



GETTING TO KNOW CEREBRAL PALSY

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



Module 5 Everyday Activities

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

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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 5

EVERYDAY ACTIVITIES

PLANNED OUTCOMES

When you have finished this workshop, you should have a clearer understanding about how to use everyday activities to develop your child with cerebral palsy. You should be able to explain this to others in your family or community.

Everyday Activities

You are the most important caregiver for your child with cerebral palsy. Think about the time you spend every day with your child, doing everyday things with her.

Question:

What activity is depicted in each poster?

What activities do you do everyday or every week?

Which of these activities do you do with your child?





Here is a list of some everyday activities:

- dressing your child
- cooking, cleaning, and doing the washing
- going on an outing
- toileting your child
- feeding your child
- giving your child medication
- helping her get to sleep
- visiting friends
- playing with your child
- going to the clinic...

Question: *And what do you think your child needs to learn in order to develop?
(HINT: Remember the development chart that you ticked off in
module 2 and the goals that you set for your child?)*



This is what your child needs to learn:

- moving and balancing,
 - using her hands,
 - communicating and interacting,
 - learning to be as independent as possible in self care activities,
 - relating to others,
 - thinking and playing,
 - moving from place to place.
-
- With all the washing and feeding and dressing and giving medication and other things that you have to do with your child daily, you may already be very busy and feel quite stressed. And you may be caring for other children too.
 - Maybe you are wondering when you will now also find time and energy to do a lot of exercises to help your child develop.

Question: *Do you feel like this?*



You need to do all these daily things with your child anyway. So if you can do them in such a way that you are stimulating your child **at the same time**, this will help your child **a lot** with her development.

We will now learn how you can use these everyday activities to help your child develop.

Look at these picture strip stories:

uMama KaSive



uMama kaVuyo



Question:

What do you like, or not like, in each of them?

What do you think your child would like, or not like, when you are bathing her?



This story demonstrates how to **communicate** with your child in an everyday situation. We first discussed this in our session about communication.

Look at these pictures again. They illustrate some of the things that we discussed about helping a child learn to communicate.



Notice how Vuyo's mother in the second bathing picture strip uses these ideas to help her child to learn to communicate.

So far, we have concentrated on only one skill – communication. We now need to look at the other parts.



Question: *Apart from communication, how is this caregiver in the bathing picture strip also helping her child to develop other skills?*

MOVEMENT

The caregiver is helping the child:

- to sit by holding her in a **helpful position** while she moves her arm to reach up to her head.
- by encouraging her to balance while moving her limbs. (In the top row, the caregiver always holds on to her child, as she has never become aware, or given the child opportunity, to learn some balancing for herself).

USING HER HANDS

- The caregiver involves the child in the washing by helping her to hold the soap or wash cloth

SOCIAL AND EMOTIONAL

- The child is learning a self-help skill, bathing. Over the months, this child is learning to bath herself, with just the amount of help and encouragement she needs on each occasion.

THINKING AND PLAYING

- The child is playing and having fun while learning.
- The caregiver first performs the activity but **involves** her by communicating what she is doing - > then she **involves** the child by helping the child to do it with her - > then she lets the child do more by herself and only points out what is needed -> then makes the request and stands back while the child does it herself.

SUMMARY

A helpful position makes it easier for a child to be **more involved** with everyday activities. She may be able to look around and watch what is happening in the room; or it may become easier to communicate with others. She can also use her arms more easily during activities.

Remember, cerebral palsy affects each child differently, so don't expect the same abilities for each child. However, all children need to be stimulated in order to develop as much as they can.

Using a helpful position during everyday activities

In Module 3 we learned about positions that can either help or hinder a child's development. To refresh our memories we will look again at what makes a position helpful or unhelpful.

Checklist

Head and body
Legs and feet
Shoulders and arms

Question:

*Do you remember how it felt to be in these positions?
Which of these positions are helpful and which are poor?*



This is a helpful position because:



Head and body

- Head is in the middle and level and the chin is tucked in slightly. The child can look at people or objects in front of her

Legs and feet

- The pelvis is level - not turned to one side
- The legs are not crossed

Shoulders and arms

- Shoulders are helped to come forward which helps her to bring her arms together to hold a toy
- It also makes it easier to open and use her hands.

