MODULE 6:

Feeding Your Child

Facilitator note: This is a long module split over 2-3 sessions. As a facilitator you are not expected to be an expert on nutrition, but it will be helpful if you can identify opportunities to link with any local or regional nutrition programme; all low and middle income countries will have a nutrition programme.

Materials

For activities: Jug of water, glasses, dessert spoons, yoghurt and face cloths. Pictures of positions. Laptop and projector for showing video clips and recipe sheets. There is a short feeding video clip available from Hambisela (contact info@hambisela.co.za) and the film 'Wrong from the Start' (available from the organisation MAITS at http://www.maits.org.uk/). For more information check out Module 10 Resources.

For demonstrations: Large rag doll, special seat with straps, small towels you can roll up, normal chair, large glass, small plastic beaker, dessert spoon, plastic teaspoon,

For explanations: Pictures for positioning section.

For practical feeding session: Small plastic beakers and plastic teaspoons (enough for the whole group).

In Bangladesh, malnutrition was noted as an issue for a number of the children on the training course. Ten out of 153 children died during an 18 month period, and in most cases these children were malnourished. This would link in with other available evidence about the increased vulnerability of disabled children to being malnourished and it is of critical importance in the training sessions to minimise this risk [1-3].

It's not enough to only address improved feeding practices! The project identified possible linkages with national and local nutrition programmes in order to clarify how the most vulnerable children and families could be linked into their services.

Activity This activity is designed to help caregivers understand what it feels like to be fed by someone else and not very well. ASK mothers/caregivers (NOT children) to work in pairs: ASK them to take turns to feed one another. The person being fed should be given a mouthful of yoghurt or a sip of water with their head leaning back, and then turned to one side, then flopping forwards. ASK How easy or difficult is it to swallow in each position? How does it feel to be fed?













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

- 1. Understand the range of difficulties that a child with cerebral palsy may experience with eating and drinking, and the implications of these.
- 2. If your child is not independent in eating then you should be able to work out how to make feeding her easier and more enjoyable for both of you. You will also know what strategies to use to reduce the risk of food and/or drink going onto the lungs.
- 3. If your child has some independence in eating, then you should be able to teach her to eat more independently.
- 4. Know what a balanced diet is and have ideas on how to maximise your child's nutritional intake.

FEEDING YOUR CHILD



Materials Display Poster 6.01



Ask the group *Why are eating and drinking important?* Discuss the main benefits in the group: That good eating and drinking are important for nutrition and hydration, and therefore for growth and health.



Activity Ask the group What is a nutritious or 'balanced' diet?

Display Poster 6.01



Show the poster and discuss the food groups and that a combination of these will give energy and vitamins, which are vital for ALL children, including disabled ones. Help the group to list what items in the local diet provide the main sources of nutrition.

Explain that many children with cerebral palsy have feeding difficulties. These affect their ability to eat and drink enough (leading to malnutrition and dehydration) and can cause chest infections due to food and drink going down the wrong way and into the lungs.

Possible feeding difficulties and associated problems for a child with cerebral palsy



Ask the group to discuss the sort of difficulties that they experience with feeding their own child. Write up responses and use the list below to ensure all the following difficulties are mentioned and discussed.

Difficulty controlling her head

- Her head is floppy and she struggles to keep it upright
- She pushes her head backwards

Difficulty controlling her body

- She cannot sit by herself and struggles to keep her body upright
- It is difficult to hold her body upright when feeding her as she pushes back or struggles to keep her body still

Difficulty controlling her mouth/lips/tongue

- She struggles to close her mouth and food or drink spills out
- She struggles to chew her food
- She struggles to swallow/takes a long time before swallowing her food
- She chokes/coughs a lot when eating
- She pushes the food out of her mouth with her tongue
- She struggles to eat what other children her age are eating and only eats soft food

Difficulty eating on her own

She struggles to hold things and bring them to her mouth

Mood

She is often very unhappy during mealtimes and cries or screams and rejects her food

Other problems

- She often vomits after eating
- She suffers from frequent constipation
- Sometimes parents feel extremely frustrated and angry because feeding her is so difficult

Voices of Parents

"I feel angry sometimes and hit him when I have to force him hard to eat. At that time I have to hold all his limbs down in lying position."

