

The international newsletter on community action in disability and development

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OVERVIEW

Approaches to communication

This issue of Disability Dialogue focuses on increasing the awareness of, and improving approaches to, people with communication disabilities.

What is communication?

People communicate with words, by speaking, reading, writing or with signs, gestures or pictures.

Communication involves sending a message and someone else receiving and understanding it. All of us can experience difficulty communicating, for instance if someone cannot understand the message we are sending or we cannot receive or understand a message someone is sending to us.

Studies have shown that people with disabilities identify the ability to communicate as a priority that follows closely other basic survival skills such as access to food and shelter. We all need to be able to communicate to share our thoughts, feelings and ideas, and the ability to communicate is an important step in building relationships with our families, neighbours and communities.

Communication

- For communication to be able to take place, we need someone to communicate with and something to communicate about.
- Communication starts at birth.
- Communication is a two-way process - it always involves two or more people.
- Communication involves sending a meaningful message and understanding the message received.
- To communicate, we use symbols. When symbols are organised into a system they make a language.
- Language can be verbal or non-verbal. Body language is an essential part of communication.
- Successful communication involves many different steps. Breakdown in communication occurs if any of the people taking part in the process have difficulty at any step.

Adapted from: Let's communicate: a handbook for people working with children with communication difficulties (see Resources, p12).

Front page photo: CICE

What is communication disability?

Communication disability can be explained as 'when a person's ability to communicate is affected by an impairment and by other people's reaction to their impairment, resulting in a breakdown in communication.'

Studies have shown that about half of the disabled people seeking help from educational establishments and community-based rehabilitation (CBR) projects have difficulties communicating. This is often not realised because disabled people are usually grouped according to their impairment (e.g. hearing impairment, learning impairment) and not by their inability to perform certain functions. A CBR worker is just as likely to be asked to help someone with a communication disability as they are to be asked for help to support someone with difficulties in movement. This fact is not reflected in CBR training or CBR work activities, which tend to focus on developing skills to support people with difficulties in physical movement.

In the words of one Ugandan community worker: "As soon as I realise that the person cannot communicate I feel quite helpless... I do not know how I can help them and so I do not visit them again." In many countries, developing services for people with communication disabilities is a low priority. Services that do exist do not reach most people who need them.

Developing services

Effective services for people with communication disabilities can be developed by

- listening to people with communication disabilities and identifying what their needs are.
- listening to local service providers, e.g. CBR workers, health workers,

household members and other carers, and identifying what their needs are.

- involving people with disabilities and local service providers in planning, developing and implementing projects to address these needs. This may be:
 - a project to increase self-esteem for people with communication difficulties
 - a skills building project to give service providers the skills to work with people with communication difficulties
 - community education programmes to raise awareness about positive approaches.
- raising awareness about people with communication disabilities in the community, and in health and education services particularly.

Sally Hartley, Senior Lecturer, Community Disability Studies, Centre for International Child Health, Institute for Child Health, 30 Guilford Street, London WC1N 1EH, UK.



(Sally Hartley)

Focusing on attitudes

Disability Dialogue 1 included *From talk into action in Angola*, an article on using focus groups.

The focus groups used in the article were a mix of ages, backgrounds and disabilities. However, in South-east Asia groups may be more effective if they contain people of similar types, e.g. all women, all children, all older people. This prevents older or more socially or culturally powerful people dominating the group. This may mean conducting more focus groups, but can help ensure all members of the group take part in discussions.

In some areas in South-east Asia, people believe that disability is a punishment from someone in the spirit world. This produces shame and a tendency to hide disabled people. I knew a family for six months before I accidentally saw a disabled child while he was being rushed off and hidden in an upper room. Are these beliefs common in other areas?

I will be sharing ideas from the article with others. Perhaps we can use them to search out attitudes, identify problems faced by disabled people and their families, and help disabled people and their communities become more aware of simple changes within their power that can make life for disabled people better.

Linda Peagram, Director of Health Projects, Asia Rural Life Development Foundation, PO Box 80322, 8000 Davao City, Philippines.

DPOs in Zambia

CBR News 32 included an article on disabled people's organisations (DPOs), which drew this response from Zambia.

We have formed a DPO in Zambia, not because of conflict, but to help disabled people and those with mental impairments whose families have neglected them. After discussions with disabled people and their families and health workers, we identified the basic needs of disabled people to be the same as those for non-disabled people: food, shelter and clothing.

We also talked to the families of disabled people and encouraged them to treat disabled and non-disabled people alike. We organised activities, including sport, to help motivate disabled people. We need education and understanding in Africa and if we fail to have these we may end up destroying our resources.

