block, Jayanagar Post, Byrasandra Main Rd. Bangalore – 560011 M – 9845462451 E mail: kpamrc@gmail.com	Mr. Venkatesh K.R Mr. Radhakrishna V.G.

18.	<p>Livelihood Resource Centre, #34, 6th main, Kodihalli, Old Airport road, HAL 2nd stage extension, Near Leela Palace Bangalore – 560008 M: 9591508493 E mail: sarusri.r@gmail.com</p>	Ms. Saritha
19.	<p>MORE V-357 A, Appa Rao garden, Madanapalli, Chittoor Dist. AP Pin- 517325 M – 09440124930 E mail: moreprasada@yahoo.co.in</p>	Mr. Prasad A.
20.	<p>Mumbai Cheshire Home, Mahakali Caves Road, Andheri East-Mumbai M: 09867282240: Email: kalidasrote@yahoo.co.in</p>	Mr. Kalidas Rote
21.	<p>NAB, Nasik, Plot No. 66, Lane No.3, MIDC Satpur, Nasik, Maharastra-422007 Ph: 0253-2353578, M: 09850885413 nabdeafblind_86@rediffmail.com</p>	Ms. Jyoti Prakash
22.	<p>Narendra Foundation, Siddapura – post, Pavagada Tumkur, Pin – 572141, M: 9482154261 E mail: Narendra_found@rediffmail. com</p>	Mr. Natesh N.K.
23.	<p>National Association for the Blind 80, Manchadi Vila Road, Plamoodi, Trivandrum, Pin – 695003 M: 09442636211, E mail: nabkerala@gmail.com</p>	Mr. Shidci G.

24.	Nav Bharat Jagriti Kendra, AT Amriti Nagar Post:Korrah, Dist: Hazaribagh, Jharkhand-825301 Ph: 263332, M: 09162448448 nbjkco@gmail.com, sumeetagagarwal22@gmail.com	Sumit Agarwal
25.	ORRC, Balajinagar, Chodavaram, Vishakhapatnam, AP Pin – 531036 Ph: 08934247728, M: 9951116166, E mail: orrcdm@gmail.com	Mr. Ramesh M.
26.	Samuha Samarthy, Kustagi Road, Near Bharath Gas godown, Koppal, Pin – 583231 M – 9945802204	Mr. Basappa H.N Mr. Babumiya
27.	Samuha Samarthy, Kustagi Road, Near Bharath Gas godown, Koppal, Pin – 583231 M: 9449481425	Babumiya
28.	Sankalp, 1 Rupali Vihar, Sharanpur – 247001 Ph: 0132-2765145, M: 09412231020 rekhak2@gmail.com	Ms. Rekha Kumar
29.	Shree Ramana Maharishi Academy for the blind, J. P Nagar, 3rd Cross, 3rd Cross, 3rd Phase, Bangalore – 560078 M- 8105728684 Email: rameshshrmab@gmail.com	Mr. Ramesh G.
30.	Sightsavers GC-104, Sector- 111, Sat Lake, Kolkata-700106 Ph: 40087764, M: 09433789089 smohanta@sightsavers.org	Mr. Sudipta Mohanty

31.	Sightsavers, C-39, Panchsheel Colony, Jaipur Ph: 2812081, M: 09772093603 psinha@sightsavers.org	Mr. Prabhat Sinha
32.	SSM Trust 5/2, 2nd main road, Raja Colony, collective office road, cantonment, Trichy, Tamil Nadu – 620001 M – 09443716520 Email: ssmtrust@gmail.com	Ms. Selvarani Rajrathnam
33.	Sumanahalli LRRTC Vishwaneedam PO Magadi Rd. Bangalore Pin 560091	Mr. Adhisayanathan D.
34.	Unnati, G-1/200, Azad Society, Ahmedabad-380015 Ph: 079-26746145, M: 09427630087 socialinclusion@unnati.org	Ms.Geeta Sharma
35.	Vaanmuhil, 15, Kavitha Nagar, Maharaja Nagar, Tirunelveli – 627011, M – 09442618117 E mail: vaanmuhil@gmail.com	Mr. Britto M.A
36.	VRTC for Blind, Haibowal Road, Ludhiana – 141001 pH: 0161-2301425, M: 09855601245/9316901521 csraviindia@gmail.com	Mr. C.S.Ravindran

