

Mongolia Community-based Rehabilitation (CBR) Programme

Understanding what works and what does not – For Planning Future Strategies of CBR Implementation

Community Based Rehabilitation Program for People with Disabilities in Eastern Aimags
of Mongolia (Co-funded by European Commission)



*Training of CBR teams from Eastern part of Mongolia
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INTRODUCTION

A community based rehabilitation (CBR) programme for persons with disabilities in the Eastern part of Mongolia was initiated in the beginning of 2008. During the first semester of 2008, it was decided to collect baseline information about persons with disabilities in Mongolia through two questionnaires. This information was collected from the new areas where CBR programme had just started, as well as from other areas of Mongolia, where CBR programme was started many years ago.



For this purpose, in collaboration with the Mongolian partners, a Questionnaire A1 was prepared for collecting general information about persons with disabilities. This questionnaire was used to collect information from a total of 344 persons spread all over Mongolia, including the new areas where the new CBR programme was starting.

Another questionnaire A2 was also prepared that asked persons about the kind of CBR activities that were most useful and important for their lives and about other CBR activities that were not functioning so well or that needed strengthening. This information was collected from 282 persons from 5 districts of national capital Ulaan Baatar and from some aimags in the Western part of Mongolia, where CBR programme is already started.

The purpose of this information collection was to identify areas of activities most useful to the persons with disabilities in Mongolia.

The two questionnaires were translated into Mongolian language and distributed to the Aimag (province) CBR coordinators along with a set of instructions. The data collected from the questionnaires was re-translated into English and then transformed into tables for analysis. Main findings of the data analysis, detailed analysis of data and detailed tables of data collected are presented respectively in Annex 1, 2 and 3.

Finally, after completion of information collection, a field visit was organised from 5 to 24 June 2008, for Dr S. Deepak from the Medical and Technical support office of AIFO. The objective of this visit was to meet the different stakeholders and collect direct evidence through participatory methodologies, about the needs, expectations and problems faced by persons with disabilities in Mongolia. Annex 4 provides a calendar of field visits that covered 3 aimags and six urban districts, leading to meetings with hundreds of persons with disabilities as well as representatives of Organisations of Disabled People (DPO), authorities, NGOs, universities, etc. Annex 5 provides a detailed report of the



different field visits and discussions. Finally annex 6 provides details of persons contacted during the field visits.

This report brings together the main results of information collected through the two questionnaires and from the field visits, to present an overview of CBR activities in Mongolia, especially in terms of developing new strategies. Annex 7 presents the two questionnaires, A1 and A2, used for this purpose.

MAIN RESULTS

Age group and sex distribution of persons surveyed

Among the 344 persons who answered the Questionnaire A1, 159 were male (46%) and 185 were female (54%).

The survey covered 60 persons in the Eastern part of Mongolia. Among the interviewed persons, 27 (45%) were male and 33 (55%) were female and the male/female ratios seem to be well distributed in different age groups. The survey respondents can be sub-divided into following groups according to age and sex:

< 5 yr		6-15 yr		16-35 yr		>36 yr		Subtotal		Total
M	F	M	F	M	F	M	F	M	F	
1	0	6	5	8	13	12	15	27	33	60

Among the 284 persons who participated in the survey in the urban areas of Ulaan Baatar and Western part of the country, 132 (46%) were male and 152 (56%) were female. Globally this sample compares well with sample selected in the three eastern aimags.

However, in this sample, the male/female distribution in different age groups is different. Males are more in all the age groups below 36 years while females are more in age group older than 35 years, as shown in the next table. Thus this sample seems to be different from the sample in eastern part of Mongolia, but it is not possible to comment on the reasons and implications of this difference.

