Diversity and Disability Rights

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Introduction:

There are three examples from Anantapur district, Andhra Pradesh, India which attempts to enable persons with different disabilities, their families and community to value difference and diversity adding to richness of life.

The first one was started in 2000 with people with mental illness using a community development approach.

The second in 2009 to establish a cross disability district DPO where difference is valued as adding richness to life and where each leadership position is held by a person with a different disability or their caregivers.

The third in 2010 on providing assistance to those who need high support in villages using a multi sectoral approach.

All the three examples are in line with CRPD principles using CBR as the strategy to deliver.

1. Community Mental Health program:

Social Action for Child Rehabilitation, Emancipation and Development (SACRED) was founded in 1994 and started work with disabled people in 1996. It currently works in 430 villages of 12 blocks, 4 in Kurnool and one in Anantapur districts called Anantapur rural block. The focus of its work is to build sustainable DPOs. It achieves this goal by enabling persons with different disabilities and their caregivers to form themselves into Cross Disability Self Advocacy Groups (CDSAGs) and for them, in turn, to establish block level DPOs. At present there are 365 CDSAGs with 4175 members and 5 block level DPOs.

Its program is comprehensive: providing medical rehabilitation, promoting inclusive practices in education and in livelihood. Self advocacy by CDSAGs and DPOs is at the core of its work.

One of its DPOs called GRAMIKYA VIKALANGULA ABHIVRUDDI MANDALI (GIVAM) has advocated successfully on a community mental health program. One of the main outcomes of this program is that the members of 214 CDSAGs and 5 DPOs made up of 2394 members recognise people with mental illness as potential members of their groups and many of them work actively towards their inclusion.

GIVAM in Anantapur rural is a sustainable rural DPO. It was founded in 2003.

It advocates and works closely with authorities concerning education, health, livelihood and social security. They have their own source of monthly income of INR 16,000/- (266 Euros). Their income is from running a local transport service, a three wheeler called Auto Riksha in India, by lending a filler machine which is used for mixing concrete and from a book binding workshop.

Community mental health program:

Basic Needs India (BNI) is an independent Indian NGO founded by Basic Needs International UK. Its approach to the work with people with mental illness is innovative. It takes a community development approach in working with people with mental illness. This holistic intervention includes:

- Identification,
- Counselling family members and the person,
- Medical treatment, referral, training caregivers,
- Enabling members to get back to their original profession, eg: teaching, training etc,.
- Encouraging members to engage in social and livelihood activities including household work, and
- Encouraging them to join CDSAGs

BNI does this in partnership with other NGOs like SACRED. It carries out capacity building exercises:

- Consultation Workshops.
- Awareness Building Activities
- Peer Group meetings.
- Rallies
- Community Group meetings.
- Community education through T.V.
- Cultural Programmes.
- School Education Programmes.
- Referrals & Treatment.
- Training of Rural development workers.
- Livelihood programmes.
- Advocacy

Role of DPOs in the Programme :

- Identification of persons with Mentally illness and Problems, issues, and needs through Rural Development Workers.
- Preparation of Action plan and implementation of Community mental health and development program activities.
- Inclusion of persons with mental illness in to CDSAGs and DPOs.
- To support them in getting financial assistance from Government and Banks for livelihood activities,
- Monitoring the program
- To advocate on issues concerning mental health especially, for the Government to implement the District Mental Health Program (DMHP)
- Taping resources from NGO and Government for this program.
- Build rapport with line departments such as health, education, Revenue etc…
- Network with likeminded DPOs, NGOs and Village organizations and block level women's organizations,

The following tables illustrate the progress of this program:

Year wise statistics of People with mental illness in the program:

S.No	Year	Major		Minor		Total		
		Male	Female	Male	Female	Male	Female	Total
1.	2000	08	04	02	-	10	04	14
2.	2001- 2002	19	09	07	03	26	12	38
3.	2002- 2003	10	06	12	07	22	13	35
4.	2003-2004	08	06	10	08	18	14	32
5.	2004-2005	24	19	17	12	41	31	72
6.	2005-2006	29	14	18	17	47	31	78
7.	2006-2007	21	16	10	08	31	24	55
8.	2007-2008 Expansion area	50	32	33	18	83	50	133
9.	2008 – 2009	7	24	22	31	29	55	84
10	2009- 2010 (Jan to Dec 2010)	3	6	3	1	6	7	13
10.	Network I.K.P – DRDA	41	25	27	24	68	49	117

	Anantapur Dt.							
11	MEPMA Anantapur Municipal Corporation & Guntakal Municipality	30	15	20	16	50	31	81
	Total	250	176	181	145	431	321	752

Status of people with mental illness in the program:

Persons identified with Mental illness	752
Referred to psychiatrist	614
Under Treatment regular	556
Under treatment irregular	58
To be refer for treatment	138
No. of Stabilized Persons	320

Persons with mental illness in Livelihood activities:

Financial assistance from DPOs	130
Livelihood activities carried out by them with the supported of CDSAGs	107
Livelihood activities carried out by them with the Families and Community members	44
Financial assistance from Government as subsidy on Loans from Banks	16
People in National Rural Employment Guarantee Act (NREGA)	244
Total	541

Systemic change:

The community mental health program commenced with SACRED in 2000 in partnership with BNI. At that time, there were no services in the district for people with

mental illness. BNI trained the DPO members and staff members of SACRED on identification, counselling, awareness building etc,. With the help of The National Institute for Mental Health and Neuro Sciences (NIMHANS), the identified people had to travel about 100 Kilometres to get assessed and to take treatment. This meant spending money for two people to travel (the person with mental illness and a family member, the family member loosing the day's wage). (most people in the program belong to families with daily wage earners as landless agricultural labourers or as marginalised formers).