LIST OF DPOS AND REPRESENTATIVES PARTICIPATED

SL	DPO/Address	Representatives
1.	Advocacy Forum for Persons with Disabilities H.No. 17-1-391/V/13, 1st Floor, Saraswathi Nagar, Saidabad, SaidabadHyderabad - 500059. Mob – 9490747662	Mr. Haribabu G
2.	Amarjyothi Angavikalanga Kshemabhivruddhi Sangha Mob – 9731614700	Mr. Ramachandra NP
3.	APVM E9, Vikarpuri Colony, Kharkana, Secunderabad 500009 Mob – 9449023464, 09494228165, 09291514842	Mr. Surender Taduri Mr. Guguloth Venkanna
4.	Bihar Viklang Manch-BVM	Ms. Viashnavi Mr. Rakesh Kumar
5.	CADRE H.No. 17-1-391/V/13, 1st Floor, Saraswathi Nagar, Saidabad, Saidabad Hyderabad - 500059. Mob – 9490938522	
6.	Chhattisgarh Viklang Manch-CVM	Mr. Ishwar Chata
7.	Coorg LCD Project Cheshire Homes India, Coorg Pollibetta Kodagu Mob – 9880541552	Mr. Nishabuddin P K
8.	CVHV, Ashmitha Collectives H no 12-106/2, Vidiyanagar 509324 Mob – 9885625406	Mr. Abdul Sayeed Ali Ms. Thirupathamma M

9.	DISAI Society 6-1-324/1 Padmaraonagar Secunderabad. Mob – 984949969	Mr. Choudhary KSN
10.	Gujarat Viklang Manch-GVM	Mr. Atul Parmar
11.	KARO – KARNATAKA No 73, 4th Cross 5th Main Shankarnagar Mahalakshmi Layout, Bangalore 96 Mob – 9035739540	Mr. Ramanathan G Mr. Virupakshi H.
12.	LCD Nagapattinum DPO Project No. 16, Kallazhagar Illam Elancheran Nagar, Velipallayam Nagapattinam - 611 001 Tamilnadu Mob – 09842919357	Mr. Ashok Kumar S.
13.	LCD Prakasham DPO Project # 6-96, 1st Lane, Srinagar Colony, Behind St. Xavier School, Kurnool Road, ONGOLE - 523 002. Prakasam District, AP Mob - 91 8592 656557	Mr Chejarlaiah G.
14.	MORE DPO MORE, V-357 A Appa Rao Garden, Madanapalli, Chittoor District AP Mob – 9440124930	Ms. Eshwari M
15.	MP Viklang Manch-MPVM	Mr. Rajendra Chauwan Ms. Anitha Nirgude Mr. Vipin Kumar Mr. Hemant Kushwa Mr. Kailash Septa Mr. Bhanwar Kashwa Mr. Gopal Paldiya

16.	Narendra Foundation Siddepura, Hosakota Mob – 9449239659	Mr. Sudheendra Kumar K N
17.	NPDO 16-11-310/14/5/1B Malakpet Hyderabad Mob - 94403 60507, 94409 43677, 8978187478	Mr. Srinivasulu M. Ms. Santhakumari K.
18.	Orissa Association of Blind	Mr. Sanyasi Bahara
19.	Orissa State Disability Network Samarth, AT-Netaji Subhash Marg, PO. Chatrapur, Dist: Ganjam-761020 Ph: 06811-260146, M: 09437049457/09861063851 samarth_gdohwa@yahoo.co.in	Mr. Ananda Rao
20.	Orissa Viklang Manch-OVM	Mr. Pranab Sahu Mr. Niranjan Bahara
21.	People with Hearing Impaired Network (PHIN) Mob – 9948370063	Ms. Janaki V
22.	Rajasthan Viklang Manch-RVM	Mr. Ratan Lal
23.	SPARC DPO, Bharabanki	Mr.Kamal Kishore
24.	SPEED SPEED, near vigyan Grammar High School, Amangal, Mehboobnagar – 509321 Mob – 9912193875	Mr. Venkatesh A

