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FINDING OUT ABOUT CBR

TRAINING MATERIALS FOR COMMUNITY BASED
REHABILITATION WORKERS



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1. WHAT IS CBR ?

There are many different ways of explaining what CBR is and why it is such a good way to help people with disability. Here are some ways of describing CBR.



CBR is a way of thinking not a specific program, organization or group of people.

CBR is a mix of many different activities all focused on helping solve disability issues.

CBR can bring change to: a) people with disability, b) their families, and c) people in the community. The CBR philosophy focuses on the fact that most people in the community do not understand disability and do not accept disabled people as equal. To improve the lives of disabled people a CBR programme must also try to change community attitudes and behavior.

CBR helps people with disability in many areas including: health, income and social security, education, legal rights, and social participation.

CBR projects involve people with disability and their family members in all activities. People with disability are seen not just as recipients of help but as experts who can help teach others and manage the CBR activities.

CBR uses community resources at many levels: in the neighborhood, in the district and province and even the national level.

CBR is not the opposite of rehabilitation services provided in large institutions or hospitals. These institutional services are part of a the resources that can be used in CBR. An important part of CBR is the referral to specialty services at the national, provincial and district level.

CBR projects look different in different areas or communities. This is because CBR is based on the specific needs of that community and local resources. For example, one community may need income generation programs as a priority while another may need disability prevention and child care first. There is no single way to do CBR.





CBR should fit into the existing system. Developing a new system in the government or voluntary sector for CBR is too expensive. Instead CBR programs should be grafted on to existing programs if possible. For example, a women's development group might be used to introduce special child care co-operatives for mothers of children with disability. Income generation for disabled farmers might be added to a programme for agricultural workers.

CBR is not an instant solution. CBR is successful when communities recognize and accept that people with disability have the same rights as everyone else.

Here is one definition that brings these different ideas together.



CBR IS A FOCUSED COMMUNITY DEVELOPMENT PROGRAM IN THE FIELD OF DISABILITY PREVENTION AND REHABILITATION.

THIS APPROACH ENABLES COMMUNITY MEMBERS TO OBTAIN A BETTER UNDERSTANDING OF DISABILITY ISSUES SO THAT THEY WILL PROVIDE POSITIVE ENVIRONMENTS FOR, AND IMPROVE THE QUALITY OF LIFE OF, PEOPLE WITH DISABILITIES.

CBR IS A COST EFFECTIVE WAY OF ACHIEVING EQUALITY AND FULL PARTICIPATION OF PEOPLE WITH DISABILITIES WITHIN THEIR OWN FAMILIES AND COMMUNITIES.

2. CBR WORKS AT MANY LEVELS AND INVOLVES LOTS OF PEOPLE

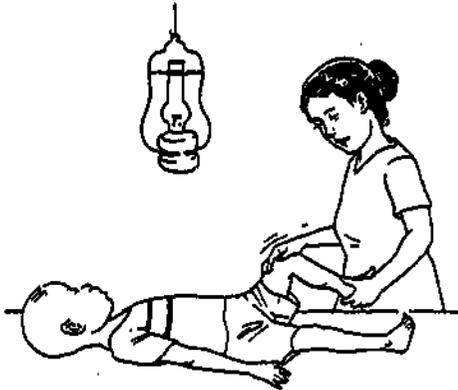
This table shows that CBR does not just work at the local community level. Because CBR is a way of thinking and not a set program, CBR activities can take place at many levels in the government and society. Many people at each level can be resources. The table shows many different departments, organizations, and people who can be a CBR resource. Usually these people support CBR from jobs that they already have. For example, a doctor in a specialty hospital is not likely to be a full time CBR worker but might be a member of the CBR advisory group at the provincial level or might volunteer to teach the local CBR workers how to prevent pressure sores in people that can not move; a teacher might volunteer one evening a week to give informal education to a child with disability who can not attend school.

Anyone at any level can be a resource for CBR

LOCAL COMMUNITY	DISTRICT/	PROVINCIAL	NATIONAL
* HEAD LOCAL COMMUNITY	* DISTRICT GOVERNMENT & RELIGIOUS LEADERS	PROVINCIAL/STATE HEADS & POLICY MAKERS:	MINISTERS & POLICY MAKERS:
* RELIGIOUS LEADER	* DISTRICT NEWSPAPER & RADIO	* HEALTH	* HEALTH
* SCHOOLTEACHERS	STAFF FROM:	* LABOUR	* LABOUR
* SOCIAL WORKERS	* HOSPITALS	* EDUCATION	* EDUCATION
* HEALTH CENTER	* SCHOOL	* SOCIAL AFFAIRS	* SOCIAL AFFAIRS
* WOMEN'S GROUP	* NGO's	* INFORMATION	* INFORMATION
* LOCAL SOCIAL ORGANIZATION	* BUSINESS SOCIAL ORGANIZATIONS	* TRANSPORTATION	* TRANSPORTATION
* TRADES PEOPLE		* SPECIALTY HOSPITALS	* LEGAL EXPERTS
		* TRADE UNIONS	* NATIONAL TV, RADIO, PRESS
		* REHABILITATION SPECIALISTS	* INTERNATIONAL SELFHELP GROUPS FOR DISABLED PEOPLE
			* ACADEMIES* TRAINING PROGRAMMES FOR REHAB. WORKERS

3. EXAMPLE CBR ACTIVITIES AT DIFFERENT LEVELS

Village



- Screening for childhood disability and early intervention program, to teach parents simple play activities to promote development of disabled children.

