

MODULE 5:

Everyday Activities



Materials

Buttons/bottle tops, everyday household objects such as plastic cups, cutlery etc., Flip chart and Pictures 5.1-5.5



Icebreaker

Put a handful of buttons/bottle tops (different sizes and colours) on a blank piece of paper in the middle of the group. Ask each group member quickly to give one idea of how she could use the buttons to teach things to her child/ren (not necessarily children with disabilities). For example: counting, colours, shapes, building, threading, using them to create pictures etc. (Feel free to use other objects, such as plastic cups, cutlery, etc, if you don't have buttons available).



Explain

Outcomes for the module (on flipchart).
As a caregiver you will:

1. Have a clearer understanding about how to use everyday activities to help your child with cerebral palsy to develop.
2. Be able to explain this to others in your family or community.



Activity

Put up picture 5.1 (or individual photos of everyday activities from your local context).
Prompt questions for discussion:

What activities are shown in the poster? What activities do you do every day or every week? Which of these activities do you do with your child? Are there any other things you do with your child that are not shown in the poster?

Remind the parents/caregivers that they are the most important caregiver for their child. Think about the time you spend every day with your child, doing everyday things with her. List the various everyday activities on the flipchart.



Picture 5.01



Ask What skills does your child need to learn in order to develop and become more independent with these everyday activities? (**HINT:** remember the development chart that you ticked off in Module 2 and the goals that you set for your child?) Allow for discussion and use the checklist below as needed.

This is what your child needs to learn:

- moving and balancing
- using her hands
- communicating and interacting with others
- thinking and playing
- learning to do things for herself

With all the washing, feeding, dressing, giving medication and the other things that you have to do with your child, you may already be very busy and feel quite stressed. Plus, you may be caring for other children as well. Maybe you are wondering when you will also find the time and energy to help your child to develop. Do you feel like this? Allow sufficient time in the group to discuss these feelings. Use the example from Bangladesh below to prompt discussion.

In Bangladesh, many parents talked about feeling tired, or not having enough time to care for their child, with variable amounts of support from other family members.

A 'Quality of life' questionnaire was used [1] to measure the impact on family life of caring for a child with a disability. The main caregiver – mainly mothers – scored significantly higher in terms of impact on Quality of Life compared to local parents without a disabled child, on a whole range of measures. They were more anxious, more tired and stressed, felt less supported, and found it more difficult to communicate their concerns to other members of their family [2]. High levels of stress in caregivers are frequently reported in other studies [3-4].

Building 'treatment' for their child into everyday activities is therefore essential for parents who have limited time for caring for their child.



Explain that as caregivers 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 without taking up any additional time.



