PROMOTING EMPOWERMENT

Emancipatory Research in Community-Based Rehabilitation Programmes: A Guide for CBR Programme Managers

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This Guide is available in English, French and Italian. Translations of this Guide into other languages are welcome. Comments, feedback and examples from other CBR practitioners will help us to improve this Guide. Send information about translations, examples, comments and feedback to sunil.deepak@aifo.it

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“I believe that all human beings have the right to be independent, to guide their own lives and to take decisions about themselves. Often persons affected with leprosy and persons with disabilities find themselves in situations where these rights are limited or negated. I think that in our work with marginalized and vulnerable persons, it is fundamental that we work with them and support them so that they gain control of their own lives. So that we all can be “human beings like others”, as Raoul Follereau used to say.

I would like to dedicate this guide to all those persons who work in the field to support and fight for rights of all human beings, especially of the more marginalized persons.”

Dr Anna Maria Pisano
President AIFO

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This Guide is a result of an emancipatory research initiative called S-PARK/CBR. Many organizations and institutions collaborated in this research initiative. It involved a large number of people with disabilities, their families and communities from nine sub-districts of Karnataka state in India. We would like to acknowledge their support and express our thanks to all of them.

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This research was a wonderful opportunity for us to meet so many persons from different backgrounds, to gain new understandings about what it means to be a person with disability in a rural area of South India. It was also an opportunity to learn about the potential of CBR to promote participation, inclusion and dignity of people with disabilities.

S-PARK/CBR RESEARCH TEAM
Parthipan Ramasamy, Research officer India
Jayanth Kumar, Research coordination India
Sunil Deepak, Research global coordination

ACRONYMS

CBR	Community-Based Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Peoples' Organization
ER	Emancipatory Research
ESG	Empowerment Support Group
MOB	Maria Olivia Bonaldo rural health organization
RCG	Research Core Group
SAG	Scientific Advisory Group
SHG	Self-Help Group
S-PARK/CBR	Samagama Participatory Action Research and Knowledge in Community-Based Rehabilitation
SRMAB	Sri Raman Maharishi Academy for Blind
WHO	World Health Organization
WHO/DAR	Disability and Rehabilitation team of WHO

BACKGROUND

RESEARCH

“Research” is a systematic search for information and new knowledge.

Research carried out in the field such as a Community-Based Rehabilitation (CBR) research programme is called “applied research”. Applied research can be useful for:

- Identifying important problems
- Designing and evaluating policies and programmes
- Applying the knowledge to improve programme activities.

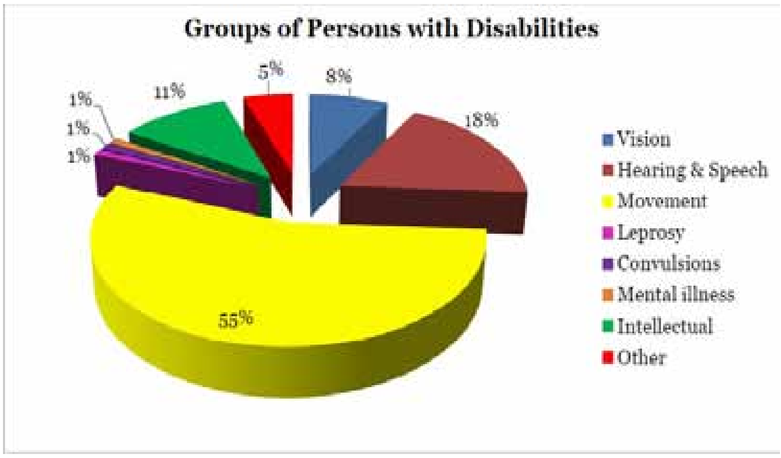
Normally, research is carried out by persons with academic training in conducting research.

EMANCIPATORY RESEARCH IN CBR

Emancipatory research (ER) is research carried out by people with disabilities in ways that promote their empowerment. It uses a human rights approach that informs them about their legal and moral entitlements. ER helps them to understand how different barriers prevent the participation and inclusion of people with disabilities in their communities. ER also identifies strategies for overcoming those barriers.

DEVELOPMENT OF THIS GUIDE

This Guide is based on the experience of implementing an ER project within a much wider research initiative called S-PARK/CBR. The research investigated the Mandya CBR programme in Karnataka state in India and was carried out between 2010 and 2012.



The Mandya CBR programme is managed by two voluntary organizations (MOB and SRMAB). Together they cover nine sub-districts with a total population of about 2.2 million. The CBR programme directly involves around 23,000 persons with different disabilities.