< 5 yr		6-15 yr		16-35 yr		>36 yr		Subtotal		Total
M	F	M	F	M	F	M	F	M	F	
6	1	29	11	45	37	52	103	132	152	284

Kinds of disabilities

Overall, the survey involved persons with all the different kinds of disabilities including persons with mental illness. From the eight different disability groups mentioned in the WHO manual on CBR, the only group of disabilities missing was that of persons with loss of sensation (persons with leprosy), as there are no leprosy affected persons in Mongolia. Looking at the two samples (from eastern and western parts of Mongolia), there are some minor differences in the percentages of different groups of disabilities.

The survey in the Eastern part of Mongolia involved all the different groups of persons with disabilities according to the classification given in the WHO CBR manual. An analysis of the questionnaires shows the following situation:

Kind of Disability	Number of persons	% of total
Physical (movement) disabilities	15	25%
Vision disabilities	9	15%
Convulsions	9	15%
Mental illness	3	5%
Intellectual /Learning disability	8	13%
Hearing & speech	8	13%
Multiple	8	13%
Total	60	100%

The situation of different disabilities among the surveyed population in urban areas of Ulaan Baatar and Western part of the country showed the following situation:

Kind of Disability	Number of persons	% of total
Physical (movement) disabilities	97	34%
Vision disabilities	20	7%
Convulsions	28	10%
Mental illness	15	5%
Intellectual /Learning disability	30	11%
Hearing & speech	45	16%
Multiple	49	17%
Total	284	100%

There are some differences in the survey samples chosen in the two areas, however, in both areas all the different groups of disabilities are represented.

However in both the areas, an analysis of questionnaires shows that the classification of the different disabilities is not very clear. For example, many of the persons classified as “convulsions”, also mention “mental illness” and “intellectual disabilities” in their answers. Similarly many persons classified as “mental illness”, also mention “intellectual disability” or “convulsions” in their description. Thus there seem to be persons with multiple disabilities, who are placed in one specific disability group.

It will be important for the national CBR team to provide clear definitions of different disabilities and how to classify them in Mongolia so that all the different aimags (provinces) use the same criteria. If placing persons under “multiple disabilities” does not allow for proper planning of services, alternative systems of classification should be looked at, that allow flexibility and clarity of information.

Education level of surveyed persons:

Mongolian children usually start primary school at 8 years. Before that, they may go to kinder-gardens (nursery schools). Thus the children below 5 years were excluded from the analysis about the education status of the surveyed persons.

In the Eastern part of Mongolia, among the 59 persons above 5 years, 22 persons (37%) had no school education.

If we look in terms of kind of disability, persons with movement disability had greater opportunities for some school education. While 50% of persons with hearing and speech disability, 33% of persons with vision disability and 33% of persons with mental illness had no education, the situation was worse among persons with intellectual disabilities (87%), multiple disabilities (63%) and convulsions (63%).



Among the 37 persons who had some school education, 6 persons (10%) had less than 5 years of school, 22 persons (37%) had 6 to 8 years of schooling. Among the 7 persons who had more than 9 years of school education, 6 persons (86%) had a movement disability.

However, if we keep account of the age at which the person became disabled, among the 34 persons who had disability since birth or before 5 years of age, 18 persons (53%) had no school education, another 3 persons (9%) had less than 5 years of school education

In the Western part of Mongolia and in urban districts of Ulaan Baatar, the situation was similar though with some variations. Among the 277 persons above 5 years, 61 persons (22%) had no education, while remaining 78% had some education.

In the group of 61 persons who did not have any education, 54% were women and 46% were men. While 22% of persons with hearing and speech disability, 25% of persons with vision disability, 18% of persons with physical disability, 16% with multiple disabilities 7 % with convulsions and 13% of persons with mental illness had no education, the situation was worst among persons with intellectual disabilities (57%).

In the age group above 16 years, 36 persons (16%) had university education. In this group, 44% were persons with physical disabilities and another 31% were classified as “multiple disabilities”. The remaining 25% belonged to other disability groups. In this group of persons who had university education, 53% were women and 47% were men.

However, if we take account of the age at which the person became disabled, 95 persons (34%) had disability since birth. Among these 95 persons, 87 were more than 5 years old and among these 87 persons, 45% had never been to school, another 21% had less than 5 years of schooling, while 20% had education for more than 9 years.



