

Community-based Rehabilitation (CBR) & UN Convention on Rights of Persons with Disabilities (CRPD)



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International Workshop on Community-based Rehabilitation (CBR) and U.N. Convention on Rights of Persons with Disabilities (CRPD) was organised jointly by Disability & Rehabilitation team of World Health Organisation (WHO/DAR) & Italian Association Amici di Raoul Follereau (AIFO/Italy), with support from Disabled Peoples' International (DPI), Norwegian Association of Disabled (NAD) and International Disability & Development Consortium (IDDC) on the occasion of First Asia Pacific CBR Congress.

Technical coordination of the International Workshop was under Mr. Gianpiero Griffò from DPI and Ms. Francesca Ortali from AIFO/Italy. The workshop organisation, secretarial and logistical support was provided by Ms. Simona Venturoli & Ms. Felicita Veluri from AIFO/Italy.

This workshop report has been prepared by Dr Sunil Deepak, Medical Support Department of AIFO/Italy. The pictures used in this report are from the presentations made by workshop participants.



Opening session (from left) Chapal Khasnabis (WHO/DAR), Akiko Ito (UNDESA) & Francesca Ortali (AIFO/Italy)

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Acronyms Used in the Report

Acronym	Full Name
AIFO	Italian Association Amici di Raoul Follereau
CBR	Community-based Rehabilitation
CRPD	Convention on Rights of Persons with Disabilities
DPI	Disabled Peoples International
DPO	Organisation of People with Disabilities
ECOSOC	Economic & Social Council of United Nations
HRA	Human Rights Approach
IBR	Institution-based Rehabilitation
IDDC	International Consortium on Disability & Development
MGDs	Millennium Development Goals
NAD	Norwegian Association of Disabled
NGO	Non-Governmental Organisation
RBA	Rights-based Approach
SCRPD	Secretariat for the Convention on the Rights of Persons with Disabilities
SHG	Self-help Groups
TDAP	Taluk (Sub-district) Disability Advocacy Programme
UN	United Nations
UNDESA	United Nations Department of Economic & Social Affairs
WHO/DAR	World Health Organisation/Disability & Rehabilitation team

FINAL RECOMMENDATIONS

International Workshop on Community-based Rehabilitation (CBR) & United Nations Convention on Rights of Persons with Disabilities (UN CRPD)

1. CRPD is a legal instrument and it reinforces the CBR programmes. CRPD is based on the human rights approach and the CBR principles fit in with the CRPD.
2. CBR approach places special importance on working with poor, disadvantaged and discriminated persons in both rural and urban areas and is a key tool in promoting empowerment of persons with disabilities.
3. CBR is a strategy for inclusive development and should be promoted as part of all development efforts. CBR programmes should have a critical self-appraisal if their own activities, organisation and implementation are in line with CRPD. Persons with disabilities should play central role in all the processes of CBR, from planning to implementation to monitoring and evaluation.
4. CBR programmes should work to disseminate CRPD in all communities and among other stakeholders. For working with CRPD, CBR programmes also need to network among themselves.
5. CRPD and other rights-based instruments should be incorporated in all training programmes related to CBR. The regional and national CBR strategies, millennium development goals, other strategies should keep account of CRPD.
6. DPOs and CBR programmes should work together. CBR programmes should facilitate, promote and strengthen DPOs at all levels, with appropriate empowerment activities and instruments. CBR programmes should support networking between DPOs at grassroots level and national level. At the same time, DPOs should support strengthening of CBR programmes.
7. To develop concrete policies on disability, at local and national level, it is necessary building a Disability Action Plan, based on CRPD and involving DPOs in all phase of the process. CBR should be one of the components of Disability Action Plan.
8. Persons involved in CBR programmes, in collaboration with DPOs & disability movements, should continue to advocate in their respective countries for signing and ratifying of UN CRPD and its Optional Protocol.
9. CBR programmes should work together with persons with disabilities & DPOs in advocacy for making the governments accountable in implementation of UN CRPD. CBR programmes have a role in promoting advocacy for making sure that national laws are in line with CRPD.
10. CBR programmes can also support monitoring of implementation of CRPD in the programme areas, based on principle of the art. 33 of CRPD.
11. CBR can play important role in reaching more discriminated groups of persons with disabilities such as women & children, emigrants with disabilities, persons with complex dependency needs, persons who can't represent themselves, etc. for ensuring that benefits of CRPD reach them.

**International Workshop on Community-based Rehabilitation (CBR) and U.N.
Convention on Rights of Persons with Disabilities (CRPD)**
WORKSHOP REPORT

OPENING SESSION

Mr. Chapal Khasnabis, from WHO/DAR welcomed the participants to the workshop. He felt that the workshop was an important opportunity for developing CBR work in coming years, especially for people of Asia-Pacific region. He noted that Asia Pacific region has a rich history of CBR and it is important to see how CBR and CRPD can work together. There is a gap between the policy and the practice. Some countries have signed CRPD but face challenges in putting the conventions into practice.

It is important that the Health Ministries are involved in discussions about the ratification of CRPD in the parliament, to understand their own role in its implementation. The laws proposed in any country to fulfil the obligations of CRPD, have to keep account of the local conditions. For example, if the law has a clause that in 6 months all buildings will be made accessible, and another clause that all persons will have right to assistive devices, then are these clauses realistic?

Mr. Khasnabis concluded that in the real world, where the majority lives, it has problems of survival, problems of access and quality of services. These have to be kept in mind for operationalising CRPD and making sure that its benefits reach all the persons.

Ms. Akiko Ito, from UNDESA secretariat started with an introduction to DESA's work on disability. DESA supports intergovernmental processes (General Assembly, ECOSOC and the Commission for Social Development) to develop normative and policy framework and standards on development. DESA works with governments, civil society, academic institutions and other stakeholders. SCRPD/DESA served as the Secretariat for the UN Ad Hoc Committee on Disability that drafted the Convention.

As a focal point on disability of the United Nations, SCRPD/DESA is mandated to play a central role in moving forward the disability rights agenda in the broad developmental frameworks, promoting the rights of persons with disabilities in all aspects of economic and social development.

Through *the new disability architecture*, which consists of the World Programme of Action concerning Disabled Persons, the UN Standard Rules and UN CRPD, the international community has directed its attention to the full and effective participation of persons with disabilities from the rights-based approach, in society and development.