This is a poor position because:

Head and body

- Head is pushing back and turned to one side, and she only looks at the ceiling.

Legs and feet

- The hips are turned to one side
- The legs are crossed
- The feet are pointing down because of the stiffness of the legs

Shoulders and arms

- The hands and arms are stiff, and the hands are closed. It will be very difficult for the child to play with something





This is a helpful position because:

Head and body

- The head is upright, the child can look at what she is doing
- The back is upright

Legs and feet

- The hips are bent
- The legs are relaxed

Shoulders and arms

- The shoulders are slightly forward and relaxed so it is easier for the child to bring her arms forward
- The arms are forward and close to the body so the child can use her hands



This is a poor position because:

Head and body

- This child is not supported enough. She is unstable.
- Her body is leaning to one side.

Legs and feet

- Her hips are turned and leaning to one side.
- Her legs are pressing together.

Shoulders and arms

- Her shoulders are pushed too far forward.
- One arm is stiff against the body and her hand is in an awkward position. She cannot use that hand.



So we see that in a comfortable and helpful position:

Head and body

- The head is not pushing back or falling forward. It is not turned to one side. It is upright and in the middle
- The body is not pushing back or folding forward. It is not leaning to one side. It is upright and in the middle

Legs and feet

- The hips are not rotated or leaning to one side. They are level and centred. They are bent, not pushing straight or pulling up too much
- The legs are slightly open, not pressing together or crossing.

Shoulders and arms

- The shoulders are not too far back or too far forward
- The arms are not pulled up above the shoulders or stiff next to the side of the body.

They are close to the body and forward so that the child can use her hands. The hands are open if possible.

A helpful position will also make it easier for the child to be **more involved** during everyday activities. It may enable her to look around and watch what is happening in the room or make it easier to communicate with others. It can also make it easier for her to use her arms to take part in the activities.

Helping your child be more involved in everyday activities

Look again at the second bathing picture strip. Look at **where** the mother is supporting her child.

Question: *What do you see as her balance becomes better?*



As her balance improves, we can see that the mother gives less support.

In the second story are some examples of where you can put your hands.

There are other useful ways of giving support to your child.

Let's look at some of these.

Shoulders

This works especially well for children who move a lot.



Notice that the child's feet are supported and in a good position

Chest

Notice that the child's feet are supported and in a good position.

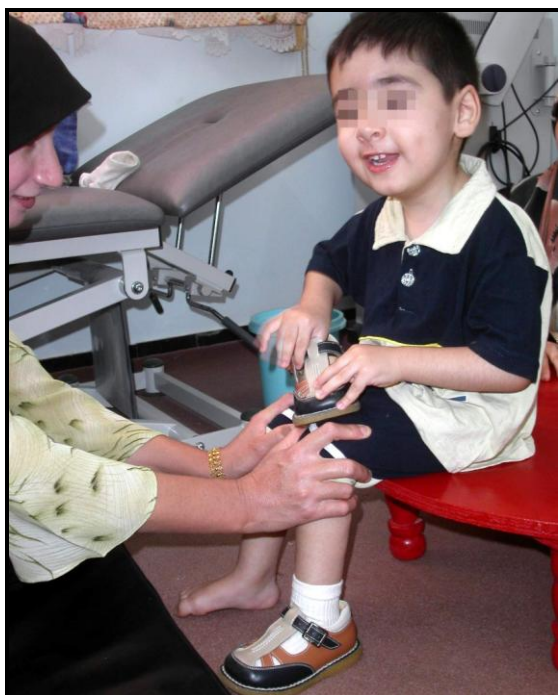
Notice that the carer's other hand is on the child's back.



Hips



Knees



Remember: It all depends on how much balance your child has. Try these positions and activities, and see which works for your child.

Earlier we talked about you needing to do all the daily activities with your child. And that if you can do them in such a way that you are stimulating your child **at the same time**, then this will help your child **a lot** with her development.