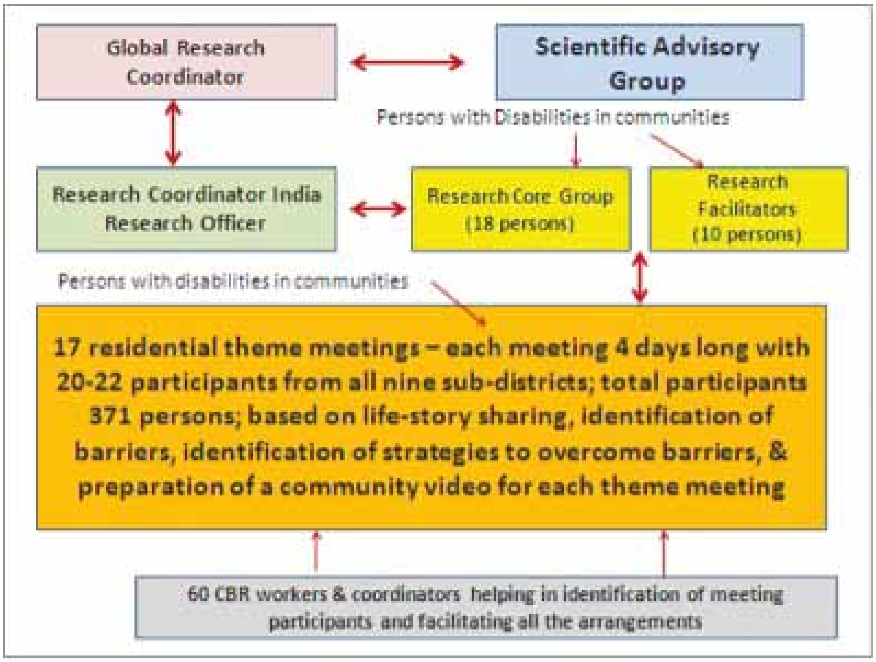
The graph above shows the different disabilities of people involved in the Mandya CBR programme including - visual, hearing and speech, mobility, convulsions, leprosy-related, psychosocial and intellectual disabilities.

In addition, Mandya CBR involves some other groups such as persons with albinism, persons of small stature and persons with multiple disabilities. Women and men with all these different disabilities were included as the researchers.

This ER worked mainly through sharing of life stories and identification of barriers. It collected information in three areas:

- Needs, problems and barriers linked to different kinds of disabilities
- Five areas of the CBR matrix - health, education, work, social and empowerment
- Some cross-cutting areas such as poverty, gender, violence and sports. Cross-cutting areas are problems that are experienced by people with different disabilities.

The following figure presents a graphical overview of S-PARK/CBR initiative:



More information about this research is available at the following web page:
http://www.aifo.it/english/proj/research/sparkcbr/index.htm

One conclusion of this research was that ER is feasible in CBR programmes in rural areas of the developing world. This means that people with disabilities from communities with few resources can do research that improves services, fights against barriers and promotes their own empowerment. It can be done by all the different groups of people with disabilities.

Another conclusion was that ER can strengthen CBR programmes and Organizations of People with Disabilities (DPOs).

TARGET GROUPS AND OBJECTIVES OF THE GUIDE

This Guide is written for organizations and persons involved in CBR projects. It is also targeted at DPOs, especially those working at community and peripheral levels.
Our aim is to produce a clear guide for persons working in CBR programmes. We want people without any previous experience of research to understand it. We hope that CBR workers will carry out simple emancipatory research (ER).
The Guide focuses on practical rather than on theoretical aspects and gives examples from a successful ER project.

Persons and organizations without any previous experience of conducting research will need some basic understanding about research issues before starting any field research. Examples include how to identify research questions and methods to obtain answers, understanding how to select a sample and how to make the findings as valid as possible.

If you have no previous experience in conducting research, you can find some basic information on how to do research at the links given below:

- http://www.aifo.it/english/proj/research/sparkcbr/attachments/basics_of_research_manual_draft01.pdf
- Chapter 2 of “Health Policy and Systems Research - a Methodology Reader” edited by L. Gilson, available at: http://www.who.int/alliance-hpsr/resources/alliancehpsr_reader.pdf

INTRODUCTION TO EMANCIPATORY RESEARCH IN CBR

ER should satisfy the following conditions:

- People with disabilities from the CBR project should **participate as researchers**. They should work in partnership with other researchers including CBR staff, in ways that respect their human dignity.
- It uses methods that encourage building critical consciousness and understanding among all the persons and organizations involved in the research. Critical consciousness is awareness of the different barriers faced by people with disabilities and the social, political and economic causes of those barriers.
- It builds understanding and solidarity among persons with different disabilities, especially the more marginalized and oppressed persons.
- It promotes a critical understanding of human rights, CRPD, and national laws and schemes related to disability.
- It promotes the strengthening of organizations of people with disabilities including SHGs, DPOs and federations of DPOs.
- It results in concrete and practical changes in the daily lives of people with disabilities both directly and indirectly.