An Inter Agency UN Support Group on the CRPD was set up in 2007. Last year during the 63rd session of the General Assembly, the resolution 63/150 of 18 December 2008¹, highlighted that for the achievement of the Millennium Development Goals and other internationally agreed development goals, it is necessary that persons with disabilities are included in all its processes, so that the mutually reinforcing cycle of poverty and disability is broken. Persons with disabilities should be agents and beneficiaries of all aspects of development, human rights and peace and security of the international community.

¹ Contained in A/63/424, as draft resolution I.

The Assembly, in the same resolution, requested the Secretary-General for “updates” of the World Programme of Action and a “report” on the situation of persons with disabilities in the context of MDGs.

Ms. Ito concluded with some suggestions about some issues related to CRPD for the discussions of the workshop.

FIRST SESSION, UNDERSTANDING THE UN CONVENTION ON RIGHTS OF PERSONS WITH DISABILITIES (UN CRPD), Session Coordinator Ms. Francesca Ortali, Session Rapporteur Ms. Sarmila Shrestha

The session started with some presentations, that were followed by discussions in small groups and finally plenary discussions.

Plenary Presentations

UN CRPD and evolution of CBR, presented by Gianpiero Griffo: Gianpiero, explained that he is a member of world council of Disabled Peoples’ International. He explained that having a Convention is an important change, as it moves the discussions from the “needs” to the “rights”. CRPD should be the basis for interventions in all countries in future, and in all policies at all levels. The impact of this change is the Human Rights approach, a move from medical to Human Rights model, with mainstreaming in all policies and obligation to involve Persons with Disabilities in decision-making.

He discussed the differences between medical model of disability and the Human Rights approach (HRA). For HRA, persons with disabilities are citizens with different abilities. It acknowledges that they live with discrimination & lack of equal opportunities and thus for HRA, “treatment” means social inclusion because, competences are located in all the members of society.

He looked at indicators like unemployment rate, to show that discrimination and inequalities exist even in developed countries. Stigma is a great barrier, disabled persons are often seen as invisible citizens. Disability results from interaction between persons and environmental and attitudinal barriers.

Disability is an ordinary condition of life, it is a part of human diversity and society needs to include participation for all persons. At global level, majority of disabled persons are in rural areas, but only 2% receive some support, 96% do not have formal education. Impact of CRPD should reach to all local authorities, to address these inequalities. He concluded that there is also a need to look for new indicators, to measure discrimination and lack of opportunities.

Mongolia CBR Programme, empowerment of DPOs and ratification process of CRPD, presented by Ms. Tulgamma Damdinsuren: Mongolia had important political changes in 1990s, when socialist regime was replaced by democratic governance. Since then many NGOs including DPO have been started. At present there are about 2000 NGOs and 70 DPOs in Mongolia. DPOs are based only in the national capital Ulaan Baatar. A DPO federation was set up by the Government in 1998 but in beginning of 2007, this structure broke down. After CRPD was approved, another group started as national level networking of DPO and has become a new national DPO federation.

National CBR programme (NCBRP) in Mongolia supported by AIFO/Italy collaborates with national DPO federation as a partner. This partnership had resulted in training for capacity building of DPOs with funding by UNDESA in 2006. Similar capacity building activities of DPOs are continuing since 2008 through EU funding.

Activities for ratification of CRPD – NCBRP in collaboration with DPI/Italy conducted training on Human Rights for DPOs and for decision makers. A training manual was developed. NCBRP will continue to work with DPOs and national federation on implementation of CRPD, supporting its monitoring and promoting awareness.

Plenary Presentations of Small-Groups' Discussions

Small group were asked to discuss specific themes. A brief summary of each small group discussion is given here.

National experiences of monitoring rights at local level, group discussions were facilitated by Chau Cao Minh, and were presented by Diane Mulligan: There were different examples from Afghanistan, Vietnam, India about monitoring of CRPD at local levels. It was felt that there is lack of monitoring experience at local and government levels and national Human Rights institutions. Many countries have not yet ratified CRPD so they are behind.

In some countries, CRPD is ratified but not yet implemented, and role of CBR is not clear. State should take action and involve stakeholders, there CBR can play a role. DPOs have knowledge and expertise to contribute, but we need to have framework for monitoring and implementation. There is also a need for capacity building on monitoring, and we need some baseline information.

DPOs and CBR have supportive role in developing action plan, at the same time, their role is critical in identifying issues that are left out, at different levels including at grassroots levels, including violation of human rights at family level. Another issue is to see how does this information feed into monitoring at local and national levels. We also need to build on existing structures. Similar structures are already there in many countries on women and child rights, so we can learn from them. Advocacy and education at all levels are needed and CBR has crucial role in educating local authorities and communities.

UN CRPD and contribution of rural areas to promote ratification: Discussions facilitated by Jayanth Kumar, & presented by Sayema Chowdhury: Local authorities have a in the ratification of CRPD. Many countries have ratified CRPD, and in this process DPOs and local authorities have played a crucial role, for example, in Liberia, India, Bangladesh, & Afghanistan.

Bangladesh ratified CRPD in November 2007, and then ratified Optional Protocol in May 2008. Umbrella DPO organisations have played a good role in the ratification. In India, after 2 years of ratification, things seem good on paper, and Government has defined roles of different Ministries, but for the implementation, a lot remains to be done. In Liberia, they are trying for the ratification, and there is a Commission, with 3 places for persons with disabilities in the parliament, and they have set-up a watchdog committee for CRPD. In Afghanistan there are representatives of 34 provinces on CRPD group and they have to try to make the implementation smoother and report to governors.

Recommendations from the group – Accessible information is needed about CRPD and it needs to reach people, and people have to understand what CRPD mean to them in concrete terms. Many CBR & DPO persons do not know about CRPD, so their capacity building is also needed. There can be media such as posters on CRPD to create awareness, but this should be by governments for issue of ownership. Posters of NGO are there but they are less effective.

CRPD is already translated into Bangla and English Braille in Bangladesh. The group also emphasised role of media. Linkages need to be developed at national and grassroots level as often information does not reach grassroots levels. In India, there are some significant laws, (for example 3% of all national and international funds should be for persons with disabilities and all disabled persons should get an identity card), but in reality, 50-60% of disabled persons do not have identity cards, so linkages need to be stronger.

