



Assessment of Approaches and Practices of Disability Network Organizations in Pakistan

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Foreword

International Non Governmental Organizations (INGO's) that have broadened their horizons and interposed the word "Developmental" in their categorical title, as the acronym INGDO denotes, must take cognizance of the dictum which states that there is "No Development without Research". The Research referred to is not biomedical research but enquiry into the reason for inequities in development, with its effects on health, as widely interpreted viz. the attainment by all the citizens of the world of a level of health (as defined in the preamble to the WHO Constitution), that will permit them to lead a socially and economically productive life.

It is to the credit of Sightsavers that they have identified "research for development" as a priority activity in the new direction that the organization is pursuing. This comes at a timely moment when there is a confluence of interest in achieving the millennium development goals, emphasis on addressing the social determinants of health and, last but not least, universal health coverage based on principles of equity dictated by social justice and the right to health of every citizen. In this context the need for appropriate research and information, to inform the projects and programmes, assumes importance, to know whether proposed strategies and interventions are effective and efficient.

The messages that unfold in the pages of this compilation holds lessons that can be further pursued and validated to provide the evidence base for policy, programming, implementation and measuring outcomes, in the priority areas, as determined by the local communities with unmet needs.

The initial studies that are described in the first compilation, of which this study is a part, give credit to the contribution of national and other local Sightsavers personnel, who took up the challenge thrown by Sightsavers, of making research the cornerstone for all the aforementioned areas of work. They identified multi – disciplinary partners and research centres of excellence, both from within and outside the country, in conducting studies. They have done the groundwork for the much needed collaborative efforts of the future. The Sightsavers teams have also recognized that operations research as well as health and education systems research are both modulated by local political systems, culture, belief systems, socio-economic factors etc. and the results do not necessarily lend themselves easily to extrapolation to other settings.

The compilation of results and reports from studies such as this report on priority areas identified at the local levels of Sightsavers' activities, marks the beginning of an educational

process that would facilitate the implementation of best practices in the chosen area of work, whether health, education, disability or human development.

It is hoped that these compilations of some preliminary studies titled “Sightsavers Analysis and Research Annual (SARA) 2010” is the forerunner of an annual publication to influence progress both in research activities and their translation to improved implementation and measurable outcomes.

Finally, we would like to pay a tribute to the immense contribution made by Dr Haroon Awan who provided the enlightened leadership for this endeavor and to his colleagues both at Haywards Heath and at Regional and, most importantly, at country level, for their efforts, as a team, to make it happen.

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Preface

Research is rapidly emerging as one of the key components of national development processes. Globally, it has been recognized that research is no longer a specialized field restricted only to academia. It has now found its place in evidence based planning for development initiatives, is a vital part of monitoring and evaluation systems and quality improvement frameworks, and is increasingly finding its way into the lexicon of policy and decision makers. There is also a global recognition that research capacities need to be strengthened in the south and that more south-south and north-south collaborations need to be fostered.

Sightsavers is an international organization with a development focus particularly in the areas of health, education, disability and community development. In 2008 when the new 5 years organizational strategy 2009 – 2013 was being developed, research was identified as one of the strategic objectives and key internal driver for programme development, quality improvement and advocacy. This research report, which is part of a collection of works and reports included in the Sightsavers Analysis and Research Annual (SARA) 2010, reflects these aspirations and commitment to strengthen south-south and north-south research partnerships.

One of the issues that have been of major concern to Sightsavers is how research could be linked with policy and practice. Oftentimes, it has been noted that research is undertaken on academic grounds but does not meet the needs of policy makers. On the other hand, it may be linked to policy but lacks the link with practice and operations. As part of the organizational strategy, Sightsavers developed a scalability approach for its programme interventions that incorporates the stages of piloting, demonstration, policy change and taking to scale. Based on this overarching principle, our approach to research is based on what we call the PRPP Paradigm – which simply states that research requires a participatory process that involves Policy makers, Researchers, Practitioners and the People or communities where research is undertaken.

In 2010, we launched an internal small grants research call for proposals from the Sightsavers Country Offices. One of the requirements of the call was collaboration with local policy and research institutes and researchers. This report is an example of the studies included in SARA 2010 and generated through this call. Our aim was to generate evidence to support implementation of our organizational strategy particularly in the areas of health systems strengthening, improving quality of education, and promoting disability research.

We hope that this research report will be of thematic and programmatic interest and that the evidence can be used to improve programme design, inform programme policies and operational strategies, strengthen quality and M&E systems, facilitate new research partnerships, identify areas for operational research, provide a strong rationale for policy advocacy and developing good practices, and last but not least motivate new research in eye health.

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Acronyms

AIER	American Institute of Education Research
APCD	Asia Pacific Development Centre on Disability
BMF	Biwako Millennium Framework
DFID	Department of International Development
DGSE	Directorate General of Special Education
Disability KaR	Knowledge and Research
DPO	Disabled Persons Organization
JICA	Japan International Cooperation Agency
MoSWandSE	Ministry of Social Welfare and Special Education
NGO	Non Government Organization
NISE	National Institute of Special Education
NPA	National Plan of Action
PWDs	Persons with Disabilities
SAARC	South Asian Association for Regional Cooperation
SADF	South Asian Disability Forum
STEP	Special Talent Exchange Programme
UNCRPD	United Nations Convention of Rights of Persons with Disabilities
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
WHO	World Health Organization

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We are particularly grateful to the government officials for according us the time and opportunity for the interviews.

We thank Sightsavers for funding this vital baseline research about disability networks.