Let's look at some examples of how we can use different everyday situations to help our children to develop.

One of the things that a caregiver does many times a day is pick up and carry her child. Let's look at how to do this so that it helps her develop.

PICKING UP

Poor way

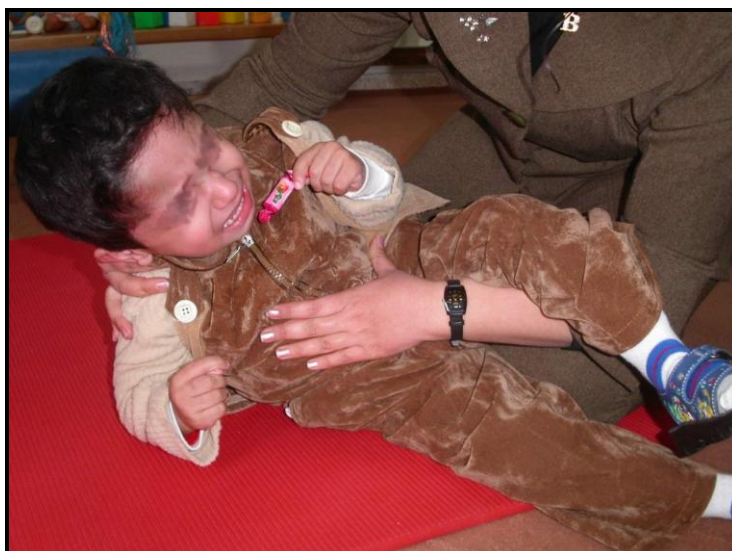


- Her head falls back
- It's very uncomfortable for her
- She can't 'help' to be picked up

Helpful way

To make it easier to pick up your child and to prevent poor positions:

- Roll her to one side and support her head
- Bend her legs
- Lift her close to your body – encourage her to push herself upright on her arm if she can
- Put her down in the same way
- Remember to use both sides



Taking care of your own back!

Remember to pick your child up in such a way that you are not harming your back:

The harmful way:



Bending forward with your legs straight will cause small injuries to your back every time you do it. Over time you may develop severe backpain.



Picking up to protect your back:



- Bend your KNEES and keep your back straight or even slightly hollow.
- It is sometimes easier with one foot slightly in front of the other one.
- Hold the child as closely to your body as possible before lifting.
- Lift by using the strong muscles of your legs and not your back
- If your child becomes much bigger and heavier, preferably do not lift her alone, but ask someone to help you.
- Count before lifting so that the two people lifting, do so at the same time.

CARRYING

Poor way

This picture shows a poor carrying position.

- Her head is falling back
- She can't see
- Her body is stiff and straight
- Her arms and hands can't do anything



Helpful way

There are different helpful ways to carry your child. Look at these different pictures that each shows a helpful way to carry your child. Some of the pictures indicate specific ways to carry a child for a very specific reason which will be discussed. Carry your child in a way which corrects the poor positions as far as possible.

CARRYING IN A HELPFUL WAY CHECKLIST

Head and body

- A more upright position will help her to hold her head up and look around, even if it can only be for short periods at a time.

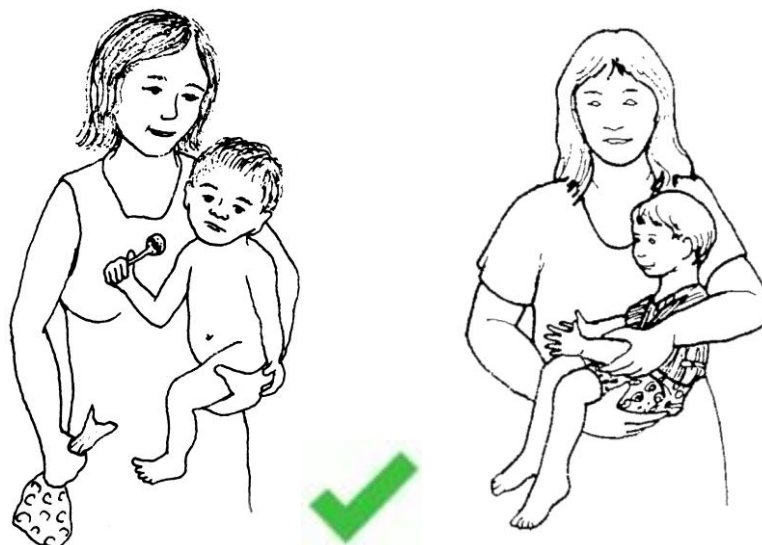
Legs and feet

- Use positions that keep the hips and knees partially bent and the knees separate