CBR can play a role of mitigating this gap between national and local levels. There are also gaps between CBR and Disabled People's organisations (DPOs) – CRPD is mainly on DPO, it does not properly acknowledge CBR. On the other side, CBR also needs to incorporate rights and needs, and CBR and DPOs need to come together.

Representatives from Nepal also shared their experience, and proposed that CBR should play active role in implementation and monitoring of CRPD. In Bangladesh local administrations, disabled persons from CBR and DPOs are preparing candidates for elections, Government was proactive in ensuring their participation, and this can become stronger.

Changing attitudes of professionals is crucial. One example is, “don't see the wheelchair, see the person sitting on it”, as often we see first wheel chair and then the person.

CBR has to go beyond the boundaries of project areas in reaching DPOs and making governments accountable, do advocacy for amendment of national legislation for updating it in view of CRPD. CBR can also play crucial role in training, in policy advocacy and in media advocacy.

Policies on disability – relationship between CBR and UN CRPD: discussions were coordinated and presented by Istvan Patkai: Existing policies need to be updated. Policies should come from a good local participation. It is important that we get examples of local good practices. It may not be a good thing to start these discussions with international laws and create too high expectations.

CBR is important for local planning from different sectors, such as livelihood, education, health, however, it should be expanded as a process, should be on going. An action plan needs to be developed otherwise policies remain only in theory.

Education dimension is a big area. Local groups are very important, such as pressure groups, Self-Help Groups (SHGs), DPOs, etc. who can share local practices and network among themselves.

Promote enabling environment in countries for implementation of CRPD by raising awareness, translation of materials, policies, etc. as these need to be understood by

disabled persons and communities. If DPOs and other groups are not there, CBR should promote and strengthen such groups.

Plenary Discussions & Comments on the group presentations:

A question was raised about appropriateness of CBR in terms of implementation of CRPD. CBR approach is seen as much wider, it may not concern only persons with disabilities and may also include other vulnerable groups, so in such a situation, how can CRPD be addressed by CBR?

Sayema: in Bangladesh our work is with persons with disabilities and their families. CRPD is all about changing the society and environment, we all are part of this environment. CRPD is based on human rights model of disability, it has a broader definition, looking at barriers created by society and if you have to remove barriers, you have to address all society and families. CBR works for that.

Jayanth: CBR has a crucial role in implementing human rights approach. Only 2 countries in our group have ratified CRPD, so a lot more can be done by the CBR programmes.

Venkatesh: It is government's business to pass legislation, while the responsibility is on the civil society to hold government accountable and make them deliver. So we have a role as community members. We have to understand the differences between needs and rights on the ground, and we can involve institutions like law schools to come up with training programme on these issues. Organisations like CBR Forum and AIFO/Italy can invest energy at innovative ways to do it. We need to think out of usual thinking.

SECOND SESSION: RIGHTS-BASED APPROACH & CBR – Session Coordinator Farida Yasmin, Session Rapporteur Sibghat Rahman.

Like the first session, this session started with some presentations, that were followed by discussions on specific themes in small groups and then presentations of these discussions in plenary.

Presentations in Plenary

Right based Approach (RBA) and role of community DPOs, presented by Jayanth Kumar: Since the Universal Human Rights declaration in 1948, there have been a number of international declarations and conventions, UN standard rules, CRPD, etc.

RBA or the rights based approach, is a conceptual framework – every individual has a right to develop and change. There are many interrelations in terms of self advocacy, equal participation, inclusive approach, empowerment, etc.

There are organisations at state level and there is a movement at national level; we require more efforts by NGOs on RBA – for many persons the meaning of RBA is not clear, we require capacity building of NGOs. Also for DPOs, their leadership, disability movement and persons involved in inclusive development, capacity building is needed. We also require focused efforts to strengthen disability movement.

Rights based approach and mental illness, presented by D. M. Naidu – All of us are born with rights, Right to live starts in mothers' womb, so why do we need to talk of these

rights? Because these are often violated. The evolution is from needs to the rights. A basic difference between the two is that needs can be fulfilled, rights have to be exercised.

Communities and families play a vital role in persons with mental illness in ensuring rights and fulfilling duties. Women face double disadvantage.

Among the different rights, the right to information means people have a right to know the nature of illness, different healing options and care needs. Right to choice and informed consent, and right to refuse treatment are also there. Accessibility and availability of services as close to where people live is also a right. There is right to inclusion, to form support groups, to join develop processes without stigma or discrimination.

Right to family, right to intimate sexual relationships, to marry and to have children are equally important. Other rights include the right to food security and nutritious food, right to free environment and bodily integrity.

Persons with mental illness are vulnerable to sexual abuse, persons are put into solitary confinement, shackled and locked, other people exercise power on their bodies. Their right to liberty – optimum participation, free movement, least restrictive environment, is violated. There is right to well being – to play and leisure, to participate in social and cultural functions. There is right to socio-economic security, to entrepreneurship, to alternative employment, to insurance, to housing, to own property, with necessary assistance. In the name of guardianship, there are human rights violations.

Farida Yasim: In our experience from Bangladesh – we have a law so that persons with mental illness can not inherit property from family, can not get married and are prohibited from social inclusion. These are all human rights violations and we need to think how we can tackle these in CBR.

Yasin Wali: Attitudes of professionals are a problem, they take away their rights, they don't talk or ask to persons directly, but they talk only to family members.

Prakash Wagle: Right to refuse treatment, is also a right, to get treatment is also a right. In a hospital, how can you refuse, don't we have to look for the best interest of the person then in such situations, what do we do?

D. M. Naidu: It is like a child refusing to go to school and you can force the child to go to school. However, an adult is not a child. To think that people with mental illness are mad all the time, is wrong, as there are many lucid moments, it is important to listen and to have a dialogue. You can take of his/her rights in the name of good Samaritan, but you need to take their informed consent.

Alice Joseph: When person is violent and dangerous for the family, does this right still exist?

David Webb: These are two distinct rights – right to refuse and right to treatment are separate.

Rubiya Sultana: Rights are for human beings, human beings have many other needs and these themes are missing from the discussion. We need more experienced based discussion on role of CBR in mental illness, in terms of different aspects of CBR matrix.

