



GETTING TO KNOW CEREBRAL PALSY

A learning resource for facilitators, parents, caregivers,
and persons with cerebral palsy



Module 4 Communication

Cerebral Palsy Association (Eastern Cape)

The Cerebral Palsy Association (Eastern Cape) was established in Port Elizabeth, in 1955. The primary mission of the Association is to encourage, assist and care for all persons affected by cerebral palsy, and assist them to attain their maximum potential and independently integrate into the community. The Association is a registered Non-Profit Organisation, and is affiliated to the National Association for Persons with Cerebral Palsy in South Africa.

The Association presently operates from its own premises in Port Elizabeth. It has a permanent staff of three part-time and five full-time employees, ably assisted by a network of volunteers. The Association is directed by an Executive Management Committee of 12 members, who are elected bi-annually and serve on a voluntary basis.

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About Hambisela

Parents and caregivers are in the front-line of caring for individuals affected by cerebral palsy and assisting with their treatment. Historically, individuals in rural and under-developed areas had no or limited access to skills and training to assist them with skills development. This very often compromised the level of primary care and therapy that individuals affected by cerebral palsy could obtain in these areas.

To address this problem and improve the level of daily care available to individuals affected by cerebral palsy, especially in rural and under-developed areas, the Cerebral Palsy Association (Eastern Cape) identified a need to transfer skills to parents and caregivers through the following measures:

- Develop training programmes in basic skills for parents and primary caregivers of individuals affected by cerebral palsy;
- Present these training courses to parents and primary caregivers;
- Facilitate specialized therapy training for nurses and sisters from community clinics;
- Develop the pool of specialized therapy skills in the Eastern Cape, especially in rural areas;
- Offer supplementary therapy to individuals from schools in the Eastern Cape, to supplement the reduction in therapy support from schools.

In 2005 the Cerebral Palsy Association initiated the Hambisela project as Center of Excellence in Therapy for Cerebral Palsy, to develop and promote excellence in therapy for cerebral palsy through community-based programmes.

Hambisela is based at the Association's premises in Port Elizabeth. Hambisela has developed a series of 7 training modules in the "Getting to know Cerebral Palsy" series, each comprising a Facilitator Manual, an Activity Pack, course display material, and a Trainee Handout. Hambisela is using this series as a primary resource to develop the skills of parents and caregivers of children with cerebral palsy in the community.

Getting to know Cerebral Palsy: List of Modules:

Module 1: Introduction

Module 2: Evaluating Your child

Module 3: Positioning Your child

Module 4: Communication

Module 5: Everyday Activities

Module 6: Feeding Your child

Module 7: Play

MODULE 4

COMMUNICATION

PLANNED OUTCOMES

When you have finished this workshop, you should understand and be able to explain to someone else:

- **what communication is**
- **why it is so important**
- **what you can do to help your child to communicate**

Communication

In this module we are going to take a good look at „**communication**“.

Question: *How do we communicate?*



Think about this, and discuss it with others.

Question: *Besides trying to talk with words, what else could we use to communicate?*

