Flashcards Cerebral Palsy



- **These flashcards contain information about working with people who have Cerebral Palsy (CP) in low resource areas.**
- **These Flashcards are made for the use of fieldworkers.**
- **These flashcards are a revised version, based on the information about Cerebral Palsy from the RehApp CP (resource for home-based rehabilitation)**

rehapp rehapp CP

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What can you do with these flashcards:

- To help guide your visits to families that have a family member with CP.
- Make an inventory of the needs of the person with CP and his/her family.
- Learn about the implications of a disability for the person and their family.
- Use them to do an assessment.
- Use them to set goals for a person with cerebral palsy and to harmonise goals with the person and their family.
- Use them to help you discuss interventions with the family.
- Use them to help you keep client records.
- Use them to help you and caregivers monitor progress and the process.

The goals of these flashcards are:

- To meet the needs of people with disabilities and their families.
- To support families and fieldworkers with information to follow the rehabilitation process of a person with CP.
- To improve knowledge and skills of fieldworkers in providing basic (functional) rehabilitation services for people with disabilities and their families.
- To enhance participation in daily, family and community life.
- To improve the quality of life of people with disabilities and their families.
- To support you (as fieldworker) in the process of guiding a family by providing you with a resource you can keep with you on your phone (offline) or in your bag.
- To help train caregivers, for example in a parent support group or at home.

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Note: These flashcards consist of two parts, the first part contains information about cerebral palsy and the second part contains what you (as a fieldworker) can do by following the process of a rehabilitation cycle. These cards don't replace the knowledge and skills of doctors and therapists. We advice you to seek their advice first.

Information about Cerebral Palsy	
	Introduction
	Body functions & structures
	Activities & participation
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Cerebral Palsy

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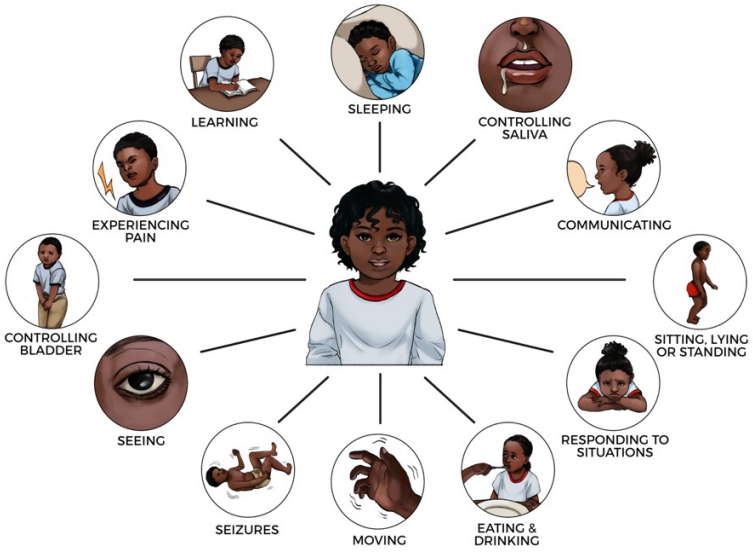
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What is CP

Cerebral Palsy (CP) is a permanent but non-progressive and not contagious disability that comes from damage to parts of the brain before the age of around three. This could have been caused before, during or after birth, resulting in disorders in development of movement and posture.

Apart from making it difficult for some people with CP to sit, stand and walk, CP can cause difficulties in other skills such as: controlling the bladder, controlling saliva, talking and eating. Some persons may also have difficulties with seeing, hearing well, or general learning. They may experience pain and may have seizures. These difficulties can affect their behaviour and their ability to sleep. Experiencing one or more of these issues makes going about the normal activities of daily living more difficult. Every person can be affected in a different way and degree. Their learning capacity might be influenced by the difficulties mentioned.



Diagnosis

CP is diagnosed by a specialist, a neurologist or pediatric doctor. If you have doubts of the child's development after reading these flashcards, refer to a doctor for further examination. It might take some time to be able to identify CP.



The extent of a disability is not determined by the diagnose alone, but the interaction between different factors. Keep these in mind when working with people with CP and their family:

- Body functions and structures= difficulties the body has on an anatomical level such as controlling the bladder, digesting food or experiencing pain.
- Activities and participation in daily life= to be able to do activities, learn the activities that are meaningful for a person. A person needs to be offered opportunities to do these activities and be involved in family and community activities.
- Environmental factors such as support of the community, access to health care services, accessibility of the house or community buildings.
- Personal factors such as character, personal preferences and wishes.

Actions to take:

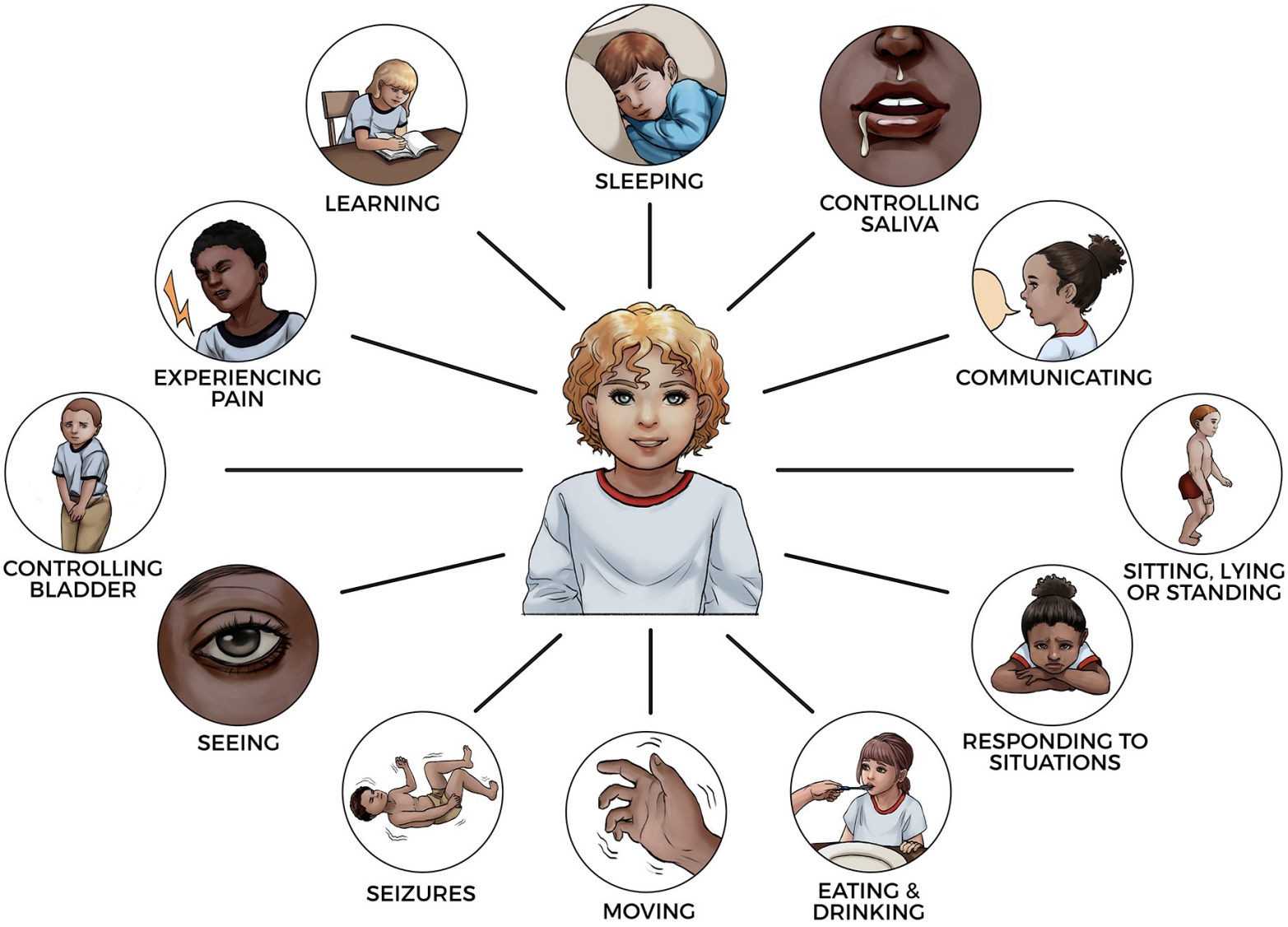
- Refer to a doctor and help the family in making an appointment. Make sure the family is able to visit the doctor. Sometimes transport is difficult to arrange for them.
- Monitor developmental milestones of a child with CP.
- Provide the doctor with information about the person such as the milestones and difficulties you have identified, in your own words.