Executive Summary

This report presents the results of research study conducted by Sightsavers in order to explore and review different initiatives taken so far for establishing disability fora, networks and consortia by Sightsavers in partnership with different partners.

The three key objectives of the research study were: to obtain evidence for advocacy on Disability Rights – particularly for local and national DPOs; to review disability related national policies and international policy frameworks; and to highlight the experiences of local-level good practices that have significant potential for replication.

The Delphi method with a few adaptations was used to conduct this exploratory research. Three major data collection techniques were used i.e., use of grey literature, use of people as informants, and use of published development literature.

The collected information revealed that there are considerable challenges for PWDs and the DPOs for networking at various levels. These challenges include their limited mobility, limited access to information and communication technology, financial constraints, lack of education, lack of exposure to opportunities and lack of skills for advocacy and lobbying.

1. Introduction

Persons with disabilities (PWDs) are mostly unseen, unheard and uncounted persons in Pakistan and they are one of the most marginalized groups¹. Disability work in Pakistan is contested and fragmented and social exclusion of PWDs in the development discourse is a major challenge. This reduces the voices, participation and recognition of PWDs in the sustainable development issues and concerns. Presently, in Pakistan very few organizations know and understand the issues of disability from development perspectives, and can sense its easy integration like gender in the development process. This exclusion undermines the abilities, competencies and capabilities of about 10% population of Pakistan, who can play a very effective role if provided with an opportunity as an integral part of development initiatives.

Services of education, training and rehabilitation for the PWDs were introduced by the private sector even before the creation of Pakistan. The Provincial Governments established such services after 1950's. At Federal level, the systematic care of PWDs was brought into focus in 1980's with the observance of 1981 as the UN International Year of the Disabled Persons. The newly established Special Educational and Social Welfare Division (1982) at the time through its attached department, Directorate General of Special Education - DGSE (1985) established Special Education Centers; Vocational Training Projects, Master Degree /M Phil/PhD level Special Education Departments at Allama Iqbal Open University, University of Punjab and Karachi University. To meet the emerging needs of human resource development, establishment of a National Institute of Special Education (NISE) was a historical achievement.

The Ministry of Social Welfare and Special Education (MoSWandSE) is responsible for formulation of policies, plans, procedures and implementation of disability related interventions and initiatives. There are challenges in coordination and collaboration with relevant ministries especially Health, Education, Labor and Manpower, Housing and Works, Planning and Development, Finance and Information and Broadcasting. A national plan of action (NPA) was developed in 2006 to translate the National Policy for Persons with Disabilities (2002) into practice; however, there is lack of ownership from coordinating agencies both in the public and private sectors and particularly at provincial level. Although there are a number of coordinating networks, they are not effectively vibrant and active for implementation of the United Nations Convention of Rights of Persons with Disabilities (UNCRPD) and NPA. Pakistan signed UNCRPD in 2009 but the cabinet of Pakistan endorsed ratification in January 2011 which will be presented to United Nations very soon for formal endorsement.

The Ministry made specific presentations to the President and Prime Minister of Pakistan along with the Federal Cabinet for raising its profile and requested for additional resources in 2010. The President and the Prime Minister of Pakistan have issued special directives in the last one year to increase the funding and special arrangements for inclusion of persons with disabilities. In spite of these high level directives and announcements, there is still a great need to improve political will and commitment of relevant stakeholders particularly in the public sector for supporting the inclusion of PWDs in policy and development initiatives.

Presently, in Pakistan, there are a number of DPOs network working independently under subregional mechanisms i.e. Pakistan Disabled Persons Organization (PDPO), Network of Organizations Working for People with Disabilities, Pakistan (NOWPD,P), Sindh Disability Forum, Khyber Pakhtunkhwa Disability Forum, etc. Sightsavers endorsed the sub-regional and regional cooperation and collaboration (emphasized in the Biwako Millennium Framework) for Action towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific (BMF) and BMF Plus Five, adopted by the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) as the framework in the Asian and Pacific Decade of Disabled Persons, 2003-2012. In August 2008, STEP, Sightsavers, Telenor Pakistan and AIER supported a national leadership conference for persons with disabilities that resulted in the Islamabad Declaration on Rights of Persons with Disabilities.

With the support of regional organizations, a regional leadership conference for persons with disabilities was organized in July/August 2010 that resulted in the establishment of a "South Asian Disability Forum (SADF)" that networks various DPOs and NGOs in South Asia, regardless of types of disability, to address a regional point of view in South Asia. In collaboration with governments, APCD, corporate sectors, international NGOs, sub-regional and regional agencies, UN agencies and other partners, SADF is expected to play a key role in bringing about a regional focus on the inclusion of persons with disabilities as a development priority.

Sightsavers has been successful in initial advocacy and dialogue for development of a mechanism on regional collaboration in close cooperation with APCD from the South Asian perspective in Islamabad. In consideration of the willingness of the Government of Pakistan, through the Ministry of Social Welfare and Special Education, to support such mechanisms, Sightsavers' strategy includes mobilization of available human, information and other resources in partnership with other governments, DPOs, corporate sectors, international NGOs, sub-regional and regional agencies including South Asian Association for Regional Cooperation (SAARC), UN agencies and other partners.

1.1. Rationale / Justification

The efforts of the public sector and UN/International Organizations have no doubt brought about a change in accelerating the services for the PWDs in Pakistan. The NGOs have also played an excellent role particularly in motivating the private sector and in creating awareness at the policy planning and implementation levels. In the past, such efforts were made at the level of individual NGOs, but now during the last decade the government in general and NGOs in particular have realized the need of developing “networks” for promotion of the cause of PWDs at national level.