25.	Sports federation for disabled Plot no 46, Lalitha Nagar Chavatapalli, Vintamoor, Nellor Mob – 9346636516	Mr. Kolli Nageshwar Rao Mr. Harish M
26.	Sumanahalli DPO Magadi Road. Bangalore, Karnataka Mob – 9886977840	Mr. Suresh Kumar Y
27.	Swami Vivekarabarde Angavikataranga Sanga SVKS Siddagantta Cikabalapur Mob – 9686285447	Ms. Bhagya B D Mr. Santosh Kumar
28.	Swedhikar Plot no 253, 1st Floor, Dhavanandnagar, Malkagiri Hyderabad 500047. Mob – 9542281239	Mr. Parasuram PV Mala
29.	Tamilnadu disabled people's organisation No 21 AA Lakeview Street Kottur, Chennai 600085 Mob - 9444115936, 9382837195	Mr. Chidambaranathan, Ms. Sangeetha, Ms. Aruna Devi Mr. Simmachandran P.
30.	Timbuctive collectives DPO 46 Primrose Rd., Bangalore 560 025 Mob – 9849580049	Mr. Chakravarthy A
31.	UP Viklang Manch-UPVM	Ms. Tarannum Bano
32.	VMS Kothapet Street, Manchili village, Attili Mandal, West Godavari District AP 534134 Mob – 9391166769	Mr. Nandoori ramesh SS

LIST OF INDIVIDUALS INTERVIEWED

SL	Name	Designation	Place
01.	A.K. Mittal	President, AICB	Delhi
02.	Bushan Punani	Director, BPA	Ahamedabad
03.	Dr. Maya Thomas	Consultant, Disability and Development	Bangalore
04.	Jose	Country Rep, AIFO	Bangalore
05.	P.K. Pincha	Special Rapporteur, NHRC	Delhi
06.	Pavan Muntha	CEO, Swadhikar	Hyderabad
07.	Punam Natarajan	Chair Person, National Trust	Delhi
08.	Sanjeev Sachdeva	Consultant, Access and Universal Design	Delhi
09.	T.D. Dhariyal	Deputy Chief Commissioner- Disabilities	Delhi
10.	Venkatesh Balakrishna	Consultant, Disability and Development	Ananthapur, AP
11.	Raghavendra B.P.	Programme Officer, ActionAid	Bangalore, Karnataka
12.	George Abraham	Director, EyeWay	Delhi
13.	Dr. Amita Dhanda	NALSAR Law university	Hyderabad, AP
14.	Ramakrishna	NAB Mumbai	Maharashtra

7.4 TOOLS

LIST OF TOOLS –

- I. **WORKSHOP FOR VOLUNTARY AGENCIES**
- II. **WORKSHOP FOR DPOS AND BPOS**
- III. **INTERVIEW GUIDE FOR FGD WITH SHGS**
- IV. **GUIDE FOR TELEPHONIC INTERVIEW WITH ACTIVISTS/LEADING NGOS**

I. WORKSHOP FOR VOLUNTARY AGENCIES

Target Group: Senior and middle level functionaries of voluntary agencies.

Objective: To capture the critical glimpses of experiences on advocacy and campaigning in disability and development along with the formation and strengthening of DPOs in the project location/s.

