Part 4:

Appendices

Part 4:

Appendix 1 – *Screening Tools*

Washington Group Questions

(Child functioning 2-4yrs)

Washington Group Questions on Child Functioning (2-4 years)		
CHILD FUNCTIONING (AGE 2-4)		**CF**
CF1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE. DOES (*name*) WEAR GLASSES?	Yes ..... 1 No 2	 2⇨CF3
CF2. WHEN WEARING HIS/HER GLASSES, DOES (*name*) HAVE DIFFICULTY SEEING? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	1⇨CF4 2⇨CF4 3⇨CF4 4⇨CF4
CF3. DOES (*name*) HAVE DIFFICULTY SEEING? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	
CF4. DOES (*name*) USE A HEARING AID?	Yes ..... 1 No 2	 2⇨CF6
CF5. WHEN USING HIS/HER HEARING AID, DOES (*name*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	1⇨CF7 2⇨CF7 3⇨CF7 4⇨CF7
CF6. DOES (*name*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	
CF7. DOES (*name*) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes ..... 1 No 2	 2⇨CF10
CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING? WOULD YOU SAY (*name*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	
CF9. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	1⇨CF11 2⇨CF11 3⇨CF11 4⇨CF11
CF10. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY WALKING? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	

Washington Group on Disability Statistics

October 2016

unicef

Washington Group Questions

(Child functioning 2-4yrs)

CF11. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY PICKING UP SMALL OBJECTS WITH HIS/HER HAND? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	
CF12. DOES (*name*) HAVE DIFFICULTY UNDERSTANDING YOU? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	
CF13. WHEN (*name*) SPEAKS, DO YOU HAVE DIFFICULTY UNDERSTANDING HIM/HER? WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	
CF14. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY LEARNING THINGS? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	
CF15. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY PLAYING? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... 1 Some difficulty ..... 2 A lot of difficulty ..... 3 Cannot do at all 4	
CF16. COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DOES (*name*) KICK, BITE OR HIT OTHER CHILDREN OR ADULTS? WOULD YOU SAY: NOT AT ALL, THE SAME OR LESS, MORE OR A LOT MORE?	Not at all ..... 1 The same or less ..... 2 More ..... 3 A lot more 4	

www.washingtongroup-disability.com/washington-group-question

Washington Group on Disability Statistics

October 2016

unicef

Washington Group Questions

(Child functioning 5-17yrs)

CHILD FUNCTIONING (AGE 5-17)		
CF1. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE. DOES (*name*) WEAR GLASSES OR CONTACT LENSES?	Yes ..... No	 2⇨CF3
CF2. WHEN WEARING HIS/HER GLASSES OR CONTACT LENSES, DOES (*name*) HAVE DIFFICULTY SEEING? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	1⇨CF4 2⇨CF4 3⇨CF4 4⇨CF4
CF3. DOES (*name*) HAVE DIFFICULTY SEEING? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	
CF4. DOES (*name*) USE A HEARING AID?	Yes ..... No	 2⇨CF6
CF5. WHEN USING HIS/HER HEARING AID, DOES (*name*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	1⇨CF7 2⇨CF7 3⇨CF7 4⇨CF7
CF6. DOES (*name*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	
CF7. DOES (*name*) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING?	Yes ..... No	 2⇨CF12
CF8. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*name*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty ..... A lot of difficulty ..... Cannot do at all	 3⇨CF10 4⇨CF10
CF9. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*name*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	Some difficulty ..... A lot of difficulty ..... Cannot do at all	
CF10. WITH HIS/HER EQUIPMENT OR ASSISTANCE,		

Washington Group on Disability Statistics

October 2016

unicef

Washington Group Questions

(Child functioning 5-17yrs)

DOES (*name*) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	 3⇨CF14 4⇨CF14
CF11. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*name*) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	1⇨CF14
CF12. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	 3⇨CF14 4⇨CF14
CF13. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*name*) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE]. WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	
CF14. DOES (*name*) HAVE DIFFICULTY WITH SELF-CARE SUCH AS FEEDING OR DRESSING HIM/HERSELF? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	
CF15. WHEN (*name*) SPEAKS, DOES HE/SHE HAVE DIFFICULTY BEING UNDERSTOOD BY PEOPLE INSIDE OF THIS HOUSEHOLD? WOULD YOU SAY (*name*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL?	No difficulty ..... Some difficulty ..... A lot of difficulty ..... Cannot do at all	

Washington Group on Disability Statistics

October 2016

unicef

Washington Group Questions

(Child functioning 5-17yrs)

CF16. When (*name*) speaks, does he/she have difficulty being understood by people outside of this household? Would you say (*name*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	
CF17. Compared with children of the same age, does (*name*) have difficulty learning things? Would you say (*name*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	
CF18. Compared with children of the same age, does (*name*) have difficulty remembering things? Would you say (*name*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	
CF19. Does (*name*) have difficulty concentrating on an activity that he/she enjoys doing? Would you say (*name*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	
CF20. Does (*name*) have difficulty accepting changes in his/her routine? Would you say (*name*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	
CF21. Compared with children of the same age, does (*name*) have difficulty controlling his/her behaviour? Would you say (*name*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	
CF22. Does (*name*) have difficulty making friends? Would you say (*name*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?	No difficulty Some difficulty A lot of difficulty Cannot do at all	
CF23. How often does (*name*) seem very anxious, nervous or worried? Would you say: daily, weekly, monthly, a few times a year or never?	Daily Weekly Monthly A few times a year Never	
CF24. How often does (*name*) seem very sad or depressed?	Daily Weekly Monthly	

Washington Group on Disability Statistics

October 2016

unicef

Washington Group Questions

(Child functioning 5-17yrs)

WOULD YOU SAY: DAILY, WEEKLY, MONTHLY, A FEW TIMES A YEAR OR NEVER?	A few times a year..... Never.....	

www.washingtongroup-disability.com/washington-group-question

Washington Group on Disability Statistics

October 2016

unicef

Informal Observation Checklist

MAITS | MULTI-AGENCY INTERNATIONAL TRAINING AND SUPPORT

Observation Checklist

Child's name **Date** **Location** **Observer's name**

Watch the child interacting with a caregiver or with other children. Interact with the child yourself. Think about the following in relation to what you would expect a child of their age to be able to do. Make a note of any areas you have concerns over.

1. **MOTOR SKILLS**
   - Can the child move and control his/her head position?
   - Can the child pick up or hold an object?
   - Can the child sit up from lying, stay sitting, stand, walk – with help / without help?
   - Is the child as able to move about like other children of the same age?
   - Watch for motor differences:
     - Startle reflex
     - Movements the child makes that the child can't control (involuntary movements)
     - The two sides of the body looking or moving differently (asymmetry)

Comments:

2. **INTELLECTUAL (LEARNING) SKILLS**
   - Does the child seem to understand what is happening around them?
   - Is the child playing / doing an activity typical for its age?
   - Did the child play with you in the way you would have expected, and in an age appropriate activity?

Comments:

3. **SIGNS OF AUTISM**
   - Is the child interested in the other children in the room, or does it prefer to play alone?
   - Did the child look at you and want to play with you when you tried?

Comments:

Informal Observation Checklist

4. **HEARING**
   - Does the child look around the room when s/he hears other noises?
   - When you said the child's name did he look at you?

Comments:

5. **VISION**
   - Does the child have obvious visual difficulties?
   - Did the child look at you when you were playing?
   - Did the child look at the play objects and could s/he follow them visually when you moved them sideways and up/down?

Comments:

6. **COMMUNICATION SKILLS**
   - Did the child understand what you said to him/her in the way you expected for their age?
   - Does the child communicate with the other children and did they talk to you in a similar way to other children of the same age?
     - Did s/he know the words for things?
     - Was s/he putting words together as you would expect?
     - Did his/her speech sound clear or slurred?

Comments:

7. **BEHAVIOUR**
   - Is the child showing sign of aggression?
   - Did the child cooperate with you when you wanted to play with him/her, or did s/he react negatively?

Comments:

CHILD PROTECTION: Is there anything that makes you think this child may be being mistreated? – Are they unusually withdrawn or afraid? Do they have marks on their body?

If so – you need to follow local procedures for reporting this.

Part 4:

Appendix 2 – *Casebook*

Casebook

(including intervention overview, Child Profile form, level descriptors, Child Health and Well-being form, Parent (and child) Interview tool, case note template)

MAITS | MULTI-AGENCY INTERNATIONAL TRAINING AND SUPPORT

CASE BOOK

For use with the Parent Guide

Caring for
Children with Developmental Disabilities

Casebook

(including intervention overview, Child Profile form, level descriptors, Child Health and Well-being form, Parent (and child) Interview tool, case note template)

HOW TO USE THE GUIDE

ASSESSMENT

Step 1: Carry out your informal screening and assessment (see samples in appendices)

- Refer on to specialists services where needed / possible

Step 2: Complete the Child Profile and Child Health and Well-being: BASELINE

Step 3: Conduct the Parent (and child) Interview: BASELINE, involving the child where possible, and together select 3 Daily Activities to focus on (eg. Toileting, Eating & Drinking, Play/educational activities).