- Simple home training program by volunteers or family after training by a field workers eg. stretching exercises for legs, dealing with unwanted behavior.

- Volunteer program to provide informal education for functional literacy for people who can not be integrated into the regular system.

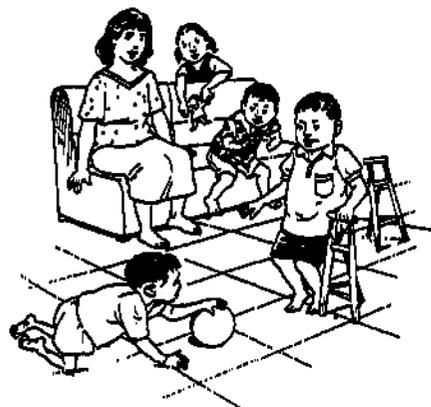
- Income generation projects that include people with disability, eg. co-operative with a revolving loan fund to start small businesses.

- Development of simple assistive devices made with local materials by local workman.

- Organization of disability insurance scheme where each family contributes a small amount of money for food each month.

- Organization of a co-operative for child care among mothers of children with disability, so that one mother cares for 3-4 children on a rotating basis, while the others work.

- Development of a buddy system where a disabled child is matched with a "buddy" who can help the disabled child participate in local youth groups.



Subdistrict and District



- Start a fund to help people who need corrective surgery or special rehabilitation procedures.

- Medical treatment such as surgery for contractures and cataracts, medicine for epilepsy and chronic mental illness.

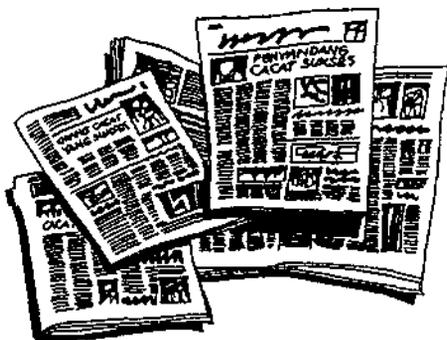


- Self help group of people with disability who carry out advocacy programs to increase government awareness about disability.



- Integrated education for children with disability who have the ability to learn.

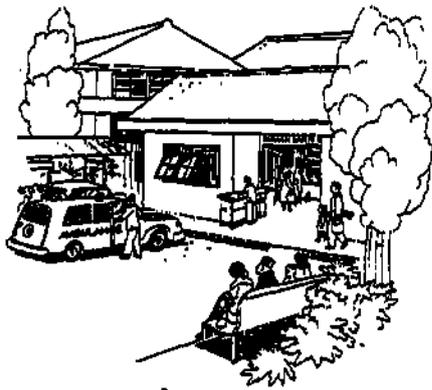
- Special programs for vocational training and assessment, eg. organize retired skilled workman to train people with disability in skills that are marketable in the local community.



- Write a weekly column in local newspaper about disability and how to help.

- Develop instruction sheets for simple aids such as crutches or walking frames and give to all health centers in the district.

Provincial Level



- Referral by CBR worker for diagnosis and treatment of complex disability.



- Long term vocational training.
- Provincial team to promote the ideas of CBR, coordinate activities, and set policy about disability programs and priorities.
- Sponsor special training for CBR workers using technical experts (eg. income generation, education, rehabilitation, community development).
- Develop human interest stories or profiles of successful people with disability for media.



- Build a float to be included in the annual parade that depicts the need for community integration.

National Level



- Referral to specialty hospital eg. orthopaedic, eye.
- Education at universities for persons with disabilities.
- Advocacy group to promote legislation to support people with disability.

- Develop materials based on child-to-child approach to disability to be included in the health curriculum in all schools.
- National organization of people with disabilities to promote CBR as an approach.
- Inclusion of CBR as an approach to disability in the national 5 year planning process.



