

POSITION PAPER
ON CBR AND WHO'S CBR GUIDELINES 2010
DISABLED PEOPLE'S INTERNATIONAL (DPI)



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TABLE OF CONTENT

BACKGROUND AND PURPOSE OF THE STUDY	3
<i>Introduction</i>	3
<i>About WHO CBR Guidelines 2010</i>	3
STRATEGY AND METHODOLOGY.....	4
HIGHLIGHTS OF THE DPI SURVEYS.....	5
<i>Phase I - Dipstick Survey</i>	5
<i>Phase II - Detailed Survey</i>	6
VIEWS OF SOME OTHER ORGANIZATIONS.....	9
<i>Views of International Disability Alliance (IDA)</i>	9
<i>Views of World Network of Users and Survivors of Psychiatry (WNUSP)</i>	10
DPI'S POSITION ON CBR GUIDELINES 2010	12
ANNEXURE.....	13
<i>Countries (DPI MNAs) that Responded to Phase I Questionnaire</i>	13
<i>Countries (DPI MNAs) that Responded to Phase II Questionnaire</i>	14

BACKGROUND AND PURPOSE OF THE STUDY

Introduction

World Health Organization (WHO) published the Community Based Rehabilitation (CBR) Guidelines in 2010. WHO and other CBR practitioners are promoting the Guidelines across the world, particularly in the developing nations. They are also talking to the Governments to adopt CBR as the strategy to realize the Convention on the Rights of Persons with Disabilities (CRPD).

Disabled People's International (DPI) is a network of national organizations or assemblies of people with disabilities, established to promote human rights of people with disabilities through full participation and equalization of opportunities. DPI has Member National Assemblies (MNAs) (associations of people with disabilities) in over 130 countries. DPI is focused on promoting implementation and monitoring of the CRPD. This includes advocating for international and national policies and programs to be consistent with the CRPD. The First CBR World Congress is scheduled to be organized in November 2012 in India. Disabled People's International (DPI) has been invited to the event.

Hence, it was important for DPI to review the CBR Guidelines 2010 and form a position whether or not to endorse them. **In order for DPI to formulate a position on the CBR Guidelines in a consultative manner, a study was undertaken to gather the viewpoints of DPI Member National Assemblies (MNAs) on CBR and the CBR Guidelines.**

About WHO CBR Guidelines 2010

The World Health Organization (WHO) has published Guidelines on Community Based Rehabilitation (CBR) for people with disabilities in 2010. The Guidelines can be downloaded from the WHO website at the [link](#)

The Guidelines are a response to the many requests from CBR stakeholders around the world for direction in how CBR programmes can move forward in line with the developments. The Guidelines provide, after 30 years of practice, a common understanding and approach for CBR; they bring together all that is currently known about CBR from around the world (being implemented in over 90 countries) and provide a new framework for action as well as practical suggestions for implementation.

The Guidelines are based on CBR Matrix developed in 2004. The Matrix consists of five key components – the health, education, livelihood, social and empowerment components. Within each component there are five elements. The first four components relate to key development sectors, reflecting the multisectoral focus of CBR. The final component relates to

the empowerment of people with disabilities, their families and communities, which is fundamental for ensuring access to each development sector and improving the quality of life and enjoyment of human rights for people with disabilities.

It is also mentioned in the CBR Guidelines that CBR is a practical strategy for the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) and to support community-based inclusive development. CBR is a multisectoral, bottom-up strategy which can ensure that the Convention makes a difference at the community level. While the Convention provides the philosophy and policy, CBR is a practical strategy for implementation. CBR activities are designed to meet the basic needs of people with disabilities, reduce poverty, and enable access to health, education, livelihood and social opportunities – all these activities fulfill the aims of the Convention.