INTERVENTION

Step 1: Provide general information to the parents from Part 2, according to the child's age and needs.

Step 2: Go through the suggestions in the Guide on the Daily Activities they have chosen to focus on. Use all of the sections relevant to the child's identified areas of need (e.g. CP and ID; ID and Autism) and levels of functioning in each.

Step 3: Support the family with these for the next few weeks.

REVIEW

Step 1: Complete the Child Health and Well-being: REVIEW and Parent (and child) Interview: REVIEW, including the child where possible.

Step 2: Discuss any changes in the scores, with the parents and child, and explore the barriers, if any, to achieving greater change.

Step 3: Reset targets with parents and child, based on this discussion. Talk about what they want to work on next. They may want to continue to work on the same activity, but to progress *within* it.

Casebook

(including intervention overview, Child Profile form, level descriptors, Child Health and Well-being form, Parent (and child) Interview tool, case note template)

CHILD PROFILE

Date……..

Staff name……..

Child name: **m/f** **Date of birth/age:**

Address:

Any given diagnoses and known medical issues:

Baby / toddler (0-2) ☐ 2+ years ☐ Teenager ☐

AREAS OF NEED						
Main area(s) of need					**Additional difficulties**	
	Yes: Level			No		Yes No
	III	II	I			
Cerebral Palsy	☐	☐	☐	☐	Hearing problems	☐ ☐
Intellectual disability	☐	☐	☐	☐	Visual impairment	☐ ☐
Autism spectrum	☐	☐	☐	☐	Difficulty understanding what people say or problems with speaking	☐ ☐
			Yes	No	Behavioural issues	☐ ☐
Profound & Multiple Learning Disabilities			☐	☐	Epilepsy	☐ ☐

Comments:

Level Descriptors

	Level III	Level II	Level I
Cerebral Palsy	 *This child needs full physical support for all activities. She is not able to sit, stand, or walk without adequate support and will probably need lifting. She has very limited use of her hands. If this child is able to talk, her speech is very difficult to understand even by people who know her well. She has difficulties eating and drinking (feeding herself, chewing and/or swallowing).*	 *This child cannot walk on his own, but he can sit if he has support. (He may need help from an adult to get into and out of a sitting position). He can hold his toothbrush or spoon, but needs help to use them. His speech is difficult to understand by people who do not know him well. He may have some difficulties with chewing or swallowing.*	 *This child can walk, but is unsteady on her feet and may need a walking aid. She is able to do things with her hands, but with some difficulty and may have problems with sitting balance when using both her hands. Her speech is fairly clear, but may be a little difficult to understand at times. She might have difficulties chewing or swallowing some foods (e.g. very crunchy, hard or chewy).*
Intellectual Disability	*This child needs help with all activities. She does not understand the task (why she needs to do it and how to go about it) nor why something could be dangerous. Her behaviour is like that of a much younger child (e.g. mouthing objects, throwing objects). Her behaviour can be repetitive and be done to stimulate or calm herself (e.g. rocking, chewing hand). She does not speak and does not understand others; others have to interpret her communication by understanding her behaviour. She may have some difficulties with eating and drinking.*	*This child needs help to carry out tasks, but with lots of repetition might learn to do them independently (e.g. dressing, washing, eating). He understands and uses some simple familiar phrases. He does not always know how to behave appropriately in different situations.*	*This child will learn to be independent with a little more help than is usually required. She is generally a slow learner, but with support will learn in time. She can talk, but usually in simple sentences. She understands everyday conversations. She will not achieve the same levels at school as her peers*

Casebook

(including intervention overview, Child Profile form, level descriptors, Child Health and Well-being form, Parent (and child) Interview tool, case note template)

Autism spectrum	*This child does not use speech. He rarely approaches adults and may not show awareness of an adult nearby. He finds it difficult to show his needs and does not seem interested in others. He often shows a high degree of interest in sensory stimulation and shows repetitive behaviour such as rocking, mouthing objects, flapping hands, etc. He can seem like he is in a world of his own. He may have behaviours that can hurt himself or others (e.g. head banging, biting self or others).*	*This child uses some words and some learnt phrases, but often repeats what he hears again and again (this may include songs, television commercials, sounds, etc.). Rather than asking for things he may either try to fetch it himself, or may place an adult's arm on the object (eg. Packet of biscuits) without looking at the adult. He can show particular interest or be disturbed by certain sensory experiences. He is obsessed with the same routines and objects. He may have rituals and interests in unusual objects or parts of objects. He likes to play alone and does not share.*	*This child seems to be developing like other children, but prefers adult company or playing alone. He may have difficulties having a conversation, but speaks normally in all other ways. He likes his routines and can become upset when these are changed. He can be extra sensitive to particular sensory experiences. As the child grows up he has more and more difficulties fitting in socially, making friends, and understanding other people's point of view.*

Child Health and Well-being: BASELINE

Child name:
Address:

Today's date……

Name of caregiver(s) being interviewed……..

Age/ DOB	Weight (kg)	Height (cm)	Ask parents how many chest infections in last 3 months	Ask parents about the child's health compared to other children	Ask parents how often this child is happy	Ask parents how much the child participates in social activities
				1. Poor 2. Reasonable 3. Good	1. Rarely/never 2. Sometimes 3. Mostly	1. Rarely/never 2. Sometimes 3. Often

Parent (and child) Interview: BASELINE

Please tick the correct box:

Scores below were given by the interviewer following the interview ☐
Or
Scores were given during the interview as reported exactly by the parents ☐

Ask the parent, and child if possible: "How well is your child managing in the following?"

Activity of daily living	**How well is your child managing? (1-5)** 
1. Toileting	1 2 3 4 5
2. Bathing	1 2 3 4 5
3. Dressing	1 2 3 4 5

4. Grooming	1 2 3 4 5
5. Eating & drinking	1 2 3 4 5
6. Brushing teeth	1 2 3 4 5
7. Educational activities/Play	1 2 3 4 5
8. Resting & sleeping	1 2 3 4 5
9. Household jobs	1 2 3 4 5
10. Going to school	1 2 3 4 5
11. Going out: to the shops / the fields	1 2 3 4 5

Say to the parents: "I want to ask you a few questions about how you're feeling about caring for this child/(use child's name). Is that OK?"

	How do you feel? (1-5) 
How *confident* are you in caring for your child? Do you know how to help your child to grow and develop?	1 2 3 4 5
How do you *feel* about caring for your child?	1 2 3 4 5
What do you find hardest and what do you find easiest?	
Is there anything specific that you think would help you?	

We're going to choose some areas to focus on with your child's learning. As your child learns to do things, it will be easier to care for them.

Summary: List targets areas selected to focus on for the next 2 months

1. **……**
2. **……**
3. **……**

INTERVENTION

Step 1: Introduce key principles to parents (Part 2 of manual)

Go through Part 2 of the Guide, selecting relevant sections based on the Child Profile

- Importance of the Daily Routine (relevant to *all* children)
- Babies and Toddlers
- Important considerations and general principles for children with CP
- Important considerations and general principles for supporting children with Social Communication Difficulties and Autism
- Supporting children with profound and multiple learning disabilities
- Supporting teenagers (additional considerations)

- Top tips: Children with hearing impairment
- Top tips: Children with visual impairment
- Top tips: Communicating with children with disabilities
- Top tips: Understanding and managing behaviour
- Basic principles on the management of Epilepsy

Step 2: Follow the guidelines for 3 core activities (Part 3 of the Guide)

Once everyone is familiar with the basic principles, use the advice in Section 3 of the manual to help guide parents on 3 activities of daily living. Select the section(s) of the Guide that are relevant to the child's profile eg. CP level II, Intellectual disability level III etc.

You may like to start with: Toileting, Eating & drinking, Educational activities (play)

Casebook

(including intervention overview, Child Profile form, level descriptors, Child Health and Well-being form, Parent (and child) Interview tool, case note template)

Visit Summaries

Visit	Date	What did you discuss (include what activities you have chosen to work on)	What materials did you use (assessment forms, sections of Guide etc)
1			
2			
3			
4			

Casebook

(including intervention overview, Child Profile form, level descriptors, Child Health and Well-being form, Parent (and child) Interview tool, case note template)

5	6	7	8

Child Health and Well-being: REVIEW

Child name:
Address:

Today's date……

Name of caregiver(s) being interviewed……

Age/ DOB	Weight (kg)	Height (cm)	Ask parents how many chest infections in last 3 months	Ask parents about the child's health compared to other children	Ask parents how often this child is happy	Ask parents how much the child participates in social activities
				1. Poor 2. Reasonable 3. Good	1. Rarely/never 2. Sometimes 3. Mostly	1. Rarely/never 2. Sometimes 3. Often

Parent (and child) Interview: REVIEW

Ask the parents (and child, if possible): "Have you noticed any changes in any of the following?"