Materials

Doll and basin of water

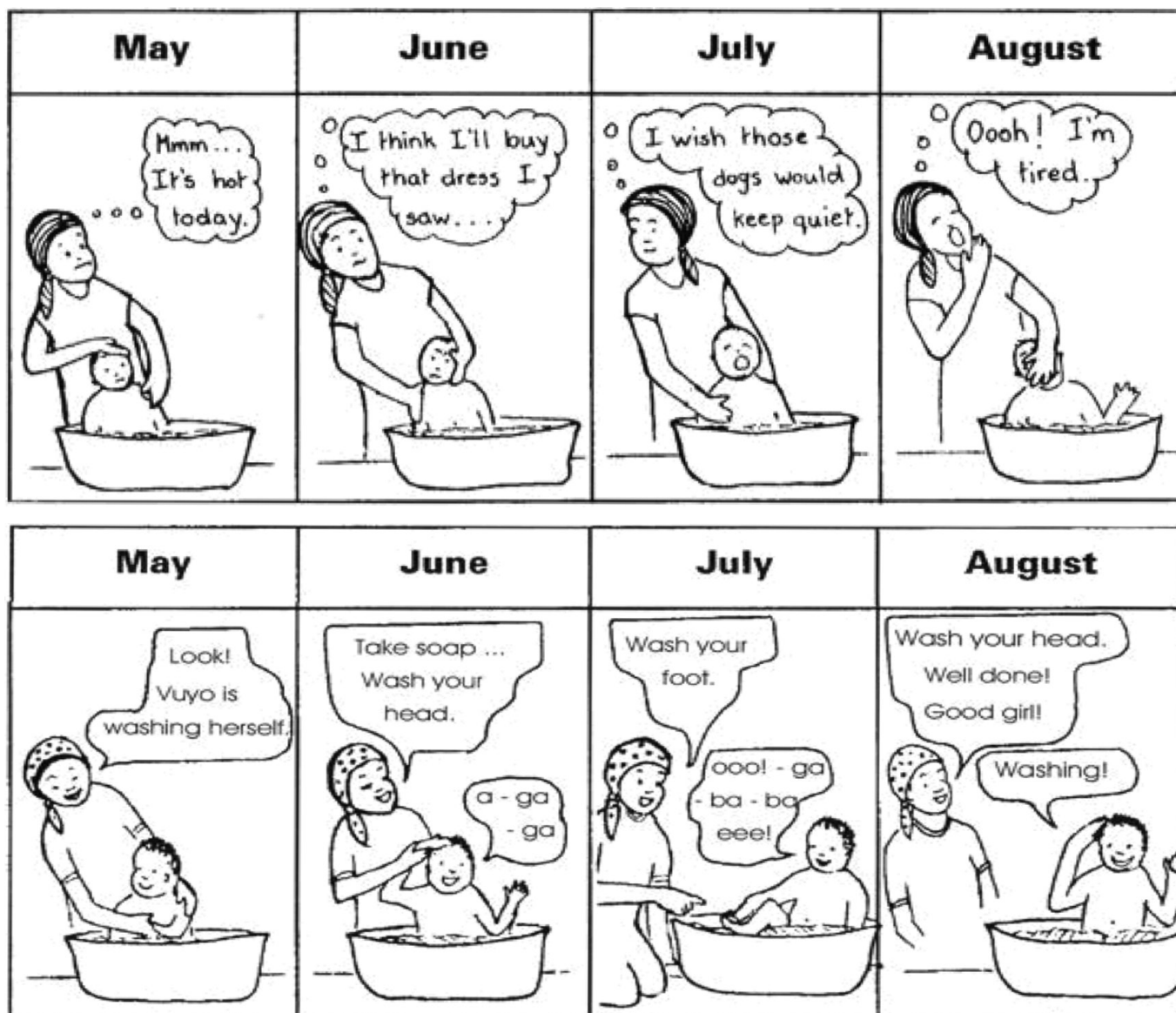


Activity Act out a role play of the two picture strips below, using a doll. Alternatively, you can ask for a couple of volunteers in the group to act out the picture strip. Ask the group to provide feedback on each role play and use the following questions to prompt discussion:

What do you like, or not like, in each of the role plays (or picture strips)? What do you think about the different ways that these two caregivers bathe their child?

In the feedback from the group, summarise the following main points, which were also covered in the Communication Module. The story/role play demonstrates how to communicate with your child in an everyday situation:

- Talking to your child about the things happening around her
- Showing her what you are talking about, and getting her to look at and feel the objects
- Offering choices wherever possible (e.g. *do you want the red cup or the blue cup?*)
- Note: You can also offer choices during bathing, such as, *what shall we wash next, your arms or your legs?*



Pictures 5.02a-5.02b



Ask Apart from communication, how is the caregiver in the second bathing role play/picture strip also helping her child to develop other skills? Cover the following checklist:

Movement and Balance

In the second bathing picture strip, the caregiver is helping the child:

- to sit by holding her in a **helpful position** (ie. Supported) 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 onto her child, so her child has not been given the 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 bathe 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 the child 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 (comfortable, supported and stable) position:
 - Makes it easier for a child to be more involved with everyday activities.
 - Allows her to look around and watch what is happening in the room and communicate more easily with others.
 - Allows her to use her arms more easily during activities.
- Remember that 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.



Activity Ask a volunteer to sit like a child in an unhelpful position and try to stack bricks. Ask them to explain how that feels. Now ask them to sit in a helpful position (thinking about the position of the feet and legs, hips, body, shoulders, arms and hands, head). Do the same activity. Ask them to explain how that feels. Is it any easier? If necessary, it may be useful to refer back to the positioning and handling module and review the key elements of good positioning and handling.