The CBR Guidelines are presented in seven separate booklets:

- Booklet 1 – the Introduction: provides an overview of disability, the Convention on the Rights of Persons with Disabilities, the development of CBR, and the CBR Matrix. The Management chapter: provides an overview of the management cycle as it relates to the development and strengthening of CBR programmes.
- Booklets 2–6 – each booklet examines one of the five components (health, education, livelihood, social, and empowerment) of the CBR Matrix.
- Booklet 7 – the Supplementary Booklet: covers four specific issues, i.e. mental health, HIV/AIDS, leprosy and humanitarian crises, which have historically been overlooked by CBR programs.

STRATEGY AND METHODOLOGY

As the first step, DPI's Research Team gathered information on the issue from the internet and from a few 'experts' in the field of CBR and disability rights. A methodology was then drawn up to gather the opinion and views of the MNAs. It consisted of two Phases:

- **Phase I**, aimed at gathering the basic level of awareness and opinions of MNAs on CBR and the CBR Guidelines, through an objective type 'Questionnaire 1', which was sent to all the 136 MNAs of DPI.
- **Phase II** of the Study comprised of an in-depth Survey for gathering more detailed opinions on CBR and the CBR Guidelines from the MNAs. The Questionnaire 2 was administered on 57 MNAs from Phase I who expressed their willingness to participate in Phase II of the Study. The Questionnaire 2 consisted of both objective and subjective type questions so that the respondents could elaborate on their opinions.

The Questionnaires were sent by e-mail to all the MNAs by the DPI Secretariat in India and the Regional Development Officers (RDOs) of DPI. They played a critical role in coordinating with the MNAs for ensuring good response.

84 out of 136 Countries (MNAs) responded to 'Questionnaire 1' and 31 out of 57 Countries (MNAs) responded to 'Questionnaire 2'. The list of Respondent Countries (MNAs) is given in the Annexure. **The overall response rate for Questionnaire 1 was 61.8%, while the overall response rate for Questionnaire 2 was 54.38%.**

The data gathered was then compiled and analyzed in order to see if a consensus is being formed on the various issues. Based on the analysis, some issues have been highlighted and a position of DPI was derived.

Limitations

- The Surveys were undertaken via e-mail and therefore the scope of discussion and elaboration was limited.
- The CBR Guidelines were available only in four languages - English, Spanish, French and Chinese. Many MNAs expressed their lack of fluency in these languages. Hence, reading and analyzing the Guidelines was difficult for them.
- There was lack of awareness about CBR and the Guidelines. Many MNAs heard about it for the first time through the Survey. Moreover, CBR is not there in some countries of the world, which made it difficult for them to comment on the Guidelines.
- Budget constraint did not allow for any other methodology like group discussions, conferences, etc.

HIGHLIGHTS OF THE DPI SURVEYS

Phase I - Dipstick Survey

Before getting opinions/views of DPI MNAs regarding the endorsement of the CBR Guidelines, it was important to know the level of information, awareness and impressions of the MNAs on CBR and the CBR Guidelines, 2010. Therefore, a simple dipstick survey (Phase I) was undertaken.

Some of the major findings of the Dipstick Survey were:

- **Awareness about the CBR Guidelines amongst persons with disabilities**

There seems to be **low awareness amongst DPI MNAs and persons with disabilities** about the CBR Guidelines. Only about 7% MNAs said there was average to high awareness of the Guidelines among people with disabilities in their countries. Some MNAs had not even heard of the Guidelines before but glanced through or read some portions of the Guidelines after receiving the information from DPI. Even amongst the DPI leaders (MNAs) only about 55% were aware of the CBR Guidelines. Only 14% of the MNAs had read the Guidelines thoroughly.

- **Availability of the CBR Guidelines in local languages**

The **CBR Guidelines do not seem to be available in any local language**, based on the responses received from the Survey. Neither WHO, nor disability organizations nor the Governments seem to have made an effort to make the Guidelines available in local languages. Hence, the reach of these Guidelines is limited. Translation in local languages becomes crucial for getting authentic feedback/consultation from DPOs.