Another 52 persons developed disability before they were 5 years old. Among them 50% had no education or less than 5 years of education while 25% had education for more than 9 years.

In conclusion, in Mongolia, the kind of disability and the age of developing the disability, may both influence the possibility of access to education, while gender does not seem to be

key factor in influencing the access to education. Persons with intellectual disabilities, persons born with disability and persons developing a disability in the early childhood are more likely to be excluded from formal education.

Social Integration

A number of persons mention receiving social pensions, their marriages and children, giving an idea that many persons with disabilities in Mongolia have the possibility of some social interaction and forming families. However, this information has not been collected uniformly in the questionnaire to provide any conclusions.



At the same time, some persons do raise issues regarding difficulties in social integration. For example, some persons have mentioned “other children laughing at them in school” and there are “negative attitudes in the somon hospital”. For example, one person with intellectual disability mentions that doctors were angry when they found

that she was pregnant. Another woman with convulsions and intellectual disability mentions that “school teachers do not want to enrol her daughter in the school”.

Support from referral medical services

Globally about 45% of persons mention at least one episode of receiving some specialised referral level services including surgeries of different kinds, diagnostic tests, orthopaedic appliances, etc. However this high percentage of referral support may be linked to severity of disability and possibility of receiving invalidity pension. Once again, this information is not collected in a uniform manner in the questionnaire, to draw any conclusions.

Duration of Contact with the CBR Programme

This information related to A2 questionnaires was collected in Ulaan Baatar and Western part of Mongolia. Overall the 282 respondents answered this question.

Table: Duration of contacts between respondents and CBR programmes

Aimags/District (Year starting CBR)	>5 yrs	2-5 yrs	1 yr	Don't know	Total respondents
Zavhan (1996)	10	8	1	0	19
South Gobi (1996)	4	11	2	3	20
Hovd (1996)	8	8	4	0	20
Gobi Altai (1999)	9	10	1	0	20
Bulgan (1996)	11	15	4	0	30
Bayan Ulgii (2005)	0	4	10	6	20
Uvs (1997)	6	4	2	1	13
Orhon (1996)	10	9	0	1	20
Arhangai (1998)	10	4	1	5	20
UB Han Uul dist (1998)	3	12	3	2	20

UB Chingeltei dist (1999)	0	11	8	1	20
UB Bayanzurch dist (1996)	7	11	1	1	20
UB Sukhbaatar dist (1996)	5	12	3	0	20
UB Songino Hairhan dist (2000)	4	16	0	0	20
Total	87 (31%)	135 (48%)	40 (14%)	20 (7%)	282 (100%)

Thus 87 respondents of Questionnaire A2 (31%) were associated with CBR programme for more than 5 years, including some persons who had been associated with it for more than 10 years. Another 135 persons (48%) had been associated with the programme for 2 to 5 years and 40 persons (14%) had been associated for 1 year or less. Finally 20 persons (7%) were unable to tell about their association with the CBR programme and these included both kinds of persons – some completely new persons for whom filling in the questionnaire was their first contact with the CBR programme as well as those, who had been associated with it for a long time and were unable to remember the exact year.

The duration of the contact of respondents can also be seen in relation to the duration of CBR programme in these aimags/districts, shown in the brackets in the first column. Thus an Aimag like Bayan Ulgii where the programme initiated in 2006, have 50% of respondents with less than 1 year of association with the CBR programme while for another 30% this questionnaire was their first contact with the CBR programme. This contrasts with Bulgan aimag, where programme was started more than 10 years ago and thus, 50% of respondents knew the programme for 2-5 years and another 33% knew the CBR programme for more than 5 years.

Since the CBR programme in the Eastern part of Mongolia is just starting, similar information was not available from those aimags (Provinces).

