



GETTING TO KNOW CEREBRAL PALSY

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



Module 2 Evaluating Your Child

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.

Funders

Hambisela is a project of the Cerebral Palsy Association (Eastern Cape). Development and implementation is supported and funded by:

Kyle Business Projects
Nightsky Ideas Trust



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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 2

EVALUATING YOUR CHILD

Question: *Last time we learned about cerebral palsy and what it is. Did you try to explain what cerebral palsy is to someone else in your home? Was it easy to find the right words to do this?*



REMEMBER:

- Everyone who comes into contact with your child regularly displays attitudes and behaviours that can either help, or hinder, your child's physical and emotional development.
- Therefore it is important that you share what you learn with the other people who are part of your child's life.
- It is each caregiver's responsibility to inform and educate the other members of their households, and neighbours, about cerebral palsy.

PLANNED OUTCOMES

When you have finished this workshop, you should have a clearer understanding about development in children and be able to explain this to someone else.

You should be able to observe your child with cerebral palsy, and show where on the development chart she is.

You should be able to show which activities could be suitable for your child to learn next.

Evaluating your child



Question: *Think about your child, and what you do with her everyday.
What are some of the skills you would like her to learn or get better at?
They could be very small skills, or something much bigger...
Write these down to remind you.*

Now think about other children in your family, or in your neighbourhood. What skills did they learn first as they grew and developed?

Now look at these four sentences that talk about different types of skills.

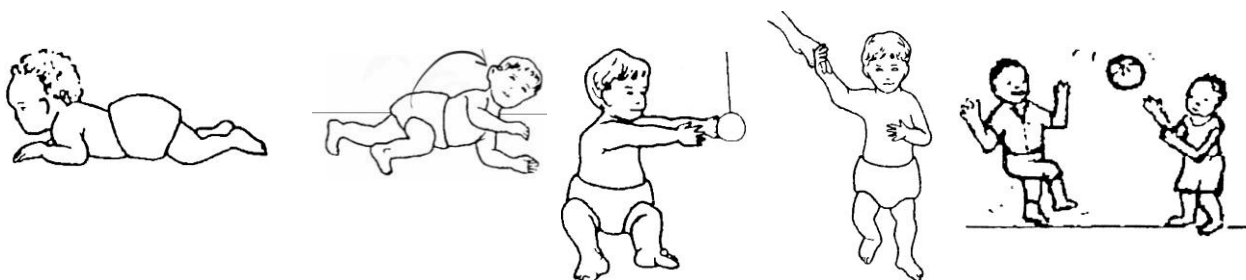
1. Communication
2. Self-care activities such as eating, dressing, toileting
3. Moving around from place to place
4. Walking (if possible)

Being able to communicate in some way with others, allows us to have and build a relationship with them.

A child with a disability can learn to help with self-care skills even if she is not able to move around from place to place, or walk.

ALL children have the potential to learn and develop these skills through a sequence of steps. **BUT**, each child will learn and develop at her own pace and in her own way.

Before you can look at how your child has developed, we need to understand how development usually happens. These pictures show the sequence in which children usually develop some of their movements.



But children don't just develop their muscles, or **movements**, they also develop in **communication**, in their **social and emotional skills** like **selfcare activities** and **relating to others**, and in their **thinking and playing**. This development will carry on, unless something happens or is missing to stop or slow the development.

These skills include:

Movement: large muscles for sitting, standing, walking, running. Small muscles for pointing, picking up things, feeding self, enjoying water and sand, feeling objects.

Communication: Using language or signs of some kind so others can see what you need or feel. Communication is not just talking.

Social and emotional skills: Self-help skills – being able to eat, drink, use the toilet or show you need to do these, and assisting the caregiver. Being part of a group, having relationships, feelings, how you behave.

Thinking and playing: Understanding what things mean, learning how things work, learning the names of things, understanding how to do things. Children mostly do this by playing.

How does learning take place?

Next time you see a baby learning to stand, or crawl, or handle an object with her hands, watch her. Watch how long she spends practicing. And watch how many times she repeats it.

We all know the saying: **practice makes perfect**. Well, that's what babies do all the time...