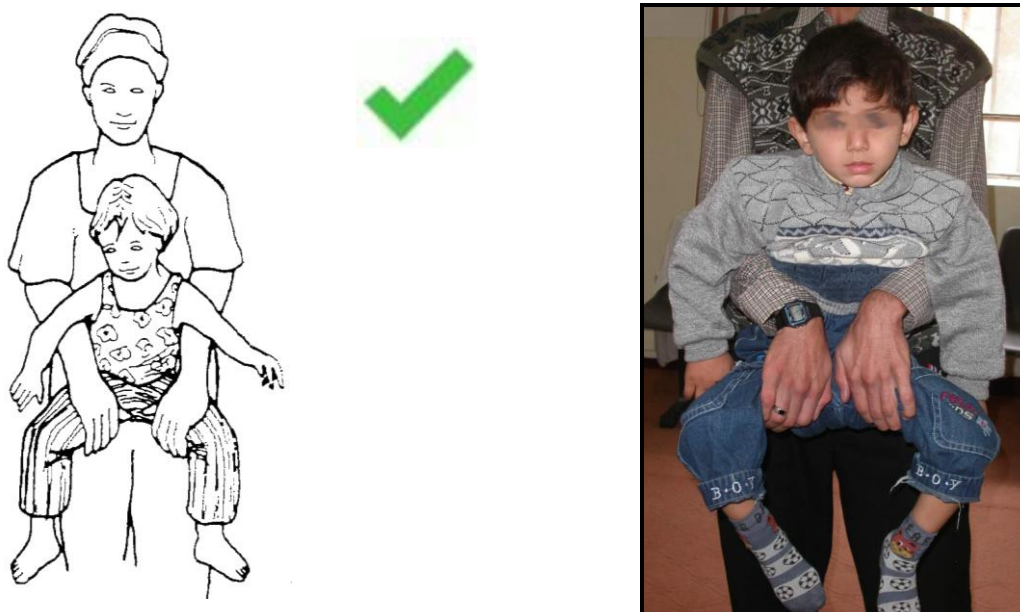
Shoulders and arms

- She can hold on with her arms
- Or she can free her arms for playing

Look at these next 7 pictures:



And how about this way to carry her? Pushing her shoulders up and forwards **helps to relax the tightness in her legs**. You can swing her from side to side in this position – now you are playing together!



You can also try these positions if your child has **uncontrolled movements**.



And if your child is **stiff and tends to curl forwards**, try carrying her like this:

And if one side is **more stiff than the other**, try to stretch that side. But don't always carry her only on one side. Sometimes change to the other side.



Try carrying your baby in this position on your forearm. It can help her **to develop control of her head** when lying face down.



And when she's bigger you can still carry her in this face down position.

Babies and children get very few opportunities these days to be face down. And so the development of extension is becoming a problem.

Even though the legs are straight, they are separate and relaxed. If the child's legs are stiff and crossed, this is not a good position to use.



