Empowerment of persons with disabilities, their families in the light of UNCRPD and CBR.

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1. Introduction: The gap between DPOs and CBR

Since its beginning in the early eighties, DPOs have viewed CBR with reservation. There are good reasons for this. CBR has been perceived as part of the medical model which is trying to fix a problem on the individual level without recognizing the other social and human rights dimensions that contribute to discrimination against disabled people. CBR has generally been under the control of non-disabled people who have acknowledged the importance of DPOs, but there has not been a true partnership between CBR and the disability movement. And this remains the case in most parts of the world.

What I have to say focuses on how the rights enshrined in the CRPD can only become a reality through cooperation between DPOs and CBR.

2. The law requires a change in social mindset

Rights will not become a reality if they are only enshrined in the statute book. They also require a change in social mindset. Bringing about a change in social mindset is a process of empowerment, which needs to happen at all levels from disabled people, the family, the community and the state level. The process to make this happen requires dissemination of knowledge, promoting inclusive practices through demonstration, acquiring skills of motivating, negotiation and advocacy, conflict resolution and problem solving.

3. CBR is a strategy for making the CRPD a reality

CRPD is a statute, a legal instrument that serves as a benchmark for making laws and policies. It is not a strategy, nor is it a method of delivery.

CBR, as described and defined in the new Guidelines, is a strategy and a tested methodology for delivery to make rights a reality. CBR has a structure. It is a system of working, a method of training for imparting knowledge, in making universal design and inclusion possible. It has methods of prevention – primary, secondary and tertiary. It has ways of imparting knowledge and skills in social mobilization, group formation and organisation, networking, advocacy, and alliance building. It is holistic, systematic, inclusive, and multi-sectoral.

The CBR guidelines emphasise that disabled people and their families need to be the engine that drives CBR. It is true that historically CBR has tended to be controlled by non-disabled people, although this is not true in countries like India where the formation of cross-disability self-help groups has been the principal model. But the new CBR Guidelines make it clear that it must be a partnership between disabled and non-disabled people.

The Guidelines also lay out ways and means of making this happen. For a right to become a reality requires individual attention. There are practicalities which need to be addressed. For example, to get a disabled child into school requires individual work on his or her case. The school needs to be prepared psychologically, physically and technically Once it has been demonstrated that inclusion is possible, then the inclusion of other disabled children will be much easier. But simply insisting on the law is not enough to make inclusion happen, not because there is reluctance but because the school does not know how to do it: individual practical action is necessary.

4. Advocacy is an essential part of the process of empowerment

The way advocacy is understood at present is that it is advocacy for policy change. But there is also a need for advocacy at local level for ensuring the delivery of programmes and entitlements, and monitoring the delivery. It is equally important that advocacy addresses issues of discrimination, exclusion, abuse and violence, and delivery of services meeting quality standards. Individual intervention with families to enable disabled members to exercise their rights is also advocacy. Advocacy in its very essence is dissemination of knowledge and information and the means of how to use them to bring about change in a given context, be it the family, community or the state at large. Therefore its relevance at different levels cannot be overstated.

Its power lies in the way it is structured to engage with the community. Its underlying principle is the non-ghettoisation of disability. The new CBR Guidelines are clearly based on the social and human rights models of disability, in which medical intervention is seen as part of the process of achieving empowerment and rights, and not as an end in itself.

5. The importance of context

According to the CRPD, disability is an evolving concept, not a fixed attribute. It depends to a large extent on context. There are differences in the way disability is perceived between cultures and in particular between cultures of the north and those of the south. The following table illustrates some of these differences.

Disability in the North	Disability in the South
1. Individualistic model of human rights	The family and community are more important than the individual.
2. Independent living is a goal.	Inter-dependence is the reality and an essential part of traditional values.
3. Human rights focus on civil & political rights, because socio-economic needs are largely met.	The right to life, food, shelter, clothing, & development of basic life skills is a priority
4. Impairment –based services as are often well or adequately developed. therefore focus on social barriers	Lack of basic services. Therefore service development at community level is a major priority. = link with right to life, health, education etc.
5. Age profile increasingly skewed towards over 60s. Disability mainly affects older people	Disability affects all age groups, but especially children. Link to CRC
6. Disability is an inevitable part of ageing.	Most impairments are preventable
7. Focus on making existing infrastructures / services accessible.	Focus on development of basic services for all.
8. DPOs can represent people with disabilities.	DPOs are usually urban-based with no grass-roots or rural constituency.
9. Disabled people are mostly urban based and relatively stable.	A large proportion are rural based. Increasing situations of conflict, displacement, & natural disasters.