Ask the group to summarise the key points about being 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 facing forwards.
- The body is not pushing back or folding forward. It is not leaning to one side. It is upright and facing forwards.

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 shoulder or stiff at 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.

EVERYDAY ACTIVITIES: WASHING AND BATHING



Materials

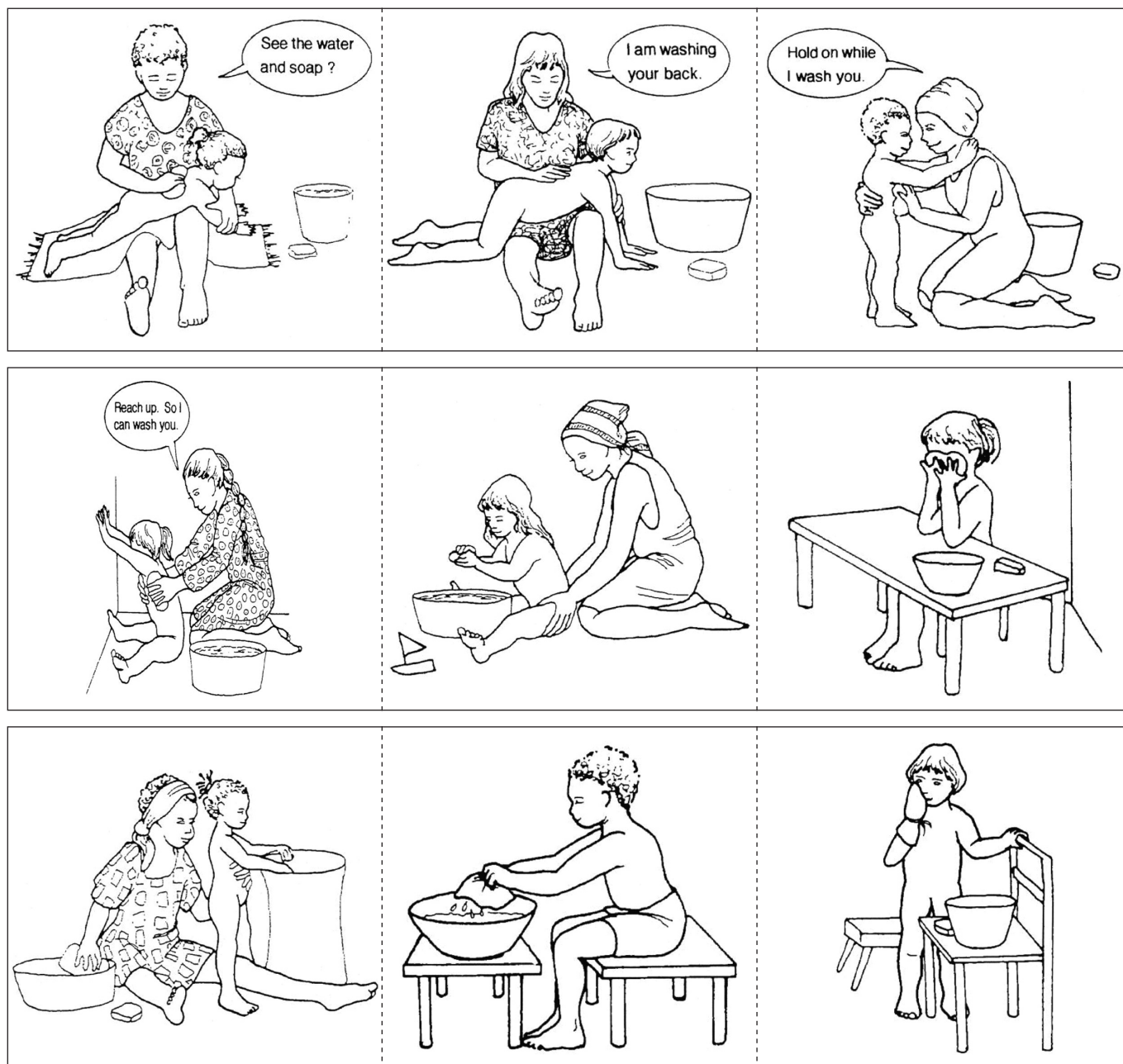
Picture strips 5.03

(Photocopy onto card, enough copies per small group)