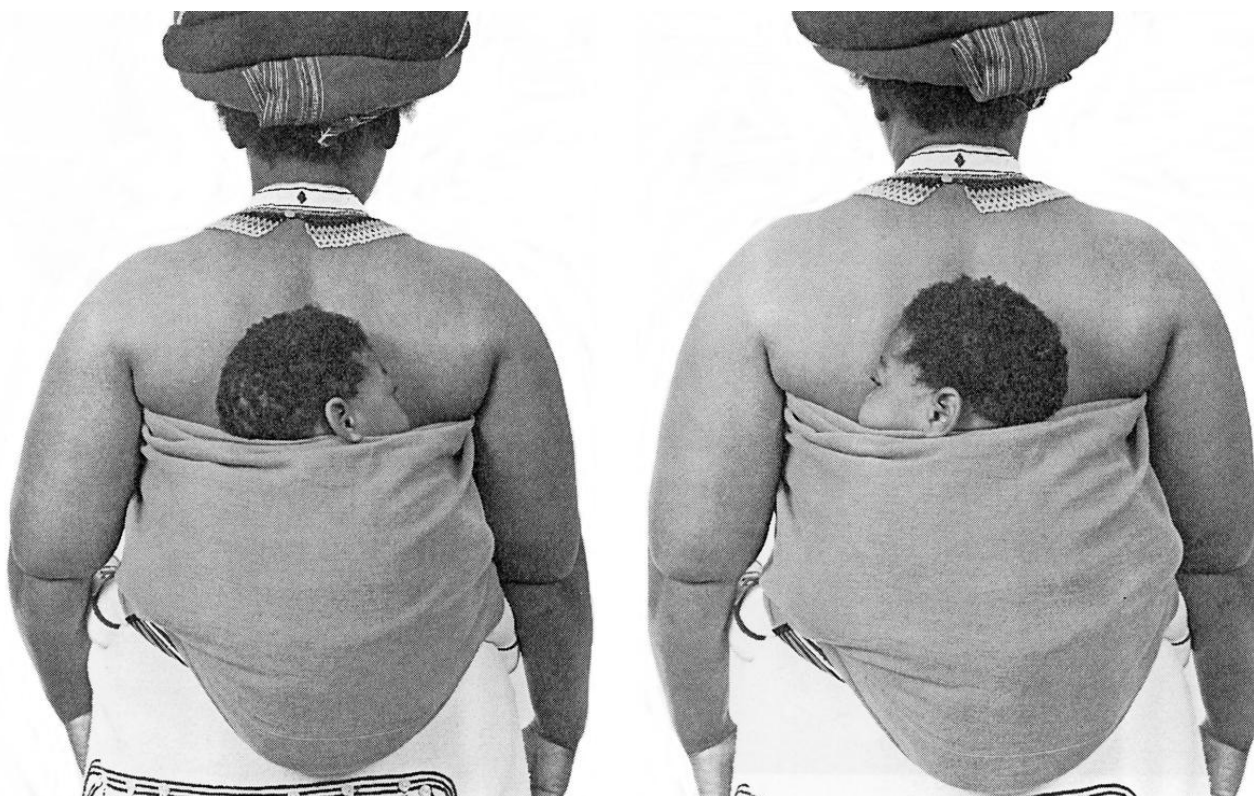
However

- if the child's legs are stiff and crossed, this is not a good position to use
- remember what we said about children who push back strongly with their heads all the time. In the same way, this carrying position may reinforce the pushing back of the head instead of being helpful.

Have you tried these traditional positions?

Make sure her hips are open, but do not force them.

Wrap her arms around you with her thumbs facing up.



Each time you carry her, turn her head to the other side



The blanket can provide full muscle support, or if you put it under her arms, she will have to work to keep her head up, and be able to move her arms.



Question: *In what position do you dress your child?*



Question: *Do you think this is a good position to dress your child? Why? Why not?*



Sitting is a useful position to use when dressing because:

- The head is upright and in the middle, the child can look at what she is doing
- The back is upright and straight and the child has to use her muscles to sit up
- The shoulders are slightly forward and relaxed so it is easier for the child to bring her arms forward
- The arms are forward and close to the body so the child can use her hands and the caregiver is encouraging her to help put her clothes on or take them off herself
- The hips are bent
- The legs are relaxed and not pressing together

- By sitting the child everyday to wash and dress, the caregiver is doing “exercises” with the child that help her develop over time. The child doesn’t have to sit on your lap as shown; she could sit next to you on the bed or in front of you on a low bench.

Question: *Why are these everyday situations so important?*



- They happen several times each day
- Natural interaction takes place
- They encourage your child to be active in helping herself
- They increase her self-esteem
- They prepare her for independence
- They use the words that we use for everyday life

Each time you do an everyday activity with your child, think how you can encourage her in her movement, communication, and in her social and emotional, and thinking and playing skills.