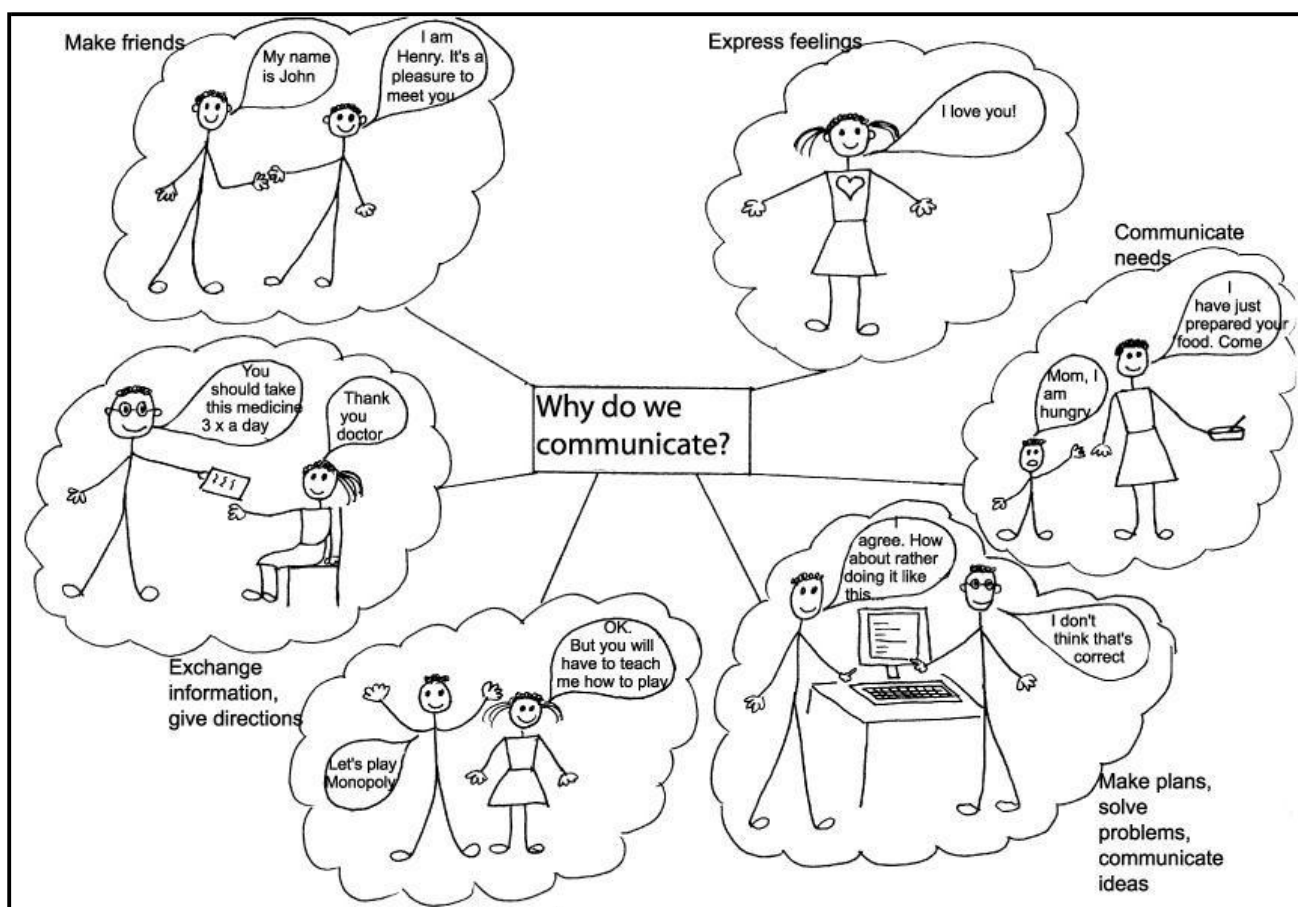


OTHER WAYS IN WHICH WE COMMUNICATE:

- **Voice:** crying, whining, laughing...
- **Body movement:** nodding head, shrugging shoulders...
- **Facial expressions:** smiling, frowning, big eyes...
- **Gestures:** waving goodbye, come here, small or big...
- **Pointing:** with the eyes or the finger...
- **Writing or drawing**

Question: *Why do we communicate?
Why is communication so important?
Think about this, and discuss it with others.*





Here are some important reasons for communicating:

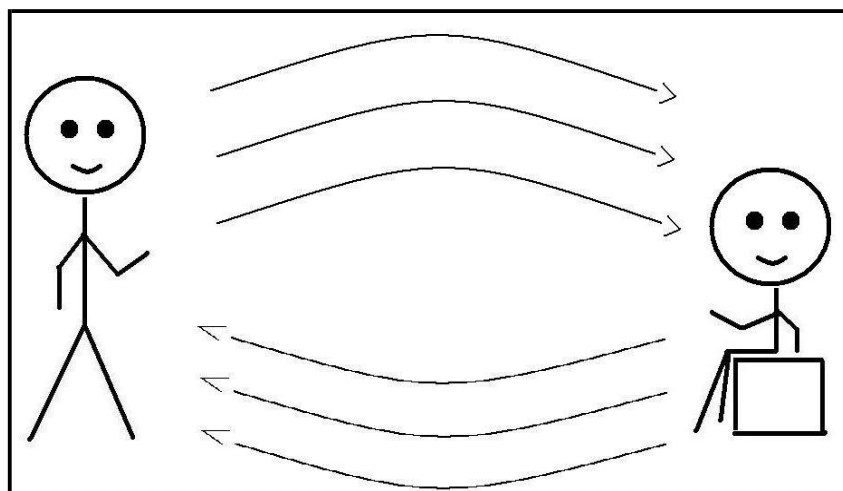
- Establish relationships and make friends.
- Exchange information, communicate ideas and give directions.
- Communicate needs and wishes.
- Develop thinking skills e.g. help us to remember, make plans, solve problems.
- Become happy and successful members of our community.

If you try to talk to someone with your mouth full of food, or while holding your tongue in your cheek, the other person will find it difficult to **understand** you. And it will also be difficult for you to make yourself understood. Or to **express** yourself.

Here then is our definition of communication:

Communication is the way in which we understand messages from other people, and the way in which we express our thoughts, needs and feelings to them.

This forms a cycle of communication.



In a child with cerebral palsy, this cycle often breaks down.

Why a child with cerebral palsy may have difficulty communicating

The following diagram shows that many parts of the brain are needed to be able to communicate without difficulty. This includes those parts of the brain controlling body movements, those interpreting information from the senses, and parts used in thinking, remembering and understanding.

Keep in mind that children with cerebral palsy may have difficulties with some or many of these.

The more areas that a child has difficulties with, the more severe the communication problem will be.

Question: *What parts of your body do you use to:*
UNDERSTAND a message?
EXPRESS yourself to get a message across?