Activity of daily living	Any change: Yes/No	Describe the changes, if any	How is your child managing now? 
1. Toileting	Y / N		1 2 3 4 5
2. Bathing	Y / N		1 2 3 4 5
3. Dressing	Y / N		1 2 3 4 5
4. Grooming	Y / N		1 2 3 4 5

5. Eating & drinking	Y / N		1 2 3 4 5
6. Brushing teeth	Y / N		1 2 3 4 5
7. Educational activities/Play	Y / N		1 2 3 4 5
8. Resting & sleeping	Y / N		1 2 3 4 5
9. Household jobs	Y / N		1 2 3 4 5
10. Going to school	Y / N		1 2 3 4 5
11. Going out: to the shops / the fields	Y / N		1 2 3 4 5

Ask the parents:

	How do you feel? (1-5) 
How *confident* are you in caring for your child? Do you know how to help your child to grow and develop?	1 2 3 4 5
How do you *feel* about caring for your child?	1 2 3 4 5
What do you find hardest and what do you find easiest?	
What has been the most helpful thing you have learned from me?	
What else would help?	

Reset targets

- Discuss any changes in the child data sheets and interview scores, with the parents and child and explore the barriers, if any, to achieving greater change.

Note the discussion here:

- Use this as a basis to talk about what they want to work on next. They may want to continue to work on the same activity, but to progress *within* it.

New targets:

1. .....
2. .....
3. .....

Part 4:

Appendix 3 – *Additional Information and Resources*

High Nutrition Recipes

Nutrition Rehabilitation Unit at ICDDR,B
An ideal home for treatment of children with severe malnutrition

In many parts of the world, HIV/AIDS is killing millions of its victims by suppressing their immune system, making them vulnerable to repeated infections. Eventually, they succumb to one of these infections. In Bangladesh, infection with HIV/AIDS is fortunately still quite rare, but we have an equally dangerous condition leading to immunosuppression, repeated infections, and all too often, death. This condition is not AIDS, rather malnutrition, but unlike AIDS, malnutrition is easily treated and can be cured, not just controlled.

In partnership with the World Health Organization, nutrition researchers at ICDDR,B have developed and implemented a standardized treatment protocol for severely-malnourished children. The protocol is based on the incorporation of the "best practices" derived from evidence-based reasoning and decades of experience on the management of severe malnutrition of childhood. Implementation of the protocol in the ICDDR,B's Dhaka hospital reduced mortality among severely-malnourished children by more than 75%. Publication of results from the Centre in *The Lancet* demonstrated for the first time that the number of deaths can be substantially reduced among severely-malnourished children with acute illnesses, including diarrhoea, pneumonia, and septicaemia by following a prescriptive treatment protocol.

In South Asia, the death rate among hospitalized children with severe malnutrition is still very high (around 20%). The treatment of the severely-malnourished children is basically accomplished in three phases: the acute phase during which the child is stabilized and death is prevented, the nutritional rehabilitation phase which aims at achieving catch-up weight gain that the child has already lost, and the follow-up phase which prevents relapse into severe malnutrition and promotes further growth and development.

Research done at ICDDR,B has shown that severely-malnourished children are more likely to die after discharge from hospital following successful treatment of acute illnesses, including diarrhoea and pneumonia. To prevent such deaths, the nutritional status of these children has to be improved through an appropriate and sustainable nutritional rehabilitation programme. This is done in the Nutrition Rehabilitation Unit (NRU) in the Dhaka hospital of ICDDR,B. Milk-based diets are ideal for nutritional rehabilitation but milk is not readily available in many places and is expensive. Therefore, a standardized diet protocol was developed in the NRU for rapid catch-up growth during nutritional rehabilitation using low-cost, culturally-appropriate and nutritious food based on locally-available ingredients. Essential micronutrients needed for the growth and development of the severely-malnourished children are also provided.

Ingredients of khichuri

Ingredients of halwa

Most importantly, the mothers or other caretakers staying with the children in the NRU are given health and nutrition education. They are advised on the correct child-rearing practices and preparation of diets used in the standardized protocol. The diets used in the standardized protocol include *khichuri*, *halwa*, and *milk suji*.

Khichuri, a low-cost, nutritious food, is prepared from rice, lentils (*dal*), green leafy vegetables, and soybean oil. Each gramme gives one kilocalorie of energy. *Halwa*, another low-cost, nutritious diet, is prepared from wheat-flour, lentils, molasses, and soybean oil. This is more energy-dense, each gramme contributing about two kilocalories. *Milk suji*, unlike *khichuri* and *halwa*, is a liquid diet prepared from rice-powder, milk-powder, soybean oil, and sugar. During nutritional rehabilitation, the amount of *milk suji* is gradually decreased while that of *khichuri* and *halwa* is increased. Recipes of *khichuri* and *halwa* are presented in the tables, and that of *milk suji* is as follows:

Ingredients of *Milk Suji*: Whole milk powder 40 g, Rice powder 40 g, Sugar 25 mg, Soybean oil 25 g, Magnesium chloride 0.5 g, Potassium chloride 1.0 g, Calcium lactate 2.0 g, Cooked volume 1.0 L, Energy 67 kcal/100 mL, Protein 1.4 g/100 mL

Preparation: Place all ingredients in a clean, dry saucepan, and mix thoroughly.

High Nutrition Recipes

Ingredients of khichuri

Ingredient	Amount	Energy (kcal)	Protein (g)
Rice	4 ounces (120 g)	415	8
Lentils (*mashur dal*)	2 ounces (60 g)	206	15.6
Soybean oil	2 ounces (70 mL)	630	-
Potatoes	4 ounces (100 g)	97	1.6
Pumpkin	4 ounces (100 g)	25	1.4
Leafy vegetable (*shak*)	3 ounces (80 g)	22	2
Onions (2 medium size)	2 ounces (50 g)	25	-
Spices (ginger, garlic, turmeric, coriander powder) to taste	50 g	22	1
Water -	2 pints (1,000 mL)	-	
Total weight of *khichuri*	1,000 g	-	-
Total energy and protein per kg	-	1,442	29.6

100 g of *khichuri* contains about 145 kcal energy and 3 g protein. One cup (130 g) of *khichuri* contains 190 kcal energy and 4 g protein.

Preparation: Place the rice, *dal*, oil, spices, and water in a pot and boil. After about 20 minutes, add the potatoes, pumpkin (cut into pieces), and spices. Just 5 minutes before the rice is cooked, add the cleaned and chopped leafy vegetable. Keep the pot covered during cooking. It takes about 50 minutes to cook *khichuri*. *Khichuri* and *halwa* can be kept at room temperature for 6-8 hours.

Add about 900 millilitres of water to the saucepan and again mix thoroughly. Cook the mixture stirring frequently with a spoon, and allow to boil for one minute. Allow to cool down and then measure with a measuring flask. If the volume is more than one litre, heat it again. If it is less than a litre, add water to make up to litre. See tables for recipes of *khichuri* and *halwa*.

A severely-malnourished child is released from the NRU when s/he has achieved the desired weight, no longer has oedema of the feet, and the mother is found to be capable of taking care of the child and preparing the diets. This usually takes about two weeks. By this time, the child is almost entirely on *khichuri* and *halwa*—diets that can be prepared and continued at home. Another advantage of these local diets is that these can also be fed to the siblings, thereby preventing them from becoming malnourished. The rate of weight gain—an indicator of the progress of nutritional rehabilitation—is comparable with that of children solely fed milk-based diets and is, on an average, 12 grammes per kg of body-weight per day.

The NRU accommodates only 18 very severely-malnourished children. Children with less severe malnutrition and children who have been released from the NRU are advised to attend the Nutrition Follow-up Unit (NFU). While these children are enrolled in the NFU until they achieve a satisfactory body-weight, their growth and development are promoted through periodic assessment of nutritional status, micro-nutrient supplementation, and counselling to mothers or other caretakers on the general condition of their children, health and nutrition interrelation, and immunization.