Remember that while your child needs to practice with you, and on her own where possible, she can also practice her skills with other members of the family and wider community so that she learns skills in relating to others.

However, you, the primary caregiver for your child, are the person who has to work out the daily routine for your child.

Every time you do something with your child, she must be in a good position.

Every time you do something with your child, communicate with her.

Every time you do something with your child, help her to be more involved in the activity.

This is how she learns and develops – in everyday situations.

Question: *Can you think how **YOU** can use bath time and other everyday activities with **YOUR** child to stimulate her development?*



Take some time to think about this, and write down a few ideas, or draw some pictures, about things you would like to try with your child this week. Refer to the development diagram so you are clear about what development skill / skills you are working on.

At the end of this manual, we have included some pictures to give you some more ideas that you can use for washing and dressing. Discuss these with any other caregivers who help you do activities with your child at home, also remembering what you have learnt from the group activities during the workshop – then try it.

Make notes, or draw pictures, about **different** ways you are going to approach each of the everyday activities you and your child do together. (This may take you some time to do, and may change as your child develops. Be prepared to change with her. If you can draw, put up some picture suggestions at home for other caregivers to do with your child).

Question:

- *At what age should I start to toilet train my child, or to teach her to give an indication that she needs to use the toilet?*
- *At what age will my child decide what clothes to wear?*
- *When can she play with other children?*



Think about these questions.

Discuss them with your family and other caregivers.

A general guideline is that you can start to encourage or help your child to do this at about the same age at which a child without cerebral palsy would start to do this.

The abilities of your child will determine how much you need to adapt the way it is done and how much you will need to help your child.

Here are some ideas and pictures that might help you, or give you more ideas about some everyday activities. They may not be appropriate for **your** child, but they may spark ideas that you can use.