Joseph Chipasha Musonda, Committee Member, Youth Care and Prevention Team, Box 370150, Kafue Estates, Zambia.

Wheelchair use

In Pakistan it is often difficult to use a wheelchair because of accessibility problems, extreme weather conditions, cultural obstacles and people's attitudes to wheelchair users.

People need to be carefully assessed before being given a wheelchair. In our experience some disabled people use wheelchairs unnecessarily; they get used to them and in time stop trying to stand or walk with aids and sometimes develop contractures leading to permanent disabilities. One reason for this is that rehabilitation services and day care centres for wheelchair users are not widely available.

We are currently working on a project, called Rehab Pakistan, to set up a network of support centres throughout the country. In addition, we encourage wheelchair users, even high level tetra and paraplegics, to stand up as a form of exercise to improve circulation, functioning of the bladder and kidneys, the condition of joints and muscles, and to prevent pressure sores.

In addition, wheelchairs supplied by aid agencies to developing countries are sometimes inappropriate, or given to people who do not need them. Staff are often not qualified to ensure that the wheelchair is suitable for the user. Careful assessment should be done before wheelchairs are given to ensure that they are appropriate for the situation. Wheelchairs are not always the solution to mobility problems and their use needs to be carefully assessed.

Farhat Rehman, Director, Community-Based Rehabilitation Programs, Association for the Rehabilitation of the Physically Disabled, PO Box 201, Peshawar, Pakistan.



Hadija Karisa, Kenya (Joseph Goma)

Educating about communication

Educating communities about communication difficulties can help them accept people with communication difficulties.

Hadija Karisa, from Kalifi in Kenya, has communication disabilities as the result of cerebral malaria.

Hadija (above) also has behavioural disabilities - she can be aggressive and is often hyperactive and disruptive.

Hadija says words that no-one can understand and she does not understand the rules of spoken language, and so cannot have conversations with other people.

These difficulties concern Hadija's mother, who is worried that neighbours and the wider community have a negative attitude towards Hadija. By working with Hadija and her family, as well as with the community as a whole, health workers could help people understand why Hadija behaves as she does, and help her to integrate into the community.

Joseph Gona, KEMRI/Wellcome Research Unit, PO Box 230, Kilifi, Kenya.

Correction to CBR NEWS

Bangladesh became independent on 16th December 1971, not 1972 as stated in CBR News 31, 1999.

Listening and learning

People working with hearing-impaired people need to listen to their experiences and learn from them.

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A study carried out at the Naran Centre for hearing-impaired young people in Zimbabwe found that the students had similar life goals to most other members of the community. They want to receive an education, learn skills that they could use to earn an income, marry and have a family. However, the reality is that hearing-impaired people in Zimbabwe (and most other countries) do not have access to the skills they need to be able to compete with hearing people on an equal basis. A lack of appropriate education is one reason for this.

About the study

Eighteen students were interviewed for the study, 12 boys and 6 girls. The interviewers used questions to facilitate discussions. Most of the discussions were carried out using sign language. Questions covered several issues, including:

- family history
- communicating with family, neighbours and the community
- communicating at school
- students' life goals.

Sign language discussions need to be planned carefully and it is important to be aware that

- it is often difficult to interpret local sign languages, even if people sign very well.
- if translators are used, they may misinterpret people's responses and change them in translation.
- the environment affects the quality of the discussion and responses.

What people said

Communicating with families, neighbours and the community. Most of the group found communication with neighbours and the community in general very difficult. Many students felt uncomfortable being around people who did not use sign language.

In Zimbabwe, there is little communication between hearing-impaired children and community members. Hearing-impaired children rarely socialise outside their immediate family.

Communicating at school

Students found communication a problem when they first came to the Naran Centre. For many of them this was because their families had developed their own kind of sign language using gestures that were understood within the family, but not outside it. This meant that many students did not understand 'official' sign language.

It is difficult for students to learn several languages, e.g. English, Ndebele, Shona and the national sign language, all at the same time. At the Naran Centre children learn the standardised signs of the Zimbabwean sign language (derived from American sign language). This can cause difficulties when they return home, because their families are not familiar with the 'official' sign language. This

The speaking people speak to themselves and do not bother to speak to us.

Eugene Sibanda

My mother and father...sign most of the time. My siblings sign most of the time I am with them. I have problems communicating with my neighbours.