Source[1]

[1] Extract from *Study of Disability in EC Development Cooperation* by Peter Coleridge et al 2010. adapted from article by Sue Stubbs in www.make-development-inclusive.org]

6. Implications for policy and programming

'There are two important implications for policy and programming following from the table above. First, disability is a feature of all societies, rich and poor, and will always be part of the human condition. Different living standards mean different *types* of disability, not *less* disability. Nor is disability primarily an issue of poverty, although persons with disabilities are disproportionately affected by poverty. Eradicating poverty will not eradicate disability. That is why it is so important to see it as a fundamental and universal issue of human rights, and not as a public health problem (like leprosy or polio) which can eventually be eliminated.' The CBR Guidelines emphasise this important understanding of disability.

'Second, differences in impairment prevalence between countries have major implications in particular for the way disability is viewed in the country and the way persons with disabilities are (or are not) included in development. People with mobility impairments but with all their cognitive and sensory functions intact are more likely to form self-help groups, and are more easily integrated into education and jobs, than those with communication and intellectual impairments. This reinforces the need to base programme design on the collection of accurate local data and not on generalised rough estimates.'[2]

CBR is a detailed, localized, case by case approach to disability which, because of this, takes context fully into account.

7. Addressing the needs of the most vulnerable.

DPOs historically do not have a good record in representing the most vulnerable disabled people, those with high dependency. And the record in CBR programmes is also weak. 'We do not really know enough about the situation of severely disabled people in poor communities. We do not have enough detailed information about their health, experience of discrimination, opportunities, marital status, sexual abuse and their position within the family. This is especially true of women with high dependency. It is disabled people with high dependency who present the greatest challenge in the quest for equality and who are easily ignored because their voices are not heard.'[3]

CBR has the mechanisms to address the needs of disabled people with high dependency. For example, in a village in Andhra Pradesh, India, a self-help group of disabled people identified the need of people with severe multiple impairments and mental impairment as a critical issue in their village. These people are represented in the self-help group by family members. Using their collective lived experience of disability, the group decided to provide support to one couple with severe intellectual disability. The support includes relief care, enabling livelihood opportunities for family members, contributing to their meals, and mobilizing grain collection from community members. Though the lead has been taken by the self-help group, it has become a community programme, albeit in a limited sense.

[2] Coleridge et al 2010

[3] Peter Coleridge: *Making the CRPD a reality through CBR: a tale of two triangles.* Paper present to Stellenbosch University July 2011. The importance of addressing the needs of those with high dependency comes from a conversation with B. Venkatesh May 6 2011.

8. De-ghettoizing disability

Rights are accompanied by obligations. Being empowered is becoming aware of this and putting it into practice. Responsible citizenship means that rights are not abused. This is also part of empowerment. It leads to the idea of active citizen engagement, which in turn leads to the need for disabled people to engage with larger social issues beyond disability.

Mainstreaming disability is a two way process. Mainstream organisations need to wake up to the fact that disability is an important development issue because it is poverty related. At the same time disabled people need to take an interest in and engage with wider social issues. For example, if disabled people do not engage actively with the issue of HIV/AIDS, which affects both disabled and non-disabled people, their perspective on the issue will be missed and they will be excluded. Another example,: domestic abuse is a social evil which affects both disabled and non-disabled people. Why should disability groups not take the lead in drawing attention to it in their own communities? This would indicate that they recognise that they have shared social concerns. And what about issues like access to water and sanitation? Access problems affect not only disabled people but also other distinct social groups. In India, for example, being the wrong caste may affect one's access to a communal well. Similarly access to education, health services and livelihoods is not only a problem for disabled people. Single mothers, or mothers whose husbands are away for long periods, who are tied to childcare have severely reduced access to income opportunities, and their children may have reduced access to education, so disabled people need to recognise this and make common cause with them.

9. Conclusion: The need for DPOs and CBR to join forces

The gulf between DPOs and CBR is unnecessary and counter-productive and needs to change. In India this change has already come a long way because of the way CBR is generally understood: the formation of self-help groups of disabled people is the CBR model adopted by most NGOs in India now, and these groups form the basis of a huge grass-roots disability movement which already, by default, has adopted a CBR approach of solving problems at the individual and local community level. They are also, as we have seen, able to address the needs of people with high dependency when they become aware of them.

CBR is not a movement but an approach and a methodology. It is the only tried and tested approach to the delivery of rights to disabled people in poor communities. It therefore makes sense for the disability movement to advocate with governments to use CBR as a strategy for inclusive development which is rights based in line with the CRPD principles.

Useful references for further reading

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