It has been experienced in Pakistan that NGOs in various forms and definitions have been bridging the gaps in service delivery in the areas of prevention, early detection, education, health, vocational training, rehabilitation and daily living skills. The NGOs sector has been growing exponentially after 1980s in Pakistan, which can be witnessed from the increase in number of NGOs in organizational size, level of function and scope of work in different thematic areas. This expansion has resulted in a shift of focus towards addressing the challenges, shortcomings and problems, such as i) building capacities and skills internally ii) adhering to the needs of transparency and accountability iii) minimizing duplication of efforts and resources by the NGOs, creating unnecessary competition iv) lack of sharing knowledge and expertise v) missing the component of sustainability vi) little attention paid to leadership succession vii) and lack of emphasis on good governance. In realization of all these challenges, there is an increasing trend of networking between NGOs and the Government which has resulted in different forms of public private partnership

To address the disability issues and to initiate long-term, sustainable changes, it is essential to build the capacities of disabled people and Disabled People's Organizations to raise their voice for their rights and engage in social / political reform through participation in political dialogue and development action at different networks and fora. There is reorganization of the needs of actions for promoting community-based inclusive development in South Asia and other sub-regions in collaboration with various stakeholders including governments, Disabled People's Organizations (DPOs), APCD, corporate sectors, international NGOs, sub-regional and regional agencies, UN agencies and other partners¹.

This research explored different initiatives taken so far for establishing disability fora, networks and consortia by Sightsavers in partnership with different partners. This research study will be a key tool for advocacy on Disability Rights – particularly for local and national DPOs. Highlighting experiences of local-level good practices has significant potential for replication – the “multiplier effect”. Moreover, the process of conducting the research and producing the report has significantly enhanced the technical capacities of research team members (comprised of Sightsavers and STEP, a national DPO Partner of Sightsavers) to carry out future advocacy research initiatives – on different thematic areas.

The local government initiative was implemented in 2001 that involved the devolution of administrative authority to the districts. The main aim of this initiative involved reducing the level of hierarchy within the province and envisaged empowerment of local communities with enhancement of government effectiveness. This reform has suffered from many challenges over the last decade. The National Finance Commission Award and 18th Amendment now focuses on devolving allocation of budget for health to the provincial authorities in 2011 and onward. The Ministry of Social Welfare and Special Education is being devolved to the provinces, and this intensifies the need for developing effective networking among DPOs for cross provincial learning and sharing on one hand, and an appropriate representation of Pakistan's disability issues at international forums in a collective and unified way on the other.

1.2. Literature Review

Most research into disability tends to focus predominantly on health or social welfare aspects. There is little co-ordination or integration between research on disability and research on associated issues in gender, social development, and human sciences. Specific attention needs to be given to both quantitative and participatory components in research methods to ensure that the different dimensions of disability are appreciated².

PWDs face a multitude of social, economic, physical and political barriers hampering their mainstreaming in society. These barriers include stigmatization and a misunderstanding of the abilities and aspirations of PWDs. Socio-economic data on disability in Pakistan is also scarce, and where it exists, it is conservative. According to the 1998 census, approximately 2.49 % of the population has some form of disability. This is significantly lower than the WHO estimate of approximately 7% and NGOs estimate of 10% of the total population. It is estimated that 66 percent of disabled persons live in rural areas: only 28 % of PWDs are literate; only 14 percent of them are in work and 70 percent are reliant on family members for financial support³.

Organizations composed entirely of persons with various disabilities - physical, mental, and sensory - have sprung up in 100 countries since mid 1970s. Disabled people have come to realize that their societies were built without their input and participation⁴. The World Programme of Action states that: "More than 500 million people in the world are disabled as a consequence of mental, physical or sensory impairment. These persons are entitled to the same rights as all other human beings and to equal opportunities. Too often their lives are handicapped by physical and social barriers in society which hamper their full participation. Because of this, millions of children and adults in all parts of the world often face a life that is segregated and debased"⁵.

It is estimated that one person out of ten is disabled by physical or mental or sensory impairment, and at least 25% of any population is adversely affected by disability. At least 350 million disabled persons are living in areas where they do not receive the services needed to enable them to overcome their limitations⁵.

The systematic care of disabled persons was brought into focus in Pakistan in 1980s with the observance of 1981 as UN International year of disabled persons. The need was then felt for their education, rehabilitation and mainstreaming both by government and by the private sector. A law titled “Disabled Persons (Employment and Rehabilitation) Ordinance, 1981” was passed in 1981. This law is a comprehensive legislation that spells out the responsibility of the state towards the prevention of disabilities; protection of the rights of Disabled persons; and provision of medical care, education, training, employment and rehabilitation to Disabled persons⁶. But it does not include the commitment to create a barrier free environment for disabled persons, responsibility to remove any discrimination against them in sharing development benefits and to counteract any situation resulting in abuse and exploitation of Disabled Persons.

There was a need to establish a framework for comprehensive development of strategies, programs and services for the equalization of opportunities for Disabled persons and special provisions for their integration into the social mainstream. Hence a National Policy was formalized in 2002. The vision of the policy was to provide by 2025 an environment that would allow full realization of potential of Disabled persons through their inclusive mainstreaming and providing them full support of the government, private sector and civil society⁷.

Even after having comprehensive legislation, Disabled persons are mostly unseen, unheard and uncounted persons in Pakistan. They are the most marginalized group of the society because no particular ministry or federal department deals with issues related to disability. Ministry of social welfare and special education is only responsible institution which touches upon Disability issues. However, there are no specific sections or departments responsible for implementation of programs at local level⁸.