Card 1

Introduction

Card 2

Introduction

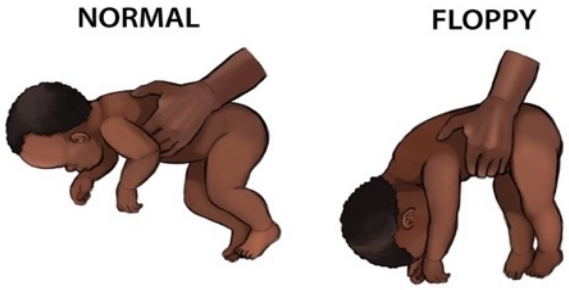


These are some of the difficulties people with CP may experience. This doesn't mean all people with CP have all these difficulties. It can be either one or two or several. It's important to get advice from a doctor and therapist to help you determine how you can coach and person with CP and their family at home, to be able to develop to their full potential.

Possible signs of CP



Missing milestones



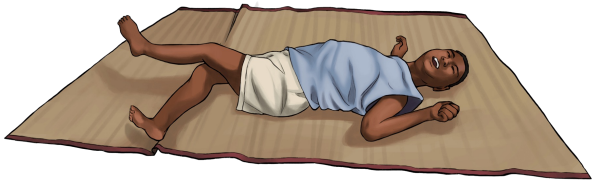
'floppy' when being picked up



Unable to hold the head



Muscle stiffness/ spasms



Poor control of muscles, reflexes and posture



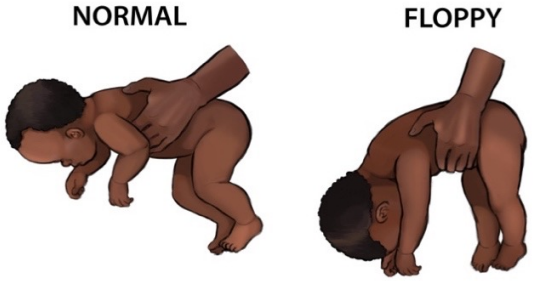
Feeding difficulties

Card 3

Body Functions and Structures

Possible causes of CP

There are many reasons why a child may have cerebral palsy. A cause can be any incident that causes damage to a part of the brain, or which affects the development of the brain, such as lack of oxygen. This damage can happen either before birth, during birth, or in the infant in the first years of life. Often the doctors don't know what caused the CP in a person exactly.

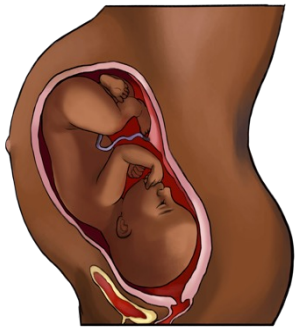


Causes before birth:

- Use of alcohol and other drugs
- Infections or illnesses of the mother while she was pregnant such as Malaria
- Malnutrition of the mother during pregnancy

Causes during birth:

- Extended stay in the birth canal
- Born too early is a risk factor



Causes after birth:

- Brain infections
- Malaria, Jaundice, Meningitis
- Head injuries
- Lack of oxygen e.g. due to lung problems, near drowning

Prevention and early detection

When you look at the examples on the right, the importance of maternal health before and monitoring after birth is evident for prevention, early detection and early intervention.

The sooner these children receive professional support, the better. This will have a positive effect on what they are able to do in the future in terms of developing movement, learning and daily skills compared to no treatment and support.





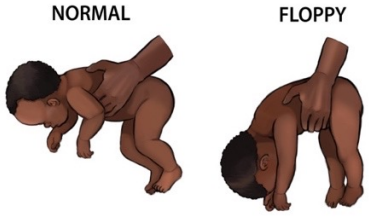
Actions to take

- Provide pregnant mothers with information about good nutrition for themselves and staying healthy.
- Provide information about good nutrition for the child.
- Stress the Importance of mosquito nets against Malaria.
- Stress the importance of going to a doctor when milestones are not reached or when having any worries about the child.
- Teaching caregivers the milestones of normal development and how to monitor their child's development.

How CP can affect the body?

A person with CP, among possible other difficulties, has trouble controlling and moving their muscles. The parts of the body that are affected depends on which part of the brain is damaged. The type of CP that the child has, depends on different factors, for example how early in pregnancy the brain was damaged.

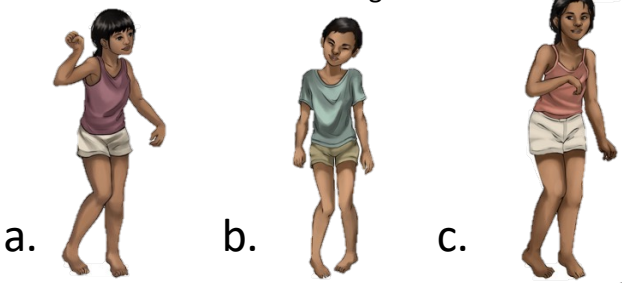
Sometimes babies with CP do not appear any different from other babies. Children who have CP are affected differently depending on where and how the disturbance in brain development occurred.



Types of CP

There are four main ways in how a person's movements might be affected, depending on the location of the brain damage:

1. Spastic: Stiff muscles. Most children with CP have spasticity. Different parts of the body can be affected: a) Both arms and both legs can be affected. If so, then the muscles of the trunk (body), neck, face and mouth are often also affected. b) Only the legs are affected, with maybe to a lesser extend the arms. c) One side is affected: the arm and leg.



Early signs of CP

At birth, a baby with CP may appear limp and floppy. Stiffness appears seldom right after birth but usually after a few months.