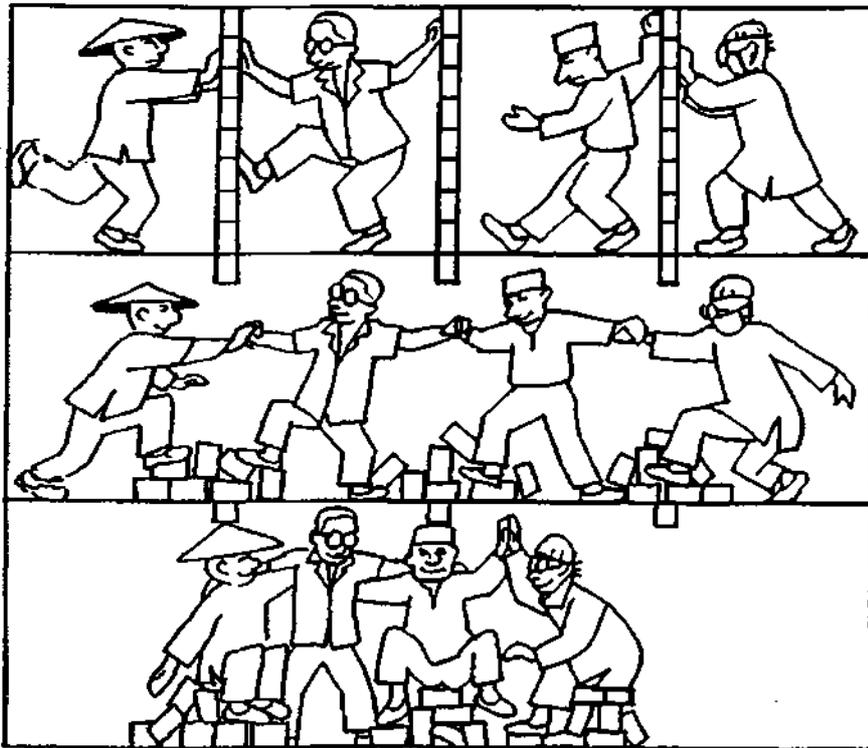
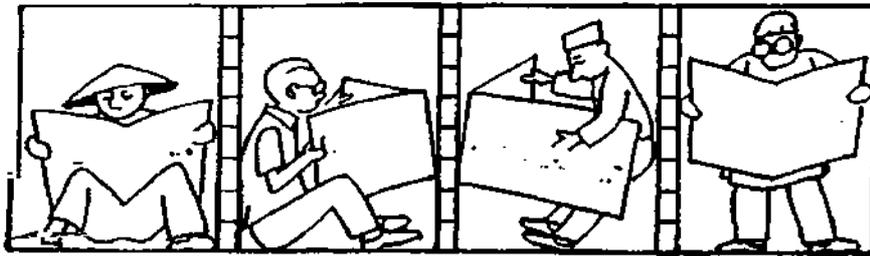
- Short public service announcements on national TV about disability issues.
- Inclusion of CBR as a topic in all related national conferences such as medical rehabilitation, physiotherapy, special education, and social work.



ALL OF THESE ACTIVITIES MEAN THAT

COMMUNICATION CO-OPERATION CO-ORDINATION

ARE ESSENTIAL BETWEEN ALL SECTORS
INVOLVED IN CBR



4. WHAT IS A COMMUNITY ?

The word "community" has many meanings. Usually people think of a community as a geographical area you can find on a map with specific political and social boundaries. Rural communities are often like this, Finding a community in a big city is more difficult than in the rural areas. Community in a city can mean groups of people with something in common that brings together for example, the same ethnic or religious background. It does not always mean that they live in the same neighborhood. It might mean a community of workers or people who have a common interest such as sports or social work.

WHAT DOES "COMMUNITY" MEAN IN CBR ?

1. The COMMUNITY is a resource for solving disability issues

Some examples of community resources are:



- Community workers can be CBR volunteers;
- Local craftsmen make special equipment and aids;
- The community donate money, goods, or their time;
- Community activity groups can include disabled people;
- People in the COMMUNITY are a critical target of CBR in the community and trying to promote positive attitudes toward disabled people is a major activity in every CBR;

2. COMMUNITY structures also need changing

Some examples of community challenges are:



- Buildings should be made accessible for people with disabilities, using ramps, Braille signs etc
- Local people can encourage disabled children to go to school regularly, if possible along with other children from their community
- Local committees should include disabled people



- One of the goals of CBR is to help people with disability stay in their own COMMUNITIES except for short term help from specialists. Even more, the goal of CBR is to help them join in their local COMMUNITY activities.

- Through CBR the COMMUNITY learns to solve social problems using its own resources. This is how a COMMUNITY develops.

LEARNING ACTIVITY

DESCRIBING CBR TO OTHERS

A very common activity that CBR workers do is describe CBR. In groups of 3 people, practice describing what a CBR programme is and how it can help the person with whom you are talking in each of the example scenes given below. Let one person act as the CBR worker, one as the person who wants to know about CBR and the third as an observer. Remember to stress both what CBR is and why it is a good approach. The observer then makes comments at the end of the role play about how convincing the CBR worker was.

Scene #1 - The CBR worker is meeting the village head for the first time. The worker wants to get his permission to bring the CBR programme into the village. The village head does not know anything about CBR or disability. He is concerned that there are already 4 community projects in that district.

Scene #2 - The CBR worker is meeting with the mother of a child who has mental handicap and trouble walking after being sick with a high fever. The mother has not taken the child for treatment of any kind because she cannot afford to go to the city to a specialist. The family is quite poor and lives about 2 kilometers outside the village.

Scene #3 - The CBR worker is approached by the wife of a man who lost his sight in a car accident. Since that time he has stayed at home but he wants to go back to work if he can.

Scene #4 - The doctor and the nurse at the health center have heard about what your program in a nearby village. They say they are confused about what different people do to help disabled people. They have just tested a deaf boy's hearing and also given a cane to a person who is limping from arthritis.

Scene #5 - You have been introduced to a family who has 7 children, 2 of them are disabled with cerebral palsy. The parents are not very rich but have taken the children to the hospital in the capital city and have also spent a lot of money on local medicines and massage. They are disappointed that they have not yet found a cure.