One of the many sessions of nutrition counselling in the Dhaka hospital of ICDDR,B

High Nutrition Recipes

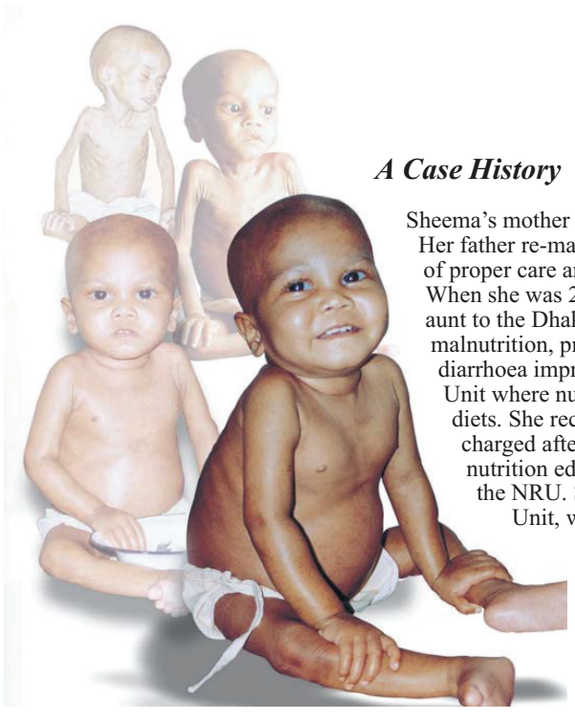
The NRU is an excellent platform not only for childcare but also for training and research. Health professionals from within the country and abroad come to the NRU for hands-on training on the management of severe malnutrition. The training programme is closely coordinated with the training modules of the World Health Organization. Staff members of ICDDR,B have been actively involved in training courses in Bhutan, Afghanistan, Uganda, Cambodia, and Sweden for doctors who intend to be involved with humanitarian activities in Africa and other regions of the world where childhood malnutrition is widely prevalent. The NRU is currently the centre for research on further simplifying the management of severe malnutrition and diagnosis and treatment of childhood tuberculosis.

Ingredients of *halwa*

Ingredient	Amount	Energy (kcal)	Protein (g)
Wheat flour (*atta*)	7 ounces (200 g)	682	24
Lentils (*mashur dal*)	4 ounces (100 g)	343	26
Soybean oil	3 ounces (100 mL)	900	-
Molasses (brown sugar or *gur*)	4 ounces (125 g)	479	0.5
Water	600 mL (to make a thick paste)	-	-
Total weight of *halwa*	1,000 g	-	-
Total energy and protein per kg	-	2,404	50.5

100 g of cooked *halwa* contains 240 kcal energy and 5 g protein. One cup (130 g) of cooked *halwa* contains 312 kcal energy and 6.5 g protein.

Preparation: Soak *dal* in water for 30 minutes and then mash. Fry *atta* in a hot pan for a few minutes. Mix *atta*, mashed *dal,* and oil with water. Melt g*ur* and add to the mixture to make a thick *halwa*.



A Case History

Sheema's mother died of childbirth complications soon after she was born. Her father re-married, and thereafter her aunt started to look after her. Lack of proper care and repeated bouts of diarrhoea made her malnourished. When she was 2 years old, she became very ill and was admitted by her aunt to the Dhaka hospital of ICDDR,B. She was suffering from profound malnutrition, pneumonia, and diarrhoea. As soon as her pneumonia and diarrhoea improved, Sheema was placed in the Nutrition Rehabilitation Unit where nutritional rehabilitation was started using local, low-cost diets. She recovered from the state of acute malnutrition and was discharged after five weeks. Her aunt was responsive to the health and nutrition education provided to her while she stayed with Sheema in the NRU. She diligently brought Sheema to the Nutrition Follow-up Unit, which proved to be rewarding. At the end of follow-up for further 5 months, Sheema was a normal, healthy child.

Contributed by
Dr Tahmeed Ahmed
Coordinator
Mother and Child Health Services
Clinical Sciences Division

Information on Polio

From: Werner, D. (1999) *Disabled Village Children: A guide for community health workers*

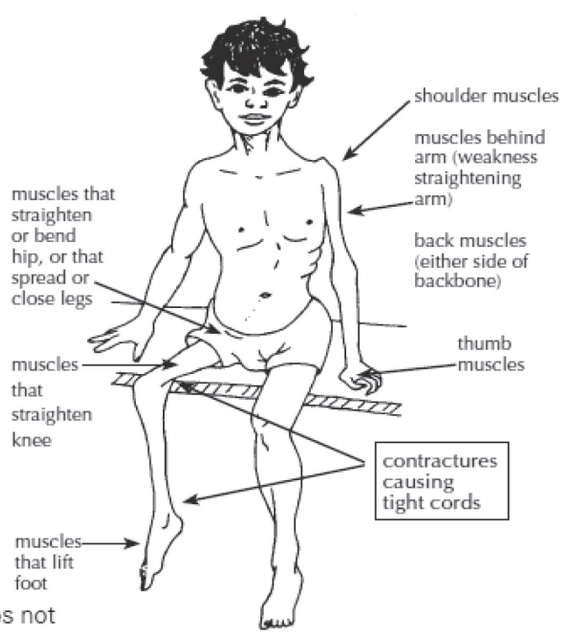
CHAPTER 7

Polio
Infantile Paralysis

HOW TO RECOGNIZE PARALYSIS CAUSED BY POLIO

- ***Paralysis*** (muscle weakness) usually begins when the child is small, often during an illness like a bad cold with fever and sometimes diarrhea.
- Paralysis may affect any ***muscles*** of the body, but is most common in the legs. Muscles most often affected are shown in the drawing.
- Paralysis is of the **'floppy'** type (not stiff). Some muscles may be only partly weakened, others limp or floppy.
- In time the affected limb may not be able to straighten all the way, due to shortening, or ***'contractures'***, of certain muscles.
- The muscles and bones of the affected limb become thinner than the other limb. The affected limb does not grow as fast, and so is shorter.

MUSCLES COMMONLY WEAKENED BY POLIO



- Unaffected arms or legs often become extra strong to make up for parts that are weak.
- **Intelligence** and the mind are not affected.
- **Feeling** is not affected.
- 'Knee jerks' and other ***tendon*** reflexes in the affected limb are reduced or absent. (In cerebral palsy, 'knee jerks' often jump more than normal. See p. 88.) Also, the paralysis of polio is 'floppy'; limbs affected by cerebral palsy often are tense and resist when straightened or bent (see p. 102).

- The paralysis does not get worse with time. However, secondary problems like contractures, curve of the backbone and ***dislocations*** may occur.

Of children who become paralyzed by polio:

30% recover completely in the first weeks or months.

30% have mild paralysis.

30% have moderate or severe paralysis.

10% die (often because of difficulty breathing or swallowing).

Information on Polio

From: Werner, D. (1999) *Disabled Village Children: A guide for community health workers*

BASIC QUESTIONS AND ANSWERS ABOUT POLIO

How common is it? In many countries, polio—or 'poliomyelitis'—was for many years the most common cause of physical disability in children. In some areas, one of every 100 persons may have some paralysis from polio. ***Vaccination*** programs have ended polio in many countries, but it is still a common problem in India, Nepal, Nigeria and Afghanistan.

Paralysis in one leg

What causes it? A ***virus (infection).*** The infection attacks parts of the ***spinal cord,*** where it damages only the ***nerves*** that control movement. In areas with poor hygiene and lack of latrines, the polio infection spreads when the ***stool*** (shit) of a sick child reaches the mouth of a healthy child. Where sanitation is better, polio spreads mostly through coughing and sneezing.

Do all children who become infected with the polio virus become paralyzed? No, only a small percentage become paralyzed, about 1 out of every 100 to 150 children who are exposed to the virus. Most only get what looks like a bad cold, with fever, vomiting or diarrhea.

Severe paralysis

Is the paralysis contagious? No, not after 2 weeks from when a child first gets sick with polio. In fact, most polio is spread through the stool of non-paralyzed children who have 'only a cold' caused by the polio virus.

At what age do children get polio? In areas with poor sanitation, polio most often attacks babies from 8 to 24 months old, but occasionally children up to age 4 or 5. As sanitation improves, polio tends to strike older children and even young adults.

Who does it most often affect? Boys, a little more than girls. Unvaccinated children much more often than vaccinated children, especially those living in crowded, unsanitary conditions.

How does the paralysis begin? It begins after signs of a cold and fever, sometimes with diarrhea or vomiting. After a few days the neck becomes stiff and painful and parts of the body become limp. Parents may notice the weakness right away, or only after the child recovers from the acute illness.

Once a child is paralyzed, what changes or improvements can be expected? Often the paralysis will gradually go away, partly or completely. Any paralysis left after 7 months is usually permanent. The paralysis will not get worse. However, certain secondary problems may develop—especially if precautions are not taken to prevent them.

What are the child's chances of leading a happy, productive life? Usually very good—provided the child is encouraged to do things for himself, to get the most out of school, and to learn useful skills within his physical limitations (see p. 497).

Can persons with polio marry and have normal children? Yes. Polio is not inherited (familial) and does not affect ability to have children.

Information on Polio

From: Werner, D. (1999) *Disabled Village Children: A guide for community health workers*

SECONDARY PROBLEMS TO LOOK FOR WITH POLIO

By **secondary** problems, we mean further disabilities or complications that can appear after, and because of, the original disability.