"I beat her because it's hard work for me and it takes a long time."

I always feel impatient because he cries a lot, so I shout at him and bite him." [4]

HELPING YOUR CHILD TO EAT AND DRINK



Explain There are 6 key aspects to helping your child eat and drink more healthily and easily. The whole of this session will be exploring each of the 6 issues:

Picture 6.02



1. Environment and hygiene

- Make sure you feed your child in a clean space where there are as few distractions as possible.
- Make sure you have washed your hands, your child's hands and the utensils, in 'good water'.

2. Diet

- Children with cerebral palsy need a balanced diet that is especially high in energy, which
 comes from fat and oil. If you follow this diet your child will be stronger, healthier, and
 happier and be able to do more things.
- These children get tired easily, so they need small meals given more often e.g. 5 meals per day.
- As drinking is difficult, these children need sips of water given throughout the day the
 equivalent of at least 5 tall glasses. This will help reduce their constipation and give them
 more energy.

3. Food consistency

- The more solid food is, the more nutritious it is. However, as we know, these children have difficulties chewing, as they don't have the muscle power, so we need to make food a bit moister and softer so they can manage it.
- We also need to make it one smooth consistency as they cannot manage a mixture of things in the mouth at once.
- Just as solids are difficult, thin fluids are also difficult for all of these children as they travel
 very quickly and can go down the wrong way, onto the lungs. Thin fluids should therefore be
 given very carefully.
- Start with food of a smooth consistency not too runny, not too solid, and not mixing solid with liquids (e.g. lumpy soups). As your child starts to develop better control over her tongue and mouth, you can increase the thickness of the food. This will encourage her to learn to chew and in time, she may be able to manage more solid food.

Discuss the foods the participants usually feed their children. What nutritional value do they have? What is their consistency? How might you modify the diet of your children and ensure the food is of a good consistency. Discuss recipes e.g. usual weaning foods, and ways to mash up family foods etc.

4. Positions for feeding



Materials

Cards 6.03a - photocopy enough for the group and cut out.

Activity Remind the group that they have already had a module on positioning, and check what they remember from that. In small groups or pairs, look at the card sets (a+b) showing different positions. Can you choose which you think is the best position for feeding, from each set. Can you say why you chose one position rather than the other? See Resources at end of module for answers to this activity.

Cards 6.03a





Explain that it is also important to keep your child sitting up for 30 minutes after meals. This will reduce the risk of vomiting after eating.

FACILITATE the group to summarise the key aspects of good positioning, i.e. HEAD AND BODY: Sitting upright. Head facing forwards and neck long

SHOULDERS AND ARMS: Forwards

LEGS: Hips and knees bent at 90°



Materials

Rag doll and pictures 6.04a-6.04d

DEMONSTRATE AND EXPLAIN the following ways to position a child for feeding using a rag doll and a supportive seat for demonstration. Put pictures 6.04 up to illustrate the discussion.

If you're sitting on a chair, couch, or bed to feed:

- Make sure that you are comfortable, with a cushion behind your back and another under your supporting elbow.
- Keep your upper arm firmly against the top of her head, and not behind her neck. Make sure you can see your elbow.
- Hold your child's bottom firmly between your legs so that she cannot push back.
- Support her knees with one leg and her back with the other. Raise the leg that is supporting her back, by putting something under your foot, to make her back straight.
- Bring her arms forward so that her shoulders also come forward.