- **Involvement of MNAs in the preparation of the CBR Guidelines**

Most DPI members did not participate in the formulating of the CBR Guidelines. Only about 12% MNAs said that they or any other member from DPI participated in the consultation process. The involvement of people from grassroots is crucial because CBR is mainly meant for them. CBR Guidelines seem to be based more on the knowledge and experience of non-disabled people rather than persons with disabilities.

- **Leadership role of persons with disabilities in CBR programs**

CBR programs seem to be mostly run by non disabled people, which has been reinforced in the Study. Only 15.5% MNAs mentioned that persons with disabilities were leading most of the CBR programs in their country.

- **Implementation and impact of CBR programs**

Even though CBR programs have existed for several years now, particularly in the developing countries, **its reach to persons with disabilities seems to be still minimal.** Only 13% MNAs said that majority of persons with disabilities were covered under CBR programs in their country. Most countries (61%) did not have a National Policy on CBR.

- **Compliance of the CBR Guidelines with the CRPD**

The CBR Guidelines neither seem to be contrary to the CRPD, nor are they fully compliant. About 31% Respondents mentioned that the CBR Guidelines were fully compliant with the CRPD; 21% said 'somewhat' and 36% said that they 'do not know'. The number of Respondents who said that the Guidelines did not comply with the CRPD was 'zero'.

Phase II - Detailed Survey

Those MNAs who expressed willingness to participate in the detailed Survey were included in the Phase II of the Study. The participating MNAs were required to read at least two booklets of the CBR Guidelines thoroughly - one, the 'Introductory Booklet' and second, any other, based on their area of interest, before answering the Questionnaire.

- **CBR as the strategy for implementing the CRPD**

DPI MNAs seem to be not having an extreme view on the issue. 42% of the Respondents felt that 'CBR' is the way forward for implementing the CRPD. 55% of the Respondents felt that 'CBR' is one of the strategies for implementing certain aspects of the CRPD.

The MNAs feel that provision of rehabilitation in the community is definitely a much required need and is also mandated in the CRPD. Rehabilitation has also been made holistic in the CBR Guidelines, covering issues beyond health. In fact, a few of the responses from the developed countries which did not have CBR felt that it would be useful if CBR could be started in their countries as well so that services are available at the doorstep and there is community involvement.

The concern of most MNAs is about the implementation of CBR. In the past thirty years, CBR has not been able to bring systemic changes to meet the basic needs of persons with disabilities through changes in policies and the attitudes. The view of MNAs is that even with the new Guidelines, the work would continue to be focused on individual (which is needed) but may not bring larger change. **Hence, many DPI MNAs feel that CBR could be one of the strategies for implementing the CRPD but it cannot be the only strategy, as proposed by the CBR Guidelines.**

- **Comprehensiveness of CBR Matrix and the CBR Guidelines**

The DPI MNAs have not given a clear verdict on the issue. 42% Respondents felt that CBR Matrix was comprehensive and 48% felt it was not. **Some MNAs felt that the Matrix was progressive, but it is still not fully in line with the CRPD.** For example, certain rights mentioned under 'Social' cut across various life domains, which has not been reflected in the Matrix. It was also felt that the framework/matrix for implementing the CRPD should be formulated with the CRPD as the base document, and thus ensuring adequate coverage of all its Articles.

- **The title for the Manual and terminologies**

There was no clear mandate on the issue. 48% of the Respondent MNAs felt that CBR was the right terminology and an appropriate title for the Guidelines, considering that rehabilitation is a crucial aspect and it is cross cutting, as given in the Guidelines. 42% MNAs felt that the title was inappropriate. Some MNAs had suggested that the subtitle given in the Guidelines 'Community based inclusive development' can be made the main title, in order to reflect the broader agenda addressed in the Guidelines. They also expressed the concern that if the main title is changed to 'inclusive development', the Guidelines would have to be completely revised and they should be based on the CRPD. They would need to cover all the Articles adequately of the CRPD. Hence, **the purpose and the content of the document would determine the appropriateness of the title. It was also felt by some of the MNAs that the terminologies such as 'Community Based', 'Managers', etc. have to be used very cautiously, as they have certain connotations attached to them.**