STEPS FOR PLANNING AND IMPLEMENTING EMANCIPATORY RESEARCH

The following steps may be needed, not necessarily in this order, for planning and carrying out ER:

A. Identifying possible topics for emancipatory research and making a research plan

B. Identifying groups of people with disabilities who are going to do the research

C. Clarifying the role of CBR staff in the research

D. Identifying external scientific and expert support for the people with disabilities doing the research

E. Organizing training for the persons who will do the research

F. Identifying the supporting mechanisms for the emancipatory research implementers

G. Deciding the most important topics for research

H. Choosing the methods to do the research

I. Getting everyone involved in the research

J. Documenting the research process

K. Analysing the research results

L. Distributing and sharing the research results

All these steps will be discussed briefly in this Guide. Throughout this document text in boxes reports experience acquired during the S-PARK/CBR ER programme.

A. PREPARING THE GROUND

ER can be a **transformative process** for the CBR staff and for people with disabilities, their families and communities. Transformative process means one that brings practical changes to communities. It has to include all the stakeholders from the beginning, especially disabled persons and their communities. The stakeholders are all the people interested or concerned with the research topics. Involving them means that they can contribute to the research and feel responsible for the new understanding, knowledge and results from the research.

Not all the groups of stakeholders will be involved in the research process in the same way. Usually a smaller group of persons will have a more intense and regular involvement in the research. It may be easier to focus on people with disabilities who already have some kind of formal or informal leadership role in the communities. These can include representatives of Self-Help Groups (SHGs), representatives of local DPOs, and representatives of DPO federations.

Other research activities will require much wider involvement of people with disabilities in the communities. Meetings can be organized with larger numbers of people with disabilities and other community members. Thus, they can all participate in the groundwork for the research. They can give their opinions about key issues for research and provide their suggestions about people with disabilities who can be involved in specific research activities.

It is important to ensure that **all** the different groups of people with disabilities, both men and women, are involved in these discussions from the beginning. Usually some groups of persons such as persons with hearing and speech disabilities, persons with intellectual disabilities, persons with mental illness and people with disabilities due to leprosy may face more difficulties in participation. Even when they participate in meetings, they may not speak during discussions. You need to keep this in mind and adopt suitable strategies so that **all** different persons can participate and express their opinions, if necessary with the help of their care-givers.

INITIAL COMMUNITY AWARENESS

The research team had organized two preliminary meetings with representatives of people with disabilities to create awareness about the emancipatory research. About a 100 persons took part at each meeting.

Afterwards a draft research protocol, or detailed plan for the research was prepared. Finally a third community meeting was organized to present the draft. Participants included representatives of the district DPOs and many active members of SHGs.

Some individuals who had been active in the disability issues in the district were also invited to this meeting. About 60 people with disabilities took part.

Efforts were made to ensure persons from all the different areas covered under the CBR project were present. Persons from different socio-economic backgrounds and different age groups were invited. Though efforts were made to invite both men and women with disabilities, few women came to this meeting.

Many persons asked, “What will I get from the meeting?” CBR staff were not sure how to answer this question. Staff were not clear about the purpose of the research so it was not easy for them to explain the purpose of the meeting to the people.

In the meeting, some persons were disappointed that they did not get anything. They had come hoping to receive something like loans or technical appliances. The research team realized that they had not prepared the CBR staff properly for organizing this meeting.

B. IDENTIFYING RESEARCH IMPLEMENTERS

ER is carried out or implemented by people with disabilities in collaboration with other groups of persons such as CBR staff. As CBR programmes may involve hundreds of people with disabilities, you need to identify a small group of persons who will be the main implementers of the research.

Creating a core group of people with disabilities who will play a leadership role in the research is fundamental to the process of emancipatory research. The group has to be big enough to include the different stakeholders among people with disabilities. At the same time, it has to be small enough so that it can be managed and persons in the group can work together.

IDENTIFYING THE RESEARCH IMPLEMENTERS

The initial idea was to create three groups of researchers among people with disabilities from the Mandya CBR programme -

- A group of 16 persons, representing different groups of people with disabilities, for finalizing the research protocol and for supervising the whole process. They were called Research Core Group (RCG) or Empowerment Support Group (ESG).
- A group of 10 people with disabilities for organizing and running the research meetings (Research Facilitators).
- A group of people with disabilities who will prepare the meeting reports in local language (Kannada) and in English called rapporteurs (two persons, one male and one female).

About 50% of these persons were women. They included persons with different education and socio-economic backgrounds. CBR workers and district DPO played a key role in identifying them.