Mahesh Chandrashekar: When state machinery is not functioning, services are missing, can CBR provide services and for how long?

D. M. Naidu: In Karnataka, we started by forming groups of persons with mental illness. The groups themselves put pressure on government for services. Only people can make government work. It took us 6 years. Sustaining the change in community is needed.

Jayanth Kumar – Many NGOs and CBR programmes don't think in terms of Human Rights approach. Only a few NGOs work on this approach.

Gianpiero Griffo: When we were discussing CRPD, we also discussed who can represent persons with intellectual disabilities and persons with mental illness? Some persons momentarily or all their lives can not represent themselves – for them CRPD is asking for human rights approach. When a person has a crisis, at that time, the person does not have right to take legal decisions, and at that time, family can decide. However, we can not accept that in such a situation, family can decide to put this person in an institution for the life. Families can have right to take decision only for the time of the crisis. We need to respect human rights. In many countries, persons lose all the rights when they go to mental health institutions. After the crisis phase, persons have the right to return to the society and decide how to continue.

Francesco Colizzi: In Italy, for more than 70 years, from 1904 to 1978, there was a law that denied totally the human rights of mentally ill persons. The 1904 law considered mentally ill persons as dangerous for themselves and for society. This was changed in 1978. The present law has now 30 years of application, and it is very different. Now persons with mental illness have global human rights, they can go and refuse treatment, live where they want, can marry, work, etc. The change is important in two aspects – transition from asylums to community based psychiatry, and there are no more mental hospitals. We have a network 640 mental health centres and 150 centres in hospitals for acute care services, but all these are voluntary admissions. There are no forced admissions, with only one exception – when a mentally ill person is confused, is in severe acute crisis and refuses any treatment or any alternative, and there it is important to guarantee their right to treatment. Request to treatment in such situation has to be guaranteed by two doctors and a judge for a period of 7-14 days. This has been the first experience in the world of this kind.

Abdul Rehman: I am involved with Mental illness in Afghanistan, but in this discussion we didn't hear anything about CBR and CRPD, we heard only about CBR and mental illness.

Plenary Presentations of Small Groups' Discussions

From Needs to rights – human rights and CBR, group discussions were facilitated and presented by *Prakash Wagle*: Finding a balance between rights and needs is important. There is no one solution, right to a service is addressing a need. Needs should be inseparable from rights – for example, what support do I need to achieve my rights, move from charity to rights approach? In programmes, are people with disability included in decisions on money and services?

We often ask about relationship between family members, persons with disabilities and CBR workers. But some times CBR workers are also family members or are themselves, persons with disabilities. Attitude change towards mutual respect is needed.

Disability should be seen as human diversity, not as a problem to be solved but it is important to recognise diversity, to assist disabled persons to make their own decisions, moving towards supportive decision making in terms of knowledge and understanding.

Relationship between rights and CBR – human rights activists are educated in human rights but may know nothing about disability; disability organisations are good on disability but not so much on human rights; so the two groups would need to come together and may be to become one.

What kind of good practices examples are there in the area of human rights for persons with disabilities? We can't use the same approach in all countries. In some countries, advocacy would lead to jail. There is another kind of example from India – NGOs already working on other issues, they can be stimulated to work also on disability by training them to include disability issues in their programmes. In Nepal, women federation groups have also started to work on disability, so they train all stakeholders. This issue can be included in school curricula so that all school children are aware about it.

From needs to rights and the role of CBR: Discussions in this small group were facilitated and presented by *Razi Khan*. This group also discussed barriers created by the society and how to achieve access to services. Barriers are physical and environmental, then there are communication barriers. For example, doctors and schools don't understand sign language. There are also attitudinal barriers. At the same time, there is lack of services and their affordability, not just for persons with disabilities but for all the population.

For fighting discriminating practices, appropriate laws may be missing and self advocacy by disabled persons, and also by families and communities, is needed. Mobilization of all available resources for overcoming barriers is needed.

CBR and CRPD – Convention comes from a higher level, CBR comes up from grassroots so both are complementary. CBR matrix provides a basis for developing a network to address issues raised by the CRPD. CBR programmes can provide actual experiences in the countries on implementation of CRPD.

Activities – a twin track approach is proposed. There should be specific solutions and services and advocacy for raising up the issues at national level and with authorities. Organising Self-Help Groups (SHGs) and DPOs will indirectly help CRPD. Also awareness activities by CBR increases impact of CRPD.

Involvement of different stakeholders is needed for referral support – without referral services, CBR alone can not work. Media is important for information and advocacy. Develop monitoring and evaluation to see if there is improvement, and document best practices. Sustainability is an important issue, adaptability and cultural sensitivity are also needed. Psychosocial issues also need to be included in CBR. Compassion and justice are also important issues along with rights.

From the needs to the rights – what kind of services for inclusion of persons with disabilities, these discussions in small groups were facilitated and presented by *Lemuel Boah*: NGOs instead of only providing services through CBR, they should facilitate services also from the Government (mainstreaming). NGOs need to look at advocacy, linking between different stakeholders and putting pressure on state. This means there is need for national framework and identify role of each stakeholder, to have a framework for avoiding fragmentation of efforts.

CBR can also provide good affordable and replicable local examples for the Governments, on issues of inclusion, education, etc. CBR programmes need to be more comprehensive, more inclusive of persons with disabilities. DPOs are sometimes seen as a problem, rather than as a resource and a partner. Some times, CBR is not a community-owned process but remains a project that ends with funding. So there is need to have more unified ways of implementing CBR.

NGO supported CBR programme is sometimes started as a fill-in-gap where state has failed. So initial approach on CBR was different, but now it has to change. It has to network and to support, but it can't substitute state responsibility.

CBR matrix components and priorities will differ according to the local context. In some places, more economic activities may be needed and in others, more health activities. Important to involve disabled persons in planning of CBR, in prioritising of services – lack of planning results in a feeling that disabled persons are being used or manipulated, so that creates problems.

Best practices – in terms of participation of persons with disabilities in planning of action plan and implementation, CBR at grassroots level, network with other service providers and ensure follow-up at community level to find out what happened after referral, these different aspects need to be documented and shared.

In the area of research, CBR programmes lack funds. To overcome this, there was an example of students who studied issues of CBR for their thesis, at the same time, it also helped CBR programme to understand and guide their own planning.