Furthermore, benchmarks described in the policy seems highly ambitious and as unachievable without having single responsible department or ministry for the implementation of the policy. Population statistics on which the policy is based is conservative and vague. Disabled persons can be visible if national censuses and surveys are strengthened enough to properly report disabilities in national statistics. According to the Disability KaR project report, where ever disability mainstreaming policies have been developed, the results have been disappointing. For example, South Africa has perhaps the most comprehensive legislation and policy framework for fully integrating disabled people of any country in the world, but due to non-participation of Disabled persons in the decision making process it has not been implemented⁹.

The ultimate goal is to achieve disability equality¹⁰. It is understandable that the culture and practices of institutions or states cannot be transformed at a stroke, but the challenge for the government and development agencies in Pakistan is to begin the journey by bringing disabled people into development action and policy dialogue as equal partners.

Networks are the flexible and sometimes informal form of collaboration in the sense that they function primarily on the basis of information exchange and building coalitions, lobbying for specific legislations or issues and learning amongst members. A network is also a group of individuals and/or organizations who, on a voluntary basis, exchange information or undertake joint activities. Networks also organize themselves in such a way that their individual autonomy remains intact. The relationships are voluntary, involving mutual or reciprocal activities, and do not affect the independence or autonomy of those who are networking. However not all information sharing constitute networking - networks are more free flowing, reciprocal, and multi directional exchanges of information, ideas and resources. An example of this is the Girl Child Network (<http://www.girlchildnetwork.org/>).

A network that promotes coordination and cooperation has been a key form for organizing development practice: coordination between government, NGOs and donors. However, the role of the state in development has changed, from that of the state as the all encompassing provider, to that of the state as regulator. This change has implications for the areas in which the state can legitimately be seen to have a coordinating role¹¹.

The United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), in the Biwako Millennium Framework (BMF) places strong emphasis on the importance of developing networks of centers of excellence in focused areas of disability to maximize cooperation and collaboration. Following this, the Asia Pacific Development Center on Disability (APCD) was established in Bangkok, Thailand (Biwako Millennium Framework (BMF) towards an Inclusive and Barrier Free and Rights Based Society for PWDs in Asia and the Pacific).

As part of the BMF commitment, recently in 2010 Islamabad Recommendations on Regional Networking and Collaboration in South Asia were endorsed with an aim to recall sub-regional and regional cooperation and collaboration for the Biwako Millennium Framework for Action towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities. In Asia and the Pacific, BMF and BMF Plus five has been adopted by the United Nations Economic and Social Commission for Asia and the Pacific [UNESCAP] as the framework in the Asian and Pacific Decade of Disabled Persons, 2003-2012.

Islamabad recommendations also endorse the establishment of "South Asian Disability Forum (SADF)" that networks various DPOs and NGOs in South Asia, regardless of types of disability, to address a regional point of view in South Asia. In collaboration with

governments, APCD, corporate sector, international NGOs, sub-regional and regional agencies, UN agencies and other partners, SADF is expected to play a role to highlight a regional focus on the inclusion of persons with disabilities as a development priority. The secretariat of SADF is located in Islamabad, Pakistan.

In Pakistan there is a great need for collective efforts at national level to emphasize mainstreaming of disability through the implementation of existing laws, e.g. UNCRPD (recently signed by the government and approved by the federal Cabinet for ratification), National Policy for PWDs 2002, and National Plan of Action 2006 etc. In Pakistan Disabled People Organizations (DPOs), there is a need to provide the opportunity to share ideas and information, especially at the district, provincial and national level. The networks of DPOs have played an important role in facilitating information-sharing amongst organizations of disabled people from different countries and regions. In this regard Leadership Training Seminars and regional meetings of World Congresses provide forums for formal and informal information exchange.

The Islamabad Declaration on the Rights of Persons with Disabilities (PWDs) signed on 14th August 2009 by key disability players and major stakeholders, DPOs and Civil Society Organizations also made some concrete recommendations in this context such as:

- PWDs themselves need to create opportunities to develop networks of key stakeholders in addressing the issue of inclusion holistically at national and local levels.
- Develop closer co-ordination between government ministries, departments, civil society organizations, and corporate sector and consumer groups for purposes of undertaking campaigns for social inclusion at the national and local levels.
(The Islamabad Declaration on the Rights of Persons with Disabilities (PWDs) endorsed on 12th to 14th August 2009)

Networking is currently considered a suitable approach for different organizations to improve performance and enhance impact. Since many NGOs, particularly DPOs are small and dispersed, networking is commonly seen as a cost-effective means to share information and spread knowledge about grassroots' needs, solutions and best practices. Also, networking is believed to strengthen NGO's ability to speak with one voice and to significantly increase their impact as policy negotiators and advocating agencies.

Overall, there are numerous success stories and good practices of networking in development sector across the globe, and a few even in disability sector. However there is paucity of information and research about determining the effectiveness and utility of DPO's networks in the developing world. This research is an attempt to emphasize the endeavours

of disability related development organizations and Disabled Peoples' Organizations (DPOs) for mainstreaming of disabled persons in Pakistan, in the milieu of International Disability movement, encompassing a review of disability related national policies, and international policy frameworks.

2. Methodology

The research was designed to review the disability NGO and Government network approaches as development interventions, to develop a better understanding of how it is practiced, and the nature and implications of inter-organizational relationships. This exploratory research has been carried out with a few adaptations from the Delphi method in which open-ended questionnaires and probing gave participants the opportunity to respond in their own words, rather than forcing them to choose from fixed responses. The questionnaire used and networks interviewed are shown in Annexure 1 and 2 respectively.