Lovemore Shakede

sometimes makes parents reluctant to send their children to special schools. Parents would rather their child attended a local school, but teachers at local schools are reluctant to accept hearing-impaired children because of communication problems.

Conclusions

The Naran Centre study highlights the need for teachers (especially teachers of hearing-impaired students), researchers, the government, and others involved in education to listen carefully to the needs of hearing-impaired children and adults in order to work with them to develop ways of learning that address their needs.

As yet, no practical changes have been made at the centre as the result of the study, although changes are occurring at a national level. The Ministry of Community Development has set up a fund to meet the needs of disabled people and an MP is looking into the needs of disabled people in parliament. However, the needs of disabled people in rural communities have received little funding and attention.

Silas George Nyoni, headmaster, Levi Tswatswa, deputy headmaster and education audiologist, Naran Centre, Jairos Jiri Association School for the Deaf, Gweru, Zimbabwe.

Servious Dube, research fellow, Institute of Child Health, University College London, 30 Guilford Street, London WC1N 1EN.

Grace Kamanga, Donor Relations Officer, Jairos Jiri Association Headquarters, Bulawayo, Zimbabwe.

Special education for the hearing impaired

In Zimbabwe, there are two special schools for the hearing-impaired: the Naran Centre and Morgenster. Two other schools have resource centres for the hearing-impaired that only admit hearing-impaired children who can speak. The Ministry of Education also runs some rural resource centres that provide mainly primary education.

The Naran Centre runs academic and vocational courses for up to 350 students. It set up its vocational unit after finding that students returned home without the skills they needed to find work.

A joint programme by the Institute of Child Health, UK, and the Ministry of Education and local non-governmental organisations in Zimbabwe, is working to provide services for hearing-impaired people in the community, by training local non-specialist teachers in simple communication skills, on how to adapt their classes, motivation and community participation. This is a pilot programme and its effect still needs to be evaluated.



*Mallappa, a disability worker with the Samuha-Samarthya project in south India, has worked with Shantamma (left), an eight-year-old girl with a hearing impairment, to help her communicate. Now Shantamma goes to school, where the teacher, with Mallappa's help, has adapted lessons so Shantamma can join in.
(Ruth Duncan)*

Involving the community

Involving the community in community-based rehabilitation services can help people with communication disabilities.

Community-based rehabilitation (CBR) projects are often staffed by local people and should involve the local community. If the community is aware of the needs, abilities and potential of disabled people, it will be easier for them to integrate into their community. If you are working with a person with a communication disability it is good to involve the local community in assessment and therapy.

Assessment

When initially assessing a person with a communication disability, assess the person in a community setting and include input from as many people as possible. Immediate family, teachers or neighbours will all see a disabled person's abilities from a different perspective. Observe the person in different settings, communicating with different people. This will help to establish a picture of their communication ability.

Ask them about all the different settings they might find themselves in,

e.g. the school or the village shop. Make a list of all the different people they communicate with, e.g. neighbours, shopkeepers, health workers, teachers. Think about how to introduce opportunities for communicating with new people. Planning activities

Communication occurs in many different situations and for many different reasons. Activities should be as meaningful and realistic as possible.

- If you are teaching a child to ask for items, do not limit this to items in the house.
- Take the child out to the local shop with the task of buying some tea and sugar.
- Involve the owner of the shop by explaining what you are doing and by showing him or her how to respond to the child.

This kind of activity is much more meaningful for the child and he or she will learn more quickly and easily. It also teaches the community what the child is able to do.

People with a communication disability usually develop non-verbal ways of expressing themselves, e.g. by signing or using pictures. The whole community needs to be aware of this, not just family and friends. If people understand how the child communicates, they can respond to his or her efforts.

Using simple role plays or exercises, e.g. by telling people they are not allowed to speak and then giving them a simple message that they must communicate to others in a non-verbal way, can show people the benefits and power and also the limitations of non-verbal communication. People often just need an opportunity to discuss and ask questions to become more open and understanding of a child's needs.

Checklist

When planning a programme to link communication and community the key points to remember are to

- observe the person in different settings.
- gather information about his or her communication ability from different people in the community.
- set goals that will help and encourage the person to communicate with everyone.
- make sure activities are functional and meaningful.
- make sure everyone knows about the different methods of communication the person may use.

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Key terms

Assessment - gathering information about a person's ability and disability

Integration - making it possible for people with disability to live a fulfilling life within their community with dignity

Working for integration

In Uganda, a new project has helped children with communication disabilities.

Government reform and constitutional changes have greatly increased public awareness of disability in Uganda. Many children with disabilities now have the opportunity to go to school and this has created a high demand for services. However, there are few services for children with communication disabilities.