Washing and bathing

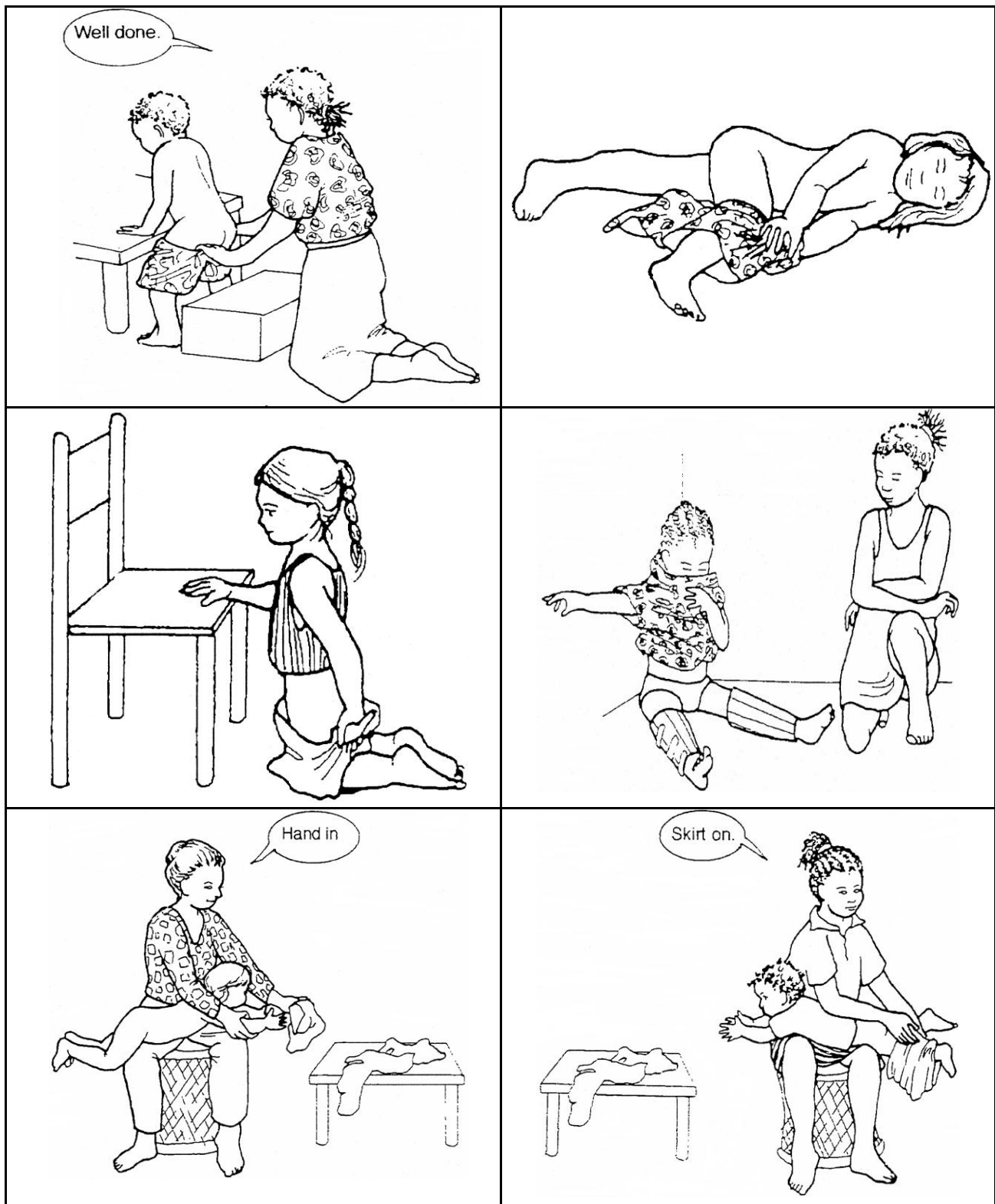




Dressing positions

Give her just the help that she needs, give her encouragement, and the words she needs, and be creative in trying new positions that might work for her...