Overall this process worked in the research, though there were some problems. Some of the persons selected for the roles were not very active or had other engagements and were unable to participate in meetings. Thus, they were replaced after some months. Initially it was not easy to find any representatives of deaf persons, persons with mental illness, with convulsions and with intellectual disability. However with time, all the different groups of persons were represented.

They included some disabled CBR workers. However, it was not possible to find a person for preparing English reports from the CBR programme. Therefore a disability activist with experience of CBR from outside the CBR programme was identified for this role.

SPARK/CBR research showed that persons with different disabilities and very different backgrounds, including persons without any formal education, can be researchers in the emancipatory process.

C. ROLE OF CBR STAFF

CBR programmes are supposed to work in active collaboration with people with disabilities, their families and communities. Thus, CBR workers and people with disabilities in the communities should see themselves as partners. However, often CBR workers see themselves as "service providers" while people with disabilities are seen as "service receivers".

In ER, where our goal is to involve people with disabilities as the "research implementers" is it possible to involve CBR workers? Isn't there a risk that CBR workers will try to dominate and show that they have more knowledge and skills?

This is a complex issue and requires careful reflection and planning.

Many CBR workers are themselves people with disabilities. Involving CBR workers in ER, to work together with people with disabilities, can create partnerships between the workers, people with disabilities and the communities.

It can also be argued that the purpose of the research is to strengthen and improve the CBR programmes. The involvement of CBR staff in the process of building critical consciousness and understanding of barriers is central to the goals of ER.

At the same time, research may bring out examples of where the CBR programme is not working well and may be seen as a criticism of the CBR workers. It is also possible that some of the people with disabilities may be afraid of speaking frankly in front of CBR staff for fear of hurting them or of losing the services from the CBR programme.

It is important for the research to be organized in a way that underlines the values of mutual respect and dignity of all the persons involved, both the CBR workers and people with disabilities. The roles of each group involved in the research and in the decision-making process must be made clear. Depending upon the topics of research, the two groups may need some separate spaces for their discussions without the presence of other persons.

It is important for CBR managers to bring out these issues in a neutral way to ensure that both the groups understand it. They have to reassure people with disabilities that they need to share their real feelings, opinions and ideas. They also have to reassure CBR staff that research is for strengthening CBR activities and not for punishing persons. Their views are valued and what they have to say is intended to improve services, not to remove them.

CBR WORKERS AND PEOPLE WITH DISABILITIES

Mamatha, a member of the ESG, said "In the meeting, CBR staff was conducting the meeting and my role was that of observer. I felt that they were not taking into consideration my opinions and suggestions. So after the meeting, during the review process, I shared my feelings with the whole group. It was agreed that our opinion will be equally important. Person conducting the meeting has to listen to our opinions and suggestions."Putlingamma, another member of the ESG said, "I like the meeting with CBR staff because it helps me to understand what kind of work they do, how they take decisions, what kind of challenges they face."

D. EXPERT SUPPORT

Conducting research on disability issues requires skills from different disciplines such as statistics, sociology, anthropology, rehabilitation and education. There may be some people with disabilities from the CBR project who have some of these skills. As CBR projects are often in poor rural areas, it is unlikely that you will find all of this expertise locally.

Thus an appropriate group of persons with expert knowledge may be needed to support the people with disabilities implementing ER. Following the ideals of ER, this external group of persons with specific skills should also, where possible, be people with disabilities.

A key source of persons for the external support group may be local or national federations of DPOs. Another key source may be local or national NGOs that are active in the field of disability. Finally, appropriate persons may be found from academic and research institutions.

SETTING UP A SCIENTIFIC ADVISORY GROUP

A Scientific Advisory Group (SAG) was created. It included two persons from universities, two persons representing federations of DPOs and four persons representing NGOs working in the field of disability and rehabilitation. Most of the SAG members were also people with disabilities.

SAG members advised about the research methods and reviewed all the research protocols prepared by the RCG.

They also participated in three review meetings, where they listened to the research work done by the RCG, shared their own ideas and promoted critical consciousness about the significance of issues emerging from the research.

At all times, it was clarified that SAG members' role was advisory and that the RCG had to take the final decisions about the research.

E. TRAINING OF RESEARCH IMPLEMENTERS

People with disabilities selected to conduct the research process are likely to be a mixed group. They need some general skills such as how to work in a group, how to resolve conflicts and how to work together with other people when conducting ER.

Depending upon the kind of topics selected for the research, they also need some skills such as choosing research methods that make the results as valid as possible, preparing reports and facilitating meetings. They will also need to know about participatory methodologies, the Convention on the Rights of People with Disabilities (CRPD) and the social model and human rights model of disabilities.

Training for each skill requires - that the information needed is defined, that there is a training plan and that suitable trainers are available. It is important to make sure that training is accessible to all the different groups of people with disabilities. All documents may be needed in large print, braille and simple language.