Plenary Discussions and Comments on Group Presentations

Bina Silwal: Gender discriminatory practices in the Asia region need more attention. These lead to disabilities like mental illness. For example, violence at home leads to disabilities and mental illness, similarly there are nutrition-related practices that lead to disabilities among women and girls.

Day 2

SESSION THREE: CBR PROGRAMMES, PERSONS WITH DISABILITIES AND DPOS, Session coordinator *Venkatesh Balakrishna*, Session Rapporteur *Zemerai Segeb*.. The session also started with some presentations.

Plenary Presentations

Overview of DPOs and CBR interface, presentation by *Mahesh Chandrashekar*: He talked about the formation of CBR Forum in Bangalore (India) since 1996. CBR Forum

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works in remote rural areas. Its objective is to work with disabled persons, families, communities, SHGs, local authorities, NGOs partners, etc.

One of its strategies is the TDAP or the *Taluk* (sub-district) disability Advocacy Programme with different NGOs partners. It is a strategy to build capacities, promote participation and advocacy at sub-district level. The initial capacity building programme is divided in 2 days. First day is dedicated to DPOs and interaction with local governments. They invite DPOs, persons with disabilities and administration in a Public Hearing, where NGOs partners provide written presentations. Also leaders and media are invited. The second day is dedicated to CBR personnel and coordinators. Advocacy plans are shared.

Key learnings /achievements from TDAP experience: In districts, where TDAP was carried out, local governments allocated funds for DPOs, and now utilise 3% of development funds for persons with disabilities and 3% of houses built under government schemes are allocated to persons with disabilities. Disabled persons have succeeded in ensuring the involvement of local government. Positive experiences have been one of the factors that influenced the reposition of CBR Forum.

CBR Forum strategy to work with district level with DPOs: each partner federates the persons with disabilities into DPOs representing village/partner level. 10 disabled leaders from each of the 8 Federations at the partner level form Sub Committees. In conclusion, they got the great result of obtaining visibility of disabled persons and their issues in the decision making forums at district level.

CBR and DPOs from point of view of DPO, presentation by *Jannatul Ferdous*: She gave an introduction about DPOs in Bangladesh including cross-disability DPOs for taking forward the movement. She explained that “movement from SHGs to DPOs in Bangladesh are outcomes of self-help initiatives, and the understanding that we have to fight for our rights. These start from group solidarity, sharing of experiences, insights and experience, and gradually move on to collective actions for changing the situation.”



She showed pictures of a SHG in a slum of Dhaka, where persons are sitting in a circle, to explain the importance of power relations, so that “all persons are at the same distance from centre. Participants include men, women, children, all mixed up, all can contribute in a participatory way – this is our basic idea that leadership capacity can be supported from SHG to national level. There is a gap between SHG and DPOs. Our achievements include ensuring participation of women disabled persons.”

She also spoke about her personal experiences and how she faced social barriers after severe burns and is discovering a new identity as a writer. She feels that her life started for a second time. According to her education is the fundamental part of rehabilitation.

Women, children and persons with severe disabilities in DPO, presented by *M. Srinivasalu*: Mr. Srinivasalu was representing a DPO from Andhra Pradesh. In this DPO, 50% women members are mandatory. The total active members of this DPO are 7000. They produce a newsletter since 1996, and have trained about 1000 volunteers.

3 years ago, they have started a CBR programme. Their organisation won the national award in 1999, in 2004 some of their representatives took part in state elections. Their successes include the acceptance of dwarfism as a disability after a high court victory. They are also working with leprosy cured persons, have managed to get a marriage incentive of 10,000 rupees for disabled person. Now all persons with disabilities have a right to a house, previously only married persons could get a house, but now unmarried disabled persons can also get house benefit,

Women and children with severe disability in DPOs – often parents and siblings don't want disabled women to be part of DPOs or participate in advocacy programmes. Parents and teachers don't understand about rights of children with disabilities. Caregivers are often poor and struggling for their livelihood.

Village communities often see SHGs as only for saving and credits, not as an instrument for development. In the communities, charity has been the main way of addressing needs of persons with disabilities.

Mr. Srinivasalu said as DPO, that they can influence vote banks and decision makers. Disability is not related to caste or religion and so together as group they should influence legislators and council members. A deaf woman is now president of deaf association, and hearing impaired network is also being supported. There is a network of women with disability.

Plenary Presentations of Small Groups' Discussions

Participation of persons with disabilities in decision-making – discussions in this group were facilitated by *Geraldine Mason Halls* and presented jointly by *Christina Parasyn* and *Yasin Wali*: It should be important to define some standards of participation. For example, look at how is participation? Are persons with different disabilities participating? Is the participation in the whole process of planning, implementing, monitoring, etc. or only in certain activities? In which specific issues are disabled persons included, for example are they included in discussions about social, economic and political issues? If different people can participate and feel valued, that is important for real inclusion.

How to support participation in CBR programmes – there should be discussion on who should participate, ask how was the participation, so that information can be shared. Training can be organised with DPOs on how can they participate, how should they present the information so that authorities can understand it, etc. At the same time, make other stakeholders understand how and why it is important to have participation of persons with disabilities.

Disabled peoples may also need training on financial and organisational management as they also need to be responsible for funds they receive. If they provide time, that is also valued so that they can be employed as consultants.

Good practice example – Women with disabilities were included in the monitoring process of a CBR programme on how funds were used. In CBR Forum in India, persons with disabilities participate in organisational meetings and set up the agenda. International disability alliance and its relationship with UN described by Akiko Ito is another good

example. CBR programmes should be accountable to stakeholders so DPOs should be involved in all aspects of CBR.

Tools for promoting participation at local levels in CBR programmes, the group discussions were facilitated by *Mervat Hana Maher* and were presented by *Shireen Khalil*: All relevant international declarations, Convention, etc. regional declarations, national legislation information, and CBR matrix should be shared with DPOs and persons with disabilities in rural areas to get fuller understanding.

For planning CBR activities, data about disabled persons may be needed – census may be the best way to get that information, though not many countries collect such information in national census. CBR programmes also need information about the local authority system, who is responsible for what, which authorities are supposed to do what activities, etc. This information is an important tool for the people in communities. Persons in rural areas are usually poorer and have less resources, so unless they have resources, they will not be able to participate. They need to see direct benefit to being together, this helps them to meet regularly, and to feel that positive changes can happen.