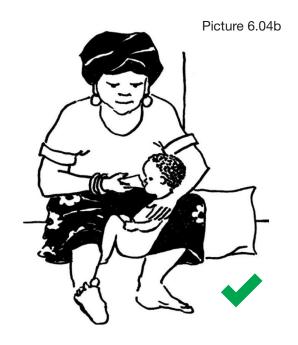


Explain or demonstrate other strategies that can be used to help good positioning:

- If your child is sinking down too far between your legs, try putting a firm folded towel/blanket under her bottom.
- Remember her back must be straight, not rounded.
- If her back is still too rounded, slip a folded towel over a piece of board behind her back to give her something to lean against.
- Your child may have a specially adapted seat, which is ideal to use when feeding her.

If you are sitting on the floor:

 Try to sit with your back against a wall to rest your back Keep your upper arm firmly against the top of your child's head – not behind her neck. Make sure you can see your elbow.



- Put a cushion under your raised knee to keep yourself comfortable and to keep her back straight.
- Make sure your child's bottom is well between your legs so that you can keep her hips firmly bent.
- For the bigger child, or for one who pushes back very strongly, try resting her bottom firmly on the floor and then push her legs up towards her chest.
- Place your leg firmly across her feet to hold them flat on the floor.

Sitting in a supportive chair







Picture 6.04c

Picture 6.04d

Picture 6.04e

- A seat like this can give your child all the body support that she needs, leaving you free to concentrate on your feeding technique.
- Make sure she is correctly seated and positioned, using rolled up towels or cloths if necessary to support your child well, as you have been shown.
- Positions for feeding the child on her mother's lap are likely to be very difficult with older/bigger children, and are more suitable for younger children.
- For those older/bigger children, a supportive seat will probably be the only way to achieve a
 good feeding position. As a child grows you need to make sure that the chair still fits. Do not
 squeeze a child into one they have grown out of.



Explain the following summary points:

- Be sure your child is in a good position before you begin feeding her!
- The position you use will make feeding either easier and safer, or more difficult and unsafe.
- It is especially important that the head is not leaning back or flopping sideways and that the chin is tucked in slightly, to make swallowing easier and safer.
- You can play with your child in these positions too that way she gets used to the
 position before you try feeding her, and you also get comfortable with using these
 positions.

5. Utensils

Show a dessert spoon and plastic teaspoon.



Ask trainees Which is better for feeding their child and why? Make sure the following points are covered:

- The teaspoon is better, both in terms of giving small, manageable mouthfuls as well as preventing harm caused by biting hard onto it.
- The best way to feed using a spoon is to give food from the front and straight –
 place gently on the lower lip so that the child can feel it.
- It should **not** be dragged up over the top lip when taken out. Correct placing of the spoon in the mouth helps the child to develop the lip control needed for taking food off the spoon.
- Feeding by hand may be appropriate, if the child can manage a more solid consistency.

Show a tall glass and a short plastic beaker (e.g. medicine cup or lid of baby's bottle).



Ask participants Which is better for feeding their child and why? Make sure the following points are covered:

- The tall glass makes the child's head tip back, meaning that drink will not be swallowed well and may go onto the lungs.
- The small beaker is easier to control in terms of giving small sips and again prevents harm if bitten.
- Avoid using bottles beyond the normal age for suckling as they prevent the development of normal drinking skills.

6. Helpful and Responsive Feeding



Explain

- Make sure that your child takes only small mouthfuls and one mouthful at a time.
- Don't rush! Give your child plenty of time.
- Your child may need support to keep her mouth closed and encouragement to Chew. If her mouth is closed when eating, she will find swallowing easier, lose less food through spillage, and therefore eat more.
- You can help her by providing support to her jaw, as shown in the pictures below. Your child may resist this at first, so it is helpful if you allow your child to get used to her face, lips and jaw being touched, when you are sitting or playing with her.
- Be sensitive to your child's needs and support them as required.
- Talk to your child to encourage her to eat and have fun at mealtimes. Be gentle in your words and actions.
- Watch your child's reactions and feed them in a sensitive manner. Watch to see when they are ready for the next mouthful. Pause or take breaks if needed.
- Never force feed.
- Stop when the child indicates they are tired or have eaten enough.
- Interaction and fun at mealtimes improve a child's communication skills, and the caregiver-child relationship.
- Active and sensitive feeding encourages the child to want to eat. Research shows that children fed in all of these ways eat more and put on weight.