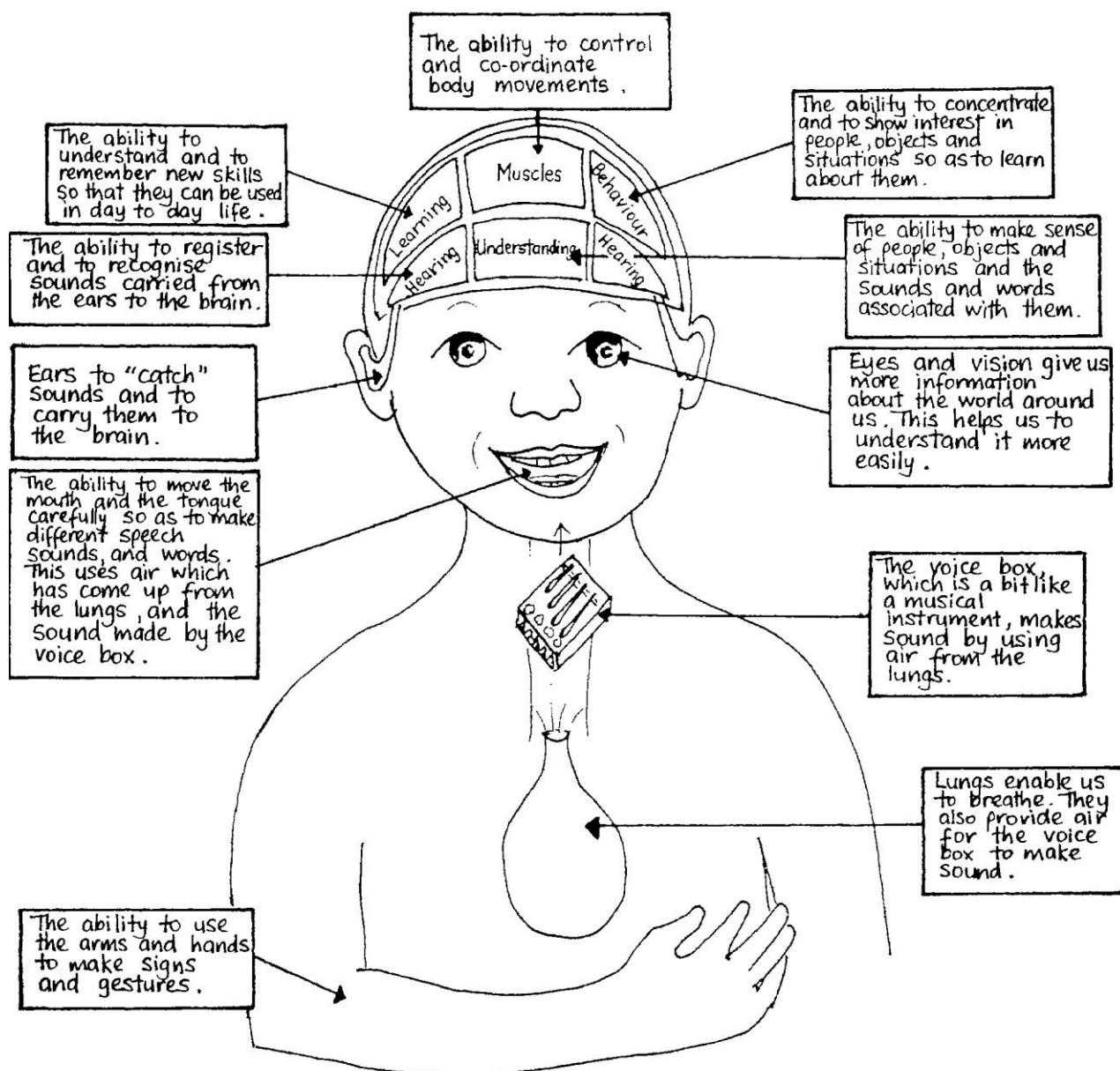


To understand a message you need:

- Ears and/eyes to see and hear the message
- The part of your brain that makes sense of what you have heard or seen (intellect)

To express yourself you need:

- The intellect to know how to express yourself
- Mouth and throat to work to make sounds and words out of the sounds (tongue and mouth)
- Control of your body parts to make expressions/ gestures



If a child has difficulty with any of the areas shown above, he will have difficulties with communication.

Question: *Where is the breakdown in communication for a child with cerebral palsy? (Will it be with understanding, or in expressing?)*



Let's look at where it breaks down.





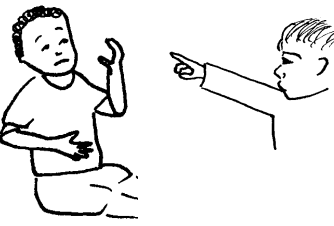
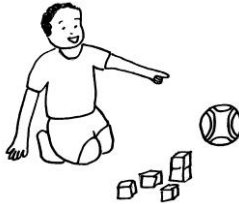


A child who has cerebral palsy and who has an intellectual disability (that is, who is slow to learn):

- will have difficulty with both steps -- **understanding** and **expressing**.
- How much difficulty depends on the extent and areas of damage in the brain.

A child who has cerebral palsy and has no intellectual disability:

- will **not have difficulty with understanding.**
- If she can talk, she will be able to express herself, though it may be a bit unclear.
- If she cannot talk, it may be **difficult for her to express herself** and very often she is then labeled as having an intellectual disability.
- She will need to be taught and encouraged in other ways to express herself, otherwise her communication cycle breaks down.