Workshop Design –

Sr No	Topic	Time
1.	Introduction of the participants.	30 Min
2.	Introduction to the workshop, objectives and expected outcomes.	15 Min
3.	Experience sharing by each participant/participating organizations on advocacy, campaigning and facilitating DPOs in small groups of 5-6 and presentation to the main plenary by each group	1 Hour for experience sharing & 10 mins per group for presentation with 10 mins for discussion

4.	Brainstorming on the concept, present understanding, meaning and definition of Advocacy and Campaigning and summing up by the facilitator.	45 minutes
5.	<p>Small group discussion and presentation –</p> <ul style="list-style-type: none"> ● What is a DPO in your understanding? Who are the active members of DPOs? ● What role are DPOs playing in your program? ● What are the objectives and activities of DPOs in your project? ● How effective are they in advocacy and campaigning? ● What micro and macro advocacy issues they have taken up? ● What is your general feedback about DPOs in relation to relevance, effectiveness, efficiency, impact and coverage? 	45 Min for small groups, 15 mins for presentation per group with 15 mins for conclusion
6.	Brief presentation on the differences between advocacy and liaisoning followed by discussion and summing up by the facilitator	60 mins
7.	Understanding the successes and failures of advocacy efforts by voluntary agencies and DPOs “Sharing of experiences”	60 Min

8.	<p>What are the key issues of the disability sector which urgently require micro and macro level advocacy? “Discussion in small groups Group division is based on macro issues, micro issues, strategic partnership and potential partners</p>	45 Min for small group discussion, 10 min for presentation per group followed by 10 mins conclusion
9.	<p>What is the Perceived and proposed Role of of international agencies such as, CBM, LCD ETC in promoting advocacy and DPOs in future? Brain storming and summing up by facilitator</p>	60 mins
10.	<p>Group discussion on following questions for 45 minutes in small groups and presentation in the main plenary</p> <ul style="list-style-type: none"> ● Can you list the known agencies such as disability organizations, development organizations, DPOs, Federations and confederations of disabled people advocating for the rights of disabled people? ● In what areas capacity building required for DPOs, Disability agencies & Development agencies? ● What support you expect from international organizations such as Sightsavers, LCD, and CBM etc in capacity building process? 	10 mins for presentation per group followed by 10 mins conclusion
11.	<p>Summing up and conclusion of entire workshop.</p>	60 Min

II. WORKSHOP FOR DPOS AND BPOS

Target group: Senior and front line leaders/heads of DPOs and BPOs.

Objective: To understand the involvement in advocacy, campaigning and building groups and federations of disabled people; and to explore the possibilities in partnering with international organizations such as Sightsavers, LCD, and CBM etc for micro and macro advocacy initiatives.

Workshop Design –

Sr No	Topic	Time
1.	Introduction of the participants.	
2.	Introduction to the workshop, objectives, methodology and outcomes.	
3.	Introduction of each DPO, experiences on advocacy and campaigning	Each DPO 10 mins with 20 mins for conclusion
4.	Group discussion in small groups on following topics and final presentation <ul style="list-style-type: none"> ● What is advocacy? ● How it is more effective than other activities? ● How have you advocated [strategies] at both the micro and macro level? ● Have you partnered with voluntary agencies? Why and how effective has this been? ● What is your general feedback about voluntary agencies? 	45 mins group discussion 10 mins each group 10 mins conclusion

	<ul style="list-style-type: none"> ● Are DPOs equipped to undertake advocacy and campaigning at both the micro and macro levels? How? ● Who were your partners in the advocacy process? 	
5.	Brainstorming on identifying issues both micro and macro level advocacy	60 mins
6.	<p>Group Discussion –</p> <ul style="list-style-type: none"> ● What are your successes and failures in advocacy? ● When did you succeed and fail? ● What contributes to success? ● How effective are you in advocacy? ● What changes you have noticed as a result of advocacy? ● What should be done to strengthen your advocacy efforts? 	<p>45 mins group discussion 10 mins each group 10 mins conclusion</p>
7.	What is the perceived and proposed role of international organizations such as Sightsavers, LCD, and CBM etc in advocacy?	30 mins
8.	In what areas you require capacity building? Why?	30 mins
9.	<p>Group work –</p> <ul style="list-style-type: none"> ● List the key players in advocacy for disabled people. ● List key DPOs and BPOs involved in advocacy. ● List key agencies involved in advocacy. ● Why do you think promoting DPOs is important? 	<p>45 mins group discussion 10 mins each group 10 mins conclusion</p>