Picture 6.05a Picture 6.05b

Demonstrate this on the doll, and put the pictures (6.05a, 6.05b) on display.



Activity

- 1. Show the 'Before and After' clips you have prepared (See Resources). Each time, show the Before clip and ask people to comment on the feeding methods and the difficulties the child is having. Watch the After clip and ask participants to comment on what is different. Discuss what the caregiver was doing differently to improve feeding and how the child was responding.
- 2. Practical feeding session: If there is time, ask parents to sit in a circle and either give their child a drink or feed them some yoghurt, trying to follow all the advice. Go round the group helping them. Encourage parents to help one another.

If there is no time, ask them to practice what they have learnt at home.

In Bangladesh the video clips were a very popular activity and prompted considerable discussion. You will need to make your own video clips of children demonstrating good and poor feeding practice – don't forget to get permission from parents to make the clips and explain how you will use them with training other groups.

MODULE - SESSION 2



Materials

Pictures 6.06-6.07

For activities: A laptop with DVD drive and projector, and the film

'Wrong from the Start'.

For practical feeding session: Families to bring food they would normally give their child for lunch (cooked). Plastic teaspoons (not flimsy or brittle) – enough for the whole group.



Activity ASK the group how feeding has gone since the last session – have they been able to follow the recommendations? If not, what has been difficult? What positive things have they been able to do?

As a recap of all the points covered in the last session, show the educational film (25 mins). Provide support and advice to those who state that following the recommendations has been difficult.

TOWARDS INDEPENDENT EATING



Materials

Pictures for promoting independent eating 6.05a-e



Activity Ask parents to work in small groups and read out the case study from Bangladesh below (Replace this case study with another one if not suitable for your context).

Questions for parents: What would be your advice to the mother/parents of this child? What could be done differently (allowing the child to eat with their left hand, eating with a spoon in the left hand may be more culturally acceptable)? Why? Who else needs to be involved in finding solutions (raising awareness within the wider family)? How do you feel about letting your child try to feed herself? How do you feel if your child makes a big mess whilst they are eating? Does it worry you?

Voices of Children

Ansar is 9 years old. He attends school and is in class 1. He has a weak right leg and hand, and needs help with dressing himself. He feels happy that his adoptive father loves him very much. He loves swimming in the river, playing with his friends, and going to school. He feels sad when he can't join in and play with other children.

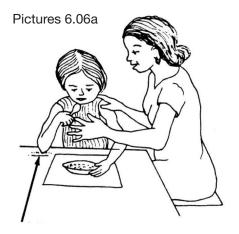
"I feel sad when I see other children playing as I cannot run and play like them." He also feels sad because: "I can't eat with my right hand. If mother doesn't want to feed me, I cry I cry in anger when I'm hungry and my mother delays feeding me."

Child, Bangladesh

Explain the advantages of their child becoming independent. Some of the parents may not think this is appropriate, either because it would mean you are not 'looking after' your child properly, or because it is not normal for young children to feed themselves.

The child will be more interested in eating and less reliant on their parent. As a parent you are very busy and may not always have enough time to feed the child. It is important to realise that children enjoy the sense of independence and react against a feeder that is 'controlling'. Yes, yes, yes! There WILL be a lot of mess, but remember that all children make a mess when they are learning to eat. Children with cerebral palsy may make more mess, but it is part of learning and developing control.