- **Leadership role in the hands of persons with disabilities**

65% of the Respondent MNAs felt that the CBR Guidelines would help in changing the current scenario of non disabled people controlling the lives of persons with disabilities. The Guidelines do talk about inclusion and participation of persons with disabilities. Only about 29% felt that it would still leave persons with disabilities in a position of dependency. **Based on the result of the Survey, one can say that MNAs seem optimistic that the Guidelines would help changing the existing power equation in favor of persons with disabilities.**

- **Inclusion of families of persons with disabilities in the CBR Guidelines**

94% MNAs mentioned that 'families' have been rightfully included in the Guidelines. DPI MNAs feel that **families play a crucial role in the rehabilitation of many persons with disabilities.** The concern expressed by a few, particularly by the mental health sector is that legal capacity and decision making by persons with disabilities has not been elaborated in the Guidelines.

- **Compliance with the CRPD**

Several questions have emerged from MNAs with respect to the compliance of CBR Guidelines with the CRPD. What makes a document compliant or not compliant? There seems to be no clear parameters to judge the compliance. The CRPD is a fairly new instrument and the understanding of the nuances of the CRPD may not still be understood by the most people.

Some of the questions related to compliance with the CRPD that emerged have been listed below.

- Primary Prevention of impairment has been covered in the CBR Guidelines. The CRPD does not include Prevention. Would that make CBR Guidelines contrary to the CRPD?
- Mental Health, Leprosy, etc. have been mentioned in a separate booklet. Would having a booklet specific to certain impairments make it non compliant to the CRPD? What about other impairments?
- Does the cursory mention of the Articles of the CRPD make the document compliant to the CRPD? For example, doesn't legal capacity and other rights need to be explained in greater detail?
- The involvement of people with disabilities in the development of the document has not been adequate. It also falls short of the philosophy of DPI, "Nothing About Us, Without Us". Would that make the process non-compliant to the CRPD?
- The leadership of persons with disabilities and role of DPOs has not been emphasized. Moreover, the CBR manager is the primary stakeholder of these Guidelines, who seems to have been made all powerful. Would that affect the democratic approach?

- **Endorsement of the CBR Guidelines**

No clear mandate emerged from DPI MNAs in the Surveys regarding the endorsement of the CBR Guidelines. 48% of MNAs voted 'yes' for endorsing the CBR Guidelines, 45% said the Guidelines require some changes. Very few (only 3.2%) were totally against endorsing the Guidelines. **It seems that the MNAs were keen to have the Guidelines reviewed in the light of the CRPD and the concerns expressed by them in this regard.**

IEWS OF SOME OTHER ORGANIZATIONS

DPI Research Team had also contacted a few other confederations/networks of disability organizations, to get their views on the CBR Guidelines - International Disability Alliance (IDA), World Network of Users and Survivors of Psychiatry (WNUSP) and International Disability and Development Consortium (IDDC).

IDA has prepared a draft paper on their reaction to the World Report on Disability, which had a section on CBR. The draft report was available with DPI as it is a member of IDA. WNUSP shared the mail that they had sent to WHO stating their reasons for not endorsing the CBR Guidelines. IDDC mentioned that they have been closely associated with the developing of the CBR Guidelines, from the time of inception till now. They have set up a Task Group which is preparing a paper on the linkages between CBR and the CRPD, in view of the global congress of Agra in November 2012. They also mentioned that they are open to views of DPOs and wanted to engage in dialogue with DPI on the issue. IDA's and WNUSP's views are given below.