10.	What is the structural, functional, strategic and philosophical difference between DPOs and NGOs? Individual feedback in writing.	
11.	What kind of support do you require from international organizations such as Sightsavers, LCD, and CBM etc to strengthen advocacy in your respective areas? Brainstorming.	30 mins
12.	How international organizations such as Sightsavers, LCD, and CBM etc should strengthen its advocacy efforts through partners and DPOs? Brainstorming.	30 mins
13.	How international organizations such as Sightsavers, LCD, and CBM etc can promote and strengthen DPOS and BPOs to ground advocacy? Group discussion	30 mins
14	Feedback and conclusion	30 mins

III. INTERVIEW GUIDE FOR FGD WITH SHGS

1. Group details

- Name and location
- Total members, with gender, impairment & age break up
- Duration/Years of functioning
- Achievements so far
- Total savings/Credit
- General activities

2. Objectives

3. How far you have reached in achieving your set objectives?
4. What is your understanding of advocacy?
5. Have you tried to advocate through your group?
6. How far you have succeeded in your advocacy efforts?
7. Narrate few success and failure stories of the advocacy efforts of your group.

8. Do you think, is there a need to organize and strengthen disabled peoples' groups? If yes why?
9. Is there a need for advocacy in your region? If yes why?
10. Who did advocate? Who partners with you?
11. What is the role of organizations in advocacy and group building?
12. What are the issues which need advocacy efforts in your region?
13. Are you aware of international organizations such as Sightsavers, LCD, and CBM etc and their work?
14. What should be the role of international organizations such as Sightsavers, LCD, and CBM etc in promoting advocacy and DPOs?
15. What is your expectation from international organizations such as Sightsavers, LCD, and CBM etc in future towards disability and development?
16. How can you partner with international organizations such as Sightsavers, LCD, and CBM etc to strengthen advocacy and DPOs in India?

IV. GUIDE FOR TELEPHONIC INTERVIEW WITH ACTIVISTS/ LEADING NGOS

1. Factual information, personal details
 - a. Name/Designation
 - b. Name and address of the agency associated
 - c. Year of service/Experience in the field
 - d. Area of expertise
 - e. Experience in working with DPOS
 - f. Experience in Advocacy and campaigning.
2. What is your understanding of advocacy and campaigning?
3. What is the present situation of advocacy and campaigning in the sector in the country?
4. How far this is effective and useful?

5. What should be our strategies to make it effective?
6. What are the priority issues for advocacy and campaigning?
7. What is the scope for collective advocacy and campaigning by INGOs and NGOs?
8. What should be the role of international organizations such as Sightsavers, LCD, and CBM etc in advocacy and campaigning in future?
9. What is your experience of working with DPOs?
10. Can you list a few DPOs which you know?
11. What is their role in advocacy and campaigning?
12. How effective have they been so far?
13. What should be the role and position of international organizations such as Sightsavers, LCD, and CBM etc' with regard to DPOs?
14. Any other comments

7.5 TERMS OF REFERENCE

Terms of Reference

Developing road map for Sightsavers and CBM SARO(S) (Asia South – South) for advocating for rights of PWDs – Strategy for working with BPOs and DPO s in India

BACKGROUND

Sightsavers International earlier the Royal Commonwealth Society for the Blind, works to combat blindness in developing countries, restoring sight through specialist treatment and eye care. Sightsavers supports people who are irreversibly blind by providing education, counseling and training. Today, Sightsavers works with partners in over 30 countries and its mission has expanded to also provide services to the blind and campaign for the eradication of needless blindness.

Sightsavers programme have been providing direct service delivery

to the beneficiaries of eye care & social inclusion projects. The services thus have been mostly limited to what the implementing partner agencies could deliver directly. The emphasis of the programme has been on social inclusion and economic rehabilitation of the blind and low vision persons in the rehabilitation projects. The initiatives have been project based targeting the needs of limited number of beneficiaries.