Activity In small groups, Look at each of the pictures below in turn and discuss how the child is being helped to eat independently. Ask if anyone in the group has tried this with their child? Explain that these pictures give some ideas on how you can help your child to feed herself:

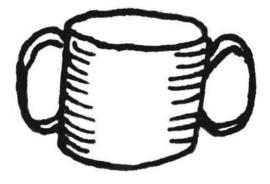


Let her rest her elbow on the table if it gives her more control



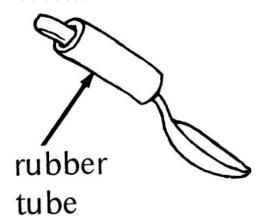
Lifting the table up on blocks to bring the bowl of food closer to her mouth may also give her more control.

Picture 6.06c



If she has difficulty controlling a cup with one hand, try using a cup with two handles.

Picture 6.06d





Explain and demonstrate on a doll: Hints to encourage your child to eat more independently:

- In the beginning, guide her hand to help her learn to feed herself
- Put a biscuit in her hand, guide it to her mouth, and see what she does with it...you might be surprised at how much she manages to feed herself
- Don't stop her putting her hand in her food and trying to feed herself
- Put a wet cloth under the bowl to stop it slipping on the table
- Try bending the spoon so the food still comes towards her at the right angle
- Put some padding round the handle to make it easier for her to grip and hold the spoon

BRUSHING TEETH



Ask Why do you think it is especially important to clean the teeth of your child with cerebral palsy?

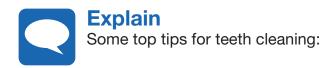


Explain that a child with cerebral palsy is very much at risk of developing problems with her teeth and gums. Discuss in the group and ensure the following points are covered:

- We all use our tongues all day long to clean our teeth, however as your child has difficulty moving their tongue, this is not happening.
- The child who drools a lot does not swallow properly and has an open mouth most of the time. This allows germs to collect in the mouth.
- It is important that your child's mouth is always as clean as possible to prevent germs going down into the lungs if they have swallowing problems.

Therefore:

- You should clean your child's teeth carefully after every meal and especially after sugary snacks and drinks!
- Some children with cerebral palsy have very sensitive mouths which can make it difficult to clean their teeth well, so extra care is needed.



- Make sure that you and your child are in a good position before starting. Pay special attention to the position of her head and neck.
- Rinsing can be very difficult. You may have to bring her body forward so that the water can run out.
- It is easier to use a small bowl for spitting out and rinsing, rather than a fixed basin.
- Giving firm pressure on the cheeks towards the lips could help the child to spit out.
- If there is any area with problems like pain or sensitivity, do those first so it can get done while your child is still relatively relaxed.

FACE CLEANING



Explain

- Some children with cerebral palsy need to have their faces cleaned often. This can be because of drooling or food spilling out of the mouth when eating.
- It will help your child to learn to close her lips if cleaning her face is done in such a way that
 it gives her the feeling of a closed mouth. This can also help to teach your child to swallow
 her saliva instead of letting it dribble out.
- Use firm pressure on the cheeks and lips using a dabbing movement not wiping.
- Always dab towards the mouth, as if you are helping to close the lips.
- Dab from the left and right side of the mouth. Then the chin and lower lip. Then the upper lip.
- Tell your child to swallow when you are doing this.







Take Home Messages:

1. Children with cerebral palsy often have problems with eating and drinking. These problems can result in malnutrition and chest infections. There are a lot of things a caregiver can do to help reduce these difficulties.

2. You can:

- Feed your child small and frequent meals of a balanced diet which has extra fat or oil
 in it.
- Give food of a texture your child can manage e.g. smooth, not too runny, not too solid or chewy.
- Position her correctly in an upright or almost upright position, with her chin tucked in slightly.
- Give her small mouthfuls of food and small sips of water, slowly, using a small utensil.
- Give positive verbal encouragement and NEVER force feed.
- Help and encourage your child to feed herself.
- Teach other family members to feed your child or to support her to feed herself.
- 3. Children with cerebral palsy need special care with regards to teeth-cleaning and facewashing.