The Mukono Integrated Day and Boarding Primary School was set up to

- act as an experiment for inclusive education.
- bring together parents of children with communication disabilities to share their views and feelings.
- support children with specific learning difficulties, who can succeed in mainstream education, but need specialist support.

Forty-four children attend the school, 22 of whom have communication disabilities. The school also supports 3 nursery children and 3 primary school children in Kampala. Mukono's director visits these schools to support the teachers. Teachers can also attend workshops on specific topics and can borrow resources from the Mukono Resource Centre. Mukono runs sensitisation workshops for both teachers and parents.

Success stories

The success of the school can be illustrated in a number of ways.

- Headteachers from local primary schools refer children to the school for assessment and ask for advice on how to support these pupils.
- The school's enrolment rate is increasing for regular pupils as well as those with impairments.
- An eight year-old boy, who came to the school with speech and language difficulties, has started back at mainstream school.

Activities include

- assessment of impairment - this is one of the school's key activities. There are very few speech and language professionals in Uganda, so many children come to Mukono for assessment.
- teaching general subjects.
- counselling and guidance for parents.
- educating community leaders about the needs of children with disabilities and special learning needs.
- creating educational resources.
- empowering parents and teachers.

Challenges faced

The school faces a number of challenges, these include

- lack of stable funding - this is the biggest challenge.
- understandable, but unrealistic expectations of parents.
- the belief of some parents of children without impairments that disability is contagious.
- high staff turnover as a result of poor motivation and unrealistic expectations from teachers.

Lessons learned

While supporting the government's efforts to meet all children's educational needs through mainstream education, there is still a need for specialised centres where children can go before integration into mainstream education.

Governments need to consider developing support models to match their local capabilities. These may include

- in-school training for teachers of children with special needs.
- ensuring that staff are motivated to work with children with communication difficulties.



At Mukono, children with communication disabilities are assessed and placed in the class that best meets their needs. (CICE)

- giving early intervention a high priority, so children obtain appropriate help and learn faster.

In Uganda, a community-based model is the best way forward if children with communication disabilities are to maximise their potential. It is hoped that Mukono will serve as a model of good practice. No similar projects have yet been set up, but Mukono has raised awareness about children who do not fit into traditional impairment categories.

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Key terms

Inclusive education - when education aims to meet the needs of all children, disabled and non-disabled, in a mainstream, community-based setting.

Integration - see page 5

Sharing skills

A new training initiative in Sri Lanka aims to give speech and language therapists the skills they need to work in community programmes.

It is estimated that 2 to 3% of the Sri Lankan population has a moderate to severe disability and almost half these people also have some form of communication disability. In Sri Lanka, there are few government services for people with communication disabilities and these are all based in urban areas. This means that many people who need services cannot access them. There are also a number of non-governmental organisations providing services in Sri Lanka.

The Sri Lankan government has a commitment to provide education to all children, but there are only a few special schools or special education units in regular schools that provide services for children with communication disabilities. Ear, nose and throat clinics in some teaching and provincial hospitals provide some services. The Ministry of Social Services has a Community-Based Rehabilitation (CBR) programme, but its impact on people with communication disabilities has not been assessed.

A lack of trained professionals has been a major drawback in the development of services for people

with communication disabilities. In 1998, a two-year diploma course was introduced at the University of Kelaniya, Sri Lanka, in collaboration with the Institute of Child Health in the UK, with the hope that the training course might become a model for other professional courses. The course focuses on training therapists to work in collaboration with CBR services and in a participatory way.

Learning to share skills
Students on the course are encouraged to work with communities and families, to transfer their skills to others and advocate for people with communication disabilities, including the promotion of self-advocacy. In addition to theory and practical placements, students take courses on disability issues and how to transfer skills to others.

Students on the community and disability module consider the social aspects of disability and the role and views of family, community members, health workers and services. On the transfer of skills course, students learn how to carry out a needs assessment, to plan and hold workshops, and how

to teach in a practical and enjoyable way. These modules consist of 30 hours of class teaching and about 10 hours of visits or related activities. Students also spend 3 weeks at a community project.

Putting theory into practice
In March 2000, 9 students from the course visited 3 different community projects. At the projects, students learned that the role of speech and language therapists was to help people with communication disabilities to 'talk' in many different ways. Students shared ideas about

- the importance of knowing how much a person can understand.
- sign language and gestures.
- using pictures and objects to express needs.
- using play to learn.
- helping children to listen and concentrate better.
- using everyday household tasks to teach children.
- positive ways to encourage children.