S. HOW CAN THE COMMUNITY BE A RESOURCE ??

The most common type of community resources are people who donate their time as volunteers and their money to help a project. But the community can provide resources to a CBR program in many other ways. They can:

- 1 Learn to accept people with disabilities and give them opportunities to join in community life.
- 2 Learn and practice behaviors that prevent disability.
- 3 Find neighbors who might need the help of a CBR program and refer them to the local CBR worker.
- 4 Work as CBR volunteers. People can donate their time to many CBR activities, for example project management, helping a disabled person in the home, or visiting schools to help students with disability.
- 5 Help with fund raising. This can be directly by giving money or goods (such as wood for special chairs or ramps), by donating space in a building, or organizing a community fair to raise money and community awareness.
- 6 Provide technical expertise about small businesses to help an income generation project. Skilled community members can train disabled people by giving them apprenticeship training in their businesses or by acting as an advisor to the project.
- 7 A less direct way of acting as a resource is by support effort of self help groups or CBR income generation projects. For example, the community can buy products made by a local co-operative. Community members can also hire disabled people trained in the CBR project.

LEARNING ACTIVITY

WHAT CAN I DO TO HELP??

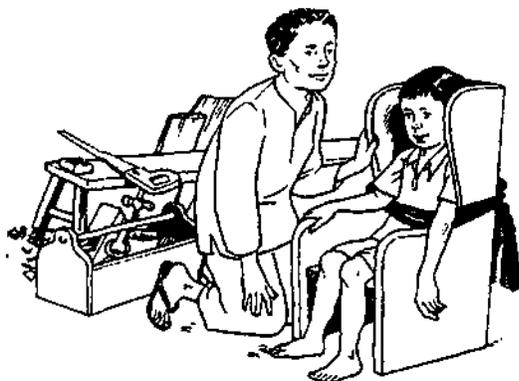
Edi is a 11 year old boy who was born with a disease that made his head grow too large for his body. It is so heavy that he cannot lift it us himself. He also has very poor eyesight and is a slow learner. All of his life Edi has lain on the floor or in bed. His parents are quite poor but have bought a television so that Edi can have something to do during the day.

In small groups try to answer both of the following questions.

What can the community members do to help Edi and his family ?

How has the community been developed by helping Edi ?

One of the most important principles in CBR is that the community is a resource for people with disability. The story of Edi shows many different ways that the community can help.



- The local workman can use his skills to build a special chair for Edi.
- The owner of wood shop can donate the materials for a chair or give a discount.
- The school teacher or a volunteer can give informal education now that he can sit up.
- The leader of youth group can arrange for a volunteer to read to Edi every week.
- The neighbor can help with special exercises to give Edi's parents a break from doing them.

Another important principle is that by doing CBR the community learns and develops itself. So the community also benefits.

How has the community developed by helping Edi ?

- The community can see that something simple can improve Edi's life and make his parents happy. They can see that disabled people can change and grow.
- The community now has skills to make special equipment for persons with disability. Even though it is unlikely that another child would be born with that disease, the community members now know that special equipment can be used, and have learnt some basic principles.
- Children get to know that children with disability and learn that they are no different than themselves. Learning these attitudes early will make more accepting community in the future.
- By solving a disability problem, the community is more motivated to solve other problems in the community. Success at solving one problem leads to confidence and motivation to solve others.

People with disability and their family members are also key community resources. Not only are they expert on the experience of disability (what it is like and what is needed) but they are often expert in how to help.

LEARNING ACTIVITY

Diah was 5 years old when she got sick with a high fever. Afterwards her left arm and leg did not work well. She kept tripping when she walked and her arm was floppy. Diah also had trouble learning new things and sometimes her words were in the wrong order. Her parents had 6 other children and lived 90 kilometers from the nearest city. Her mother and father both worked in the fields most of the time. After Diah's illness her mother was afraid to leave her alone. They did not have a car and most of the other family members had moved to the capital city.

Discussion Questions

1. Why didn't Diah get help?
2. Who do you think could help now ?
3. How could you help ?

6. WHY IS CBR A GOOD APPROACH TO SOLVING DISABILITY ISSUES ?



Coverage

CBR programs can usually help many people with all types of disability and can cover large geographical areas (especially rural areas) because programs do not depend on a building or highly trained professionals.

Cost

Building and maintaining special facilities with technical equipment, and employing professional staff is costly. CBR is less expensive BUT it is not a free program. All CBR programs have operating costs.

Disability issues

CBR projects can include all approaches to disability issues: prevention of disability, direct rehabilitation, integrated education, advocacy, income generation, social integration, and community education.

Impact

CBR programs have an impact on more than just disabled people. They also help families of disabled people and members of the community through awareness and education.

Community Education

Because the program is in the community and usually include many awareness activities, CBR helps to make changes in the knowledge, beliefs and way people act toward disabled people. Without this, disabled people will never be integrated into community life.

Integration

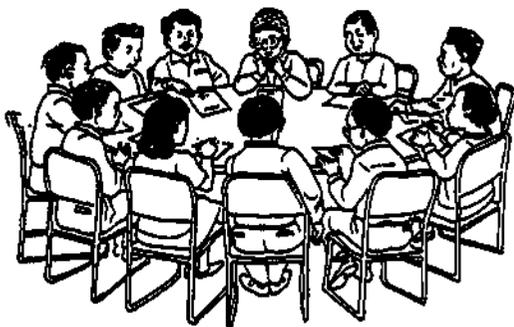
The goal of CBR is to help disabled people stay in their own local communities. They then have a better chance of joining the community than if they are sent to a special institution in another area.