Even with the best of planning, some of the persons being trained for ER may not be able to continue and will have to be replaced. Planners need to think about possible replacements and how they will be trained.

TRAINING OF RESEARCH FACILITATORS

Ten people with disabilities (five male and six female), all above 18 years old, and with 11 to 12 years of school education, good communication skills (both speaking and writing) were identified from the project area as facilitators. They participated in a week-long full-time residential training course.

Some of them were individuals well known in their communities, some were leaders of SHGs or DPOs/federations and some were people with disabilities working as CBR workers.

The training included - an introduction to CBR projects, information about different disabilities, the social model of disability, the principles of the CBR approach, a background to research, preparation of a research protocol, and the emancipatory approach. It also covered the roles and responsibilities of research facilitators, participatory methodologies, communication skills, observation methods, video recording, and conducting group discussions.

Training included role-plays and simulations of research meetings. All the training sessions were in the Kannada language. All training documents were translated into Kannada and distributed to the participants. By rotation, different participants prepared daily reports of the training course.

F. SUPPORTING MECHANISMS

Persons with disabilities from the communities, involved in implementing the research, may require specific support. It is important to discuss together their roles in the ER process and what kind of support is needed to fulfil that role.

EXAMPLES OF SUPPORT

Here are some examples of support from S-PARK/CBR research, so that people with disabilities could work effectively:

- Some persons required support for accessing research information and documents. This included large size printout of documents, braille documents and the help of a sign language interpreter.
- Some persons needed help to come to the meetings, as public transport in their areas was very difficult.
- Two persons involved in the research had full-time jobs. A research coordinator had to explain the importance of the research work to their employers who then agreed to give them leave.
- One person involved in the research explained that she was unable to continue because her family was not happy that she was going out so frequently for meetings. A CBR worker went to her home to talk to her parents and explain the importance of research to them.
- Whenever, a person had to leave their village or be absent from their job for a research meeting or work, they were given a small amount of money as compensation.

G. IDENTIFYING RESEARCH TOPICS

ER can look into a wide variety of issues to gain new insight, understanding and to find solutions.

People with disabilities are often among the poorest in a community and thus face issues of survival, shelter and sufficient food. In rural areas access to services such as health care, technical appliances and education is often limited and difficult. Some of these services may be totally absent, for example public transport.

While all people with disabilities may face some common barriers, some disabilities may also be linked with specific barriers. For example, persons with leprosy-related disabilities, persons with convulsions, persons with mental illness and persons with albinism, might face serious issues of stigma and social discrimination.

Persons may face negative attitudes in their own families. Isolation, lack of social life, abuse and violence are common problems in many countries and societies.

Oppression and marginalization on the basis of gender, religion, ethnic or linguistic origin, caste or sexuality may be issues for all the persons in communities. Disability may be an added factor for marginalization, exposing persons to multiple oppressions. For example a girl child with disability from a minority group can face marginalization in many different ways.

All these can be topics of ER in a CBR programme. As there are so many issues, some way of identifying priorities for research topics may be needed.

IDENTIFYING ISSUES FOR RESEARCH

Through group discussions, people with disabilities discussed and found many different issues that they faced. There were 33 cross-cutting issues that the participants thought were important. These included motherhood for women with disabilities, physical accessibility, transport, minority communities and political participation.
It was not possible for ER to look into all of these issues. So they were asked to organize them in terms of:

- Importance of the issue
- Feasibility of doing research on the issue
- Possibility of making a change in the situation.

Thus, all the issues were prioritized and then grouped together for similarities. The issues that were very similar were combined. For example, social stigma, inferiority complex, attitudes and social discrimination were all combined into one issue called "Attitudes, stigma and discrimination".

Finally nine priority cross-cutting issues were identified as ER topics: Attitudes, stigma and discrimination; poverty and disability; accessibility, physical accessibility and access to services; children with disability, orphans with disability; violence and physical abuse; sports, culture, entertainment; aids and technical appliances; gender and disability; and elderly persons and disability.

H. DECIDING RESEARCH METHODS

ER is seen mainly as qualitative research. Sometimes, both quantitative and qualitative methods may be combined for a better understanding of topics. Critical reflection on the research process and the results of the research is a key activity. This is essential for promoting critical consciousness and empowerment of persons participating in the research.

Some examples of **quantitative research** that can be carried out under the emancipatory approach are:

- Number of men and women with disabilities having access to mobility appliances
- Number of people with disabilities who report episodes of psychological and physical abuse and violence
- Number of people with disabilities who receive disability pension.

While the quantitative research provides information about the extent of a problem, **qualitative research** can go deeper to understand the topics.