Capacity building and awareness raising and media can be useful tools. Some countries, media is more willing, while in other countries, they want money. Media is a powerful tool.

What kind of activities need to be done – involve persons with disabilities in planning of CBR activities, their voice must come in the planning stage and not later. So provide access to DPO group and its meetings through an accessible meeting place, disabled friendly environment. Transportation and mobility needs may need support. Find a communication tool for the whole group, so that information is accessible, friendly for all the different disabled persons, including those who can not read, and those who can't receive emails. Plan the calendar of meetings well in advance, so that people know when is next meetings, extra meeting can be done but a fixed system should always be there.

Peer modelling can be very important. Sometimes, parents of girls do not wish their daughters to participate. Similarly, some persons with disabilities do not see any benefit in participation, so someone from same gender or same disability needs to come, explain and share with them to convince them about participation.

If at least some of CBR workers are also persons with disabilities, this also helps. Involving leaders, community leaders, religious leaders, etc. is also important. Economic activities, fund raising activities are important. Make sure to remove barriers to participation due to gender and cultural issues, for example by women-only meetings. Activities with parents are also important for higher participation.

Expert coming from higher education backgrounds and more developed parts of the countries, they usually take over, they think they know better, so they marginalise persons with disabilities and see them as mere service receivers. This happens when a CBR programme sees itself as a service provider and need fulfiller, not as empowerment promoter, so in those conditions participation will not work.

Human rights and network of DPOs, discussions were facilitated by *Elisabeth Cross*, and were presented jointly by *Parvati Oli & Sarmila Shrestha*: The national level DPOs usually do not reflect the reality of people living at grassroots. Single issue disabled persons' organisations like IDEA (that brings together persons affected with leprosy)

should be encouraged to look beyond their own issues, to join national DPOs and to use CRPD as a tool.

Need to balance – CBR is just one way to approach human rights. Right to a service means fulfilment of needs, services have to be inclusive. There is need to move from charity to rights. It is important to make sure that persons with disabilities are included in key areas such as decision-making regarding funds and services, etc.?

Relationships of disabled persons/family/CBR worker, is not always possible to separate the three, as disabled person or family member may also be CBR worker and there is need for mutual respect, for this an attitude change is required. Some times, we have to assist persons with disabilities to make their own decisions – sometimes if needed, substitute “decision making” with “supportive decision making”.

Is unification of DPOs in cross-disability organisations a strategic goal in CBR? Some members of the group felt that at grassroots we need advocacy with one voice so cross-disability organisations are needed, while at national level, we need to address different needs of persons with disabilities, so different disability-specific DPOs may be better. Other persons in the group were of the opposite view, suggesting cross-disability organisations at national level and specific disability organisations at local levels.

Good practices examples - In Mongolia unification of DPOs has been very important to express common needs – networking to express common rights. Thus in terms of long term goal, together we can achieve more, cooperate and collaborate. In Nepal the national federation was earlier strong in advocacy but now it is also involved in project implementation, and has lost focus.

DPOs may also become donor driven, INGO have their own focus, so strong and united DPOs are needed. When there are risk of external funding defining everything and there is undue influence of donors, it is important to first define the vision and the mission of the organisation before cooperating at national level.

Plenary discussions and comments about group presentations

Question: In Afghanistan most activities are carried out by NGOs, while DPOs work in advocacy, can DPOs also be active in service delivery?

Chapal Khasnabis: There can't be no one answer to this question, it depends upon specific country context. For example in Malawi, DPOs manage national CBR programme, they follow the CBR matrix, and this programme works in collaboration with Government of Malawi.

Venkatesh Balakrishna – Advocacy and Human Rights depend upon our capacity to think and decide. If environment is right, SHGs and DPOs, can start also CBR activities.

Mahesh Chandrashekar: As CBR Forum we are do not use the word “SHGs”, we prefer to use the word “DPOs”. In our context, SHGs are only for savings and credits activities and they do not do advocacy work.

Chapal Khasnabis – Again the terms we use depends on the specific country context. During a field review, it was found that some countries don't want DPOs, some other

countries don't want SHGs. In some countries, if 6 persons meet they risk being put into jail. Thus there is diversity among different countries. In the CBR Guidelines we are using both the terms, "SHGs" and "DPOs".

Gianpiero Griffo: Role of DPOs in CBR varies in different countries. The real question is perhaps what is the power of persons with disabilities? CBR serves for empowerment, but if in community there is already a strong organisation of persons with disabilities, it can also use CBR as a strategy. Regarding discussions on the use of terms like "SHGs" and "DPOs", I think that you have to ask, people are getting together for which objectives? DPOs are supposed to work for rights and advocacy, for all other needs, SHGs can bring together persons and thus SHGs can be of different kinds.

Ventkatesh Balakrishna: It is not true that SHGs can't work for advocacy and rights. SHGs also do it and to say that they do not do it would undermine the power of SHGs.

Madan Upadhyay: DPOs can also be involved in CBR delivery. There is a lot of diversity – all countries have governments and not all have DPOs. Disability issue has to be part of national development, recognition of disability as an example of human diversity is part of government responsibility to all citizens. As long as NGOs and DPOs take responsibility, governments are happy that no one is asking them to do anything, so we have to ask governments to do more.

Venkatesh Balakrishna: It has to be a twin track approach, for both service delivery and advocacy, and if governments are not providing some services, some NGOs or DPOs can provide that service, but at the same time, they need to do advocacy for Government to take its responsibility.

D. M. Naidu: Concepts of disability and development are in evolution, people can experience organic growth in both dimensions. If goal is promoting empowered disabled persons exercising their rights, attitudes of persons matter more than nomenclature, so please do not hamper things by obsessions about terms. We have evolved from IBR to CBR.

I have an example. Rajendra Foundation in India, it started with a CBR programme in few villages with support from Action Aid. Today this small group has become a DPO at district level, its structure has changed. It started in one *panchayat* (village council covering 6 villages), from there it has reached district level covering more than a million persons and it has done this by working together with persons with disabilities. They know what they want, and they are not satisfied with just social welfare. They have now a district collector who does not hold any meeting without inviting DPO federations. DPOs involve trade unions, they work with other development processes like watershed project, and they are very visible in the district as they promote integrated community development.