Full participation of people with disability



CBR provides a chance for disabled people to participate in all aspects of the program and not just receive services from others. In many CBR programs, disabled people can act as managers, fieldstaff, evaluators, or advisors.

Flexibility



CBR is a way of thinking about disability and is not a set program. Therefore, it can better meet local needs and fit local situations.

Community Development

When the community learns that it can help persons with disability, it develops into a better community. It can use the skills learned in the CBR project to help solve other social problems. It also increases people's feeling that they have the power to improve things in their own community.

2. STARTING A CBR PROJECT

The following steps are guidelines only. They do not need to be followed in a specific order and often two or three steps happen at the same time.

Identifying the Needs of Disabled People

All CBR programs must be based on the needs of people with disability and their families. There are several ways of finding out what is needed:



a) Household survey of all disabled people in the area.

b) Meeting with representatives of people with disability and local leaders such as the religious leader, doctor and school teacher.

c) Review existing information from the government about numbers and types of disability. Although this usually does not give details, it can tell you what kind of disability is most common and in what area most people with disability live.

d) Hold a village meeting and invite anyone to attend who is interested in disability.



Getting Government Co-operation

An important step is to get official recognition of the CBR project from the district head. Although the government might not have an active part in your project, it is necessary to inform them about your activities. In many cases the CBR project works closely with government. Often a CBR group, committee or team is set up. It may have representatives from the following government departments and agencies: a) health; b) education; c) social welfare; d) labor; e) department of information; f) relevant voluntary organizations; g) at least one representative of people with disability or their family members.

CBR Seminar

Usually a seminar about CBR is needed for interested government and voluntary organization people in the district. For most people CBR is a new idea and they need to know more about what it is and why it is a good approach to disability issues.

Community Meeting

A community meeting about the CBR project is an important first step in community education and support for the project. This is usually held after the entry strategy has been developed so that people can be told about the project activities. Community meetings need to be both informative and educational. But some kind of entertainment like slides, video or a play will help to get people to the meeting. A time for question and answer about disability is important and will give the CBR team some idea about local attitudes and knowledge.

Identifying Local Resources

Because people are usually not very familiar with disability issues, they do not always know that there may already be resources to help people with disability in the community. Members of the CBR Team or the CBR worker should interview many different people from the local area to make a list of resources which can support the CBR programme. Some of these local resources are in the government, for example: the Ministry of Health, Social Welfare, Labor, Education, Planning, and Information. Other sources of help are: local voluntary organizations, organizations of people with disability, religious groups that provide social service, local businesses, the media and craftsmen.

Training CBR Workers



Every CBR project has some type of worker although often the workers are volunteers and may be people with disability or family members. Training can be done all at one time, for example a two month intensive training or in shorter seminars over a long period of time interspersed with field work.

Fund Raising

Developing a strategy for funding to maintain the program is important. Even if there is outside special funds to the start the program, it will eventually have to support itself so that fund raising should be considered right at the beginning. Some examples of fund raising are developing a local disability insurance plan like a health, plan and adding a fixed budget line into the local municipal budget. A contribution from the family of disabled people (even if only a small amount) and the community are important for ownership of the programme. If all funds are given by voluntary organizations, the program will probably stop once the "outside" funding stops.

Choosing an Effective Entry Programme

The Exhausted CBR Initiator

The CBR program started with a big bang. Over 100 people came to the first community meeting and decided that getting education to disabled children was a big priority. The CBR worker was enthusiastic. In the first month she met with teachers in 10 schools, had a meeting with head of the education department, started a manual for teachers to help them integrate children into the classroom, and began to build a ramp in her yard to show how children with problems walking could get into the school. She also wrote to an international agency about getting special equipment for blind children and at night tried to teach herself braille. She also had the first meeting of a parents of disabled children support group. By the end of 6 months she had about 15 activities started but none of them were really going well.

There are many CBR activities and it is not always easy to decide which one to start with. It is usually good to begin with one or two activities only. Some ideas that might help you decide what activity to begin with are:

- An activity that is very visible. This will raise community awareness about CBR. If you introduce an early detection of disability into a baby weighing program many mothers and health staff will be involved. If you start a child to child disability prevention program in the school, teachers, children and their parents will begin to learn about CBR.
- An activity that shows CBR can improve the lives of disabled people will help convince people to support CBR. A program that integrates 10 people who use wheelchairs into a local factory will give a good impression of CBR while a program that begins trying to change policies will take much longer to have a result. Changing policies is important but the community also want to see how the program helps people with disability.
- Many programs join in with an already successful community program, for example adding informal education for disabled adults into a rural literacy program. This strategy usually may cost less to do than beginning a new project. But more important it builds on something that is already in the community.
- Often there are so many needs that the CBR workers wants to try to meet them all at the beginning. It is better to try a small specific activity that you know you have people and funds to complete, than to launch a huge program for which there may not be sufficient resources. Starting in a small ways and proving success is the best basis for a larger project.
- An activity where people with disability have an active role sends a strong message to others about your project. Whether disabled people are helping with planning and decision making, organizing a self-help group, or acting as CBR workers it is important that the communities sees people with disability and their families as an active part of the project.