For example, if quantitative research shows that only a limited percentage of people with disabilities receive mobility appliances, then qualitative research can help to understand the barriers to receiving mobility appliances. In this way, qualitative research can also help to find strategies for overcoming those barriers.

A key step in the research process is to apply knowledge of CRPD and the social model of disability to try to understand the situation. Consider how individuals, families, communities and societies build stereotypes and barriers. Think about how people with disabilities and their organizations (DPOs) can fight those stereotypes and barriers.

Individual and collective advocacy, or action and support, for promoting a positive change within families, communities and the legal framework of the country, are a part of the ER process.

UNDERSTANDING BARRIERS THROUGH LIFE STORIES

A total of 371 people with disabilities took part in research meetings. It was decided to collect some basic quantitative data about all these participants such as age, gender, education level and membership of SHGs and DPOs. It was thought that this quantitative data would provide additional information about the lives of people with disabilities.

The main focus was on qualitative research based on sharing of life stories. The research topics were identified by representatives of people with disabilities. For each topic, the RCG identified criteria for inviting persons from communities to share their life stories. For example, for the meeting on education, it was decided to select participants with different disabilities who had no or little education as well as some participants who had university level education.

During the research meetings, participants were invited to share the major events of their lives, the barriers they had encountered and how they had overcome those barriers. Facilitators asked questions to bring out specific issues related to the research topics.

The key role of life stories in this research was to identify barriers and possible strategies to overcome those barriers of different stakeholders. Meeting participants were helped to critically examine the barriers they faced in their daily lives. They were helped to reflect on whether they could change those barriers by themselves, together with their families or together with DPOs. They also discussed whether local authorities, government and CBR programmes could be asked to do more or do things differently.

The approach of "sharing of life stories and identification of barriers" was selected for the research as it was felt that it would build critical consciousness. It helped the participants to see that despite their different disabilities, their coming from different parts of the districts and from very different family and educational backgrounds, they all faced the same or similar barriers. The discussion on how the different barriers could be overcome was important for persons to decide collective action and how the CBR programme could improve its own way of working.

The participants were also asked to mark their villages on the map of the area. This stimulated the understanding that men and women of different villages and communities faced the same barriers. It also helped them understand their numerical strength and that working together they can promote change.

At the end of the meetings, to help them to reflect on their discussions and to promote critical consciousness, participants were asked to plan and record a one-hour video. This reported the main issues from their meeting. All of them were asked to participate in the video, each of them contributing with a two to three minute message.

Finally, at each meeting, a report was prepared in Kannada. The report, in clear language, was shared and approved by all participants before the end of the meeting. This was another way to ask meeting participants to reflect on their experience.

Key persons, from national and state level DPO federations and local authorities, were invited to some meetings, so that they could provide their input about the barriers faced by persons living in rural areas.

The ER project used a variety of approaches and methods during the meetings to help and stimulate people with disabilities to understand and to take collective action to overcome different barriers.

I. COMMUNITY PARTICIPATION

A key aim for ER in CBR programmes is to expand the research process to include a larger group of persons. CBR projects wishing to adopt ER need to look at different ways in which the research process may involve larger numbers of people with disabilities and their communities.

INVOLVING COMMUNITIES IN ER

People with disabilities had prepared one-hour videos during the research meetings, in which all meeting participants had taken part. Meeting participants were asked if they wanted to show their video to their communities. Some agreed and it was decided to test the impact of the videos in those communities.

The meeting report of one such community video show explained:

"The room where we wanted to show the video was full of people. Everybody knew that a blind girl from their village had participated in the video and they all wanted to see her. Village president, schoolteacher, priest, everyone came. There were many persons who had to be turned away because there was no place left in the room.

The video was from the research meeting on livelihoods. So before showing the video we had discussion on what kind of livelihood opportunities are there for people with disabilities in the communities.

Then Savitha shared her experience of going to the research meeting. She said that she was afraid to go the meeting as it was outside the village and how a CBR worker had to convince her. The meeting was useful because she met many other disabled persons and learned about different schemes of professional training and work for people with disabilities.

Savitha also talked about making the video and how she was nervous. People in the meeting laughed when Savitha talked about this experience.

In the video when Savitha sang a song, everyone clapped.

People watched different people with disabilities tell about their lives and their difficulties in finding work. After the video there was some discussion on what could be done to help people with disabilities to become independent."

J. DOCUMENTING THE RESEARCH

ER is an "action research". This means that the process of building understanding about the causes of barriers and how to overcome them often leads to practical action.

For example, in the S-PARK/CBR research, the discussions about the laws related to the percentage of the village budget that should be used for people with disabilities immediately led to advocacy actions in many villages to access those funds.

ER has the potential to generate many local actions and changes. However, in such a situation it is easy to focus all the attention on "action" and not enough attention towards preparation of systematic and complete reports about the research - how the research was carried out, what information was collected, what understandings were gained and what actions resulted from the research.