In Sightsavers strategic plan for 2009 – 13 has a one of the long term goals to ensure that *“visually impaired people are equal members of society and governments implement obligations under international conventions for disabled people”*. To achieve the long term goal Sightsavers wishes to develop programmes that will *“Enable BPOs and DPOs to advocate effectively for their members rights”*. Sightsavers has traditionally worked with general development organisations who now have also developed some understanding about the needs if VI persons and disability in general. Thus Sightsavers also wishes to include them in the process where possible.

CBM is an international development organisation, whose primary purpose is to improve the quality of life of the world’s poorest persons with disabilities and those at risk of disability. CBM works with partner organisations in low-income countries to ensure that persons with disabilities and their families have ready access to:

- Affordable and comprehensive health care and rehabilitation programmes,
- Quality education programs, and
- Livelihood opportunities.

Working with persons with disabilities, CBM advocates for their inclusion in all aspects of society.

As of 2009, CBM supports 732 projects in around 113 countries in Africa, Asia, Latin America, and Eastern Europe. Through its partner organisations, CBM currently reaches 18 million people and aims to reach many more in the coming years.

CBM uses comprehensive, sustainable, and community-focused approaches, which contribute to poverty alleviation and self-reliance. CBM partners develop high-quality preventive, curative, educational, rehabilitative, livelihood, and advocacy programmes, which are designed to maximise the quality of life of persons with disabilities.

India has PWD Act and has also ratified UNCRPD but unfortunately the disability related movement in India continues to remain fragmented in approach. Sightsavers believes besides providing direct service delivery it is now also important for it start advocating for rights of PWD s that will influence the policies and practices of the government thus benefiting larger section of PWDs.

PURPOSE

The purpose of study is:

To identify how best can Sightsavers & CBM SARO(S) advocate for the rights of PWD s by working with BPO s, DPO s and general development organisations.

SPECIFIC OBJECTIVES

The objectives will be

1. To identify major organisations (BPO s, DPO s and NGOs) who are actively working for the rights of PWDs.
2. To understand the major issues related to rights of PWDs on which advocacy work is going on or will have to be started for in India.
3. To understand the strategies adopted, programmes implemented and learning by organisations (NGO, BPO & DPO) for advocating for the rights of PWD s.
4. To identify the capacity building needs of the BPO s and DPO s and the strategy of the same.

5. To develop road map and strategy for Sightsavers and CBM SARO(S) to develop and implement advocacy programme in India.

METHODOLOGY

In order to achieve the above objectives the following strategies are being proposed:

1. **Implementation Team:** A core team will be formed to handle the project assignment. This team would take help from different field experts within and outside as and when required.
2. **Review of literature:** To understand the current environment and work that is going on the country and to identify the players in this field.
3. **Workshop:** Organizing a workshop of different organisations working for rights of PWD s to understand the issues, strategies and learning. To also understand what role Sightsavers & CBM SARO(S) can play and how it can get involved.
4. **Visit to organisations / field:** To look at the documentation, publications and to visit the programme if any at field level.
5. **Focus Group Discussions:** With disabled people and their caregivers who are currently involved in advocacy, to understand their needs and advocacy efforts that are being undertaken.
6. **Draft Document:** The draft document will be developed covering all the objectives of the study and circulated for comments.
7. **Sharing with Sightsavers' & CBM SARO(S) team and partners:** The draft document will be shared with the staff of Sightsavers & CBM SARO(S) and comments from them will be compiled and forwarded to this project team for analysis and incorporating the same in the document if feasible. Appropriate justification will be provided for not incorporating any of the suggestions and the same will be communicated to Sightsavers & CBM SARO(S) staff.

8. **Final Roadmap:** After incorporating the inputs from the Sightsavers' & CBM SARO(S) team and partners, a final document will be prepared and submitted.