THEY PRACTICE

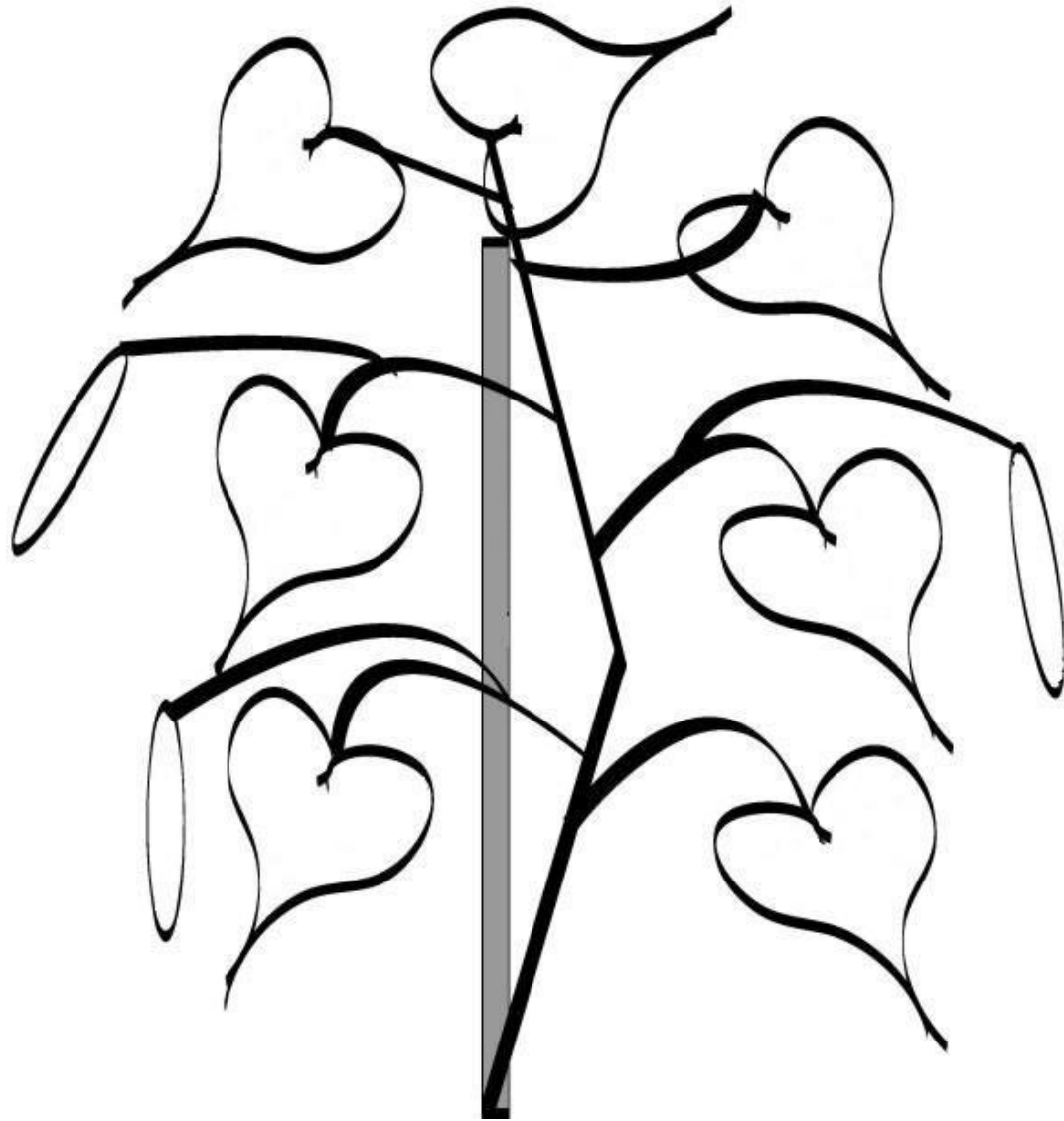
Babies practice by doing the same activity over and over and over again until they get better at it. But we have also learned that a baby or child with cerebral palsy has damage to areas in her brain, and therefore **may not be able to move by herself**, or perhaps only with great difficulty. Or maybe when she does try to move by herself, her tongue or limbs or head keep going into really difficult positions.

Can you think how you have seen your baby / child trying to do things?
And what happens? So what does a baby / child need?

HELP TO PRACTICE

So she can't practice by herself. That is why development in a child with cerebral palsy is slowed, or blocked, or seems to be stopped. If your child has difficulty practicing on her own, you will have to help her practice, over and over again.

This diagram of a bean plant illustrates the development of a child.





Question: *Think about how plants grow and develop.
Have you ever grown a plant? Was it easy?
What did the plant need in order to grow?*

Many plants need help to grow and develop well. Just as the plant needs water to help it grow, so your child needs **your help** in order to grow and develop well.



Question: *Have you seen a plant tied to a stick when it's young?
What is the purpose of the stick?*

Just as some plants need a stick to help them to grow up straight, so your child may need assistive devices like a buggy or a wheelchair or a standing frame to help her to be in a good position so that she can learn to use her muscles and help them to grow and develop well.