Overall, the data collection was distributed into three main categories which were: i) use of grey literature, ii) use of people as informants, and iii) use of published development literature. Different data collection techniques were used for each of these three categories.

A. Use of Grey Literature

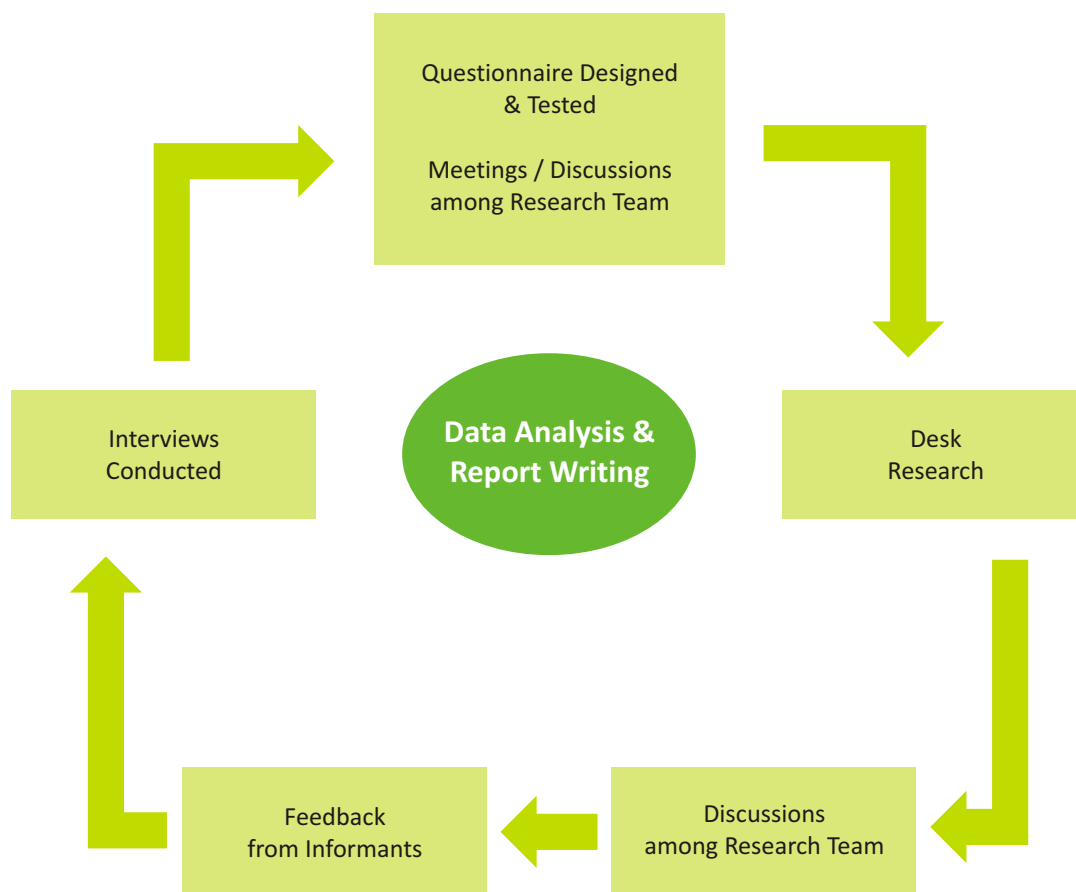
Information about disability networks especially in the context of meanings, understanding and practices was analyzed from the grey literature that served as a central data resource. These sources are discussed under the literature review section.

B. Use of People as Informants

The information was collected from 24 key informants through a semi-structured interview format which was pretested and revised accordingly. In addition to 24 key informants, discussions were held with key experts (from government and private sector) through focused group discussions to obtain the insights for practices and understanding of Disability Networks with a loose semi-structured interview format. Focus Group Discussions were conducted with DPOs in Karachi, Islamabad and Lahore about DPO networking and its developmental approach in the context of practice, meaning and relationships.

C. Use of development literature

The data collected and information generated from the reports and key informants was complemented with the reviews of developmental literature. The key areas of interventions in relation to synergy and inter-organizational relationships were reviewed.



3. Results & Analysis

As per respondents, generally, networking is synonymously used with the forum, collaboration and cooperation within formal and informal settings. Overall respondents defined networking under three main categories.

- Linkages between two or more organizations
- To make a pressure group
- It is an awareness raising tool

A network's value and utility stands or falls on members as sources of useful information to be shared. Networks are a valuable part of people's ability to respond to human service needs outside the boundaries of formal organizations. Networks and networking are valuable organizational outreach mechanisms and strategies for achieving the mission and objectives of many NGOs and CBOs. Networks essentially reach out to embrace diversity. Members work together towards a common goal. Networks tend to be decentralized with the participating members. Examples of coordination networks in Pakistan include Pakistan Association of the Blind, National Committee for Prevention and Control of Blindness, National Rural Support Programme Network, Network of Pakistan Poverty Alleviation Fund, NGO Resource Center Karachi, etc.

A. Key benefits of Networking

The respondents attributed key benefits from networking in the following ranking and preference in ascending order:

1. Enhanced voice for advocacy especially for rights and empowerment of PWDs and DPOs because of pressure groups and lobbying.
2. Resource mobilization and information sharing becomes easy and cost effective.
3. Exposure opportunities are made available and new opportunities of working together are known and explored.
4. Learning is increased by virtue of interaction and participation, and helps many organizations to move towards a shared goal.