Activity Look at the picture strip . Discuss in small groups what you can see in the pictures, and what is being done to stimulate the child's development in each example. As a whole group, ask how they can use bath time to stimulate their own child's development

Pictures 5.03



DRESSING POSITIONS:



Activity Look at the picture strip . Discuss in small groups what you can see in the pictures, and what is being done to stimulate the child's development in each example. As a whole group ask how they can use dressing to stimulate their own child's development. **Key points:** 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. The last two positions shown in the pictures work well with children who move a lot.

Pictures 5.04



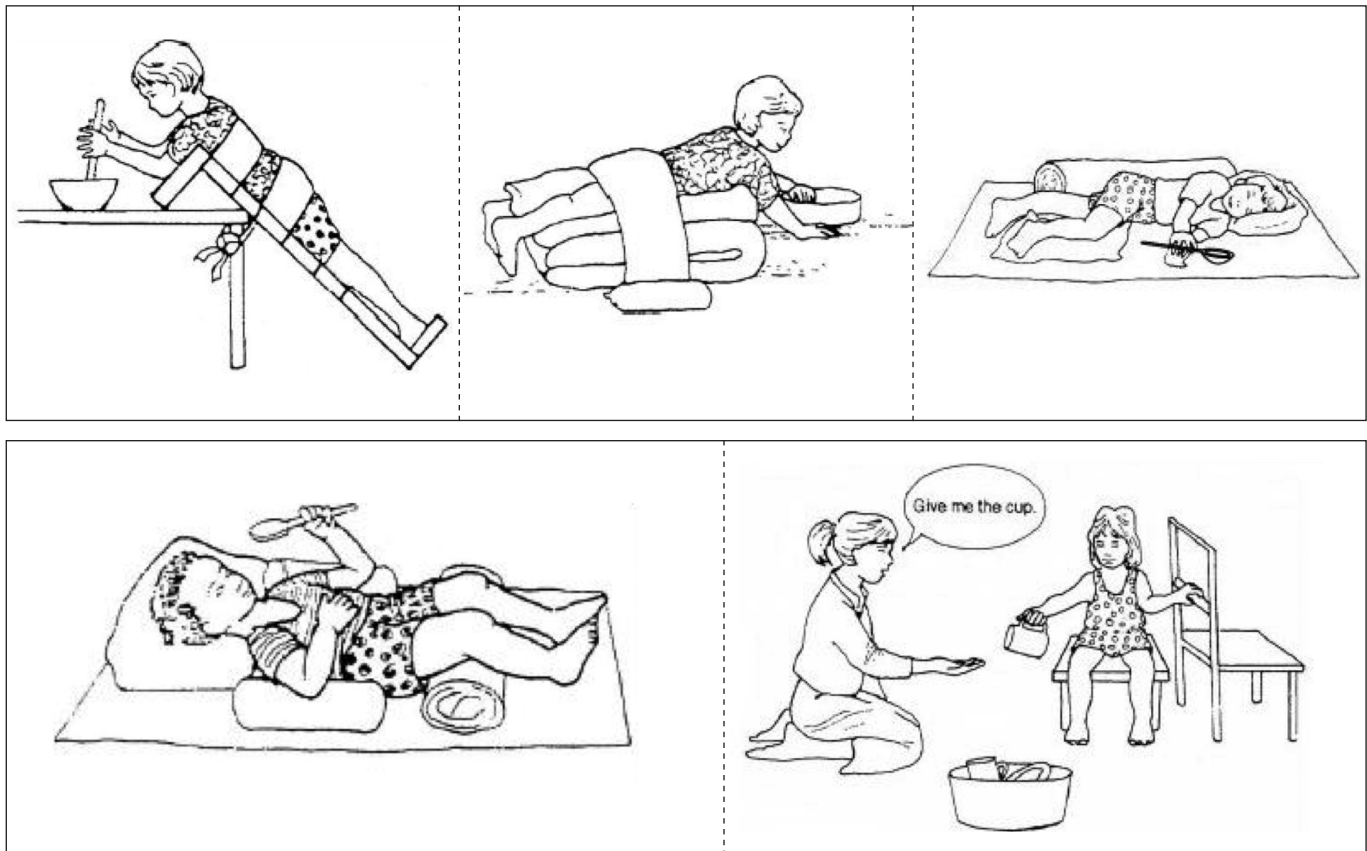
WHILE YOU ARE COOKING, CLEANING AND WASHING