These are some possible signs for CP:

- ❑ Missing milestones in development like not being able to sit upright alone around six months
- ❑ Unable to hold the head up when lying on their stomach or when sitting
- ❑ Feeding difficulties like difficulty swallowing by coughing or choking when eating or drinking
- ❑ The baby feeling 'floppy' when being picked up (see picture on the left)
- ❑ Mainly using one side of the body (arm and leg)
- ❑ Poor control of muscles, reflexes and posture
- ❑ Muscles feeling stiff or spasms

2. Dyskinetic: Involuntary movements. These children experience uncontrolled movements in their arms and legs, which seem to be moving all the time. Sometimes the arms and legs push backwards and become stiff when the person moves.

3. Ataxia: Shaky movements, poor balance and lack of coordination. The child has difficulty sitting and standing. S/he walks with their feet wide apart, tends to fall or stumble, has difficulty walking in a straight line and they might seem very clumsy when using their hands.

4. **Mixed CP**: Some children can show more than one type of movement pattern.

It can be difficult to identify the type of CP. This is done by a doctor or therapist. Provide them with information about what the child can do and has difficulty with, in your own words.

Card 4

Body Functions and Structures

Card 5

Body Functions and Structures

General health

It is important, when first meeting a family with a family member with CP, to check the general health. A person who stays almost always inside the house and/or cannot move by him/herself can affect the health and fitness of that person. The risk of developing illnesses such as fever or problems with the lungs is higher and there is a risk of developing pressure or friction wounds. When the person has difficulty eating and drinking, there is a risk for malnutrition and dehydration especially when being fed lying down. Unsupervised use of medication by a doctor can result in harmful effects.



Actions to take

- ❑ Check the general health of the person with CP as well as the caregivers.
- ❑ Refer to a doctor when you observe the following:
  - ongoing or reoccurring fever
  - heavy coughing, difficulty breathing
  - inability to cough when needed
  - malnutrition (small height and weight for age)
  - dehydration (skin stays raised after pinching, skin not turning pink < 2 seconds after pushing the skin with your nail, fast/irregular breathing)
  - seizures that repeat or first-time seizures
  - open wounds or heavy scars on the body
  - Jaundice signs (yellow skin and white of eyes yellow)
  - choking when eating or drinking
  - insufficient use of medication
  - signs of abuse (carefully discuss with caregivers first) such as: bruises, scratch-, bite-, burn marks, extremely nervous or aggressive, dirty clothes and hygiene, bad teeth

Pain



Children with CP can experience pain due to difficulties such as:

- curve in the spine (scoliosis)
- The hip(s) not positioned well in the hip socket are painful when moving or being moved.
- wounds due to friction or pressure
- Not being able to swallow and digest well. If food flows back from the stomach, it can make the digestive structures irritated and painful and there is a risk of flowing into the lungs which could cause a lung infection.
- Stiff muscles can cause painful muscles or spasms
- Stiffness of the muscles combined with inactivity of the person and not being able to change positions of the body during the day and night can cause the muscles to shorten and create deformities in the arms and/or legs.
- When not being able to move by yourself and being inactive, this can cause constipation and stomachache.

Pain can be observed by the person or family describing the type of pain and location. If the person cannot speak, can the person point to the painful places? If not, observe if the person shows pain by emotions, facial expression or body language such as negative response to touch.

Actions to take

- ❑ Check, through interviewing, observing and assessing if the person has pain using the information above.
- ❑ When you suspect any of the problems above, refer to the health clinic or hospital. Make sure the family knows where to go and has the means (money, transport) to go.
- ❑ Make sure the person can change positions (sitting, lying, moving from one side to the other) or instruct the family how to help.

Card 6

Body Functions and Structures

Sleeping



Being active, by moving or being moved, throughout the day is important to feel tired enough to sleep. Inactivity and sleeping often during daytime can cause difficulty to sleep at night.

Pain, general health and seizures can cause problems in gettting to sleep, sleep deeply or sleep several hours in a row at night. Sleep is important for the body to recover from activities in daily life and to regain energy. It is important to stay healthy and fit. Newly borns sleep 16 to 20 hours per day, infants up to 14 hours, toddlers about 12 hours per day, schoolage children 11 hours, adolescents 9 to 10 hours and adults 7 to 9 hours.

Actions to take

- Ask and find out if and why sleeping is difficult. In case seizures, pain or general health is a problem, refer to a doctor and inform the doctor with details.
- Find out if the person needs support of the body while sleeping, for example if the person has difficulty moving themselves.
- Find out if the person is active enough during the day. If the person has difficulty moving themselves, find out and instruct caregivers how to support or stimulate the person to move.
- When the person lies on the floor or couch throughout the day, arrange a special chair or wheelchair to be able to sit and move around or being moved around for example by family, friends or neighbours. See the 'activities & participation' cards for more information.

Seizures

Seizures can be caused by a condition called 'Epilepsy'. This is not contagious, it is not a spirit that possesses the person, but it is an overload of stimuli in the brain that causes the brain to discharge. There are different types of epilepsy ranging from blank staring (= absence), chewing and not responding, small or large shaking movements. Medication might be needed to control the seizures. Ask a doctor for advice. You can download a poster of the steps below on: www.epilepsynorcal.org/seizure-first-aid/.

First aid

1. Make sure the person is safe. **Block** hazards.
2. **Loosen** tight clothes.
3. **Don't** put anything in the mouth.
4. Roll the person to the **side**.
5. **Cushion** the head with a pillow or clothes.
6. **Time** the seizure with a clock or watch. Most seizures should end in a few minutes.
7. Do **not** hold or grab the person
8. Speak **calmly**
9. **Explain** to others what is happening
10. **Stay** with the person until they are awake and alert.



Call an ambulance or visit a doctor immediately when:

- Seizure lasts longer than 5 minutes
- When seizure repeats
- Person is injured or sick
- Difficulty breathing
- Seizure occurs in water
- First time seizure

Card 7

Body Functions and Structures

Feeding

Many people with CP need more time to chew and/or swallow and may have difficulty chewing and swallowing solid or fluid food. Feeding in a lying position can cause coughing, choking or vomiting and it creates the risk for the food or drink to flow back up and into the lungs. This can create a lung infection. Difficulty in eating and drinking can cause malnutrition and/or dehydration and therefore requires attention. Safe feeding requires: good seating position, giving enough time to chew and swallow, communicate to introduce a new bit.

Make sure the family has the financial and transport means to visit the doctor as this condition is life threatening.

Actions to take

- Bring the family immediately to a doctor if the child is dehydrated or has malnutrition!
- Make sure if feeding is safe: does the person have difficulty chewing and/or swallowing, in what position is the person being fed, how is the person being fed so is he/she given enough time to swallow?
- Instruct the caregiver on safe and supportive seating and eating & drinking.
- Observe how the person is being fed. Does the caregiver talk to the person while feeding, introducing when a new bite is coming so the person is prepared?
- Find out if feeding is easier in a different position such as on the lap in a slight upright position or in a chair.
- Find out what types of food the person can and cannot eat. Involve a nutritionist if feeding is difficult.