5. This enables to refine a clear vision to the DPOs as more knowledge and orientation is attained through networking platform.
6. Complement synergies by bringing together like minded organizations.

B. Key Challenges of Networking

The respondents provided the following key challenges in ascending order:

1. Leadership especially the vested interests and lack of succession planning. Single person organization leading different kinds networks of disabled people.
2. Unequal distribution of resources among members i.e. generally urbanized groups have more control of and access to resources than rural groups.
3. Delays in timely and correct information flows i.e. the information rests with selected groups and its flow is not very timely for many instances to DPOs who do not have access to IT services.
4. Personality and organizational conflicts among DPOs of Pakistan i.e. many young individuals have been trained and oriented about disability in development and there is greater tendency of personal dominance and cultural strictness.
5. Mobility of PWDs to attend meetings because of resource constraints and accessibility barriers.

After analysis of the information collected through this study, it was revealed that there are considerable challenges for PWDs and the DPO for networking at various levels. These challenges include their limited mobility, limited access to information and communication technology, financial constraints, lack of education, lack of exposure opportunities and lack of skills for advocacy and lobbying.

Most of the PWDs struggle to become part of the disability networks as they don't have necessary knowledge and contacts for getting themselves registered as organizational entities. They do networking in the form of loose structures but don't have access to formal networks at provincial and national level in Pakistan. There are certain networks in Pakistan whose member organizations are like minded and have formal forums where they interact on a regular basis for exchange of experiences and information.

One of the objectives of a disability network is to act as national / provincial / district / local

resource center for organizations working for and with persons with disabilities by providing them space and a voice. These networks also plan and implement various programmes and activities to strengthen the governance, management, operations and programmes of organizations working for persons with disabilities. Most of the networks do aim to enhance capacity development programmes to improve the governance, management, operations and outreach of disability related organizations.

In Pakistan there are a few networks, who work to collect, collate, process and disseminate reliable data and information about disabilities, persons with disabilities and organizations working for them. These networks create mass awareness about the issues and challenges faced by persons with disabilities and organizations working for them and undertake advocacy with key stakeholders (particularly the government, civil society organizations, media, academia, donors and philanthropists) to address issues and challenges faced by organizations working for persons with disabilities. Another important objective of these networks is to create linkages among organizations working for persons with disabilities, government, business and media.

There are certain networks that are not sustainable mainly because of their dependency on an individual's leadership and personal contacts. Such networks do not promote equal participation of member organizations. The mainstreaming of disability in government policy and practice has been the key demand of the international disability movement for decades. It is also the central theme of UN's standard Rules on Equalization of opportunities for Disabled persons (1996). But, as of yet, nowhere in either the North or the South has mainstreaming happened (KaR, 2005)¹². Mainstreaming disability into development cooperation is the process of assessing the implications for disabled people of any planned action, including legislation, policies and programs, in all areas and at all levels. It is a strategy for making disabled peoples' concerns and experiences an integral dimension of the design, implementation and monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that disabled people benefit equally and inequality is not perpetuated.

One of the major advantages of networks highlighted by several respondents was that of facilitating resource mobilization for member organizations working for persons with disabilities. It is one of the strengths that attracts the member organizations for getting together on a joint forum.

In Pakistan so far, no such network was found that is working to publish and distribute research materials, such as studies, journals, books, pamphlets, periodicals, literature, and other printed matters as well as use electronic media such as websites, TV, radio etc. to disseminate reliable communication and other information concerning the disability issues. There are some magazines which connect PWDs through sharing case studies, new updates regarding assistive and Information technologies etc. in relation to disability issues.

4. Discussion and Recommendations

- 1. After analysis of the information collected through this study, it is our view that a “Pakistan Disabled Network” joint web portal should be launched just like the One UN Programme. There is need of information sharing amongst DPOs and NGOs.**

The DPOs and NGOs engaged in care, welfare, training, empowerment and rehabilitation of PWDs have very limited knowledge about the policies, plans, projects in public and private sector. They also have very little information about the international commitments, agreements, protocols and conventions. Through the development of joint web portals for these networks, information can be shared in a more effective, planned and organized manner. The concerned departments at federal, provincial and district levels and development organizations with the technical and/or financial assistance of UN/International organizations can help to establish resource and information centres, training/orientation programmes and workshops for such networks.

- 2. Networks are found without formal characteristics such as registered/legal bodies with bye laws, a permanent address and defined ownership like formal organizations. The common features of an organization and network is that they have shared objectives and goals where networking works in a democratic way.**

To establish any network is quite a difficult task. The big and powerful DPOs/NGOs normally overshadow the small organizations particularly those established in small towns, urban slums and rural areas. Most of the DPOs/NGOs (members of networks) and even network themselves are not aware about the system of registration or they don't bother to be registered to avoid monitoring of the registration authority. From a legal point of view, all DPOs/NGOs/Networks should be registered under any law enacted for registration purposes. All these organizations need to be trained in preparation of bye-laws, setting goals/objectives, filling up of registration proforma and system of registration. This task may be undertaken by the concerned government authority like social welfare department, cooperative society departments, district administration etc. The networks need training to function in a democratic style which can be arranged by the successful networks, government departments and UN/international organizations.