Ask each parent to identify at least one thing that they will do differently at home as a result of today's session. Ask parents to teach this to at least two other members of the household so that they are also able to help. In the next session they can feed back on how successful this was.

In Bangladesh parents recipes for khichuri or suji were shared with caregivers (see Resource section). Suji can be made thicker by cooking for longer and runnier by adding more milk/water; Khichuri can be made thicker by adding less water during cooking and thinner by adding water afterwards. If necessary, try to modify the consistencies of the food they have brought today. You can use cereal powder (like Cerelac) to thicken the food they have brought.

Additional guidance is available through The International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDR,B) which has a nutrition unit that provides guidance and useful recipes for home treatment of malnutrition. More information is available at http://www.icddrb.org/

MODULE - SESSION 3

Facilitator note: If time allows, this is a really valuable session which allows an opportunity to test out parents' learning in a supportive environment. Remember that these training sessions are also important social support mechanisms for caregivers as well. Try to make it an enjoyable and social occasion.

In preparation for this session, ask parents to make a suitable nutritious dish from locally available foods, and bring it along to the session. Alternatively, if cooking facilities are available, ask parents to bring the ingredients and prepare the food together.

Activity Ask parents to show the group the food they have prepared for this session. Discuss together the consistencies, whether they seem appropriate for their children, and how they might be modified to be thicker or runnier. Ask the parents to sit in a circle, or in small groups, and feed their child the food they have brought, trying to follow all the advice. Support them individually and encourage parents to help one another.



Ask each parent to identify at least one thing that they will do differently at home as a result of today's session. Ask parents to teach this to at least two other members of the household so that they are also able to help. In the next session they can feed back on how successful this was.

References

- 1. Khan, N.Z., et al., *Mortality of urban and rural young children with cerebral palsy in Bangladesh.* Developmental Medicine & Child Neurology, 1998. **40**(11): p. 749-753.
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- 3. Wu, L., et al., Association between nutritional status and positive childhood disability screening using the ten questions plus tool in Sarlahi, Nepal. Journal of health, population, and nutrition, 2010. **28**(6): p. 585.
- 4. Adams, M., et al., Feeding difficulties in children with cerebral palsy: low cost caregiver training in Dhaka, Bangladesh. Child: care, health and development, 2011.
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- 7. Yousafzai, A.K., et al., *Beliefs about feeding practices and nutrition for children with disabilities among families in Dharavi, Mumbai.* International Journal of Rehabilitation Research, 2003. **26**(1): p. 33.

RESOURCES

Video Clips: Short video clips on feeding can be obtained from Hambisela at **www.hambisela. co.za** and from MAITS at **http://www.maits.org.uk**. MAITS is an international organisation which exists to empower education and health professionals to enhance and develop the services they provide to individuals with disabilities in resource-poor settings through sharing knowledge and practice. Alternatively you can make your own 'before' and 'after' video clips to illustrate improved feeding practices.

Answers to the Positioning Quiz

Cards 6.03b

1.b.



Child held upright to make lip closure and swallowing easier. It is very difficult to swallow with your head back.

2.a.



Don't force head forward. Cradle base of head in your bent arm using same arm to bring child's arm forward. Use your other hand to press firmly on child's sternum.

3. a.



Support base of head in bend of your arm. Hold child's arms firmly forward. This, and pressure on sternum (mentioned in 2), help to reduce extensor pattern.

4. b.



Use your legs to support child in a good, upright position with child's hips and knees flexed.

5. b:



While sitting, hips and knees should be flexed at 90°. Arms should be forward with tray as support. Feet should be supported.

6. a.



Give food from the front, slightly below. Ensure child's head is symmetrical. This makes eating and swallowing easier. **Recipe Sheet** (for Bangladesh – for *Khichuri* and *Suji*). You will need to find suitable local recipes for the country where you are running the course.