Activity Look at the picture strip . Discuss in small groups what you can see in the pictures, and what is being done to stimulate the child's development in each example. Cover the following key issues in the group discussion:

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

Pictures 5.5





Activity In small groups, ask each caregiver to share one or two areas of daily living activities that they would like to work on with their child (refer back to their home visit/individual assessment form).

Take some examples of activities of daily living activities they have chosen and ask the group to break the tasks down into small steps. Ask them to draw these if it helps. Then ask them to think about what their own child is able to do/which steps in each of the tasks. Encourage the caregivers to help each other to come up with ideas.

Then, ask them to consider the following:

- Which everyday activity/ies are you going to work on? (Think of an activity that you would really like your child to become more independent in.)
- Which step in each activity does your child need to learn or practice next?
- How will you support your child to learn that next step?
- Look specifically at the positioning and how you are going to encourage your child to be more involved in the activity.

Encourage caregivers to share any success stories during this session and the following session.

TOILETING



Explain You may be wondering at what age to start toilet training, or to teach your child to give an indication that she needs to use the toilet. You may also wonder at what age your child will decide what clothes to wear or when she will play with other children.

A general guideline is that you can start to encourage or help your child to do things at about the same age at which a child without cerebral palsy would start to do them. The abilities of your child will determine how much you need to adapt the way each activity is carried out and how much you will need to help your child.

In Bangladesh, issues related to toileting were a priority for many parents. These included needing children to be able to communicate clearly when they needed the toilet, or helping children to be independent in toileting, where possible. Extra time was needed to address this.

Two case studies of parents who stopped coming to the training sessions highlighted the stress of the parent and neglect of the child. Children were lying in their own urine for several hours until their parents had time to clean them.

"I do pottery all day long, and I have to cook food three times a day. My father-in-law is ill and I have to take care of him. During sharecropping, when the crops arrive at our house, I have to work on that and I have to look after my disabled child all the time."

"My husband sometime helps me a bit in household work, but he does not help me in any work with our child. He has almost no interest in the child. I feel stressed working so much I never get the chance to relax. That's why I always feel weak. My daughter urinates and defecates lying down and it gets on her body, and I find it difficult to clean her up."

Mother, Bangladesh



MONITORING PROGRESS

Ask the caregivers to share one or two ideas that they have learned today and that they will share with other family members/caregivers at home, such as the different ways in which they are going to approach certain activities they do every day with their child.



Materials

Take home messages on flipchart

Take Home Messages:

- It is important to identify helpful positions for everyday activities.
- Every time you do something with your child, help her to be more involved in the activity, and communicate with her.
- Cerebral palsy affects each child differently, so don't expect the same abilities in each child. However, all children need to be stimulated in order to develop as much as they can.

References

1. Varni, J.W., et al., *The PedsQL™ family impact module: preliminary reliability and validity*. Health and quality of life outcomes, 2004. **2(1)**: p. 55.
2. London School of Hygiene and Tropical Medicine, *The Impact on family life of caring for a disabled child; lessons learnt from Bangladesh*. Forthcoming publication
3. Hartley, S.O. V.P., Bagawemu, A., Ddamulira, M., Chavuta, A., *How do carers of disabled children cope? The Ugandan perspective*. *Child: Care, Health and Development*. 31 2 167-180. 2005.
4. Mobarak, R., et al., *Predictors of stress in mothers of children with cerebral palsy in Bangladesh*. *Journal of Pediatric Psychology*, 2000. **25(6)**: p. 427.