Look again at the communication part of our development chart.

 <p>Expresses self using sounds and facial expressions</p>  <p>Makes eye contact.</p> <p>Coos and gurgles when talked to</p>	 <p>Repeats sounds and gestures</p>  <p>Responds to simple commands.</p>	 <p>Expresses self using gestures or pointing</p>  <p>Able to make choices</p>	 <p>Expresses self using words</p>  <p>Talks about what she does</p>
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- Communication skills develop according to a sequence of steps.
- From birth the baby expresses herself using sounds (e.g. crying) and facial expressions.
- To encourage the child to interact, it is important that she learns to make and maintain eye contact. At first she may only look at you briefly but later she may be able to keep eye contact for longer. Babies are initially more interested in faces and then later in objects.
- She learns about taking turns when her mother responds to her sounds. She may start to coo and gurgle when talked to and may later be able to repeat sounds and gestures.
- Observe for gestures / sounds that she may use to express herself, and respond consistently and immediately to any attempt she uses to initiate communication. This will encourage her to communicate.
- As her understanding improves she will start to respond to simple commands.
- Give your child choices during the day. This can increase her motivation to let you know what she wants. For example, let her choose between two different tops/pants or skirt when dressing her in the morning. You could also let her choose whether she wants something to eat or something to drink first at a mealtime.
- Listening and understanding comes before talking, as we can see from the chart.
- Learning that prepares a baby for speech begins early, long before she says her first word.



- We know that **most** children with cerebral palsy can hear, so they listen to the words you say and in time (usually) they begin to use words themselves.
- Babies need to learn to chew to help develop control of the movements of their tongue, cheeks, and lips. This is **very important for the development of talking.** (Many children who have difficulties controlling their tongue and mouth often get given ONLY soft food -- so they never really practice using their mouth and tongue).
- Important: Make sure you attend to any sign of earache in your child. If left untreated, this could lead to ear damage and loss of hearing.
- Remember in the first training module we mentioned that children with athetoid type of cerebral palsy often have hearing loss which could require use of a hearing aid!




Question: *What do you think is the most important thing that you can do to help your child to develop communication skills?*



Talk to her!!!

Here are some ideas of HOW to talk to your child:

<p>Talk to your child about things happening around her.</p>	 <p>Look! Chipo and Jim are playing while we cook sadza.</p>
<p>Get down to her level and face her when you talk.</p>	 <p>Let's go and see Mother</p>

<p>Before you talk to your child get her attention by tapping her and calling her name. Make sure she is looking at you when you talk.</p>	 <p>Shupikai!</p>
<p>Show her what you are talking about and, if possible, bring objects to her, to feel or look at.</p>	 <p>Look! I've bought some new shoes!</p>
<p>Do not force her to speak.</p>	 <p>Try to tell me with your hands.</p>

<p>Be alert to any attempt she makes to communicate and always respond to her.</p>	
<p>Encourage any means of communication.</p>	
<p>Give your child time to respond.</p>	

<p>Take time to sit with your child and talk to each other without lots of other distractions.</p>	
<p>Make sure you do not talk about your child in front of her.</p>	

- Remember:
- Get the child's attention
 - Good positioning – for both you and the child
 - Eye contact
 - Talk about what is happening
 - Use facial expression
 - Take turns, and encourage participation
 - Praise and encourage
 - Do NOT use baby talk

OTHER WAYS OF COMMUNICATING

Children with cerebral palsy will often need to use another way of communication to support speech, or instead of speech.

At first, all young children with cerebral palsy should be helped to develop ALL methods of communication. As they get older, if it becomes clear that speech will be their main way of communicating, then concentrate on developing their speech. Talking (speech) is their easiest link with other people.

However, for many children with cerebral palsy it will become clear that spoken language will NOT be their main way of communicating. So we must concentrate on helping them to develop their skills in using other ways to communicate, such as picture boards, communication boards, signing, gesturing, or written language.