The district hospital in Anantapur had a post for a full time Psychiatrist. This post was not filled. The reason given by the health department was that there were not sufficient numbers of persons with mental illness in the district to warrant to deploy a psychiatrist in the hospital.

GIVAM advocated effectively and consistently over three years with documentary evidence at the local, district and state levels. As a result a full time psychiatrist has been deployed in the district hospital. He has replaced BNI in the district in that he carries out its functions regularly such as capacity building.

2. Cross Disability district DPO (DDPO):

Promoting self-help groups of persons with disabilities (SHGs of PWDs) at the village level has become a common practice in community based work with disabled people in South India from about the mid 90s. The representatives of these SHGs have come together and form themselves into block level federations or DPOs.

Current reality: village level SHGs are still constituted by persons with different disabilities and their caregivers where persons with disabilities are unable to represent themselves. Whereas the DPOs are largely constituted by persons with Physical disability and with visual impairment. In most DPOs, persons with intellectual disability, with Cerebral Palsy, with hearing impairment, or with multiple disabilities are not represented. Conducting a study to understand the dynamics that contribute to their non representation in DPOs, can, in itself, be useful and revealing.

One of the contributing reasons could be the hierarchy that has developed, almost naturally among persons with different disabilities. Not surprisingly, this hierarchy is based on the natural phenomenon of the survival of the fittest. So, the higher and more powerful the level, greater is the force that keeps the most vulnerable out of the race. This force is invisible and is part of the human psychic.

An experiment:

Noticing this dangerous phenomenon in disabled people's organisations (DPOs), an experiment was started in May 2009 in Anantapur District of Andhra Pradesh. This experiment is based on one of the core principles of CRPD: valuing difference and diversity adding richness to life. The aim of the experiment is to promote cross disability DPO at the district level of persons with different disabilities where diversity and difference are valued

and where person representing each disability has equal opportunity to participate in decision making.

There are four NGOs which work with disabled people in this district. They are: Rural Development Trust (RDT), Society for Elimination of Rural Poverty (SERP), SACRED, and the Timbaktu Collective. They have facilitated about 28,000 persons with different disabilities to from themselves into SHGs and into block level DPOs. Probably, Anantapur is the only district in India which has a SHG of PWD in every village serviced by a CBR worker. There are 63 block level DPOs in this district.

Representatives from randomly selected DPOs came together and formed a committee to draft the constitution for such a DDPO. There were 30 members in this committee. They represented all the four major disabilities: Intellectual, Hearing, Physical and Visual. They had 13 sittings. Each sitting was at the venue of one of the four agencies mentioned above. The cost of each of the sitting was met by the respective agency.

An overview of the constitution:

Membership: Only DPOs consisting of members of SHGs can become members of the DDPO, the membership fee being rupees 200/- per DPO. The DPO should at least be two years old and should have demonstrated its capacity in management and advocacy.

Annual subscription: Each member of every village SHG shall contribute rupee one as annual subscription to the DDPO.

General Body: each DPO shall nominate five persons chosen from the SHG members to the general body of the DDPO. Each of these five persons shall represent one disability by themselves or by their caregivers where they can not represent themselves because of the severity of their disability. These disabilities include intellectual, hearing, physical and visual disabilities and mental illness / cerebral palsy.

Executive committee (EC): it shall consist of 15 members and shall be elected once in 3 years. Not less than 10 members of the EC shall be persons with disabilities and the other 5 shall be caregivers. Not less than 8 of the EC members shall be women with or without disability.

Leadership: Not more than one non disabled person can hold any of the 5 leadership positions: president, vice-president, secretary, joint secretary and treasurer. Each leadership position shall be held by a person with a different disability. There shall at least be two women in leadership positions.

The DDPO called Anantha Vikalangula Hakkula Vedika (AVHV) held its first general body on 27th June 2010 and conducted its first selection by secret ballot on the same day. AVHV was registered as a legal organisation in November, 2010.

Structure:

The district has been divided into six regions, each region covering 10 to 12 blocks. The committee (EC) of AVHV will constitute an action committee at the regional level called Regional Action Committee (RAC). The RAC members will be nominated by the DPOs of the region. Each DPO shall nominate two persons a man and a woman. The RAC will be made up of persons with different disabilities or their caregivers. It will have the same structure as the EC of AVHV and each leadership position will be held by a person with a different disability or their caregivers.

3. A project to enable persons with high support need to lead a quality life with dignity and freedom called Supported Living Project (SLP).

Introduction: The Ruaral Development Trust (RDT) was established in 1969 to work throughout the drought prone district of Anantapur, Andhra Pradesh, India. It works with persons with disabilities, women, daliths in the areas of education, health, livelihood etc,.

Its work with disabled people both in the community based and in institutions. It runs 18 special residential schools, a training cum production centre, orthotic and prosthetic workshops and with 15,000 persons with different disabilities and their caregivers in the villages of the 50 out of the 63 blocks in the district. These persons have formed themselves into cross disability self advocacy groups (CDSAGs). Nominated members from these groups have formed themselves into block level DPOs.

Rationale: Finding that family members of persons needing high support do not know where to go for what to do for getting support to their adolescent children, RDT looked for a model on how these families could be assisted. Since it could not find a community based model which is multi sectoral, it commissioned a study. The study report is attached which has an executive summery as well.

Progress to date: The project has commenced with the DPO and five CDSAGs from one block taking the lead:

- Identifying persons needing high support,
- Members volunteering to be trained as caregivers,
- Creating a fund to support activities of the project,
- Identifying locations for day respite care centres

Conclusion: All these three initiatives are at different levels of development. The underlying principles that govern all of them are in line with CRPD: inclusion, universal design, reasonable accommodation and legal capacity.

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