CONTRACTURES OF JOINTS

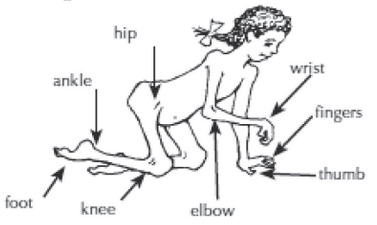
A contracture is a shortening of muscles and tendons (cords) so that the full range of limb movement is prevented.

Unless preventive steps are taken, joint contractures will form in many paralyzed children. Once formed, often they must be corrected before braces can be fitted and walking is possible. Correction of advanced contractures, whether through exercises, casts, or surgery (or a combination), is costly, takes time and causes discomfort. Therefore **early prevention of contractures is very important.**

A full discussion of contractures, their causes, prevention, and treatment is in the next chapter (Chapter 8). Methods and aids for correcting contractures are described in Chapter 59.

TYPICAL CONTRACTURES IN POLIO

A child with paralysis who crawls around like this and never straightens her legs will gradually develop contractures so that her hips, knees, and ankles can no longer be straightened.



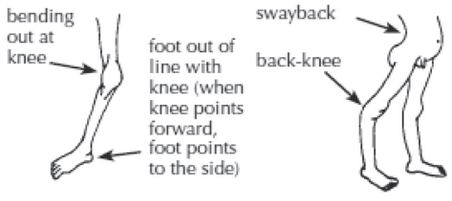
TYPICAL DEFORMITIES OF ANKLE AND FOOT

bending down at ankle (tiptoe contracture) | bending down at mid-foot | bending out at ankle | bending in at ankle

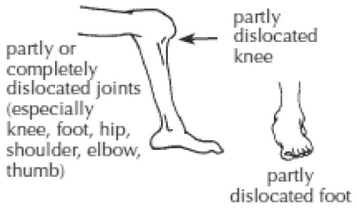
OTHER COMMON DEFORMITIES

Weight bearing (supporting the body's weight) on weak joints can cause deformities, including:

OVER-STRETCHED JOINTS



DISLOCATIONS



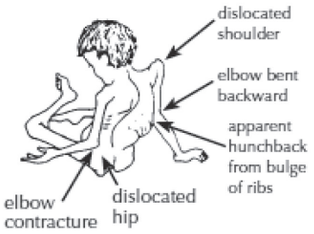
WARNING:
Dislocations like these are sometimes caused by stretching contractures incorrectly. (See p. 28.)

SPINAL CURVE

Minor curve of spine can be caused by tilted hips, as a result of a short leg.

More serious curve of the ***spine*** is caused by muscle weakness of the back or body muscles. The curve can become so severe that it endangers life by leaving too little room for the lungs and heart.

a severely paralyzed child



At first, the spinal curve straightens when the child is positioned better. But in time the curve becomes more fixed (will not straighten any more). For information on spinal curves, see Chapter 20.

Information on Polio

From: Werner, D. (1999) *Disabled Village Children: A guide for community health workers*

WHAT OTHER DISABILITIES CAN BE CONFUSED WITH POLIO?

- Sometimes **cerebral palsy** can be mistaken for polio—especially cerebral palsy of the 'floppy' type.

However, **cerebral palsy** usually affects the body in typical patterns:

Polio has a more irregular pattern of paralysis:

In cerebral palsy, usually you can find other signs of brain damage: over-active knee jerks and abnormal reflexes (see p. 88), developmental delay, awkward or uncontrolled movement, or at least some muscle tenseness (***spasticity***).

- In **muscular dystrophy,** paralysis begins little by little and steadily gets worse (see p. 109).

- **Hip problems** (see p. 155) can cause limping, and muscles may become thin and weak. Check hips for pain or dislocations. (**Note:** Dislocated hip may also occur secondary to polio.)

Note: Polio can occur before or after a child has any of these other problems. Check carefully.

- **Clubbed foot** is present from birth (see p. 114).

- **'Erb's palsy',** or partial paralysis in one arm and hand, comes from birth injury to the shoulder (see p. 127).

- **Leprosy.** Foot and hand paralysis begins gradually in older child. Often there are skin patches and loss of feeling (see p. 215).

- **Spina bifida** is present from birth. There is reduced feeling in the feet, and often a lump (or scar from surgery) on the back (see p. 167).

ALWAYS EXAMINE THE BACK IN A CHILD WITH PARALYSIS OF THE LEGS, AND CHECK FOR FEELING.

- **Injuries to the spinal cord** (see p. 175) or to particular nerves going to the arms or legs. There is usually a history of a severe back or neck injury, and loss of feeling in the paralyzed part.

- **Tuberculosis of the spine** can cause gradual or suddenly increasing paralysis of the lower body. Look for typical bump on spine (see p. 165).

- **Other causes of paralysis or muscle weakness.** There are many causes of floppy paralysis similar to polio. One of the most common is **'Guillain-Barre' paralysis.** This can result from a virus infection, from poisoning, or from unknown causes. It usually begins without warning in the legs, and may spread within a few days to paralyze the whole body. Sometimes feeling is also reduced. Usually strength slowly returns, partly or completely, in several weeks or months. ***Rehabilitation*** and prevention of secondary problems are basically the same as for polio.

DISABLED VILLAGE CHILDREN

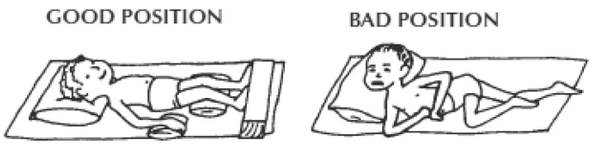
Information on Polio

From: Werner, D. (1999) *Disabled Village Children: A guide for community health workers*

WHAT CAN BE DONE?

DURING THE ORIGINAL ILLNESS, when the child first becomes paralyzed:

- **No medicines** help, either during the first illness, or later.
- **Rest** is important. **Avoid forceful exercise** because this may increase paralysis. **Avoid injections.**
- **Good food** during recovery helps the child become stronger. (But take care that the child does not eat too much and get fat. An overweight child will have more problems with walking and other movements.) For suggestions about good food, see ***Where There Is No Doctor,*** Chapter 11.
- **Position** the child to be comfortable and to avoid contractures. At first the muscles will be painful, and the child will not want to straighten his joints. Slowly and gently try to straighten his arms and legs so that the child lies in as good a position as possible. (See Chapter 8.)



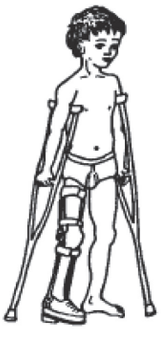
Arms, hips, and legs as straight as possible. Feet supported.

Bent arms, hips, and legs. Feet in tiptoe position.

Note: To reduce pain, you may need to put cushions under the knees, but try to keep the knees as straight as you can.

FOLLOWING THE ORIGINAL ILLNESS:

- Continue with **good food** and **good positions.**
- As soon as the fever drops, start **exercises** to prevent contractures and return strength. **Range-of-motion exercises** are described in Chapter 42. Whenever possible, make exercises fun. **Active games, swimming,** and other **activities to keep limbs moving as much as they can** are important throughout the child's rehabilitation.
- **Crutches, leg braces** ***(calipers)***, and other aids may help the child to move better and may prevent contractures or deformities.



- In special cases, **surgery** may be needed to correct contractures, or to change the place where strong muscles attach, so that they help do the work of weak ones. When a foot is very floppy or bends to one side, surgery to join certain bones of the foot may help. But because bone surgery stops the growth of the foot, usually it should not be done before age 12 or 13.
- Encourage the child to **use his body and mind** as much as possible, to play actively with other children, to **take care of his daily needs,** to **help with work,** and to **go to school.** As much as possible, **treat him like any other child.**

Information on Polio

From: Werner, D. (1999) *Disabled Village Children: A guide for community health workers*

REHABILITATION OF THE CHILD WITH PARALYSIS

All children paralyzed by polio can be helped by certain basic rehabilitation measures—such as exercise to keep a full range of motion in the affected limbs.

However, **each child will have a different combination and severity of paralyzed muscles, and therefore will have his own special needs.**

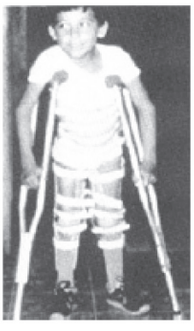
For some children, normal exercise and play may be all that are needed. Others may require special exercises and playthings. Still others may need braces or other aids to help them move about better, do things more easily, or keep their bodies in healthier, more useful positions. Those who are severely paralyzed may be helped most by a wheelboard (trolley) or wheelchair.

For this child, walking provides exercise that stretches his legs and feet, and prevents contractures. (Tilonia, India)

Every child needs to be carefully examined and evaluated in order to best meet his or her particular needs. The earlier you evaluate a child's needs, and take steps to meet them, the better.