Lamuel Boah: In Liberia, SHGs and DPOs, have differences in terms of memberships and functions.

Chapal Khasnabis: There is no clear definition of these terms that are valid for all countries. Countries make different definitions. In some places, DPOs are only adult male persons with disabilities, they do not include children or women. Some others include women and some others also include disabled children. SHGs can include disabled and non disabled members, but then the national DPO in China also has also non-disabled

members. In some countries, there are DPOs with persons with disabilities who employ non-disabled persons.

Jayanth Kumar: Our partner organisation SRMAB was started only by blind persons and was providing special education. It extended its services to rural areas, then to vocational training centre and then got involved in CBR for the last 10 years. They received the feedback that in their work participation of disabled persons was lacking, so they started involving disabled persons in their decision making. Then, they started with inclusion of leprosy affected persons. Then issues of sustainability came up so they extended the work to whole block level. Thus organisations evolve and it is difficult to give them a fixed definition.

Reza Khan: If DPOs do service provision, they need to have training in orthopaedic technician, physiotherapy, etc. If they are involved in education, they have to involve school teachers. Livelihood activities may require national skills development programme. There is national curriculum on training for each role. So we feel that DPOs are mainly for lobbying role as they don't have other trained persons.

Gianpiero Griffo: We need to be clear about roles of service providers and the interests of DPOs. There is some confusion. When DPI was born we wanted to be different from service providers. If I manage services, it is a different aspect. Defending rights has to be different from providing services. DPOs can be quality controllers inside work of service providers. So DPOs can provide services but in a separate way.

Venkatesh Balakrishna: We live in a complex world, so it is better not to have prescriptive solutions. The principles are clear – joint decision making, inclusion etc. with persons with disabilities but how you do it in each country can be different.

FINAL SESSION: UN CRPD AND CBR, Session coordinator was *Gianpiero Griffo*, Session Rapporteur was *Sunil Deepak*.

Plenary Presentations

Francesca Ortali presented a **summary report of Session 1**. *Farida Yasmin* presented a **summary report of Session 2**. *Zemarai Segeb* presented the **summary report of Session 3** on behalf of *Venkatesh Balakrishna*. This was followed by a presentation.

CBR and CRPD, by Venus Ilagan: “Thanks for this invitation to speak to you. I am happy to say hello to all of you. It is a pleasure for me to be part of it, to see familiar faces from Asia. Here I had also started. I started as part of CBR work in Philippines, in a grassroots organisation, and later became part of DPI movement. Today I am Secretary General of Rehabilitation International.

CBR has evolved over years to become a tool to promote empowerment at grassroots leaders. There has been a shift in paradigm. In the advocacy work in early nineties, persons with disabilities didn't really see themselves in CBR, they were not involved in CBR management. Looking back, I can see so many changes. Now colleagues, persons with disabilities, are leading CBR programmes, they are contributing to making these CBR programmes more effective in addressing their needs.

How can professionals work better, and how can CBR promote empowerment? This is possible, if persons with disabilities are able to go to communities to share their experiences and work with professionals. It is never a one way traffic, persons with disabilities can't do it by themselves, they need professionals and professionals need them. Over the years for both professionals and persons with disabilities, it can become a win-win situation, where each one supports the other.

Relating CBR to the Convention, is a good channel to promote empowerment. It is different when you are a person with disability in the West. In our part of the world more than 70% persons with disabilities are poor. CRPD asks for equalization of opportunities to access the services, but for poor disabled persons in rural communities, how you can access services if there is no channel to make a bridge to services? CBR is the best bridge in my own personal experience. Persons with disabilities and professionals together can accomplish much more.

Persons with disabilities can do advocacy, they act as role models, so that parents can see hope in their children. CBR programmes in the field, when social workers talk about what can be done, parents ask them what do you know about disability and my child? But if a person with disability speaks, parents understand. You tell them that, if you support the child, professionals will assist and together you all can create the difference, then the message reaches.

Each of us has a role to play, so much needs to be done CRPD alone will not make a difference if we do not take a proactive role. We persons with disabilities and professionals have to come together. Others may have their own ideas and experiences, but this is my experience.

CRPD has been driven by the South. It was started by Mexico in 2001. It had all started in 1996, when fifth World Assembly of DPI was in Mexico. There were 300 wheel chair users, the DPI meeting was on the third floor and food was on the first floor, and there were only two elevators that could accommodate 4 wheel chairs at a time. They started to serve food at 11.30 and finished serving it to all the wheel chair users at five in the afternoon. People from Mexican Government were so embarrassed, they said, "Look what we are doing, everyone had food, while persons on wheel chairs are still waiting. We lack imagination and sensitivity, we should have thought of holding at least the opening session in an accessible place." They initiated the dialogue. That is how their president asked for CRPD in the UN Assembly, "It is time to do something for justice to persons with disabilities".

We participated in the negotiations in the UN. It was very clear to us, that persons with disabilities need to speak ourselves, nothing about us without us, we are the experts on our own situation. We thought it should be same as we go to the implementation of CRPD that CBR will be the best tool to bring the CRPD to persons with disabilities. We can do it ourselves, but we always need those to assist us to claim our rights. I am a good soldier. I acknowledge so many persons like Gianpiero in this journey.

We need communities and villages to raise disabled children. In 1996 my initiation with CBR started when I went to the training organised by Einar Helander. It was the first group of persons he was training on CBR, and I was the only person with disability among the 20 participants. At first it felt very bad, I had to climb the stairs with crutches to reach my room. This was one of the challenges. This is our daily reality, the persons living in most difficult situations for whom CBR wants to work. So those difficulties, they

encouraged me. I understood that there are people who want to make a difference and I can tell them how to. I learned that not all know how to assist, that you need to say clearly “this is what I need” and then they will assist. It was a good experience. It inspired me to pursue my work.

Sunil, he was one of the lecturers in that first training course on CBR in 1996, since then I know him. Chapal, he has been so insistent in including persons with disabilities in activities of DAR/WHO. We have been partners on World Report, Wheel chair guidelines, and CBR Guidelines. So many changes have been there. Persons with disabilities should be involved in CBR and they should take active roles.