Documenting all the different phases and activities of the research through reports, images and/or videos is an important part of ER. Some of the ways in which this documentation is useful include:

- To learn lessons from different ER programmes to understand what worked and in what ways
- To provide information for future comparisons to see how situations change over a period of time
- To help people with disabilities involved in the research process to strengthen their own critical consciousness
- To share information and knowledge with others engaged in similar work.

In addition, it is important to ensure that documentation is accessible to all the different groups of persons involved in the research.

ACCESSIBLITY OF RESEARCH DOCUMENTATION

In S-PARK/CBR research different approaches were used to document the process.

All meeting participants filled in a form and the information was put in Excel sheets so that it could be counted and analysed. During the meeting, an English report was prepared for the SAG and a Kannada report was prepared for the participants. Some information was shared during the meetings through mapping exercises and pictures. In some meetings, a separate report about women's opinions and discussions was prepared. Finally, all meetings prepared a video-report in which all participants collaborated.

Special care was taken during research to ensure that research reports were accessible to all participants. For example, in the meeting on barriers faced by persons with intellectual disabilities, different designs and pictures were used to ease understanding of the issues.

K. ANALYSING THE RESULTS OF THE RESEARCH

ER requires different levels of analysis of results. Information collected during the research must be analysed in ways that help people with disabilities to gain better understanding of their own experience. This aspect of research is key to promotion of empowerment in ER.

For example, in S-PARK/CBR research, people with disabilities shared their life stories. They were helped by RCG members and facilitators who shared their own life stories. Facilitators helped listeners to share and understand life stories. They gently asked questions to identify different events in people's lives. After sharing life stories, facilitators helped participants to think of different physical, attitudinal, cultural, social, communication, and economic barriers. This helped the understanding of how barriers shaped their lives. Finally, discussions were linked to strategies for overcoming barriers and which stakeholders could play a role.

Global Research Analysis

Data and information collected during the research can be analysed by persons trained in research methods. Usually, this analysis needs support from persons with training in research such as epidemiologists, clinicians, sociologists, anthropologists, and statisticians This analysis requires skills, time and resources. Persons from relevant departments of local universities or NGOs may be interested in providing this kind of support.

More detailed information about research analysis methods is outside the scope of this Guide.

However if such a global research analysis is done, it is equally important to bring the key findings back to the people with disabilities and CBR staff involved in the ER. Some findings may not be easy to understand, so effort will be needed to work with research experts to communicate this information simply and clearly.

ANALYSING RESEARCH DOCUMENTS AND REPORTS

All meeting participants took part in preparing their own video-report at all research meetings. For each research meeting a report was prepared by a rapporteur in local language (Kannada) that was discussed and approved by all meeting participants. Another person prepared an English report for each meeting.

At the end of the research, all the life stories in the meeting reports were analysed according to certain key words linked to basic principles of CBR and to different barriers. All the demographic and general information about the participants was also analysed with the help of a statistical analysis programme.

The preliminary results of the analysis done by external persons were shared with all the members of the RCG and facilitators, for their comments and feedback.

L. DISTRIBUTING AND SHARING THE RESULTS OF THE RESEARCH

While the ER is carried out, documented and analysed, it is important to plan the distribution of the research results and new insights and understandings, to all the relevant stakeholders.

The relevant stakeholders who must share the results of ER include local communities, CBR workers, local and national DPOs, local and national authorities, national and international NGOs, specialized institutions and services dealing with disability and rehabilitation issues, and other CBR programmes.

A communication plan is needed to identify the best ways to reach and inform all these different stakeholders. The research information may need to be adapted for each group of stakeholders so that it is accessible to them.

Development of new information technologies and communication systems means that sharing of the information may also be done through social networking tools such as blogs, Facebook, Twitter, YouTube and email lists.

Equally important is to share information about the research with the scientific community through articles and reports in scientific journals. Usually, these articles are prepared by the persons who carry out the specialized global analysis of data.

SHARING RESULTS OF THE RESEARCH

Cheluvaraju was member of RCG in ER. He is also president of district DPO. After the completion of ER, he organized a meeting in district headquarters. District disability commissioner, district councillor, district education officer and many other district authorities came to the meeting. Three hundred persons with disabilities from different parts of the district participated in the meeting.

Results of ER were shared in the meeting and critical areas where Government action was needed was highlighted. District disability commissioner promised to look into all the issues raised by the persons with disabilities.

PROMOTING EMPOWERMENT THROUGH EMANCIPATORY RESEARCH

Promoting empowerment of people with disabilities, their families and their communities is a key objective of all CBR programmes. An ER approach can help CBR projects to strengthen their empowerment promotion activities.