Card 8

Body Functions and Structures



Wrong positioning



Good positioning



Good positioning



Card 9

Body Functions and Structures

Saliva control



Some people with CP have difficulty controlling saliva which can cause stigma from other people.
It is sometimes thought to be dirty or contagious, but it is a result of difficulty controlling the muscles. The saliva can smell when the clothes or the face gets wet.

Actions to take

- Make a bib from a piece of T-shirt or old towel. Don't wipe the mouth continuously as this can cause sensitivity in the mouth area.
- If possible, teach the person to keep a piece of cloth and clean the mouth.
- Being able to sit, if needed with support, has a positive effect on saliva control. Explore supportive seating.

Bladder and bowel control



For some people with CP it is difficult to manage their bladder and bowel. This is due to the problems with posture and movement. Some people might have more difficulty sensing when having to go to the toilet. Being able to feel having to go to the toilet is a criteria for learning to control the bladder and bowel.

Actions to take

- Find out if the person can feel when having to go to the toilet.
- If not being able to feel having to go to the toilet, try if the person can learn to manage timed toileting. This means go, or being helped to go, to the toilet every two hours.
- Assess if an adaptive toilet is needed. See below.

Seeing



Some people with CP have difficulty seeing. Keep this in mind. This means the eyes themselves might be good, but processing by the brain can be difficult. Being able to see well is important to understand, explore and respond to what's happening you. It is needed to feel safe and motivated.

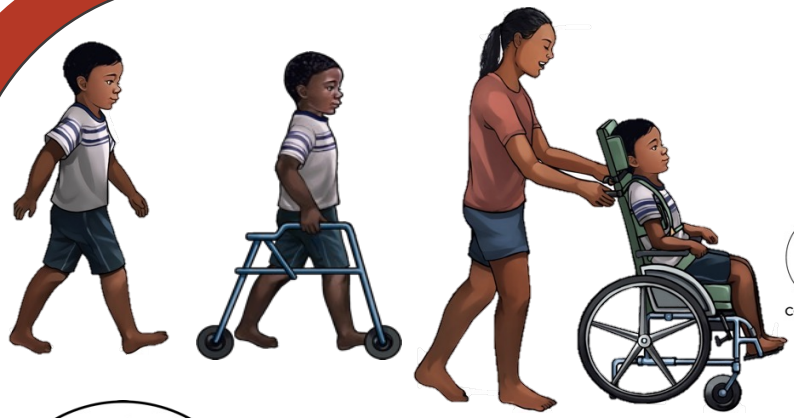
Possible signs

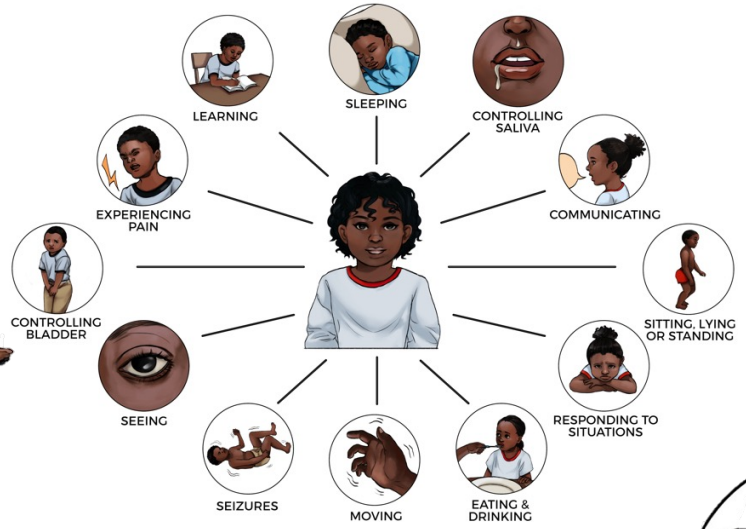
- Strong preference for colour
- The need to move or movement to keep looking at an object
- The person might explore an object in a slow manner
- Difficulty seeing with for example a lot of sounds around
- Difficulty looking at something AND explore by touch at the same time
- Delayed blinking of the eyes when an object is approaching

Actions to take

- An *eye doctor* can determine if there is a problem and what could be done.
- Good light conditions and contrasting colours might be needed for moving and doing activities. Find out if different types of light and contrast helps.

















Activities and Participation:

Information and Actions to take

















Card 10

Activities and Participation

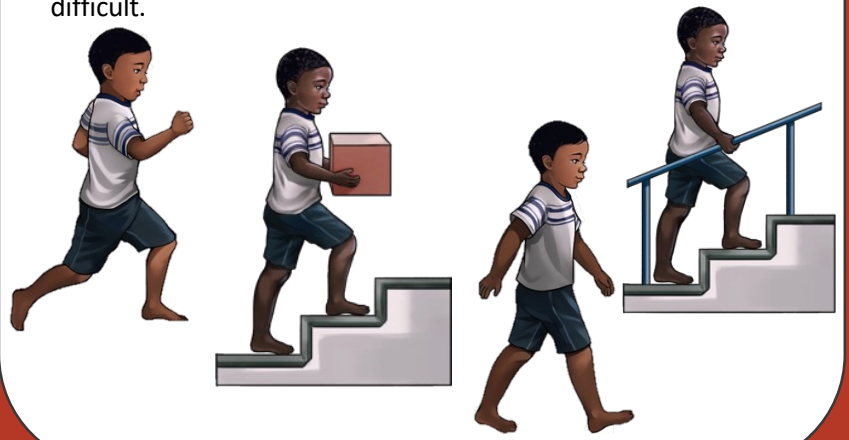
Different levels of CP

Looking at motor skills development and CP, for example being able to move around, some persons are more affected by CP than others. We call this 'severity level'. The level of severity influences the development of the child and what the child can do by themselves in daily life. The 'severity levels' are mild, moderate and severe.



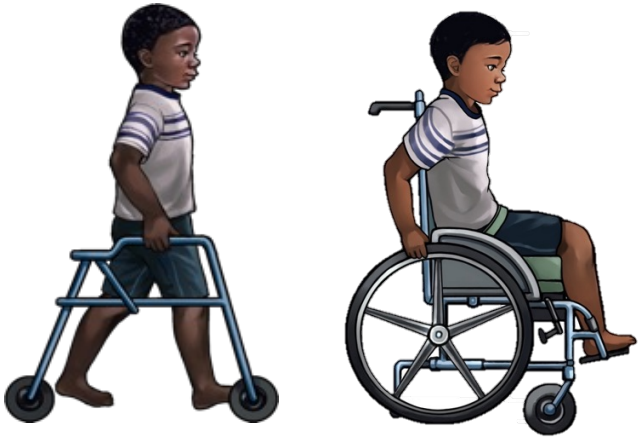
Mild

Mild (also called GMCFS* level I or II): The child can walk on their own, but the movements are a bit wobbly. The child might be able to jump and run as well. Walking long distances can be difficult.