8. FINDING LOCAL RESOURCES

Helping people with disability and their families find and use existing resources is an important activity for CBR workers.

Examples of resources that might be needed are:

- hospitals
- special schools for disabled children
- projects for income generation
- co-operatives
- prosthetics and orthotics centers
- womens advocacy groups
- special doctors
- foundations that give money for wheelchairs and equipment
- experts in starting small businesses

Because each country, region and even community is different, there is no easy way to find out who can help and how except by talking to people.

Also there are different services offered by government at different levels. For example the doctor at the health center may not know much about cerebral palsy but the children's doctor in the specialty hospital in the capital city might. So you need to know exactly where in the Ministry of Health to look for help.

To help you learn what services are already in your area, visit some or all of the following places and find out what they have to offer for children and adults with disability. In some countries or areas there may be other ministries or groups involved, for example Ministry of Co-ordination or Planning or Ministry of Information.

Some Resources in the Community to Interview

1. Representatives of the Ministry of Health
2. Representatives of the Ministry of Social Welfare
3. Representatives of the Ministry of Manpower
4. Representatives of the Ministry of Education
5. Organizations of people with disability
6. Local voluntary organizations both for people with disability and others such as church health clinics, womens' groups, income generation co-operatives and so on.

Suggested Interview Questions

The following guiding questions can help you when interviewing people in different organizations and government departments.

1. What special services do you offer for disabled people ?
2. What is the common disability problem that you deal with ?
Do you help people with all kinds of disability, for example mental illness, mental handicap, low vision ? If not, where do people with these problems go for help ?

Is there a special age group that you work with ? Are there special programs for people of certain ages for example children under five or old people ?
3. About how many disabled people do you help each year ?
4. What kind of staff do you have for example physiotherapist, social workers, small business experts, advocates ?
5. Can disabled people just come to this office for help or is there a special referral system?
6. Do you have financial help for those who can not pay for services, transportation, or equipment ?
7. Do you have special equipment for disabled people eg. braille books, hearing aids, walkers, wheelchairs ? If not do you know where do people get this equipment ?
8. From your experience what are the greatest needs of people with disability in this area?
9. Can you suggest other organizations or places I should visit that would help me know the services for people with disability ?

LEARNING ACTIVITY

WHO CAN HELP AND HOW?

One way to see how well you know local resources and the larger referral network is to try to solve some case study problems. In each case below be specific about where you would refer the person or their family naming specific places or people in your area. Don't just think of the government or obvious places-be creative in problem solving. For some of the case studies you might not be able to solve the problems because of lack of resources in your area.

1. Dwi broke his back in a motorcycle accident and spent 4 months in the special orthopaedic hospital in Solo. He is ready to go back to live with his family but needs some way of earning money. He has been using a wheelchair from the hospital but must leave it there when he goes home.
 - a. What are his problems ?
 - b. Where would you refer him for each of these problems ?
 - c. How would those organizations or department help Dwi ?

2. Sri is 3 years old and can not hear or talk. Her parents live in a small village about 1 hour outside the district capital. They work in the fields and have very little money.
 - a. Where would you refer Sri and her parents ?
 - b. What might the expenses be in getting help and how might you assist them get money to pay for costs ?

3. You notice that your elderly neighbor has quit walking around the neighborhood and she has also stopped reading the newspaper. When you talked to her you noticed a gray area in the colored part of her eye.
 - a. What could her problem be ?
 - b. Where could she go to find about it ?
 - c. If she needed surgery, where would she go ?
 - d. If he could not afford surgery, where could you go for help ?

4. Wadi is a 6 year old girl who is a big problem for her family. Ever since she was about 1 year old she is very active. She runs around the community and steals things from neighbours¹ houses. She gets angry very easily and hits other children at least once a day. Wadi will not listen to her parents and sometimes screams and holds her breath or tries to bite them. Someone from her family must always be looking out for her or she gets into trouble and the school will not take her into first level.
 - a. What are Wadi's problems ?
 - b. Who could help with Wadi's problems and what kind of help can they give ?

5. Ibu Parnyono is an 76 year old lady who had a bad stroke. After staying in the district hospital for 3 weeks it is time for her to go home. She can walk but needs a walking frame for balance and her right arm is very weak and floppy. She lives with her youngest daughter and family about 2 hours outside the city.
 - a. What kind of rehabilitation services would she have gotten at the district hospital ?
 - b. Where would you find a walking aid and who could pay for it ?
 - c. If she needs more physiotherapy, where would you refer her ?
6. Parman is a 40 year old man who is homeless. He wanders around the streets and sleeps in front of a store at night. He usually gets food from the garbage cans. He talks to himself and to cars and bicycles. The local shop owner wants do get him away from his store ?
 - a. Should he be part of a CBR programme ?
 - b. Who would you go to for help ?
7. Ety is 8 years old and is not doing well at school. She forgets what she learns and does not pay attention. She seems to be slower than the other children and very clumsy.
 - a. Who in the primary school could help ?
 - b. Where would you refer her family for help ?
8. Mira has a baby who is 4 months old. Mira is worried because the baby does not seem to look at anything and does not smile when she sees like Mira's other children did at that age. The baby is just seems to lie on the bed and not make any noise.
 - a. Who should she take the baby to first ?
 - b. If they could not help, where would she go next ?
9. Ever since she had a high fever, Ony has had fits every few weeks. She seems to faint and then her arms and legs shake and her head jerks. Her fits only last for a minute or so but she can not remember anything about them.
 - a. Who could identify what her problem is ? Does she need a specialist ?
 - b. If she needs drugs, where would she get a prescription for the medicine ?
 - c. Who could help her if she could not afford to buy the medicine ?