SAMPLING

Organisation Sampling

A list of well-known organizations working in the disability sector was developed by Leonard Cheshire Disability South Asia Regional Office (SARO) through a team consultation exercise. Based on their coverage, these organizations were classified as national, state and local level. From this list, purposive sampling was done based on the following criteria-

Geographical coverage	Organisation type	Issues working on
North India	Government bodies dealing with disability	Livelihood
South India	Disabled/Blind People's Organisations	Education
West India	NGOs working on disability issues	Health
East India	Disabled persons Caregivers/parents Associations	Elections
Central India	Development Advocacy Organisations	Extra-curricular (sports)
	Individuals active in disability and advocacy sector	Social issues like marriage, etc.
		Accessibility issues (physical access, access to finance, access to literature etc)

Following sampling, a total of 37 NGOs and 51 DPOs have been identified for consultation. (*The organization list is attached*)

Disabled People Sampling

To get the perspective of disabled people themselves and their caregivers, SARO team would also be conducting focus group discussions in each of the geographical areas given above (North, Central, East, West & South). Through the local DPOs, disabled people would be identified for the focus group.

Focus Group Discussions (FGD) 2 FGDs per location 5 locations (North, East, West, Central & South) 10 FGDs

Focus Group Discussions (FGD)	2 FGDs per location	5 locations (North, East, West, Central & South)	10 FGDs
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Sightsavers and CBM SARO(S) Partners

In addition, to the above organizations, SARO team would also be visiting two each partners of Sightsavers & CBM SARO(S) to understand their current activities and capabilities.

KEY QUESTIONS TO BE ANSWERED:

1. Advocacy Needs of Disabled People

- Identifying major issues related to rights of disabled people
- Enacting or Reform of legislations, policies to ensure non-discrimination
- Effective monitoring and implementation of existing laws, policies, schemes (PWD Act, NREGS, RTI)
- Better Grievance redressal mechanisms
- Improvement in legal and related services
- Facilitating change in attitudes

2. Current advocacy efforts

- Organisations, BPOs, DPOs currently undertaking disability advocacy

- Advocacy Strategy – Evidence based advocacy, issues, message, intended audiences, time period
- Advocacy channels used – public, direct advocacy
- Advocacy mode - events, letter campaigns, sit-in protests
- Advocacy with whom - policy makers, influential people etc.
- Advocacy aimed at – general public, health workers, policy makers etc.
- Participation by - disabled people (gender and disability break-up), caregivers, NGOs, no. of people involved
- Advocacy model – local, district, state, national level; federations, individuals, groups etc.
- Coalitions/partnerships developed
- Resources – mobilized and spent
- Advocacy Impact
- Lessons learnt and Best Practices

3. Advocacy Capacity among BPOs/DPOs and Development Organisations

- Awareness on legal provisions, UNCRPD, advocacy needs of disabled people, rights
- Assessment of their advocacy skills (planning and executing an advocacy programme)
- Assessment of resources – staff, networks/partnerships, financial resources.
- Training needs of the BPO s and DPO s in the country in general and the strategy for the same

4. Sightsavers

- Current strategy on Advocating for the rights of disabled people
- Assessment of resources - staff (number, skills), financial resources

COMMUNICATION

Mr. Pankaj Vishwakarma, Head of Programme Development, Sightsavers (India Regional Office) Sightsavers and Ms. Nagarathna, Chief Development Officer, CBM SARO(S) will be responsible for liaise with the consultant. The consultant would be able to turn to the liaison person for clarification, getting more information, setting up appointments, and getting help to deal with any, organisational agenda likewise