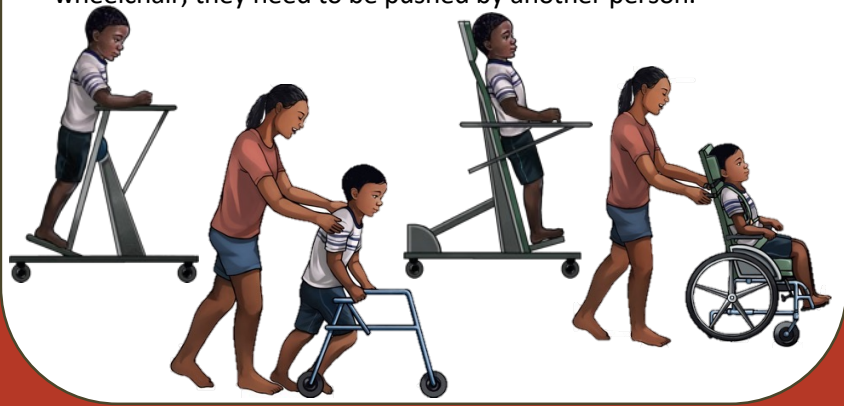
Moderate

Moderate (GMFCS level III): The child can sit on their own and move around by themselves with a wheelchair or a walker, or if these devices are not around, move by other ways such as crawling. The child needs help over long distances.



Severe

Severe (GMFCS level IV or V): The child cannot sit by themselves and needs support. Some children can roll over from one side to another when lying down or lift their heads. This child does not walk by themselves but might be able to use a walker with support from another person. If using a wheelchair, they need to be pushed by another person.

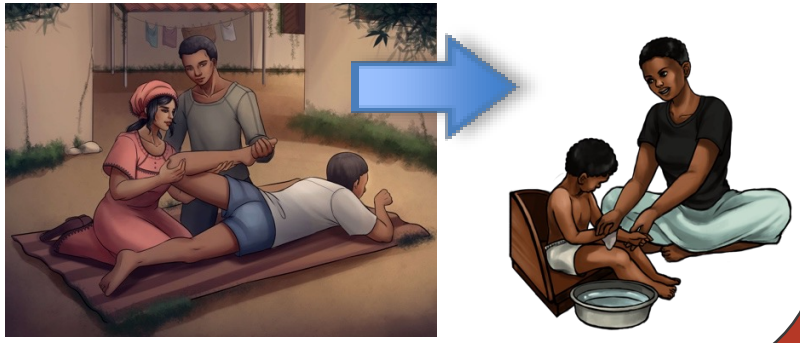


Abilities

All persons can develop to their own potential. This is influenced by the difficulties discussed earlier as well as being offered opportunities to develop, stimulated to develop and supported emotionally in a way that is motivating and encouraging. A supportive environment is very important. What a child is doing during a day depends on the home environment. There may be difference between city and rural area or one family to the other.



Many therapists and fieldworkers tend to give 'homework/ exercises' for the caregivers to do at home. Usually, they do not consider how these exercises fit within the daily routine, nor do they analyse the daily routine and how to use this. Only passive exercises do not improve functioning in activities of daily life. For that, the person needs to actively be involved in daily life activities such as moving, helping with eating, play or other. Coach the family in practicing skills that are integrated in activities that are close to daily life.



Actions to take

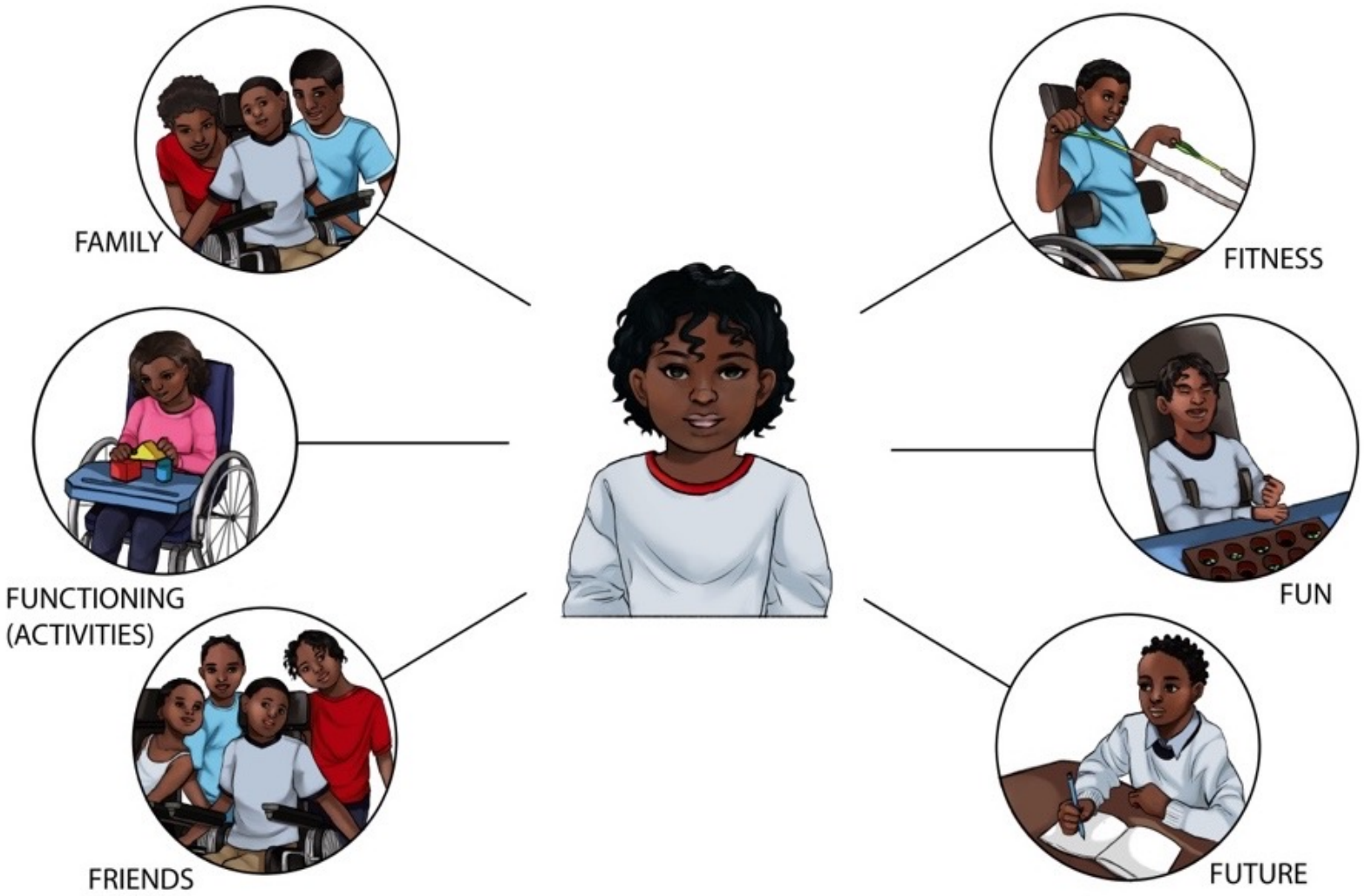
- ❑ Learn what a person likes and use that to connect to a person and get to know each other. They may like to hear stories, watching peers play or just have someone to hold their hand. Ask the family and take your time to build trust.
- ❑ Caregivers are experts of their children. Listen to their story and make an action plan together, teaming up with the family.
- ❑ Follow the steps of the Rehab cycle.
- ❑ Keep the 'Six favorite words' in mind when setting goals and making an action plan to support a person and their family. See the Favorite words on the next page.
- ❑ Include the person in (routine) activities of daily life and make it fun. This is like a therapy moment that is good for health and development. For example, you can clean the house or work in the garden and leave the person on a matrass inside if they are not able to move themselves. The person will see and hear and experience almost nothing. Or you can take the person with you, sitting in a (special) chair. The person can watch, hear and communicate with you and and learn from that.
- ❑ Focus on the abilities of a person and their and their families wishes and priorities.
- ❑ Remember that when a person cannot speak or think well, it can be difficult to know what they are feeling. They may be lonely and unhappy and need friends. Find friends who will visit, talk and play with them. Guide them if needed.
- ❑ Children with severe disabilities may be very intelligent, but their intelligence will develop limited unless they are stimulated and given opportunities to learn and participate in daily life from an early age. Ways of enabling them to go to school can completely change their lives. Try and find out what they like and want by listening to them, looking at the sounds and movements they make, the signals they give and by taking notice of them.