10. Hery was born with mental retardation. He has attended a special school for children with mental handicap for 8 years. He is now too old for the school and is living with his family in a small town. He can do all the everyday activities himself but has nothing to do all day.

a. Who could help him and how ?

11. Your aunt and uncle have just had a new baby who was born with deformed mouth and lip. There is a hole that goes from the baby's lip to his nose and he can not drink milk well.

a. What do you think you should do first ?

b. Where would you go for help ?

c. If the baby needed surgery, where would his parents take him ?

c. If they are poor, where would you find financial help ?

12. Sumarmo was born blind but has been taught by his family to dress and feed himself and to help with household tasks. He is clever and walks around the community with no help. He is now ready to go to school but the primary school will not accept him.

a. Where would you go for help ?

9. DISABILITY SURVEYS

Example Survey Questions

INFORMATION ABOUT PERSON WITH DISABILITY

1. What activities can she or he not to do because of the disability ?

- | | | |
|---------------------------------|---------------------------------------|--|
| <input type="checkbox"/> bath | <input type="checkbox"/> cook | <input type="checkbox"/> move around the community |
| <input type="checkbox"/> dress | <input type="checkbox"/> go to work | <input type="checkbox"/> join family activities |
| <input type="checkbox"/> eat | <input type="checkbox"/> go to school | <input type="checkbox"/> join community activities |
| <input type="checkbox"/> toilet | | other:

_____ |

2. What did the family do to help the person with disability ?

- | | |
|--|---|
| <input type="checkbox"/> visit health care centre | <input type="checkbox"/> physiotherapy exercise |
| <input type="checkbox"/> visit hospital | <input type="checkbox"/> traditional medicine |
| <input type="checkbox"/> visit rehabilitation centre | <input type="checkbox"/> massage |
| <input type="checkbox"/> visit specialist | <input type="checkbox"/> injection |
| <input type="checkbox"/> Visit traditional healer | other:

_____ |

HOUSEHOLD DISABILITY ISSUES

1. Does any person have trouble walking ? Yes No
- Can he **walk to the market** ? Yes No
- Can he **squat** ? Yes No
- Can he **get on the bus** ? Yes No
2. Does any person *have* trouble using their arms or hands ? Yes No
- Can he pick up a coin ? Yes No
- Can he use a spoon ? Yes No
- Can he comb his hair ? Yes No

HZH No

LEARNING ACTIVITY

COMMUNITY DISABILITY SURVEYS

The University agreed to help you conduct a village survey to find all the people with disability. They sent 3 researchers with a questionnaire and they trained the village volunteers how to use the questionnaire. After 8 weeks all the households were visited and the researchers took the survey back to the university to be analyzed. The surveys got detailed information about the disabled people so it took several months to get their report. The volunteers thought that they found about 57 people who could use the CBR program but were waiting for the results before beginning the program. When the report came it was 100 pages and filled with very useful information for the CBR manager.

Form into two groups. Have one group write down all of the positive reasons for doing this survey and the other all the negative reasons. Then have a debate where each side presents their points and tries to convince the other side that they are correct.

There is no "right" answer to this. Using a survey can be useful in some situations and less helpful in others. After the debate make a list of situation where a survey is most helpful.

A common way to begin a CBR project is with a household survey. It has many advantages:

1. All the people in need are found because the surveyors go to each house.
2. Often the people doing the survey are the CBR workers and they are introduced to the disabled people and their needs through the survey.
3. The survey results can give important program information such as the most common disability and needs, area where most disabled people live, and so on.
4. If developed correctly, the survey can be used as part of the project evaluation. The same survey could be used a few years after the project had begun and could compare the lives of disabled people before and after.
5. University researchers can be a good resource for CBR programs.

Surveys also have some problems.

1. They are often expensive unless volunteers will go house to house for no pay.
2. Surveys can take several weeks to do, especially if the surveyors are not motivated.
3. Unless very carefully written, surveys often only identify people with obvious medical disability and may not include all types of disability. Often only diagnoses are used.
4. Sometimes people are reluctant to talk to surveyors because they are not sure of the "real" reason for the survey and who will get the information. Also people may be ashamed that they have a disabled person in the family and may not tell the surveyor about that person.
5. Probably the biggest problems is that when a survey is done, it raises expectations that the CBR program will immediately solve the problems that the disabled person identified for the surveyor. There can be many months between the time the survey comes to the house and the program actually starts.

IS THE CBR PROJECT WORKING ?

It is important to work out a system of getting information about how well the project is working right at the start. Otherwise, the program may be failing and you will not be aware of this until it is too late.

These are some of the questions that the CBR Team or CBR workers need to ask themselves about each major project activity and the overall project.