Here we would like to summarize the key aspects of ER that have been already explained in this Guide and that are important for promoting empowerment:

- Ensure that all groups of people with disabilities can play active and decision-making roles in the research. If you feel that certain groups, such as persons with mental illness or intellectual impairment, cannot play these roles, take it as a challenge to involve and work with those groups. Make sure you support more marginalized groups such as women, children and the elderly, in their participation. Face your own biases to understand that inclusion and participation are possible.

- Use methods that help people to share and learn from each other's experience, that respect their human dignity and right to privacy and that show the ways to overcome barriers and obstacles. Include moments of individual and collective reflection in the research process. These will allow persons to gain new understandings about the structural causes of barriers and how these can be overcome.

- Inform persons about CRPD, use it as an instrument for discussions and guidance. Persons involved in the research can then examine their own life experiences and compare them with their rights. CRPD should become something practical and concrete that can help persons to change and improve their local realities.

- Communicate with SHGs, DPOs, federations and other organizations working in the different fields such as disability, rehabilitation, health, education, livelihood and development. Learn from others and share your own experience to show how you have brought changes in your communities.

HOW DOES ER PROMOTE EMPOWERMENT

S-PARK/CBR research coordinator Jayanth was asked to reflect on what had promoted empowerment of people with disabilities participating in ER. He came up with the following points:

- Environment: The general environment in ER meetings was open for persons to express their needs and problems, they were listening to solutions and real life examples.
- Inclusion: There was lot of attention given to inclusion in the ER such as inclusion in discussions, giving equal opportunities to different persons, encouraging participation, taking into consideration the views of everyone.
- Life stories: Sharing real life experience was a very powerful discussion, persons talked of incidents they had personally faced and the solutions they had found. This had very strong impact. These were stories of people who live in the same conditions, in the same area, they have the same problem as you. So in the end you felt that if others like me have done it, even I can manage to do it.
- Demonstration: ER meetings were an opportunity to see and learn so many things. You could see assistive devices, hearing aids, mobility canes, wheel chairs and physiotherapy. You could see the persons who were using them and ask what it meant for them. It was not just theory, but actual people were already doing it - it had a strong message.
- Information about topics such as differences between intellectual disability and mental illness, legislation, human rights, government benefits, schemes and programmes and self-care measures was being discussed in a systematic way. So persons could go back from the meeting with lots of ideas and information.
- Many external guests were involved in the ER, persons who can be seen as role models. They came and shared their life stories. They were persons who have disabilities, they come from humble backgrounds and they were successful, they had fought against the odds and overcome the barriers.
- There were many announcements during ER meetings – about membership of DPOs, about activities of SHGs, about contact information for different organizations. These also helped in promoting empowerment.
- At the start of ER meetings, all participants watched the video made during the previous meeting. So they could see the kind of impact the research was having on people with disabilities.
- Making a new video at the end of a meeting was also a powerful tool to promote empowerment. People had to think, plan and decide what kind of things they wanted to tell to others, to their families and communities. It forced them to reflect about their own lives and how they could change themselves.
- In ER, we did not limit ourselves to discussing the problems and barriers. It was equally important to discuss possible solutions. Discussing what we could do ourselves and how we could influence local authorities, were strong messages that helped in empowerment.
- We had some women-only sessions on gender that allowed participants to bring out issues that were not possible to discuss in mixed groups.

FINAL NOTES …

This Guide is a collaborative effort. It is result of interactions with a large number of people with disabilities.

We started this Guide with the idea of having something in clear language that can help persons working at community level in CBR programmes to understand the concepts of ER and use them in their daily work. The document in your hands is only a beginning, and it needs to be simplified and improved.

We also wanted this Guide to be very practical with real examples from CBR projects. For the time being, it only has examples from S-PARK/CBR research. We hope that other CBR projects will experiment with emancipatory research and share their experience with us. We shall be happy to add other significant examples to this Guide.

We welcome support from any reader who would like to translate this Guide or parts of it into other languages. Please inform us and if possible send us a copy of the translated Guide by email.

Send your comments and feedback to sunil.deepak@aifo.it.

Italian Association Amici di Raoul Follereau (AIFO) is a non-governmental organization active in 28 countries in Asia, Africa and South America. Its mission is to promote development, self-reliance and empowerment through health and social programmes focusing on persons affected with leprosy and persons with disabilities.

AIFO works closely with the **Disability and Rehabilitation team of the World Health Organization** (WHO/DAR). This guide on emancipatory research project is one of the results of a research on the impact of ten years of a cross-disability community-based rehabilitation (CBR) programme covering nine sub-districts in the Karnataka state of India. This research carried out in 2010-12 was part of the joint AIFO and WHO/DAR joint plan of work.

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