Views of International Disability Alliance (IDA)¹

- The term CBR has a history, which explains why there is some opposition to change the term. Having said this, the subtitle **'Community based inclusive development' seem to reflect better the revised scope of the new Guidelines**, which goes well beyond the traditional rehabilitation approach, focused on the individual, and moves towards an approach in which the environment needs to be adjusted.
- While some disability activists had argued that there should be no reference to rehabilitation in the CRPD, the majority view which prevailed was that the CRPD should include (as it does in its Article 26) the provisions related to habilitation and rehabilitation. **While the term CBR is not used as such, the reference to the provision of rehabilitation to be done at community level seems to establish**

¹ Draft IDA reaction to the World Report on Disability - CBR as a proposed solution in a number of areas, E-Mail from Stefan Tromel Sturmer, dated 13th September, 2012 to IDA Governing Body

a connection with CBR, but should not be interpreted as if CBR is the answer.

- The CRPD is clear that rehabilitation has a role to play for many persons with disabilities in order to be able to fully participate in society, but the CRPD is also very clear that **rehabilitation is one of many areas to be addressed if the human rights of persons with disabilities need to be ensured.**
- **The de-linking of habilitation and rehabilitation from the Article on Health is also a clear reminder that rehabilitation goes well beyond health.** On the other hand, the reference to health-related rehabilitation in the Article 25 also reminds us about the link with health and also points to another key element which is the level of obligation of the rehabilitation related commitments.
- The CBR approach was developed to fill a gap where no generic or public services were available to persons with disabilities. This means that when compared with the obligations resulting from the CRPD, except in a few countries, **the CBR approach continues to be based on specific projects in a limited number of communities,** often financed by international donors. Experience has also shown that when the support of the donors disappears, the projects very exceptionally are “mainstreamed” into the budget of the relevant public authority and there is very rarely a “scaling” up to make the services universal. Even more important, because CBR is project and community focused, it fails to address the systemic barriers faced by persons with disabilities and to some extent may even take pressure off States to ensure that persons with disabilities are included in mainstream services. So, even if all these projects would meet all of the new CBR Guidelines, **the problem remains that a CBR based approach is not eliminating the barriers that are excluding persons with disabilities in a specific country.**

Views of World Network of Users and Survivors of Psychiatry (WNUSP)²

According to WNUSP, the chapter on Mental Health (Supplementary Booklet) was a step in the right direction but it is still unsatisfactory.

- CBR Guidelines **take rehabilitation as encompassing everything that is about social inclusion,** and this keeps people with disabilities in a position of dependence, in the sense that rehabilitation is something led by professionals or by somebody other than persons with disabilities.

² E-Mail from Moosa Salie to DPI on 3rd August 2012, forwarding the e-mail sent by Tina Minkowitz, Co-chair, World Network of Users and Survivors of Psychiatry to Chapal Khasnabis, WHO

- The Mental Health Chapter is **much improved from previous versions but still has a long way to go.**
- The chapter's approach to mental health is actually based on medical model and **legal capacity/informed consent only vaguely mentioned.**
- Throughout, there are references to medical treatment and to the fact that "effective treatments" or interventions exist for mental illness. Even though it doesn't specify that these "effective treatments" are medical, it does not provide details about alternative approaches. CBR practitioners will have no way of accessing resources, such as the peer-run programs in Soteria; support groups and the Runaway House in Sweden. Instead of encouraging people to seek out such alternatives and providing information about them, the Guidelines are just encouraging people to develop good relationships with any community mental health providers in their area. This means that **CBR for users and survivors of psychiatry will be, like psychosocial rehabilitation, tied into predominantly medical model services, even if it is trying to do something different.**
- There are also references to **families of persons with mental health issues.** This is contrary to the self-conscious approach taken by the CRPD, which deals specifically with the rights of people with disabilities and not with the rights of family members. **If families are included, they may tend to be dominant and paternalistic and persons with mental health issues may not get to speak. It is not a question of ability but of power and social status.** Nothing would be lost by eliminating the references to families, as of course a person who counts on family members for support would be able to bring them along to meetings or involve them in any activities.
- The Guidelines talk about encouraging the formation of self-help groups by persons with disabilities and their families. **The formation of groups may end up being led by CBR practitioners,** as in a lot of places mental health professionals are trying to organize users and survivors of psychiatry. The manual should address these problems, maybe by talking about supporting people's chosen activities and telling them about their right to organize and not having CBR practitioners to set up groups for users and survivors.
- Finally, there are **weak references to human rights** and particularly the right to free and fully informed consent in relation to mental health treatment and hospitalization and putting practitioners on notice that involuntary treatment and involuntary confinement violate human rights and may constitute torture or ill-treatment. The manual does not even mention "free" consent but only the right to be informed. Further, it includes institutions among the "mental health services" that should be inventoried by CBR practitioners, without any critical comment.