Card 11

Activities and Participation

Card 12

Activities and Participation



CanChilds' Six 'Favorite' words in the lives of children with disabilities (2018). These are areas in the life of a person that needs to be addressed. Keep this in mind when discussing priorities and setting goals. Source: https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability

Family: represents the essential 'environment' of all children

Functioning: refers to what people do (for children, 'play' is their 'work')

Friends: refers to the friendships established with peers; social development is an essential aspect of personhood

Fitness: refers to how children stay physically active, including exercise and other recreational opportunities

Fun: includes particular activities children are involved in or enjoy participating in

Future: is what child development is all about; it refers to parents and children's expectations and dreams for their future

Card 13

Activities and Participation

Effect on daily life

People with CP are different just like any other person, also having their wishes and needs. It is important to look for the things they can do and learn and not only focus on what a person cannot do. Their strengths and abilities can support challenges in daily life. Don't assume they have no skills. Only parts of the brain are damaged, not the whole brain. The younger you start with supporting development, the better.



A person with mild CP may have some difficulties in moving and only require a little assistance to do things, whereas a person with severe CP may need daily and long-term support to move and perform all activities of daily living. Each person is unique and needs the right type of support – physically, mentally and emotionally – to allow them to reach their full individual potential.





The persons ability to walk is often one of the biggest concerns of parents. Walking is important both functionally and socially but in terms of the persons overall needs, other skills may be more important. For all people, whether they have mild or severe disabilities, to lead as happy and independent a life as possible, the following are also important:

- Having confidence in themselves and liking themselves
- Being able to communicate with others and have positive relationships
- Developing skills in self-care activities such as eating, dressing and toileting
- Being able to get from place to place for example by wheelchair
- (and if possible) walking



Actions to take

- As a child grows up into adulthood, a lot of help can be needed to maintain movement of the body and joints, and to maintain muscle strength.
- It is important not to over-help the person but to help the person just enough that they can learn to do more by themselves.
- The child with CP will become an adult with CP. Help the child to become an adult who can live with her/his disability and be as independent as possible. Set goals and actions that match needs, their age and phase in life.
- Focus on developing skills in activities of daily life, recognise and value each step. Start as early as possible.
- You can use development charts to help monitor development such as the CDC Milestones tracker: www.cdc.gov/ncbddd/actearly/milestones/index.html.

Card 14

Activities and Participation

Lifting a person

Often caregivers experience physical strain from lifting their child, resulting in pain in the back, neck or shoulders especially when the child grows older. Coach the caregiver how to lift their person with least physical strain. If the person is able to at least stand with support, let the child help where possible to move from one place to the other. Start this from an early age. A therapist or technician can help you understand how if needed and available.

Actions to take

- Bend your knees and keep your back straight.
- It is easier to pick the person up with one foot slightly in front of the other one.
- Hold the person as closely to your body as possible before lifting.
- Practice together with the caregiver.
- Lift by using the strong muscles of your legs, not your back.
- If the person becomes much bigger and heavier (over 20 kilo's), preferably do not lift her alone, but ask someone to help you.
- When lifting with another person, count before lifting so that both people lift at the same time.
- Support the persons: head and body, legs and feet, shoulders and arms.



Wrong



Good

Carrying a person

Often caregivers carry their children on the arm throughout the day. This makes it difficult for them to work in and around the house. In addition, it is good for the child's development to sit on their own, with a special seat if needed, and enjoy themselves. Sitting needs to be motivating so offer materials that stay within reach of the person to explore or work with.

Actions to take

- Don't carry a person weighing 20 kilos or more by yourself.
- If the person doesn't have to be carried: don't. Let the person help wherever possible with transfers and moving from one place to the other.
- If the person has poor control of the head, make sure the head is supported and not falling backwards. Support the legs and feet, shoulders and arms.
- Keep the person in an upright position so she can hold her head up and look around, even shortly.
- Hold the person with their hips and knees bent and the knees separate to decrease overstretching.
- Make sure the person can hold on with her arms to you if possible or use her arms freely.



Wrong



Good

Sitting



Sitting is important for:

- breathing right and easily
- safe eating and drinking
- being able to speak louder
- using your hands and arms easier and hence stimulate development and learn, at home and in school
- preventing problems such as: pressure areas, deformities of joints or deformities of the back
- making daily activities easier for the child and being (more) involved in family and community life
- being able to play or enjoy and communicate with peers
- being able to see and explore the world around you better
- the person being able to do activities by themselves as it gives better control of the hands and the head