Unfortunately, in most areas where polio is still common, village rehabilitation programs do not exist or are just beginning. Many children (and adults) who have been paralyzed for a long time already have severe deformities or joint contractures. Often these must be corrected before a child can use braces or begin to walk.

This child, who had polio as a baby, already had severe contractures in the hips, knees, and feet. (PROJIMO)



It took several months of exercises at home and then a series of plaster casts in the village rehabilitation center to straighten the contractures so he could walk with braces.

Because contractures are such a common problem, not only with polio but with many other disabilities, we discuss them separately in the next chapter. **Before evaluating a child with polio, we strongly suggest you read Chapter 8 on contractures.**

WARNING: Before deciding on any aid or procedure, carefully consider its advantages and disadvantages. For example, some deformities may be best left uncorrected because they actually help the paralyzed child stand straighter or walk better (see p. 530). And some aids or braces may prevent a child from developing strength to walk without aids (see p. 526). **Before deciding what aid or procedure to use, we suggest you read Chapter 56, "Making Sure Aids and Procedures Do More Good Than Harm."**

Information on Polio

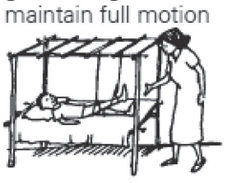
From: Werner, D. (1999) *Disabled Village Children: A guide for community health workers*

PROGRESS OF A CHILD WITH POLIO:
THE CHANGING NEEDS FOR AIDS AND ASSISTANCE

1. **exercises to keep full range of motion,** starting within days after paralysis appears and continuing throughout rehabilitation

2. **supported sitting** in positions that help prevent contractures

3. **active exercises** with limbs supported, to gain strength and maintain full motion



4. **exercise in water—** walking, floating, and swimming, with the weight of the limbs supported by the water

5. **wheelboard or wheelchair** with supports to prevent or correct early contractures

Note: These also provide good arm exercise in preparation for walking with crutches.

6. **braces** to prevent contractures and prepare for walking

7. **parallel bars** for beginning to balance and walk

8. **walking machine or 'walker'**

9. **crutches modified as walker** for balance and extra support

10. **under arm crutches**

11. **forearm crutches** and perhaps in time . . .

12. **a cane** or no arm supports at all

Note: These pictures are only an example—but most of the steps are necessary for many children. Children who begin rehabilitation late may also have contractures or deformities requiring corrective steps not shown here.

DISABLED VILLAGE CHILDREN

MEDIA CONSENT FORM

I consent to the use of photographs of me and my child

For your report to your organisation

In a published report for anyone to read

For teaching purposes

In leaflets and publications

On an organisation's website

I consent to the and use of videos of me and my child

For your report to your organisation

In a published report for anyone to read

For teaching purposes

In leaflets and publications

On an organisation's website

Child's name……..

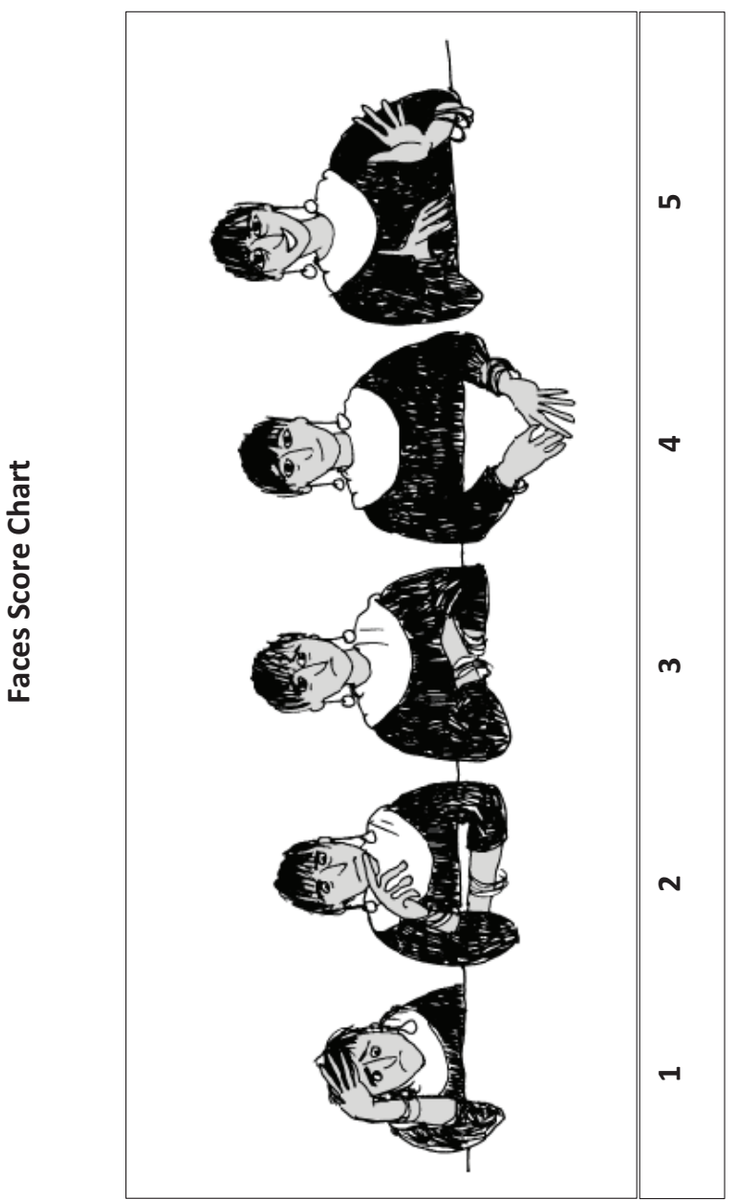
My name ……..

My relationship to the child ……

Signature ……

Date …….

Faces Score Chart



Glossary of Terms

Physical terms

Affected (side/hand/leg etc.) – part of the body that has the problem with movement or sensation

Asymmetric (movements) - non matching parts of the body

Contracture - permanent shortening of muscle or scar tissue, resulting in distortion or deformity

Deformities - parts of the body that are is miss-shapen, malformed or fixed in abnormal positions

Extension –in a full stretch

Flexed / flexion – in a bent or curled up position

Floppy – very little or no muscle tone or control

Handling – holding and moving a child

Hemiplegic - paralysis affecting only one side of the body.

Long-sitting – sitting on the floor with legs straight out in front of the body

Maintain full range of movement – keeping the body joints flexible (bending and stretching) in all directions

Mobility – moving around from one place to another

Muscle tone – muscle tension

Over-mobilise- move the joints in the body outside of their normal range

Pelvic strap – belt that holds the hips back in a chair, in order to keep the person stable whilst sitting.

Posture - holding your body in a position

Postural deformities – these include limb contractures, hip dislocation and spinal deformities

Prone – lying on your front with your head down

Reflex patterns –movements that are not in the child's control

Sit squarely -sitting with feet flat, knees and hips bent at 90 °, back not twisted and knees in line with one another

Sling –piece of cloth to support your arm or leg

Splints – an aid to hold your arm or leg in a good position to help you improve a movement, standing, walking, using your hand etc.

Stable position / stability – when the child is not going to fall into a different position

Stiff / stiffen – (non-technical) – due to increased tone - spasticity or rigidity

Supine – lying on the back

Supported seat /chair /seating - sitting on chair with a back and sides which gives greater support

Glossary of Terms

Symmetrical - both sides of the body matching, or moving together in the same way
Transfers – moving between positions; from lying to sitting; from sitting to standing; from standing back to sitting; from chair to another chair; from wheelchair to toilet
Walker – supportive frame to support child as he/she walks
Weight-bearing - taking body weight on your feet, such in as standing

Other:

Finger-foods – foods that can be held in the hand eg. biscuits
Fits – seizure resulting in reduced or loss of consciousness and/or abnormal body movements
Flash cards – picture cards to demonstrate an activity
Non-verbal cues - gestures or other body movements that communicate what the child is feeling or wanting
Pretend play – creative or imaginary play eg. the child uses a stone to pretend it is a ship; a doll for a baby..
Socialisation - meeting with different people and communicating with them
Total Communication – using several forms of communication at once, eg. showing an object, using gestures, and saying the word.
Visual timetable – a chart showing the activities of the day using pictures or objects to illustrate these, as well as the written word.

References

Resources and text books

Barnes, L. and Fairhurst, C. (2011), Hemiplegia Handbook for parents and professionals. Practical Guide from Mac Keith Press, London.

Bower, E. (Ed) (2009). Finnie's Handling the Young Child with Cerebral Palsy at Home. Elsevier, London.

CBM Flipcharts http://www.cbm.org/article/downloads/54741/Cerebral_Palsy_Toolkit_-_Part_2__Manual__English_.pdf [accessed on 15.02.2013].