Students ran a two-hour workshop on a topic that the staff of the CBR programme had identified in a needs assessment. The workshops were participatory and students were aware that they were working with staff who had a great deal of experience in working with disabled people. Workshops were designed to empower students and build on their existing knowledge.

Students evaluated the impact of the workshops using questionnaires. Responses were positive and community workers were eager to have more contact with speech and language therapists. The students benefited from their involvement in a community project and the experience of running a workshop. The project visits gave them an understanding of their role as potential facilitators of community workers' activities and of how specialist work can be supportive of, rather than in competition with, community-based programmes.

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A student shows how to use body language to communicate. (Sally Hartley)

Attitudes, knowledge and skills

How can hospital-based health workers share their skills through peer education?

In developing countries, about 80% of disabilities are mild and people with such disabilities can be helped by local people who have the appropriate skills. However, help for people with physical disabilities is usually a priority and the needs of children with communication disabilities are often ignored.

Changes in attitudes and awareness about communication needs are as important as medical expertise in the rehabilitation of children with communication disabilities. Whether in a hospital or community-based setting, the main influences on a child's life are the same - family, friends and the local community. Hospital-based health workers cannot reach all these people directly, but they can reach communities by giving parents information and ideas that are appropriate for their home situation.

- When using hospital equipment, spend time discussing what materials are available at home that could be used to achieve the same goal.
- Work with parents to identify opportunities that arise during everyday activities that will help a child develop specific skills.
- Work with parents to set realistic goals that aim to help the child communicate, not just to speak.
- Explain the ideas behind suggested activities and what they can achieve.
- Tell parents about appropriate community-based rehabilitation projects.

Communication therapy is as important as therapy for physical disabilities.

Hospital-based health workers who work in communication therapy can

- encourage all hospital-based staff to think about communication.
- provide training in communication therapy to other health workers.
- encourage joint assessments.
- encourage training institutes to include a section on communication therapy in health worker training.

It is important to increase the awareness among hospital-based and community-based health workers of the knowledge, skills and services needed for children with communication disabilities. Health workers involved in training should be adequately trained themselves in participatory training techniques before they train others (e.g. community members). Health workers can then use participatory training methods to identify the needs of participants (e.g. community or family members) and tailor training to meet these needs. This ensures that training is appropriate to the community's needs and more empowering for family and community members. In participatory training participants are valued for the knowledge and skills they bring to the training and are responsible for setting their own goals.

By training people who play an important role in the lives of children with communication disabilities (e.g. family, community members) using participatory techniques, it is possible to challenge attitudes, share knowledge and skills and make changes to the children's environment, as well as building on the children's skills.



Who to train

Trainees should be selected on the basis of the need to promote work with families of children with communication disabilities within hospitals, CBR projects, inclusive education projects and special schools. Community-based health workers could be included, if appropriate to local needs, and involved in individual projects.

Important factors in selecting trainees are

- their interest in the subject and in working with families.
- their job security - to ensure they continue working.
- that trainees are in a position to conduct training themselves at a later date.
- that trainees are, where possible, a part of a project addressing disability issues.
- there is a mixture of men and women.
- that trainees have worked with families as well as children.
- that trainees come from a variety of backgrounds - e.g. education, CBR, hospital, social work, families - to break down barriers between services.



Tips for trainers

It is important to include the following subjects in a training programme:

Attitudes about communication

- Aim to increase people's awareness of the importance of communication.
- Discover people's opinions and discuss their attitudes.
- Promote positive attitudes towards children with communication disabilities.

Using materials and adapting training resources

- Teach people how to use available resources, including training manuals.
- Training materials need to include very clear activities. Make sure people understand the reason behind a game or activity. Once people are confident about using these materials they can adapt the activities for the different needs of different children.

Carrying out a needs assessment

- Show people how to carry out a needs assessment.
- Encourage people to understand the importance of a needs assessment for assessing a child's communication skills and needs.
- Teach people how to use a needs assessment to learn about relevant community issues and beliefs.

What is communication and why do we need to communicate?

- Talk about different ways to communicate.
- Encourage people to think of all the opportunities a child has during the day to communicate.
- Encourage people to think about the child starting a conversation and not just answering questions.

The way adults communicate with children

- Think about how adults talk with a child. You can use videos to show this.
- Encourage people to let the child have a turn at communicating. Communication is not about adults just asking questions and telling children what to do all the time. Talking and playing with children is more effective than trying to teach them.