Specific aspects of CBR Programme Perceived as Useful and Positive by the Beneficiaries

The A2 Questionnaires had two questions looking at useful and positive activities of CBR programme. The answers to these two questions have been pooled together for this analysis. The analysis was done by removing the duplicate answers from individual questionnaires and then deconstructing the answers into 8 specific areas. This analysis showed the following results about the areas/activities of the CBR most appreciated by the persons with disabilities and/or their families:



CBR Activities related to work and economic independence, including vocational training activities, self help groups, cattle funds, loans, training courses, invalidity groups, etc. was the

area that was most appreciated by persons with disabilities and/or families (27% of all answers).

CBR Activities related to getting new information and practical daily living skills, including home visits, volunteers, manuals and books, learning about different possibilities of support and services, information about how to access services, learning how to take better care of disabled children in the family, etc. was the second area of appreciation by the beneficiaries (20% of all answers).

CBR Activities related to medical care, rehabilitation services, including support for referral services, access to medical services, not having to wait in a queue for checkups, paying less for medicines, receiving orthotics, prosthetics and mobility aids, etc. was the third area of appreciation by the beneficiaries (17% of all answers).

CBR Activities related to meeting other persons, sharing experiences, including cultural events, meetings and seminars, exhibitions, learning from others, sharing ideas, forming groups and DPOs, meeting persons with similar problems, etc. was the fourth area of appreciation by the beneficiaries (15% of all answers).

Feeling more empowered, receiving psychological support, feeling better and more optimistic about life, feeling less lonely, etc. was the area at fifth place for importance among the CBR activities for the respondents (9% of all answers).

Receiving humanitarian help including blankets, etc. was the area at sixth place for importance among the CBR activities for the respondents (7% of all answers).



Support for going to school and education related activities was the area at seventh place for importance among the CBR activities (3% of all answers).

Better relations and support from family and community was at eighth place for importance among the CBR activities for the respondents (9% of all answers).

About 3% of persons responded with “I don’t know” or “can not say” to these two questions, indicating that they were not aware of the CBR programme or had not received any specific benefits from the programmes.

Specific aspects of CBR Programme Perceived as being Problematic and Requiring Strengthening by the Beneficiaries

The A2 Questionnaires had two questions looking at problematic activities of CBR programme that are not working so well or that require strengthening. The answers to these two questions have been pooled together for this analysis. The analysis was done by removing the duplicate answers from individual questionnaires and then deconstructing the answers into 9 specific areas. This analysis showed the following results about CBR activities that need to be strengthened:

Issues related to lack of information, lack of awareness, lack of regular activities, including lack of events, cultural activities & meeting opportunities at peripheral level, especially bag level (26% of all answers).

Issues related to work and economic independence, including not receiving invalidity pensions, lack of working places, lack of work opportunities, insufficient opportunities for vocational training courses was the second most common problematic area for the respondents (24% of all answers).

Issues related to medical rehabilitation services, including access to specialised centres, lack of trained medical staff, long distances to reach any medical services, lack of rehabilitation services in somons, lack of rehabilitation equipment, etc. was the third most common problematic area (14% of all answers).



Lack of coverage of CBR activities especially in peripheral and isolated areas of the bags, where people had no information and difficulty to access to any services was the fourth most common problematic area (13% of all answers).

Issues related to loans, including very high interest rates, insufficient duration of loans, quantity of loans etc. was at the fifth most common problem area (7% in answers). This was the single most common issue mentioned in a very specific way in

the answers and thus requires careful consideration by the national CBR team. It may be necessary to initiate a participatory process between CBR programme decision makers and beneficiaries to review the rules regulating the loans or at least to explain the reasons behind those rules.

Lack of involvement and support from local authorities and communities, including lack of awareness about disability issues among local authorities and community leaders was at the sixth place among the common problematic areas (5% of all answers).

Lack of access to school and education related activities was at the seventh place among the common problematic areas for the respondents (4% of all answers).

Need for humanitarian aid was also at the seventh place (4% of all answers).

Attention towards needs of specific groups of persons with disabilities such as children, adolescents, wheel chair users, etc. was at the eighth place (1% of all answers).