Carrington, L., Curtin, M. (1993). Promoting the Development of Young Children with Cerebral Palsy. A Guide for Mid level Workers . Early signs of Cerebral Palsy (pp.15-16). http://whqlibdoc.who.int/hq/1993/WHO_RHB_93.1.pdf [accessed on 15.02.2013]

Cerebral Palsy Association (Eastern Cape). (2008) Hambisela: towards excellence in therapy for cerebral palsy. Version 2. http://www.hambisela.co.za [accessed on 15.02.2013]

Dodds, K., Imms, C., Taylor, N. (Eds). (2010) Physiotherapy and Occupational Therapy for People with Cerebral Palsy. Mac Keith Press, London.

Hinchcliffe, A. (2007) Children with Cerebral Palsy, 2nd edition. SAGE Publications Ltd, London.

Gettinger, M., & Guetschow, K. W. (1998). Parent and parent/child groups for young children with disabilities. In Stoiber, K. C. & Kratochwill, T. R. (Eds.), Handbook of Group Intervention for Children and Families. (pp. 345- 360). Allyn & Bacon, Needham Heights.

Hannah, L. (2001). Teaching young children with autistic spectrum disorders to learn. National Autistic Society, London.

Leicestershire County Council and Fosse Health Trust (2001). Autism: How to help your young child. National Autistic Society, London.

LSHTM (2013). Getting to know cerebral palsy. Working with parent groups – a training resource for facilitators, parents, caregivers and persons with cerebral palsy. http://disabilitycentre.lshtm.ac.uk

References

MacLachlan, H. and Elks, L. (2007). Language Builders for Complex Needs: Advice and activities to support children with severe and complex communication needs. Elklan: St Mabyn, Cornwall.

Newman, S. (1999). Small steps forward: Using games and activities to help your pre-school child with special needs. Jessica Kingsley, London

Pugmuire, A., Bishop, C., Rackstraw, E., Williams, G., Wilk, J., Prosser, L., Irons, M., Cole, N., Farrow, S. & Sudra, V. (2001). Social Communication Difficulties Resource Pack. Speechmark, Milton Keynes.

Stokes, M. (2007). Physical management in neurological rehabilitation. Elsevier, London.

Tassoni, P. (2007), Child Care and Education. 4th edition. Heinemann, New Hampshire.

Werner, D. (1999) Disabled Village Children: A guide for community health workers. The Hisperian Foundation, Palo Alto.

Wolf, L.S. & Glass, R.P. (1992). Feeding and Swallowing Disorders in Infancy – Assessment and Management. Therapy Skills Builders, Texas.

WHO (1997) Let's communicate : a handbook for people working with children with communication disorders. WHO Geneva.

WHO. (1980) Training the Disabled in the Community. Version 2. World Health Organisation, Geneva.

Research papers and position papers

Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., Paneth, N., Dan, B., Jacobsson, B., Damiano, D. (2005). Proposed definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology,* 47: 571–576.

Brossard-Racine, M., Waknin, J., Shikako-Thomas,K., Shevell, M., Poulin, C., Lach, L., Law, M., Schmitz, N., the QUALA Group, Majnemer, A. (2013). Behavioral Difficulties in Adolescents With Cerebral Palsy. *Journal of Child Neurology,* 28 (1): 27-33.

Ergüner-Tekinalp, B., & Akkök, F. (2004). The effects of a coping skills training program on the coping skills, hopelessness, and stress levels of mothers of children with autism. *International Journal for the Advancement of Counselling*, 26: 257-269.

Ertem, I.O., Dogan, D.G., Gok, C.G., Kizilates, S.U., Caliskan,A., Atay,G., Vatandas, N., Karaaslan,T., Baskan, S.G., Cicchetti, D.V. (2008) A Guide for Monitoring Child Development in Low- and Middle-Income Countries. *American Academy of Pediatrics,* 121 (3):581-589.

Franki, I., Desloovere, K., De Cat , J., Feys, H., Molenaers, G., Calders, P., Vanderstraeten, G., Himpens, E., Van den Broeck, C. (2012). The evidence-base for basic physical therapy

References

techniques targeting lower limb function in children with cerebral palsy: a systematic review using the International Classification of Functioning, Disability and Health as a conceptual framework. *Journal of Rehabilitation Medicine,* 44: 385–395.

Goddard, J. A., Lehr, R., & Lapadat, J. C. (2000). Parents of children with disabilities: Telling a different story. *Canadian Journal of Counselling,* 34: 273-289.

Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities,* 14: 159-171.

ILO, UN, WHO (2004) CBR: A Strategy for Rehabilitation, Equalization of Opportunities, Poverty Reduction and Social Inclusion of People with Disabilities. Joint Position Paper. World Health Organisation, Geneva.

Katalinic, O.M., Harvey, L.A., Herbert, R.D. (2011). Effectiveness of Stretch for the Treatment and Prevention of Contractures in People with_Neurological Conditions: A Systematic Review. *Physical Therapy,* 91: 11-24.

Kramer,M.S. and Kakuma, R. (2002). The optimal duration of exclusive breastfeeding: a systematic review. World Health Organisation, Geneva.

Novak, L., Hines, M., Goldsmith, S., Barclay, R. (2012). Clinical prognostic messages from a systematic review on cerebral palsy. *Pediatrics*, 130 (5): 1285-312.

Phillips, D. (Ed) (2012). Early Childhood Development and Disability: A discussion paper. WHO / UNICEF. UNICEF. http://tinyurl.com/bs5kqwb [accessed on15.02.2013]

Pin, T., Dyke, P., Chan, M. (2006). The effectiveness of passive stretching in children with cerebral palsy. *Developmental Medicine and Child Neurology,* 48(10): 855-862.

P. Rosenbaum, J.W. Gorter (2012) The 'F-words' in childhood disability: I swear this is how we should think! *Child: Care, Health and Development*, 38(4):457-63.

Skelton, H. and Rosenbaum, P. (2010) Keeping Current in Disability and Child Development: integrating the concepts, KC#2010-01. CanChild Centre for Childhood Disability Research McMaster University.
http://www.canchild.ca/en/canchildresources/resources/kc_disability_child%20development.pdf [accessed on 15.02.2013]

WHO (2002). Towards a common language for functioning, disability and health: ICF. WHO, Geneva. http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf [accessed on 15.02.2013]

References

WHO,UNESCO,ILO,IDDC,CBR (2010). Guidelines for Community based inclusive development. World Health Organisation, Geneva. http://www.aifo.it/english/resources/online/books/cbr/working_paper_CRPD32_CBR_Draft.pdf [accessed on 13.02.2013]

Specialist websites

CanChild Centre for Childhood Disability Research http://www.canchild.ca

Child Development Institute LLC, (US) https://childdevelopmentinfo.com

HelpGuide.org http://www.helpguide.org/mental/autism_help.htm

National Autistic Society, UK http://www.autism.org.uk

NICE (Spasticity in children and young people) http://guidance.nice.org.uk/CG145

Paper Furniture Enterprise http://www.paperfurnitureenterprise.com/apropriate-paper-based-technology

Scope UK http://www.scope.org.uk

TALC http://www.talcuk.org

UNICEF http://tinyurl.com/bs5kqwb

WHO (Disabilities) http://www.who.int/topics/disabilities/en

Assessment Tools

Gross Motor Function Classification System (GMFCS): http://motorgrowth.canchild.ca/en/GMFCS/familyreportquestionnaire.asp [accessed on 15.02.2013]

Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy: http://faculty.uca.edu/mjchidecker/Documents/CFCS_English_2011_09_01.pdf [accessed on 15.02.2013]

Washington Group Questions on Child Functioning - http://www.washingtongroup-disability.com/washington-group-question-sets

Part 4:

Appendix 4 – *Orientation to using the Guide for Parents*

Orientation to using the Guide for Parents

PowerPoint presentation in accompanying CD or relevant section of the MAITS training package *'Working with Children with developmental Disabilities and their Caregivers: A Training Programme for non-specialists in low resource settings'*

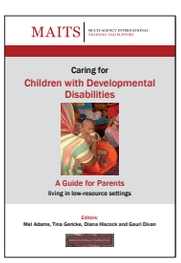
Slide 1

MAITS MULTI-AGENCY INTERNATIONAL TRAINING AND SUPPORT

Orientation to
The MAITS Guide
for Parents

Slide 2

Introducing the MAITS Guide



Slide 3

Familiarise yourselves

Activity:

In pairs, spend 5 minutes looking through the Guide

Slide 4

What is it for?

- It gives guidance on how to support a child with a developmental disability (cerebral palsy, and/or intellectual disabilities and/or autism) during the usual activities of the day.
- Following this guidance helps to prevent the child's disabilities from increasing and promotes child development, health and independence.

Slide 5

Why is the Guide useful?