Early communication skills

- ? Encourage people to help communication from an early age - not to wait until the child can walk.
- ? Encourage people to help the child listen, take turns and learn social skills by playing games with them.

Language development

- Teach about normal development of language.
- Aim to make people aware that they should work in small steps so that the child can develop slowly, and that they should give the child the opportunity to practise and to start conversations. People also need to work and talk at the child's language level.

Other forms of communication

- Teach people about other forms of communication, e.g. signing, communication using pictures. You could invite a deaf person to come and teach or make and use picture boards as part of the training session.
- Encourage people to think about what a child wants to communicate, rather than what they want to teach the child.

Special difficulties

- Teach about specific disabilities, e.g. cleft palate, autism, deafness.
- Teach people how to plan a training programme.

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All photos: Nothing about us without us by David Werner

Key terms

Participatory training techniques — actively involve participants in the training process. Participants help to plan, adapt and monitor training, so it can better meet their needs.



Working with trainers

Remember:

- the people you are training will go on to train others
- to teach adults how to pass on their skills using a participatory approach
- to make clear plans for the training course and share them with participants
- to find out about local needs before you start
- to use good training materials
- to ALWAYS evaluate what you do
- to go back and find out about the changes and challenges for new trainees.

Helping adults after a stroke

Choosing the right level of teaching material is one of the biggest challenges in training community workers. Here is an example of what the Center for Disability and Development, Bangladesh, teach about one topic in communication disability.

A person who has had a stroke may have communication difficulties. Hospital-based services for people who have had a stroke usually focus on helping them to recover the ability to carry out day-to-day activities. However, when a person returns home they often find that their biggest problem is communicating with others.

People's physical disabilities and communication difficulties after a stroke vary according to the severity of the stroke. Most people who have weakness on their right side as a result of the stroke will also have trouble with speech and language. Sometimes, people who have left-sided weakness may also have trouble with communication.

People who have had a stroke may

- be able to speak fluently, but have little understanding of what they hear (difficulty understanding).
- have difficulty finding the right words to say or may speak slowly and with difficulty (expressive difficulty).
- have difficulty both understanding others and expressing themselves.

This happens because the area of the brain that controls communication may have been affected by the stroke.

Understanding difficulties

People with understanding difficulty:

- cannot understand what others are saying or what is written
- can sometimes speak easily
- sometimes cannot understand one type of word that describes objects, e.g. hat, but if this word is used with a verb they will understand e.g. 'put on your hat'
- often use the wrong word, e.g. 'I want rain' meaning 'I want water'.

Expressive difficulties

People with expressive difficulties may not be able to speak or may have difficulty finding the right words to say, so others have difficulty understanding them, but they understand what others say. Some people with expressive difficulties

- cannot speak at all.
- can make some words or parts of words, but not whole sentences, so others cannot understand them.
- talk too much because a part of the brain is damaged so the person does not realise that they are talking too much.
- may say the same word or part of a word over and over again.

This problem can extend to writing, not just speaking. People with expressive difficulties can often hear and understand, but cannot respond, so it may seem like they do not understand.

Other communication problems

Some people have a mixture of the above and have problems understanding words and finding the right word to say. In severe cases people cannot understand or speak at all.

People who have strokes can recover from communication difficulties. Recovery takes place most quickly in the first 6 months, but slow recovery can take place over a longer period of time. The amount people recover depends on how much damage was done to the brain by the stroke. Some people can recover completely, others recover as little as a third of their former communication abilities.

Practice and encouragement from family and neighbours is very important to assist maximum recovery.

Vision is sometimes affected with sight on one side missing, so when reading, writing or using a communication board, the objects need to be in the correct position to be seen.

Communication difficulties after a stroke can be very frustrating, both for the person who has had the stroke and for their families. It is important to include family members in assessment and therapy, so they can understand why there are difficulties communicating and can work together to overcome them. Another way to help families is to encourage them to meet other families in the same situation. This way they realise that they are not alone in their frustration and can share experiences - both good and bad.

Communication assessment

It will help the person who has had a stroke, and their family, to build up their communication skills if they know what type of communication difficulty the person has. Identifying what type of communication difficulty the person has can help identify how to work with them, their family and community, to build up their communication skills.

- Ask questions slowly and clearly, but not in a loud voice - the person can hear.
- If you ask a question and the person does not respond, count to 10 and ask the question again. If there is no response, count to 10 and ask the question a final time.
- Do not have too many people present. If more than one person is talking, the person with the communication difficulty may become confused and frustrated.
- Have a family member present at the assessment. It may help them to understand why they and the person are frustrated over their problems communicating.
- Include something that the person can do in the assessment so that it is not all negative.
- Any questions you ask or objects you use should be appropriate for the person's age, sex and educational background.
- When assessing an older person, find out if they had problems hearing before they had a stroke.
- If someone has lost sight on one side, sit where they can see you.