- 3. Strong Monitoring, Evaluation and accountability system should be in place.**

The main weakness of networks is that there is no formal system of monitoring, evaluation and accountability. There should be; i) in-built system of monitoring and evaluation within the organization ii) the registration authority may develop a system of monitoring, evaluation

and accountability on a regular basis. iii) the registration authority with the help of professional organizations, UN/international agencies may conduct training programmes for the executive body of DPOs/NGOs/networks. This will help the networks and member organizations to keep their activities on the right approach and also to develop a transparent system.

4. Dedication and commitment to the cause is required.

Dedication and commitment is the most important requirement for the individuals and the organizations to achieve their set objectives. In many cases, this quality is inherent but this can also be inculcated through various techniques: i) exposure to other successful networks ii) enhance knowledge base information iii) success stories of individuals and organizations iv) religious, moral and ethical values and teachings v) minimum dependency vi) simplicity in working environment, organizational structure, cost effective automation. There are examples of model personalities like Abdul Sattar Edhi and Mother Theresa.

5. Most of the networks are not sustainable mainly because of depending on individuals and their personal contacts. All the members should participate equally.

In our culture, the networks are still passing through inception stage. Not a single network working for the PWDs is sustainable as yet. The networks have either been established on personal contacts or they depend upon personalities. The member DPOs/NGOs may need to be trained about the concept/techniques of "Group work" and also about what is their role, what are their responsibilities, how they can contribute and up to what level they are clear about the objectives of the network.

6. Careful in writing, communication and documentation.

For any network or its member organizations (DPO/NGO), it is necessary that they know about;

- i. Art of writing reports/minutes of the meetings/correspondence with individuals and organizations.
- ii. To communicate with the persons or organizations about their objectives / activities or to convey their message in an appropriate and professional manner.
- iii. To document the relevant information in the form of pamphlets, brochures, booklets, monthly/annual reports, proceedings of meetings and financial report of their own organizations.

For all these purposes, the networks and their member organizations should hire services of some educated/experienced persons or obtain services of any volunteer who knows these tasks very well. The networks should also make efforts for training of their educated members in the areas of writing reports, communication techniques and also in documentation of their records/proceedings. The relevant government departments/registration authorities, development organizations and UN/international agencies should also help the networks to train their personnel in these areas. This will not only improve the efficiency of the networks and their member organizations but will also help to develop their contacts/liaison with the concerned government departments, development organizations and donor agencies.

7. Promote DPOs formation in rural and remote areas with equal focus on women with disabilities.

Disabled people have established their own organizations in almost every country. Since 1981, Disabled Peoples' International has represented DPOs on the world stage. Throughout the world, disabled people have organized, lobbied and have been successful in getting anti-discrimination legislation. Now DPOs have official international recognition (the Convention on the Rights of Disabled People) which declares that disability is a human rights issue. There is a need for establishment of DPOs at grassroots level to raise the voice of disabled persons and these DPOs must have representation of women with disabilities. Through this platform, PWDs from remote areas can become part of the national and eventually global disability movement.

8. Active links should be developed among the network partners to increase inter organizational linkages through the technical assistance from UN/INGOs/Government.

In this era of fast track information avenues, disability related organizational networks can be strengthened through developing information sharing platforms. Technical and financial support from UN/INGOs/Government can enhance the scope and could be helpful in establishing strong bonding among different actors spreading at local, national and international level.

9. Promote local resource mobilization and transparency (equal distribution of resources should be encouraged).

Resource mobilization is one of the main significant features of a network which can enhance the sustainability of a network and commitment of member organizations. It was a very strong recommendation from most of the respondents of this study that networks need to engage every member organization, rather than one strong organization leading on that and

making decisions. In this regard most of the member organizations suggested the investment by the network on capacity building of all member organization in required skills for resource mobilization. The respondents also raised the challenge of their limited exposure to the available information for resource mobilization. Therefore, it is recommended that the disability networks need to develop their strategic plans of 3-5 years where they can articulate the needs, way forward and challenges for resource mobilization. This will provide them with more clarity about their future strategies for resource mobilization and the areas where they need to invest.

10. Young leadership should be promoted through strategic planning.

Leadership always plays key role in inspiring people and groups of people / networks towards great achievements. It provides guidelines, ways forward and strong foundations to counter challenges. Strategic business planning is vital for bringing about the desired sustainable change. It can provide a long term vision and road map to the disability movement in-country through trained and skilled human resources with clear succession planning. It will encourage and facilitate young leadership development which will sow the seed for others to become leaders. Leadership training and development can maximize productivity, shape a positive culture and promote harmony.

SWOT Analysis of DPOs in Pakistan

STRENGTHS	OPPORTUNITIES
<ul style="list-style-type: none"> • Can use Information Technology tools • Information flow is very fast • Link with national and international organizations of and working for PWDs • Members of the different networks • Good cooperation with local authorities • Involved in policy and planning with the Governments • High interest by all PWDs to attend meetings, workshops, conferences and seminars • Collective voice 	<ul style="list-style-type: none"> • Mobilize local and international resources • Integrate with mainstream development organizations • Ratification of the UNCRPD • Devolution programme after 18th amendment, will empower provinces more • Media campaigns and IEC material • Research and publications • New CBR guidelines 2010 participatory planning through networks • Collaboration at regional level
WEAKNESSES	THREATS
<ul style="list-style-type: none"> • Lack of trust amongst DPOs • No succession plan for leadership • Limited vision (no strategic planning) • Limited communication and presentation skills • Weak lobbying and advocacy skills • Less understanding of the National laws and International Conventions such as the UNCRPD, BMF, BMF Plus Five, Labor Laws • Less involvement with mainstream organizations (NGOs, Civil Society Organizations) • Mostly PWDs / DPOs do not get enough opportunities for education • Internal conflicts, politics, and perceptions • Overstretched staff • Streamline activities / lack of prioritization skills • Lack of delegation and sharing of responsibilities • Weak monitoring, evaluation and accountability system 	<ul style="list-style-type: none"> • Security concerns • High inflation gives rise to economic constraints for sustaining organization • Disability not part of the main development agenda • Low funding (Government, donor agencies, local donations) • Expensive assistive devices • Limited job opportunities • Accessibility and mobility • Staff turnover