- It helps to structure your advice to parents.
- It has pictures to help explain what you mean.
- It emphasises functional skills and participation in daily life, rather than trying to 'fix' the problem and make the child 'normal'.
- It emphasises the importance of the family and the support that they give the child.
- The advice does not require giving additional time to the child. It focuses on supporting the child correctly throughout the day, so that that *as* the child grows up, they will be able to do more for *themselves.*

Slide 6

Summary of Key Elements

- Promotes functional abilities in daily activities
- No extra time for carer(s)
- Simple but specific (categorises advice according to disability type and level of severity)

Orientation to using the Guide for Parents

PowerPoint presentation in accompanying CD or relevant section of the MAITS training package *'Working with Children with developmental Disabilities and their Caregivers: A Training Programme for non-specialists in low resource settings'*

Slide 7

How to use the Guide

Before you decide to use it:

- The child will have been screened to identify a developmental disability
- You, or a specialist, will have completed a functional assessment (ie. the child's skills and areas of difficulty)

Slide 8

How to use the Guide contd…

Complete a Child Profile (see your copy)

↓

Interview parents (and child where possible) to identify 3 goals for intervention (*see Parent Interview - baseline*)

↓

Find relevant sections of the Guide

↓

Use the Guide to train the parents

↓

Re-interview the parents (and child where possible) to monitor progress and decide on next steps (*see Parent Interview - review*)

Slide 9

ASSESSMENT
in detail

Slide 10

Revision: Why assess a child?

Brainstorm your ideas

Slide 11

Why?

- Helps to identify if a child is developing differently from their peers – you may be the first people to identify that a child has special needs.
- Will alert you to the need to seek assessment from a specialist where possible - **non-specialist support** or 'intervention' **does not** replace input from specialists, but should go alongside.
- Knowing about the child's skills and needs will help you to give appropriate guidance to the parent.

Slide 12

What assessment will you do?

Screening and basic functional assessment:

- MAITS Informal Observation Checklist
- Washington Group Q's on Child Functioning
- MAITS level descriptors for (i) cerebral palsy, (ii) intellectual disability, (iii) autism spectrum

Orientation to using the Guide for Parents

PowerPoint presentation in accompanying CD or relevant section of the MAITS training package *'Working with Children with developmental Disabilities and their Caregivers: A Training Programme for non-specialists in low resource settings'*

Slide 13

MAITS Informal Observation Checklist

Look at the copies of the MAITS Observation Checklist

Go through it as a whole group

Discuss:

How will you observe these things in every child?

Slide 14

Screening questions

Is there a standard screening tool that is used by your organisation? You may use the 10 Questions Screen, an adaptation of this, or a different tool.

Activity:

Divide into pairs and go through your own screening tool or the Washington Group Q's on Child Functioning (both sets)

- Do you understand each question?
- What would you say to a parents before doing the screen?
- Would you have any concerns in using this?

Share your thoughts with the group

Slide 15

MAITS level descriptors

If the child has any of the following:

- Cerebral palsy
- Intellectual disability
- Autism

…..You will need to work out what level of difficulty they have, using the MAITS level descriptors.

Activity:

- In pairs, read through the level descriptors (see your copies)
- Share comments and questions with the whole group

Slide 16

Cerebral palsy

Level III (severe)

This child needs full physical support for all activities. She is not able to sit, stand, or walk without adequate support and will probably need lifting. She has very limited use of her hands. If this child is able to talk, her speech is very difficult to understand even by people who know her well. She has difficulties eating and drinking (feeding herself, chewing and/or swallowing).

Level II (moderate)

This child cannot walk on his own, but he can sit if he has support. (He may need help from an adult to get into and out of a sitting position). He can hold his toothbrush or spoon, but needs help to use them. His speech is difficult to understand by people who do not know him well. He may have some difficulties with chewing or swallowing.

Level I (mild)

This child can walk, but is unsteady on her feet and may need a walking aid. She is able to do things with her hands, but with some difficulty and may have problems with sitting balance when using both her hands. Her speech is fairly clear, but may be a little difficult to understand at times. She might have difficulties chewing or swallowing some foods (e.g. very crunchy, hard or chewy).

Slide 17

Intellectual Disability

Level III (severe)

This child needs help with all activities. She does not understand the task (why she needs to do it and how to go about it) nor why something could be dangerous. Her behaviour is like that of a much younger child (e.g. mouthing objects, throwing objects). Her behaviour can be repetitive and be done to stimulate or calm herself (e.g. rocking, chewing hand). She does not speak and does not understand others; others have to interpret her communication by understanding her behaviour. She may have some difficulties with eating and drinking.

Level II (moderate)

This child needs help to carry out tasks, but with lots of repetition might learn to do them independently (e.g. dressing, washing, eating). He understands and uses some simple familiar phrases. He does not always know how to behave appropriately in different situations.

Level I (mild)

This child will learn to be independent with a little more help than is usually required. She is generally a slow learner, but with support will learn in time. She can talk, but usually in simple sentences. She understands everyday conversations. She will not achieve the same levels at school as her peers.

Slide 18

Autism Spectrum

Level III

This child does not use speech. He rarely approaches adults and may not show awareness of an adult nearby. He finds it difficult to show his needs and does not seem interested in others. He often shows a high degree of interest in sensory stimulation and shows repetitive behaviour such as rocking, mouthing objects, flapping hands, etc. He can seem like he is in a world of his own. He may have behaviours that can hurt himself or others (e.g. head banging, biting self or others).

Level II

This child uses some words and some learnt phrases, but often repeats what he hears again and again (this may include songs, television commercials, sounds, etc.). Rather than asking for things he may either try to fetch it himself, or may place an adult's arm on the object (eg. Packet of biscuits) without looking at the adult. He can show particular interest or be disturbed by certain sensory experiences. He is obsessed with the same routines and objects. He may have rituals and interests in unusual objects or parts of objects. He likes to play alone and does not share.

Level I

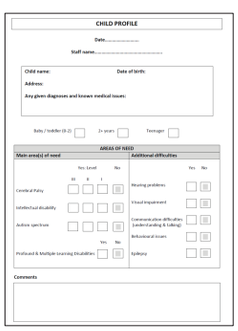
This child seems to be developing like other children, but prefers adult company or playing alone. He may have difficulties having a conversation, but speaks normally in all other ways. He likes his routines and can become upset when these are changed. He can be extra sensitive to particular sensory experiences. As the child grows up he has more and more difficulties fitting in socially, making friends, and understanding other people's point of view.

Orientation to using the Guide for Parents

PowerPoint presentation in accompanying CD or relevant section of the MAITS training package *'Working with Children with developmental Disabilities and their Caregivers: A Training Programme for non-specialists in low resource settings'*

Slide 19

Completing the Child Profile


CHILD PROFILE

Date:

Staff name:

Child name: Date of birth:

Address:

Any given diagnoses and known medical issues:

Baby / toddler (0-2) 2+ years Teenager

AREAS OF NEED

Main area(s) of need — Additional difficulties

Yes: Level III II I / No

Cerebral Palsy

Intellectual disability

Autism spectrum

Profound & Multiple Learning Disabilities

Yes / No

Hearing problems

Visual impairment

Communication difficulties (understanding & talking)

Behavioural issues

Epilepsy

Comments

Slide 20

Example 1

Sudique is 5, he has some visual problems, he has moderate cerebral palsy and mild intellectual disabilities. He has some difficulty understanding complex conversation and has slurred speech which is unclear to strangers.

Slide 21

Sudique's profile looks like this:

Baby / toddler (0-2) ☐ 2+ years [x] Teenager ☐

Areas of need							
	Yes: Level III	Yes: Level II	Yes: Level I	No		Yes	No
Cerebral Palsy	☐	[x]	☐	☐	Hearing problems	☐	☐
Intellectual disability	☐	☐	[x]	☐	Visual impairment	[x]	☐
Autism spectrum	☐	☐	☐	☐	Communication difficulties (understanding & talking)	[x]	☐
				Yes / No	Behavioural issues	☐	☐
Profound & Multiple Learning Disabilities				☐ / ☐	Epilepsy	☐	☐

Slide 22

Example 2

Ameena is 13. She has epilepsy. She has moderate autism spectrum difficulties and mild intellectual disabilities. Her behaviour can be challenging at times.

Slide 23

Ameena's profile looks like this:

Baby / toddler (0-2) ☐ 2+ years ☐ Teenager [x]

Areas of need							
	Yes: Level III	Yes: Level II	Yes: Level I	No		Yes	No
Cerebral Palsy	☐	☐	☐	☐	Hearing problems	☐	☐
Intellectual disability	☐	☐	[x]	☐	Visual impairment	☐	☐
Autism spectrum	☐	[x]	☐	☐	Communication difficulties (understanding & talking)	[x]	☐
				Yes / No	Behavioural issues	[x]	☐
Profound & Multiple Learning Disabilities				☐ / ☐	Epilepsy	[x]	☐

Slide 24

Child Profiles – practice

Activity:

- Break into pairs/threes
- Complete a MAITS Child Profile on each case study you are given (refer to the level descriptors to help)

> Share you answers with the group