Examples of other ways of communication:

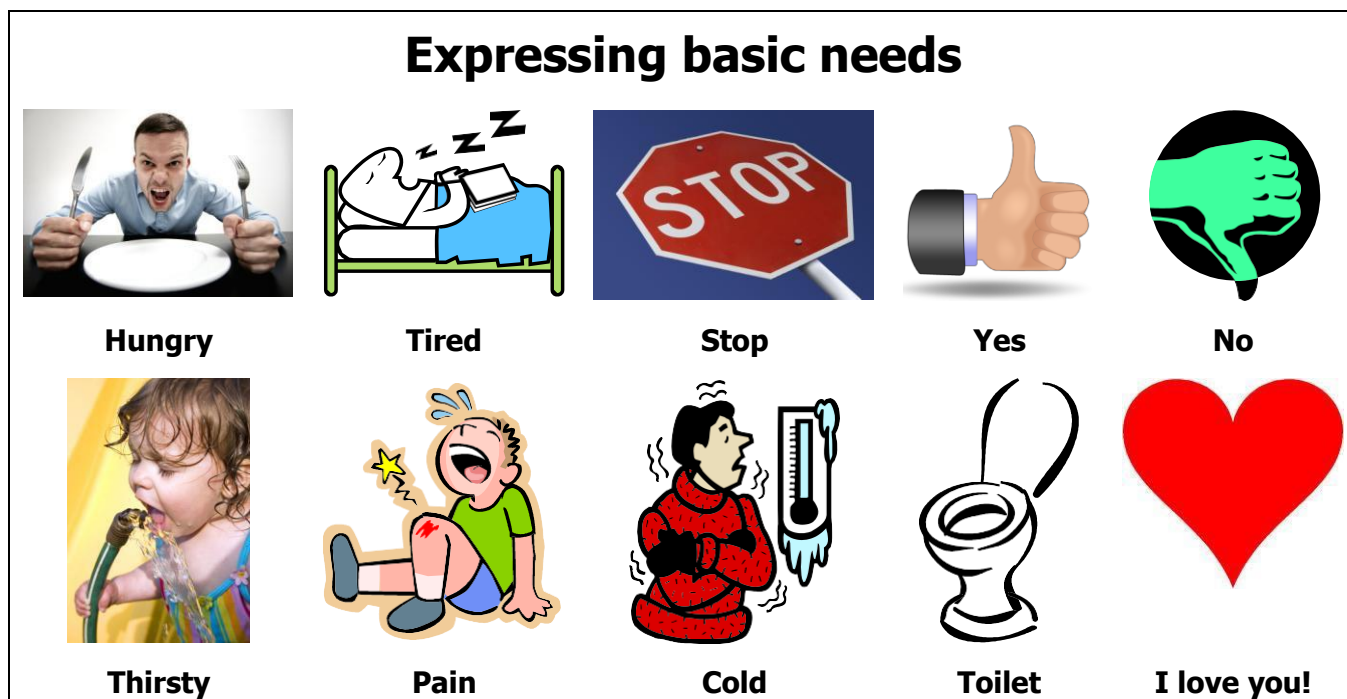
1. Making signs or gestures using the hands, arms and face to communicate a message.
2. Pointing to people / objects with her eyes or hands to communicate.
3. Pointing to pictures displayed on a chart to communicate a meaningful message.

Question: *Why is it important for children to develop skills in other methods of communication?*



It is important to encourage children with communication difficulties to be able to indicate their basic needs, so that they can become more independent.