Wrong



Wrong



Wrong



Good

Card 15

Activities and Participation

Card 16

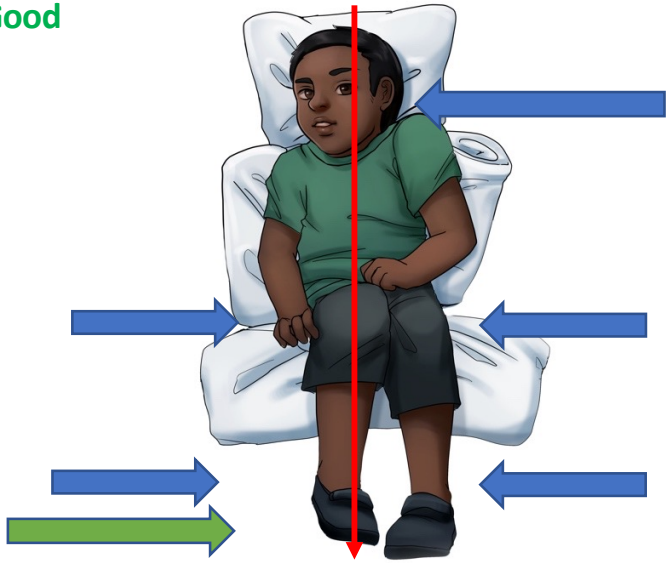
Activities and Participation

Actions to take

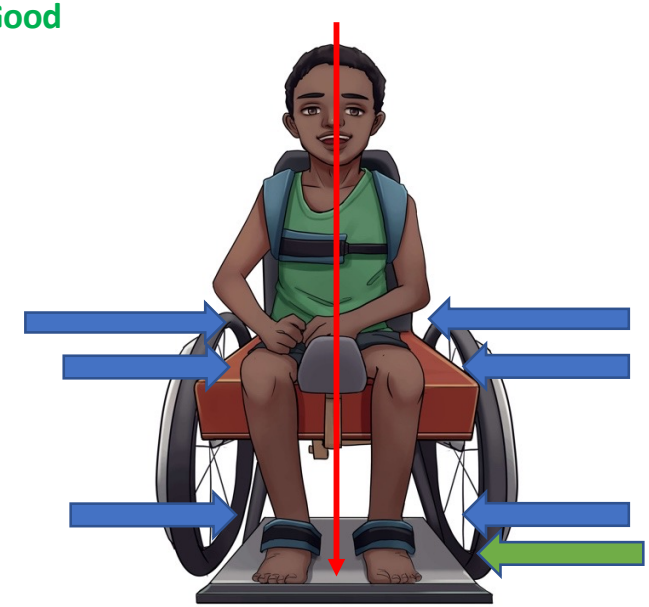
- Refer at an early age for a special chair or wheelchair if needed. Around one years old, children often can sit without support and pulling themselves to stand.
- Ask a therapist for making measurements and advice which support is needed such as padding to support the trunk, head or between the knees to prevent the legs crossing.
- If you or the family have access to pillows and towels or equipment like buggies and special chairs, then try them and coach the family how to use them. Like the picture below.
- Think and observe if support is needed of the head, trunk, legs and feet, shoulders and/or arms.
- Try to position the person with the head and trunk in one line (see red line in picture on the right).
- Make sure knees, hips and ankles are bend (see blue arrows)
- Make sure the neck is bend slightly forwards like below.
- Provide a footrest so the person can rest their feet on or so that they can touch the ground firmly (see green arrow).

- Provide a tabletop if possible, on which the person can rest his/her arms and work or play on
- If head and trunk control is difficult, tilt the chair slightly backwards. Try out how much tilt is needed and how long the child can sit in this position. Build up length of sitting gradually from 5 minutes to more.
- Check for pressure points on the joints to prevent wounds.
- Make sure the hands are free to grab, point, use and play.
- The shoulders should be slightly forward, so the arms and hands are in front of the body, making them easier to use.
- The person might need time to get used to a new position. Don't give up. Gradually build the time of sitting.
- Change positions regularly, such as every hour, to prevent pressure sores and increase in stiffness. This will increase the disability.
- Make sure the child cannot fall or hurt himself. Use pillows and soft straps for the hips and chest (never only for the chest, to prevent choking), but only if needed.

Good



Good



Lying

Many people with CP lie down a large amount of the day. This will effect the ability to use the hands, being awake and alert.
It is good to be able to move around when lying on the floor. This will stimulate moving the body actively. When the person is not able to move by themselves, it is important to help them move in different positions and support the body. Being well supported in this position helps to use the hands for example for play, or to sleep in a comfortable position.

Actions to take

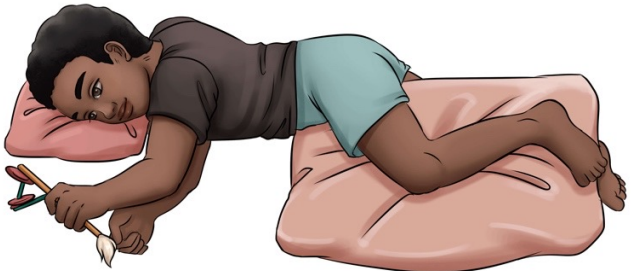
- Stimulate the person moving the body by themselves when lying on the floor.
- Look at the ability of the person to lie on the stomach, on the back, on the left and right side and sitting upright or slightly tilted back.
- Make sure the caregiver supports the person to change positions if he/she cannot do this by themselves.
- Use foam, towels, pillows, rolled up clothes or blankets to try out supporting the body of the person in different positions.
- Teach the caregiver. Show how to support lying and change positions, let them try and help with instructions, evaluate how it is going next time you visit the family.



Examples of good support in lying positions









Card 17

Activities and Participation

Card 18

Activities and Participation

Communication



Communication is important to express wishes and needs, pain, interact with familiar and unfamiliar people around you and being understood. There are different ways how people communicate: by words or body language such as expressions in the face and pointing.

For people with CP, communication with using and/or understanding words can be difficult. It is possible that someone can understand what is said but cannot respond in words. The muscles of the body involved in communication have difficulty working together which could result in not fluent and/or slow speech. Also, processing in the brain can be difficult which results in needing more time to respond or having to use other ways of communication then words:

Alternative ways (these do not replace use of words by you or learning how to use words, it's supportive for communication and learning):

- Choosing between two options
- Using daily objects to make clear which activity is coming
- Using gestures to support (but not replace) communication
- Using a picture card to communicate choices or feelings
- Using a booklet with pictures to communicate



Actions to take

- Make sure the person is sitting up and able to see what is happening around them during the day.
- Encourage other people to interact with the person. Teach family and close community members why and how to use other ways of communication with the person.
- Talk to the person throughout the day – tell them about what is happening. Use lots of facial expression and gestures to support communication.
- Before asking the person a question or explaining something specific:
  - get their attention by saying their name and using eye contact;
  - make sure you are facing one another, on the same level, and with the child sitting well supported.
- Show an object that represents what you are asking/talking about.
- Take turns and encourage participation.
- Praise and encourage – clapping, cheering etc.
- Offer choices. Make sure the child has objects and/or pictures in front of them to show you what they want.
- Encourage the child to indicate what they want by using their skills of looking, pointing, touching, gesture etc.
- Being able to communicate will enable the person to participate in daily life in the family and community, learn more easily and communicate easier with family, friends, teachers, community members and other people. Make communication possible, through words or other by trying these different ways. Keep in mind it takes time to learn different ways and sometimes you have to instruct the people around the person as well on how to do.
- Do not force the child to speak but encourage and respond to any attempt to communicate.
- If using alternative ways, make sure these objects are always within reach of the person.

See the next page for pictures how to do this.