Assessing problems speaking

1. Ask common, simple questions, e.g. 'Which of your children is oldest?'
2. If the person cannot speak, ask them to point or show the correct answer.
3. If the person can write, ask them to try and write the answer.

If the person can respond to your questions correctly, they can understand what you are saying, but cannot speak.

Assessing problems understanding

1. Put some objects on a table, e.g. a pen, a hat, a cup, a spoon, a comb.
2. Ask the person to give you one of the objects.
3. Give them 10 seconds to try to do this and, if they do not, then ask again.
4. If they do not answer, show them the object and tell them what it is.
5. Ask the question in a different way, e.g. 'Give me the object you use to drink from.'
6. Try with the other objects.
7. Give the person one of the objects and ask them to do an action with it, e.g. 'Comb your hair.' 'Put on your hat'.

8. Try using action words, e.g. 'Give me the spoon.' (Point at yourself)
- If the person cannot recognise objects, then they have difficulty understanding the words you say to them.

Ways to help

It is important to teach the person with the communication difficulty and their family to communicate with each other.

Problems speaking

1. Work on gestures or signs for simple things, e.g. yes, no, stop, want.
2. Encourage the person to point or draw what they mean.
3. Try a communication board or notebook (see below). Use one page for a related group of words, e.g. food and drink, family, activities.
4. If the person uses a wrong word and you think you know what they mean, ask whether this is the case. Ask them to repeat the correct word.
5. Do not *always* correct a person's speech or say the next word in the sentence if they speak slowly - it can make them frustrated. Do give

positive feedback when you can understand them.

























6. Sometimes singing is easier than talking and this is a good exercise.

Problems understanding

1. Use gestures or signs, not words.
2. Use simple yes/no questions, e.g. 'Would you like a drink?' (Wait for an answer) 'Tea?'
3. When you visit, work with the person in a quiet place. Background noise can make the person more confused.
4. Check the person can see you clearly.

It is important to explain these ideas to the person's family and include them in the communication process. Get them to help make a communication board and suggest words that it would be good to include. Explain to them that the communication problems are a result of the stroke, just like a weak arm or leg, and are not the person's fault. Getting angry with them will not make them better.

*Source: Center for Disability and Development, House number D55, Talbag Sarar, Dhaka 1207, Bangladesh
E-mail: cdd@bangla.net*

FOOD AND DRINK			
 COFFEE	 SUGAR	 MILK	 TAP, WATER FIRE
 BREAD	 POTATO	 TORTILLA	 BEANS
 CHICKEN	 EGG	 PIG	 COW
 FISH	 TOMATO	 CHILLI	 ICE CREAM
 SALT	 CARROT	 MARROW	 CHEESE
 EATING	 TABLE CHAIR	 KNIFE SPOON FORK	 GLASS PLATE

Making a communication board

1. Find out from the person and his or her family what they need to communicate about.
2. Make a list of words or ideas that could be used to communicate these things.
3. Develop pictures and symbols to represent these ideas. Draw pictures of these things on large pieces of paper. If appropriate, you can write the word for the object underneath the picture.
4. Choose one or two of the pictures and teach them to the person concerned.
5. When they understand the first pictures, teach them more. Teach the things most important to the person first.
6. When the person points to one of the objects, e.g. spoon, say the word 'spoon' clearly to him/her. This will gradually help them to recognise the word when people say it to them.
7. To make it easier for someone to carry the pictures around, you could transfer the most commonly used pictures (and words) into a small notebook.
8. Check the position of the person's field of vision and place the board within their sight.
9. Place the board within reach or try using a pointing stick.

IMPORTANT ANNOUNCEMENT!

**Dear readers,
In future the international
printed edition of *Disability
Dialogue* will be produced by the
Southern Africa Federation of the
Disabled (SAFOD).**

Healthlink Worldwide will continue to provide SAFOD and partner organisations that produce regional newsletters based on *Disability Dialogue*, with source material, which they can adapt and translate for use in their newsletters. In 2002, this source material has been produced in the form of three combined electronic issues of the international newsletters *Disability Dialogue*, *Child Health Dialogue* and *AIDS Action*, which look at training, advocacy, and poverty and health. These newsletters will be available electronically on Healthlink Worldwide's website (<http://www.healthlink.org.uk>) by December 2002.