Examples of basic needs:



Using gestures, facial expressions and sounds

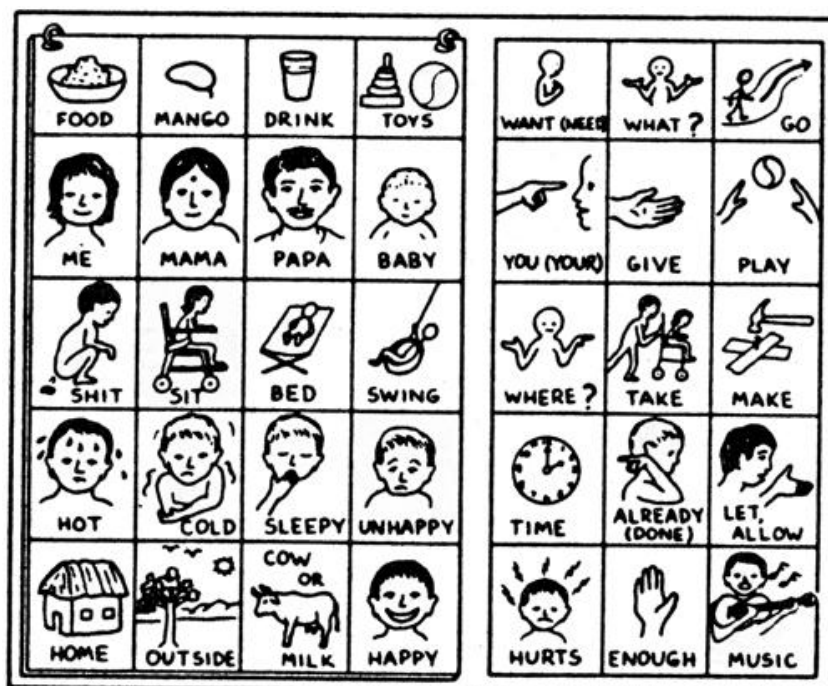
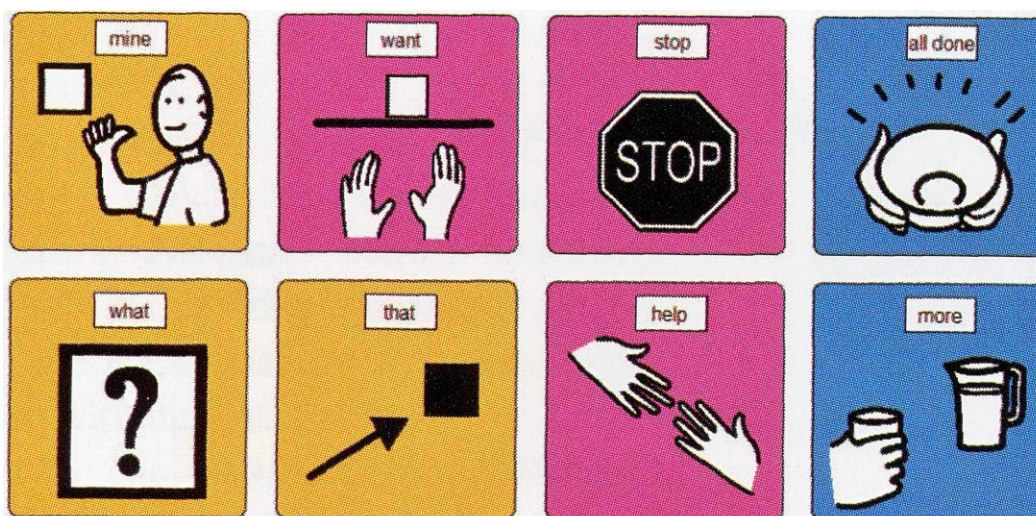
Ideas to encourage her to express herself using sounds, gestures or facial expressions.

- Talk to your child about what she needs or wants you to do for her. Ask her to show you how she indicates some of her daily needs such as „I am hungry“, „I am thirsty“, „I want to rest“, „I am cold“, and then practise these together. Encourage her to indicate „yes“ or „no“ if you ask her if she is hungry, or thirsty.
- Try to understand what she means when she uses sounds, facial expressions, body movements or gestures.
- Show her how to make gestures, and help to make them by moulding her hand(s).
- Encourage her to make choices. Ask „do you want water, or milk?“
- It is important to respond immediately to any attempt she uses to initiate communication.