DPI'S POSITION ON CBR GUIDELINES 2010

Disabled People's International (DPI) would like to take the following position on the CBR Guidelines:

The CBR Guidelines are an effort in the right direction if they are only about making rehabilitation in line with the CRPD and comprehensive. However, the document should be strengthened in certain aspects, including human rights and dignity of persons with disabilities, role of persons with disabilities and quality of services, in order to make them more effective and compliant to the CRPD.

DPI is also of the opinion that CBR can be seen as one of the strategies and not THE Strategy for implementing the CRPD. It cannot be seen as an overarching strategy for anything and everything related to disability or for implementing the entire CRPD. A tool for implementing the CRPD should be based on the CRPD and each Article of the CRPD should be covered in detail. Framework/Matrix should evolve from the CRPD. An appropriate title should be given, which would be truly reflective of this.

Countries (DPI MNAs) that Responded to Phase I Questionnaire

1. Angola
2. Antigua and Barbuda
3. Argentina
4. Azerbaijan
5. Belarus
6. Belgium
7. Benin
8. Bulgaria
9. Burkina Faso
10. Burundi
11. Cambodia
12. Cape Verde
13. Chile
14. China
15. Cook Islands
16. Cuba
17. Czech Republic
18. Dominica
19. Dominican Republic
20. England
21. Ethiopia
22. Finland
23. France
24. Gambia
25. Germany
26. Greece
27. Guatemala
28. Guyana
29. Haiti
30. Honduras
31. Hungary
32. India
33. Indonesia
34. Italy
35. Ivory Coast
36. Jamaica West Indies
37. Kenya
38. Kingdom of Lesotho
39. Latvia
40. Macedonia
41. Malawi
42. Mali
43. Mauritius
44. México
45. Montserrat

46. Morocco
47. Namibia
48. Nepal
49. New Zealand
50. Nicaragua
51. Niger
52. Nigeria
53. Pakistan
54. Panamá
55. Papua New Guinea
56. Peru
57. Philippines
58. Portugal
59. Republic of Guinea
60. Republic of Congo
61. Romania
62. Samoa
63. Senegal
64. Serbia
65. Sierra Leone
66. Singapore
67. Slovakia
68. Slovenia
69. South Africa
70. Spain
71. Sri Lanka
72. St. Kitts and Nevis
73. St. Vincent and the Grenadines
74. Switzerland
75. Tanzania
76. The Bahamas
77. The Russian Federation
78. Togo
79. Tunisia
80. Ukraine
81. United States of America (USA)
82. Vanuatu
83. Zambia
84. Zimbabwe

Countries (DPI MNAs) that Responded to Phase II Questionnaire

1. Antigua
2. Argentina
3. Azerbaijan
4. Burkina Faso
5. Burundi
6. Cook Islands
7. Czech Republic
8. Greece

9. Honduras
- 10.Indonesia
- 11.Italy
- 12.Jamaica
- 13.Macedonia
- 14.Malawi
- 15.Mauritius
- 16.Mexico
- 17.Nepal
- 18.Nicaragua
- 19.Nigeria
- 20.Pakistan
- 21.Panama
- 22.Paraguay
- 23.Peru
- 24.Republic of Congo
- 25.Samoa
- 26.Sierra Leone
- 27.South Africa
- 28.Spain
- 29.Sri Lanka
- 30.Tanzania
- 31.Zambia