In addition to the above-mentioned specific areas, a 2% of persons answered with “Don’t know” to these questions.

Many of the problems/issues raised by persons such as access to invalidity pensions or access to referral services are not related directly to CBR programme. However if local CBR committees at different levels can become an opportunity for different disability related services and decision makers to come together, CBR programme can help in raising concerns of persons with disabilities with those services and promote advocacy activities.

Usually it is difficult for persons to provide negative comments and feedback to persons who are providing the service in face-to-face interviews and thus, this part of the answers should be taken with some caution, and it is possible that many other persons had some negative experiences and comments that were not shared.

PERCEPTIONS OF KEY STAKEHOLDERS ABOUT CBR

The field visit gave an opportunity to interact with all the different stakeholders at different level, start from the most peripheral and isolated bags (villages), to somons (districts), aimags (provinces) and national levels. At these different levels the stakeholders included policy makers, authorities, service providers, community volunteers, non-governmental organisations, federations, cooperatives and groups, and hundreds of persons with disabilities and their families. Annex 4 provides a calendar of field visits, Annex 5 provides a detailed report of the different field visits and discussions, and finally, Annex 6 provides details of persons contacted during the field visits.



Interactions with persons with disabilities and their families included group meetings, home visits, semi-structured interviews, etc. The issues raised up during these interactions are quite well represented in the analysis of information

collection through the two questionnaires.

Interactions with the different stakeholders evidenced the following areas of impact of CBR activities over the past decades:

- Importance of working through existing Government structures and services: most stakeholders agreed that this was a key aspect of the CBR programme that brought together international NGO, national and local NGOs and existing Government structures and services, to work together from national level down to each aimag, somon and bag levels, without creating any new or parallel structures and services. Rather the programme strengthens the work of professionals in the Government services, making them more responsive to the needs of the communities. The recent collaboration with the national University of Health Sciences in Ulaan Baatar so that CBR strategies can be included in the training curricula of different health professionals is an important step in strengthening this link.
- Creating awareness about international norms and conventions for stimulating greater emphasis on human rights of persons with disabilities, underlining the specific issues related to groups such as women and children with disabilities, and supporting advocacy for new public policies and laws in relation to the disability has been another key aspect of the CBR programme, in close cooperation with other civil society organisations, especially federations of persons with disabilities.



- Promoting empowerment of persons with disabilities, through sharing of ideas and experiences, through setting up of small groups and cooperatives, through setting up of community level organisations of persons with disabilities in different ways, at the community level has created a vast network of activists who are gradually learning how to influence the local policies and decisions, is an important achievement of CBR programme in promoting inclusive development. At the same time, there is active involvement and support of the national federations of persons with disabilities in the CBR programme.

KEY AREAS REQUIRING ATTENTION

CBR programme has made some significant impact in Mongolia. Its strategy of working together with Ministry of Health and yet promote a multi-sectoral approach involving other ministries, departments, governmental and non governmental bodies and disabled people's organisations (DPOs) has been able to reach and mobilize important support for persons with disabilities. At the same time, with these important achievements, there are some key challenges for the CBR programme, that require more effort and new strategies for the future:

Enlarging coverage of the CBR programmes in difficult to reach isolated areas

Persons living in the bags (villages) together may constitute about one third of the population of Mongolia. CBR programme faces the biggest challenge in reaching them. The



biggest impact of the CBR programme so far has been in the urban districts of Ulaan Baatar, aimag (province) centres and somon (district) centres.

How to involve and effectively train feldschers (village health workers) is a key area that requires extra attention from the CBR programme.