I look forward to working with all of you, it is very important for us to work together. While countries ratify the Convention, there is not much happening at ground. CRPD will remain there, unless we translate it into practice, unless we work together. There is a long way to go, we need to use CBR as a channel for turning into reality the aspirations of people with disabilities. Thank you.”

Final recommendations

The plenary meeting then discussed and came with the following recommendations:

1. CRPD is a legal instrument and it reinforces the CBR programmes. CRPD is based on the human rights approach and the CBR principles fit in with the CRPD.
2. CBR approach places special importance on working with poor, disadvantaged and discriminated persons in both rural and urban areas and is a key tool in promoting empowerment of persons with disabilities.
3. CBR is a strategy for inclusive development and should be promoted as part of all development efforts. CBR programmes should have a critical self-appraisal if their own activities, organisation and implementation are in line with CRPD. Persons with disabilities should play central role in all the processes of CBR, from planning to implementation to monitoring and evaluation.
4. CBR programmes should work to disseminate CRPD in all communities and among other stakeholders. For working with CRPD, CBR programmes also need to network among themselves.
5. CRPD and other rights-based instruments should be incorporated in all training programmes related to CBR. The regional and national CBR strategies, millennium development goals, other strategies should keep account of CRPD.
6. DPOs and CBR programmes should work together. CBR programmes should facilitate, promote and strengthen DPOs at all levels, with appropriate empowerment activities and instruments. CBR programmes should support networking between DPOs at grassroots level and national level. At the same time, DPOs should support strengthening of CBR programmes.

7. To develop concrete policies on disability, at local and national level, it is necessary building a Disability Action Plan, based on CRPD and involving DPOs in all phase of the process. CBR should be one of the components of Disability Action Plan.
8. Persons involved in CBR programmes, in collaboration with DPOs & disability movements, should continue to advocate in their respective countries for signing and ratifying of UN CRPD and its Optional Protocol.
9. CBR programmes should work together with persons with disabilities & DPOs in advocacy for making the governments accountable in implementation of UN CRPD. CBR programmes have a role in promoting advocacy for making sure that national laws are in line with CRPD.
10. CBR programmes can also support monitoring of implementation of CRPD in the programme areas, based on principle of the art. 33 of CRPD.
11. CBR can play important role in reaching more discriminated groups of persons with disabilities such as women & children, emigrants with disabilities, persons with complex dependency needs, persons who can't represent themselves, etc. for ensuring that benefits of CRPD reach them.

CONCLUSIONS:

Chapal Khasnabis: CBR Guidelines started in parallel with CRPD, and we have been working to ensure that Guidelines go in same direction as the Convention. Persons with disabilities have participated in the development of CBR Guidelines since the beginning. We are very pleased with CRPD. It is a time to take an oath, that we shall take the benefit of CRPD to ensure it does not remain on paper, we shall put it into practice. We shall ensure that the benefit of CRPD reaches all sections of persons. DPOs, civil society all have to work together to ensure it becomes a reality. Thanks to all.

Sunil Deepak: I would like thanks all the coordinators and speakers of different sessions and all our partners for organising this workshop starting from WHO/DAR, DPI, NAD and other member organisations of IDDC. We had started with an idea of organising a workshop for persons coming from AIFO supported projects and we have been very fortunate in finding so many supporters and collaborators, so that the workshop became more enriching for everyone. Special thanks to all the colleagues in AIFO, and specially to Simona Venturoli and Felicita Veluri for doing all the organisational work, and to Gian Piero Griffo and Francesca Ortali for the overall coordination.

Workshop participants

	COUNTRY	NAME	FAMILY NAME
01	Afghanistan	Zemarai	Saqeb
02		Gulmackai	Siawash
03		Bashir	Ahmada
04		Mohamad Sadiq	Mohibi
05		Razi	Khan
06		Sameuddin	Saber
07		Said	Hamidulla
08		Mohammed Amin	Qanet
09		Abdul Nasir	Baryalay
10		Mohammad	Naseem
11	Australia	Christina	Parasyn
12		David	Webb
13	Bangladesh	Farida	Yesmin
14		Jannatul	Ferdous
15		Rabeya	Sultana
16		Sayema	Chowdhury
17	China	Marianne	Rizzi
18	Congo	Freddy	Sanduku
19	Egypt	Mervat	Hana Maher
20	Guyana	Geraldine	Mason Halls
21	India	Jose	Manikkathan
22		Jayanth	Kumar
23		Manimozhi	Natarajan
24		Alice	Joseph
25		Aley	Chinothuvattukulam
26		John	Peter
27		Sarfaraz Ahmad	Syed
28		Moham. Shahnawaz	Qureshi
29		Sara	Varughese

30		D. M.	Naidu
31		Venkatesh	Balakrishna
32		M.	Srinivasulu
33		Jay	Kumar
34		S. N.	Anand
35		Nicholas Guia	Rebelo
36		Chandrashekhar	Mahesh
37		Albina	Shanker
38	Indonesia	Andrew	Mohanraj
39	Italy	Giampiero	Griffo
40		Nadia	Ridolfini
41		Enrico	Pupulin
42		Sunil	Deepak
43		Simona	Venturoli
44		Francesca	Ortali
45		Francesco	Colizzi
46		Marco	Colizzi
47		Marcelo	Carrozzo
48	Japan	Takechi	Masato
49	Jordan	Maha	Al Rantisi
50	Liberia	Lemuel	Boah
51	Mongolia	Tulgamaa	Damdinsuren
52		Enhbuyant	Lkhagvajav
53		Batdulam	Tumenbayar
54	Nepal	Sarmila	Shrestha
55		Parvati	Oli
56		Prakash	Wagle
57		Bina	Silwal
58		Mary	Martin
59		Damodar	Pandit
60		Madan	Upadhayay
61	Netherlands	Ren	Verstappen

62		Roelie	Wolting
63		Anrik	Engelhard
64	New Zealand	Robert	Choy
65	Pakistan	Sibghat	Rehman
66		Yassin	Wali
67	Philippines	Istvan	Patkai
68		Michael Peter	Davies
69	U.K.	Douglas	Soutar
70		Hitomi	Honda
71		Diane	Mulligan
72	Vietnam	Lorenzo	Pierdomenico
73		Minh Chau	Cao
74		Thi Phuing	Pham
75		Van Ton	Nguyen
76		Elisabeth	Cross
77		Van	Le Ha