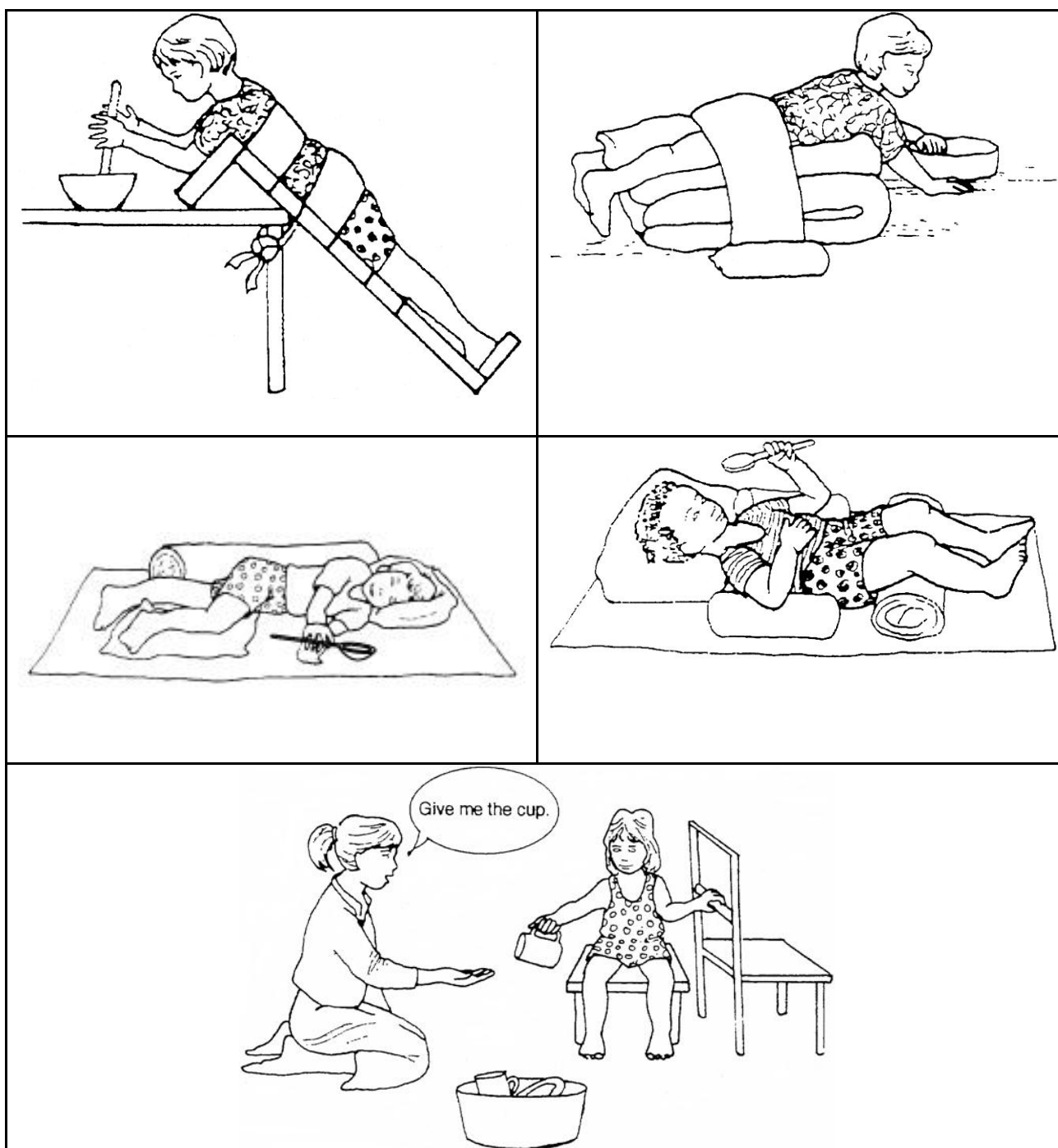




These last two positions work well with children who move a lot.

While you are doing cooking, cleaning and washing

- Make sure that your child is in a **comfortable, functional and helpful position**.
- Talk to your child about what you are doing
- Give some cleaning or kitchen equipment to your child so that she can imitate what you are doing in play.



To open legs that scissor or cross when washing or dressing

Avoid pulling the legs apart while holding onto the feet, as in this picture. This will make the legs pull together more and may cause the child pain.



Ask a therapist to demonstrate the following helpful method, explaining how it could be done for your child specifically.

- First put something under the head and shoulders to bring them forward a bit.
- Hold the child's knees and bend the legs up. Bending the hips will help to relax the legs.



- Hold at the knees and keep the legs apart as you straighten them. It may also help to turn the legs a bit outwards.

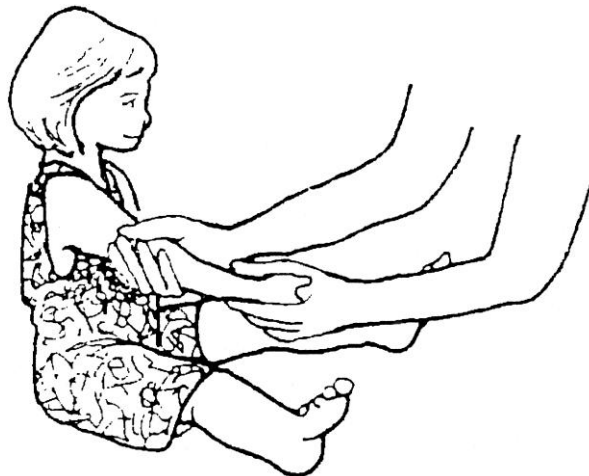
How to open the hand for washing or activity

Avoid pulling the fingers and thumb out by their tips, as in this picture. This will make the hand close more tightly and may cause injury to the fingers!



Ask a therapist to demonstrate the following helpful method, explaining how it could be done for your child specifically:

- If the child's arms are pulled into a bent position, opening the hand will be easier if the arm is first straightened. To make it easier to straighten the arm, hold around the elbow and turn the arm outward as you bring it forward. (This means that the palm of the hand will turn upwards.)
- Now it will be easier to open the hand.
- Handling the thumb at its base, take it away from the hand.
- Now open the other fingers gently.



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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