Using pictures

Ideas to encourage her to use pictures to communicate.

- Start by showing her an object or a person. Then match a picture with the object or the person. Later ask her to point to pictures only.
- Some children may have just a few basic pictures which they sometimes use to express a need. Other may have a big collection of pictures to use for quite complex communication. Pictures can include social expressions, people, things, actions, feelings, daily needs.



Question: *When would we use and encourage other ways of communication?*



When a child has difficulty getting her message across using speech, and especially when she is frustrated by her struggle to get her message across.

Question: *What should I do when I think my child needs to use gestured or picture language to communicate?*



Discuss this with your therapist or doctor. Ask for a referral to a speech therapist who can help to assess your child and decide with you and your child which communication method is best. The

speech therapist can also help to design a communication board that would best suit your child's needs.

Question: *Which other people should be involved when you have decided to let your child use sign or picture language? Why?*



It is important that everyone who is involved with your child knows and uses the same signs or pictures and so include your child in conversations. This includes the family, teacher, other people who help to take care of your child...

Only repetition and consistency will help her to learn this new way of communicating. If people do not respond to her efforts to communicate, she will not be motivated to use it.

COMMUNICATION ACTIVITIES

These are some practical ideas of how to help your child to develop her communication skills.

4.29a How to encourage your child to make eye contact

- Hold your face close to your child's face and talk to her. Try to encourage her to look at you.
- Call her name; when she looks at you, praise her by smiling and talking. Use lots of facial expression.
- Sing songs to her. She will enjoy the rhythm.
- Play Peek-a-Boo.
- Ask her to look at different objects. Shiny objects such as a chip packet turned inside out will draw her attention. You can also use every day objects with different textures or sounds. Let her play and explore objects. Talk to her about the different objects.

4.29b How to encourage your child to take turns when communicating

- When she makes a sound, uses a facial expression or body movement; copy her and then take turns „talking“.
- Respond immediately to any attempt she uses to initiate communication.
- Clap your hands and then ask her or help her to clap her hands.
- Hold a ball in front of her; ask her to wait, and then to hit the ball.
- Play music on the cell phone. When it stops, wait for a response from the child before switching it on again.

4.29c How to encourage your child to make choices

- Give her a choice of things to play with or to eat.
- Show her the things where she can see them best.

(Hold one in front of the child and say what it is; take it away; then show the other item and say what it is; take it away. Now show the child both of the items and ask her to make a choice. Ask for example „Do you want water or milk?“ or „Do you want the ball or the doll?“. Wait for a response. A response could be pointing or looking towards one of the objects. Give it to her immediately and say: „you chose the ball by looking at it, so let's play with the ball“.)

Making choices is important for children who are beginning to learn ways of communicating other than speaking.

4.29d How to help your child to understand better

- Talk to your child about things happening around her. Show her what you are talking about and, if possible, bring objects to her, to feel or look at. Tell her the names of different objects during everyday activities. Example during dressing “this is your shoes; this is your jersey it is nice and warm; feel how soft it feels...”
- You can later ask her to identify objects; show me your shoes; where is the chair? Etc
- You can teach her different categories for example body parts, animals; food; objects in the house; people they know.

We hope that you now have a clearer understanding about communication, and why it is so important, especially for children with cerebral palsy. We also hope that you will take this message to others who also care for your child, at home and in your wider community – wherever your child needs communication.

Sources and References

Ideas from many sources have helped us to develop the Hambisela programme. The following material and references have been particularly helpful, either as sources or as inspiration on how to present training, and we gratefully acknowledge their use.

In many cases we have been given permission to use photographs. Where permission could not be obtained, the faces have been re-touched in order to protect identity.

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