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Annexure 1

Questionnaire

1. Study On Approaches And Practices Of Disability Networks Organizations (government / Nongovernment) In Pakistan

SECTION: 1

Name of Organization:	Contact Person Name and Designation:
Address:	Contact Information: (Phone, Cell, E-mail address)

SECTION: 2

Questions about networking

1. Are you representing any independent disability network?

- a. Yes
- b. No

2. Are you member of any Network?

- a. Yes
- b. No

3. What is the geographical area of the network?

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4. What is the number of member organizations of the network?

5. What are the objectives of network?

6. Since how long the network is working?

7. What is the type of network (tick as appropriate)?

1) Scale

- i) Local
- ii) Provincial
- iii) National
- iv) Regional
- v) International

2) Category

- i) DPO Network
- ii) NGO Network
- iii) Govt. Network

Only for Government Organizations

1. What is the role of your organization with regard to programs for the PWDs?

2. How much budget was allocated for welfare of the PWDs during the last three years?

3. How much budget was allocated for :

i) NGOs

ii) DPOs

iii) Network

4. What is the level of collaboration with the UN Agencies/INGOs working for the PWDs ?

5. What is the role of your organization/department for the implementation of national policy of disability, NPA for the PWDs ?

8. Is the Network registered?

- a. Yes
- b. No

9. If registered, under which law and where has it been registered?

10. What types of disability/disabilities are being addressed by the network?

11. What are the advantages/disadvantages of Competition of different Networks?

12. What are the advantages/disadvantages of Coordination of different Networks?

13. What are the advantages/disadvantages of Cooperation of different Networks?

14. What is the procedure of elections and when are they held?

15. Are the strategies / policies of network aligned with

- a) National Policy for PWDs 2002, Y / N
- b) National Plan of Action, Y / N
- c) UNCRPD Y / N
- d) MDGs Y / N
- e) CEDAW Y / N
- f) CRCY Y / N
- g) Biwako Millennium Framework Y / N

16. What are the advantages of networks?

17. What are the disadvantages of networks?

18. Does the network has its own office building?

- a) Yes
- b) No

19. If Yes;

- a) Owned
- b) Rented
- c) Donated

20. Does the network receive any support from donors?

- a) Yes
- b) No

21. What type of support does the network receive from donors?

- a) Technical
- b) Financial

22. Since how long?

23. Area of collaboration

24. Shared goals/objectives, if any

25. Any support from Sightsavers?

- a) Yes
- b) No

26. If yes, what type of support from Sight savers?

27. What are the major achievements of the Network?

SECTION 3:

Questions about contribution of organization for development of PWDs.

28. What are the areas of operation (tick as appropriate)?

- | | |
|-------------------------|--|
| I) Livelihood | ix) Health of PWDs |
| ii) Capacity Building | x) Independent Living |
| iii) Quality of life | xi) Orientation and Mobility |
| iv) Prevention | xii) Accessibility |
| v) Special Education | xiii) Advocacy and Information Support |
| vi) Inclusive Education | |
| vii) Skill Development | |
| viii) Sports | |

29. Contribution of your org/network in aforementioned areas:

SECTION: 4 (A)

Questions about challenges being a network member.

1. Are you satisfied being a network member?

- a) Yes
- b) No

2. In each Case give, 3 reasons:-

I.
II.
III.

3. If representing a network, mention names of focal member/ Organization?

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4. Which network do you appreciate in Pakistan and why?

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Thanks for your time and cooperation.

Annexure 2

Respondents of Questionnaires:

- Ageing and Disability Task Force (ADTF)
- CBR Network Pakistan
- Charagh-e-Manzil
- Department of Social Development, Peshawar University
- Directorate General of Special Education, Islamabad
- Directorate of Social Welfare, Government of AJK, Muzaffarabad
- Directorate of Social Welfare, Government of KPK, Peshawar
- Directorate of Social Welfare, Government of Punjab Lahore.
- Directorate of Social Welfare, Government of Sindh, Karachi
- Dost (Dedicated Organization of Special Persons)
- Estenara Karachi
- Milestone Society for Special Persons
- Ministry of Social Welfare and Special Education, Islamabad
- National Council for the Rehabilitation of Disabled Persons, Islamabad
- National Council of Social Welfare, Islamabad
- National Forum of Women with Disabilities
- National Trust for the Disabled, Islamabad
- Pakistan Association of Deaf
- Pakistan Association of the Blind (National)
- Pakistan Blind Cricket Council
- Pakistan Cricket Association of Physically Disabled Persons
- Pakistan Special Islamabad
- PDPO (DPI-Pakistan)
- Punjab Trust for the Disabled, Lahore
- Saaya Association
- Sir Syed Deaf Association
- Society for Special Persons (SSP)
- Voice of Special Lahore

Existing Networks (who were interviewed):

- Ageing and Disability Task Force (ADTF)
- CBR Network Pakistan
- National Forum of Women with Disabilities
- Pakistan Association of Deaf
- Pakistan Blind Cricket Council
- Pakistan Cricket Association of Physically Disabled Persons
- PDPO (DPI-Pakistan)