1. Do the people with disability and their families feel that the program is helping them ?
2. How are people with disability involved in the programme? Do they have a say in decision making in the program ?
3. Is the community actively involved in the project ? How ?
4. Are the groups who were trained still carrying out the activities learned in the CBR training ? Are they doing the activities correctly ?
5. Is the referral system being used often and correctly ?
6. How many organizations and government departments are in the CBR network ? How does the program work co-operatively with each of them ?
7. Have the funds and volunteer time been used in an efficient way ? Can you link funds with specific activities ?
8. Is the community able to carry on the project without financial and technical help ?
9. Did the project meet the initial objectives and project plans ? Did the program do what it said it would ?
10. In what way has the project done something positive about the disability issues in the community?
 - Are disabled people participating more in the social life of the community ?
 - Are more children with disability getting education ?
 - Are families with disabled people increasing their income ?
 - Do more people in the community know what causes disability and what can be done ?

WHAT WILL EVALUATION TELL US ?

NO WAY OUT

The center at X consists of a very large villa and a number of outbuildings, surrounded by a beautiful, well-kept garden. It receives about thirty boarders, all of them were initially mentally retarded children in the age groups 3 to 10 years. There are several small classrooms, which look more like play rooms than a school. It has eight professional (of whom four are expatriates) and 15 additional staff for cooking, cleaning, gardening, etc. The rehabilitation programme consists of ADL training and special education and is of excellent quality. The personnel are well motivated and have activities in-and outdoors, games, etc., the whole day.

There are two children a bedroom and plenty of bathrooms. The buildings are luxurious, with marble floors, high-quality furniture, and carpets. The food is excellent, the whole place is tidy and orderly, the children look happy and love the staff.

Of course, the costs for the centre are very high and are totally donated by a foreign NGO. I visited it when it had just been inaugurated 16 years ago, and there were then some vague ideas of transferring it to a local NGO or to the government "later on". The principal felt that a few families might take home their children when their "education" was completed. Otherwise the centre might have to keep them and build a sheltered workshop for them.

Since then, almost no children have left the school, and the contacts with the parents are thinning out. Over half of the children have had no visit from a family member during the last year. There is no way out for them. The annual cost per child is now about US\$ 9,000, and the donor organization has desperately been looking for a national organization to take it over. So far, nobody has shown any interest- so there is no way out for the funding NGO either.

TRAINING FOR TRAINING'S SAKE ?

In this African country, the government has set up several vocational training centres for disabled people. The one I was shown was housed in some extremely spacious buildings; one could easily have had 200 trainees here. As was, the total came to not more than about forty.

"As usual", the disabled people were trained along conventional lines. The deaf boys and girls did carpentry. The blind youths were making baskets, and the physically disabled were learning how to sew.

As regards the carpentry, the products were of such poor quality that there was no way they could ever induce anybody to buy them. The tables or chairs had uneven legs, surfaces scratch marks, etc. The basket-weaving was done with acceptable quality, but selling these baskets would earn a hard-working disabled person not more than one US dollar a day. Those who did sewing turned out fine products. But with a sewing machine available in so many households nowadays, the prospects of earning an income from this activity are nil.

The government's austerity programme did not allow the vocational training centres in that country to operate for more than about eight months last year. The trainees were sent home to wait for the next budget year to come around. Though idle over all these months, the teacher's jobs were protected by law and they continued to draw their pay.

SOME DO IT EXPENSIVELY, WITH NOT MUCH RESULT

This is a vocational training unit for about 25 mentally retarded adolescents in an Asian country. Some of them come from the neighbourhood and go home every day by a special bus. Others come from far away and are boarding.

The trainees are taught carpentry. They have four well trained instructors. The centre is equipped with several expensive pieces of woodworking machinery. But these are not used, for the trainees could not learn how to operate them, and besides, they were potentially dangerous. Thus the training consists of sawing and drilling by hand and of polishing various pieces of wood with emery paper. These are then painted and sold as part of a toy set used in nursery schools.

The vocational training project had been going on for three years. During this period, just one of the trainees had been placed in a job. However, in order for the boy to get the job, one of the teachers was sent along for four months to help him adjust to the job.

The annual cost of training was US\$ 4,000 per trainee. These costs were covered by donations, mostly from external sources.

LEARNING ACTIVITY

THE CBR PROGRAM THAT IS NOT WORKING

The Mangkubumen CBR program trains community volunteers to work with disabled adults and children in rural areas, as well as acting as a resource centre for community groups. About 500 volunteers have been trained. After the 2 week training course follow-up visits are made to the volunteers and local community leaders at 6, 12, and 18 months.

At first local government officials and NGOs were very interested in the program and the trainers could not fulfill all the requests for training. Lots of local people came to visit the resource centre and learn about disability.

The program is now entering its 3th year. In the last 6 months there have only been 6 visitors to the resource centre and no requests by community groups for training. The two training sessions organized by the staff were not well attended. Also the staff find it difficult to locate CBR workers when they do the follow-up visits. It seems that many CBR workers have lost interest in the program. The program funding runs out in 6 months and already the staff are asking around about available jobs.

1. What are the problems in the program ?
2. What kind of monitoring and evaluation questions would have told the management that the program was in trouble ? eg. Are the disabled people happy with the program ?
3. When and how often should these evaluation questions have been asked ?