For illustrating the practical ways in which CBR programme can make a more significant impact in these far flung areas, there are three examples from the field visits:

- (a) Early identification and intervention: During the field visit, in many places persons with disabilities pointed out the high number of children with congenital hip dislocation. Such problems can be identified very early by feldschers and simple measures can help in reducing the impact of this impairment. However, if untreated, it requires surgical operation in early childhood and by late childhood, even surgery does not help. Thus feldschers must receive training in early identification and home treatment of congenital hip dislocation. Similarly, for children with club feet, early identification and referral for services such as Ponseti intervention, can play an important role in reducing the impact of the impairment.
- (b) Supporting persons who need medicines and certificates: Some persons with disabilities such as convulsions or mental illness require regular medication. During the field visit it was found that in some places drugs are provided free, in some places these are provided at a discount while in some places persons pay full cost for these. CBR programme can provide uniform information to all feldschers so that all persons can benefit and receive proper medicine. Going to somon centre or aimag

centre for certificates or prescriptions was another area of problem for poor persons in bags. Together with all concerned authorities, CBR teams in aimags can try to see if some alternative solutions can be feasible that help persons living in far away areas.

- (c) Some times, when no trained persons were available, parents read self-help manuals, shared ideas and experiences and promoted field level activities. Such parent groups and provided manuals for them can be promoted and strengthened.

Thus for extending the reach of the CBR programme in the bags, active involvement and capacity building of bag feldschers as well as persons with disabilities and/or their families can play a key role.

Promoting participatory activities of development

While the participants clearly express their appreciation for activities that provide opportunities for persons with disabilities and their families to come together, meet and discuss, find friendships, celebrate events, etc. these activities can be promoted with more emphasis. This means that CBR programme looks at these activities as strategic and important by themselves, and each Aimag is encouraged to develop plans for such activities at all levels, including cross-disability meetings at bag (village levels).



Promoting economic independence

Persons with disabilities and their families look at these as key area for the improvement in their quality of life and issues related to loans come out as the single most important area of CBR activities that requires more attention.

There is need to look at the strategy of giving loans to some persons as grants while others receive these as loans. For the persons receiving or asking for loans, it would be useful to organise Aimag level meetings to explain the rules and how these rules were decided.

It can also be useful to study other systems of supporting loans such as creation of savings scheme that help persons to understand and gain a feeling of ownership and responsibility towards the loans.

The demand for support for economic independence activities is very big and CBR programme is unable to satisfy this demand. It would also be useful to look at other networks or organisations that have specific experience in this area and can advise the project or support the project. Thus networking with other programmes and services is needed and CBR programme can play a catalyst role by organising a national meeting on this theme for sharing of experiences and ideas as well as, bringing in new partners.

Working together with DPOs

At the national level the relationship with DPOs is well established. In different aimags, CBR programme has been instrumental in creation and strengthening of DPOs. Relationships with DPOs can be in two directions:

- Supporting DPOs in their activities through capacity building or grants through CBR programme
- CBR and DPOs partnership, where DPOs monitor all disability related activities in the field such as CBR activities, implementation of UN Convention (CRPD), etc.



It seems that DPOs, especially at aimag and somon levels, tend to look at CBR programme mainly as a donor. It would be useful to promote discussions at different levels so that DPOs also assume a monitoring role, where they advice and inform CBR programme as equal partners.

Strengthening CBR coordinators

A number of persons at aimag and sub-district level especially the CBR coordinators are providing valuable inputs to the CBR programme, that goes much beyond their official duties. Some of them are forced to work in very difficult situations. Some of them have been working with the CBR programme for long times, a few ever since the CBR programme was initiated. This is commendable.

It would be important for CBR programme to support these coordinators through newsletters, exchange visits, meetings, etc. so that they feel part of a group and share their ideas, experiences and challenges with others. At the same time, efforts should be made through the Ministry of Health, so that their work and roles are recognised and valued.

CONCLUSIONS

CBR programme in Mongolia has had a huge impact in the western part of Mongolia and in the urban districts of Ulaan Baatar. At the same time, there are some key areas and challenges that need new strategies and support. As the CBR programme extends its reach to the eastern aimags of Mongolia, the lessons learnt in the past decades of CBR implementation can play a key role in strengthening the activities and making sure that these answer the needs of persons with disabilities and their families.

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