If you wish to receive *Disability Dialogue* please write directly to the organisation shown for your country or region, as follows:

Bangladesh (Bangla Notun Duar)

Social Assistance and Rehabilitation for the Physically Vulnerable (SARPV), GPO Box 4208, Dhaka 1000, Bangladesh.

E-mail: sarpv@bangla.net or
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India (Tamil Oonam Seithi)

Rural Unit for Health and Social Affairs (RUHSA), Christian Medical College and Hospital, RUHSA Campus Post Office, Vellore District, Tamil Nadu, 632 209, India. E-mail: rajaratnam_abel@yahoo.com

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Nepal (Apangata Kurakani)

Partners for Rehabilitation, International Nepal Fellowship, PO Box 28, Pokhara, Nepal.

E-mail: kurakani@bigfoot.com

Braille or audio-cassette versions

Blind People's Association of India, Dr Vikram Sarabhai Road, Vastrapur, Ahmedabad 380 015, Gujarat, India. E-mail: bpa@vsnl.com

International edition

If there is no newsletter in your region and you wish to continue to receive the international edition of *Disability Dialogue*, please write to: Healthlink Worldwide, Cityside, 40 Adler Street, London, E1 1EE, UK E-mail: info@healthlink.org.uk

If you have comments on the international edition, please write to: SAFOD, PO Box 2247, 1 Crescent Court, 130 Herbert Chitepo St/12th Avenue, Bulawayo, Zimbabwe. E-mail: safod@telconet.co.zw

RESOURCES

Publications

***Let's Communicate: a handbook for people working with children with communication difficulties*, H House and J Morris, World Health Organization in conjunction with Ministry of Health Zimbabwe and UNICEF.**

A practical manual for health workers who are involved in helping children with communication difficulties and their parents. The manual covers general aspects of communication, assessment and goal planning, common causes of communication difficulties and includes practical activity ideas, advice for parents and teaching ideas for those involved in teaching health and education workers. Available free from: Rehabilitation Unit, WHO, Geneva CH-1211, Switzerland. E-mail: florisses@who.ch

***Communicating with children: a language training manual*, Tara Winterton, unpublished, 1992.**

A manual for health and education workers on assessing and working with children with communication disabilities.

Available (for the cost of photocopying) from: Centre for International Child Health, Institute for Child Health, 30 Guilford Street, London WC1N 1EH, UK.

Hearing and communication disorders *Sheila Wirz and Sandy Winyard, Macmillan, 1993.*

This book is aimed at CBR workers and their trainers. It covers: communication; hearing and hearing loss; communication and mental impairment; communication and cerebral palsy and educating others about communication disabilities.

Available, price £4, from: Teaching-aids At Low Cost (TALC), PO Box 49, St Albans, Herts. AL1 5TX, UK. Tel: +44 (0)1727 853869 Fax: +44 (0)1727 846852

E-mail: info@talcul.org

***Helping a person who has had a stroke and Helping children who have difficulty talking and communicating*, 1995.**

Training materials for CBR workers who work with adults and children with communication difficulties.

Available from: Community Based Rehabilitation and Training Center, Jalan Adisucipto, Km 7, Colomadu, Solo 57176, Central Java, Indonesia.

Fax: (+) 62 271 780976.

Walking and talking in the village

Dale Chandler, Celine Gilbert and Andreas Fuglesang

A manual for trainers of community health workers covering general and special communication skills, including practical training exercises.

Available from: Redd Barna, Regional Africa Office, GPO 12018, Kampala, Uganda.

Organisations

Communication Therapy International is an association whose members have an interest in services for people with disabilities in less developed countries. CTI aims to encourage, promote and support the development of appropriate services in these countries by sharing experience and knowledge. *Membership details are available from*

Dr Sally Hartley s.hartley@ich.ucl.ac.uk or Judith Mitchell Judisobel@aol.com.

Disability Dialogue is the international newsletter on community action in disability and development.

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About Healthlink Worldwide

Healthlink Worldwide works to improve the health of poor and vulnerable communities by strengthening the provision, use and impact of information.

Registered charity no 27460

ABILYMPICS

The Abilympics is an international vocational skills event that takes place every four years. It is designed to:

- promote friendship and the exchange of knowledge among disabled people worldwide.
- enable disabled people to learn skills that increase job opportunities.

The 6th International Abilympics will take place in New Delhi, India, in November 2003. * **Initial confirmation of participation must be received by 31st July 2002.** For further information please contact:

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