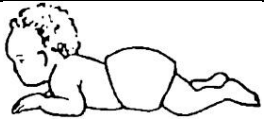
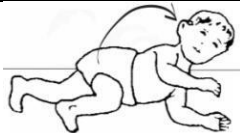




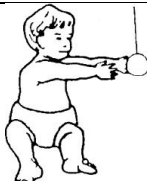










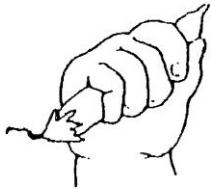











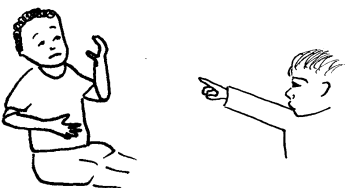



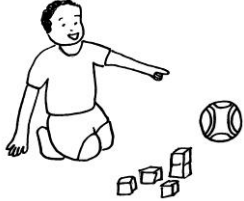




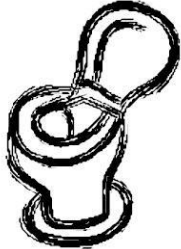

Thus a child with cerebral palsy needs **extra time** and **extra help** to keep developing.

The following chart shows the sequence in which a child usually develops the different skills.

Development Charts

DEVELOPMENT CHART: Movement	
Head and Body Control	  
Sitting	     
Moving from place to place	     

DEVELOPMENT CHART: Movement and Thinking/Playing				
Using hands	 <p>Holds with whole hand.</p>	 <p>Can hold one object in each hand.</p>	 <p>Holds between thumb and finger.</p>	
Thinking/Playing	 <p>Plays with or explores body</p>	 <p>Discover and explore objects – push, pull, throw, shake</p>	 <p>Puts objects into container and takes them out.</p>  <p>Enjoys building</p>	 <p>Sorts different objects.</p>

DEVELOPMENT CHART: Social Interaction and behaviour				
Communication / interaction	 <p>Expresses self using sounds and facial expressions</p>	 <p>Repeats sounds and gestures</p>	 <p>Expresses self using gestures or pointing</p>	 <p>Expresses self using words</p>
	 <p>Makes eye contact.</p> <p>Coos and gurgles when talked to</p>	 <p>Responds to simple commands.</p>	 <p>Able to make choices</p>	 <p>Talks about what she does</p>
Social / Self-help skills	 <p>Sucks breast.</p>	 <p>Chews solid food</p>	 <p>Drinks from a cup and feeds self most foods without help.</p>	 <p>Uses the toilet without help.</p>
			 <p>Helps with undressing. Indicates toilet needs.</p>	

Look at each section of each page of the development charts, and tick off all the things that you have seen your child do. If you are unsure, ask other people in your family, or a friend, or a therapist to help you. Put your child into each of the different positions to see what she can do. When you have finished, the chart should show where your child fits in each row.

HINT: It is possible and likely to get ticks in one row more or less advanced than ticks in another row. So do not go with what the age of your child is and where you think they should be, but with **WHAT YOU CAN SEE THAT YOUR CHILD CAN DO, OR IS TRYING TO DO, OR WANTS TO DO.**

You can get other members of your family, or community, to help you with this. Do it over a number of days or different periods of observation. If you take your child for therapy, you might like to take the chart with you and discuss it with the therapist. Remember, there is no right or wrong. You are building up a picture of where YOUR child is with her development.

Question:

*How do you see your child in 2 months time? In 2 years time?
In 20 years time?
What do you hope for your child?
Do you have goals for your child?*



Now that you have thought about your hopes and dreams for your child, and remembering the picture you have built about your child using the development chart, think about this question.

Question:

But why do you want this picture of your child???



The development chart shows you as parent / caregiver, in a clear and ordered way:

- WHAT YOUR CHILD CAN DO
- WHAT YOUR CHILD CANNOT DO
- WHAT YOUR CHILD IS JUST BEGINNING TO DO, OR TRYING TO DO
- WHICH ACTIVITIES YOU CAN TRY NEXT WITH YOUR CHILD
- HOW TO MARK HER PROGRESS

Now look at your child's chart, and mark on it which activities you plan to try with her next. Can you link these with the goals and hopes you have for your child? You may like to discuss these with a therapist too, if possible.

ENCOURAGE her to keep on doing it by herself, rather than you doing it for her. Or just give her the help that she may need. These pictures show an example of how to do this:

instead of always feeding her yourself



look for ways to help her begin to feed herself.



HINTS FOR HELPING YOUR CHILD IN HER DEVELOPMENT:

- **Help your child advance slowly, at her own speed, in small steps.**
- **If we try to go too fast because of her age, she can become discouraged by failure.**
- **Be prepared to try an activity, but also be prepared to admit that that particular activity may not work for your child at that time.**
- **Some of the activities she may NEVER be able to do. And some of them she may only be able to do with assistance.**
- **BUT GIVE IT A GO!!!!**

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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Acknowledgements

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4. Ms Hayley Rushton, NDT Speech Therapist, (Rehab, East London).

The following reviewed specific modules:

1. Ms Clare Hubbard, NDT Occupational Therapist, (CE Mobility).
2. Ms Diana Novotney, Speech Therapist, CP Association (Western Cape)
3. Prof John Rodda, Paediatric Neurologist, (Chris Hani Baragwanath Hospital and University of Witwatersrand).
4. Ms Gillian Saloojee, NDT Physiotherapist, (NDTSA).
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