CHAPTERS

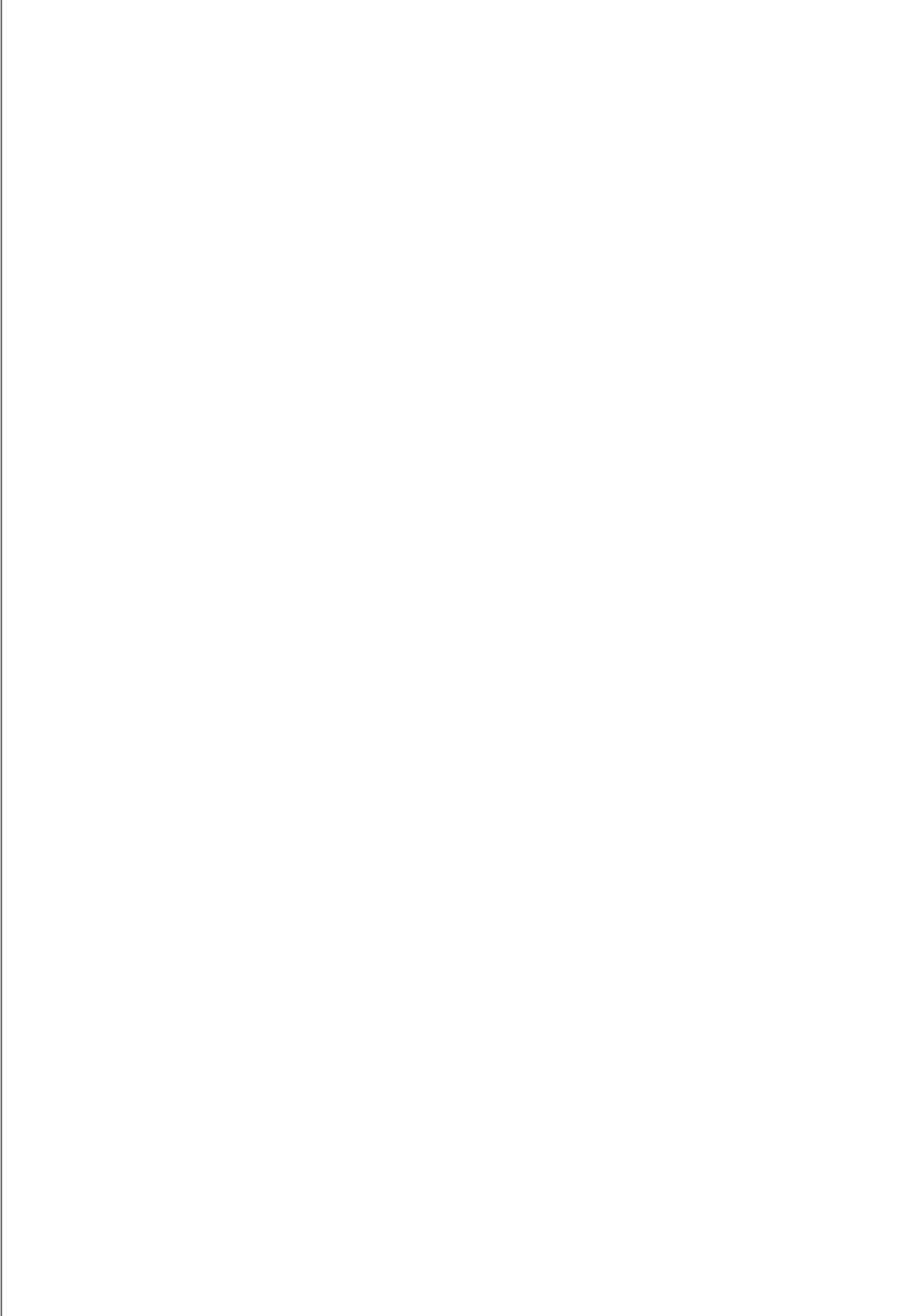
The draft document would constitute the following chapters

1. Title Page
2. Foreword/Acknowledgement
3. Abbreviations/Glossary
4. Table of Contents
5. Executive Summary (not exceeding 2 pgs)
6. Introduction – background, purpose, methodology, key questions, duration
7. Findings and Analysis (Short case stories (1-2 paras) or quotes, to be included in the relevant sections of the report)
8. Strategic Road Map for Sightsavers

Annexure

- Acronyms
- List of respondents
- Terms of reference
- List of tools







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