Card 19

Activities and Participation

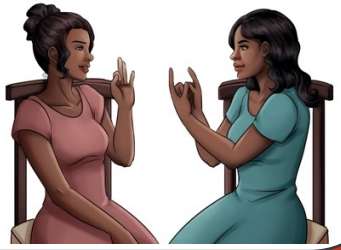
Choosing between two options



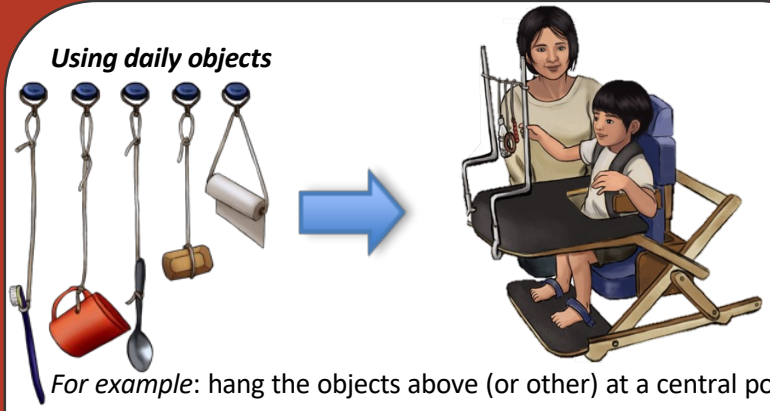
For example: during eating provide options by showing two types of food. Let the person choose by pointing which one he wants. You can do the same for play or dressing.

Using gestures to support (but not replace) communication

For example: many gestures are ones you already know. You can use pointing or 'as if' gestures such as use your hand as if you are brushing teeth to indicate it's time to brush the teeth, or the same for eating. This will help the person to understand better what is expected of him/her.

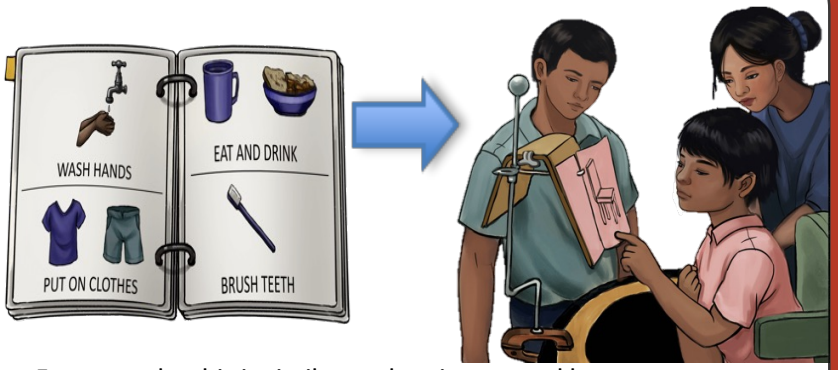


Using daily objects



For example: hang the objects above (or other) at a central point in the house. Use them to indicate to the person prior to the activity what you want to do or want the person to do. This is for people that have difficulty understanding communication.

Using a booklet with pictures to communicate



For example: this is similar to the picture card but more advanced. The cards have been bound in a booklet. This enables to add pictures on pages with topics such as: pain, eating and drinking, playing, learning, selfcare, friends and family. Keep the card within reach.

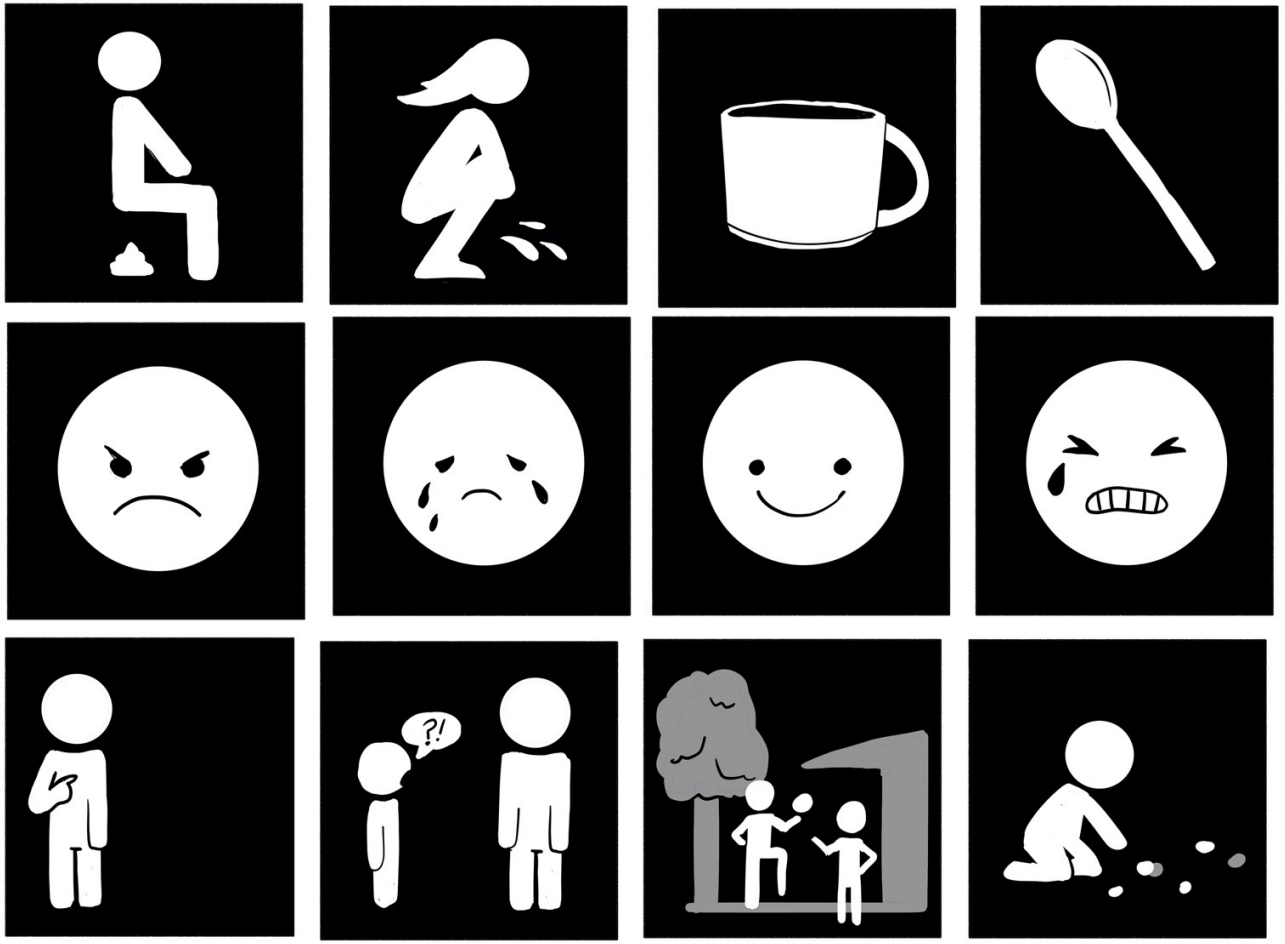
Using a picture card to communicate choices or feelings



- Make a picture card with drawings or photos that are suitable for the persons situation (see picture above and on the next page for an example).
- Begin with a few and gradually build the amount if the person understands and uses the card.
- Depending on the person, he/she can point with their hands or directing their eyes. If needed, guide their hand in the movement.
- Keep the card within reach of the eyes or hands of the person.
- See the next flashcard for an example of a picture card. Adapt for each individual person. Decide together which pictures are needed.

Card 20

Activities and Participation



Example picture card to support communication.

You can find pictures on the internet (www.sclera.be), print and paste them or draw them. Glue the pictures on a cardboard and protect with see-through tape (see picture on the right).



Card 21

Activities and Participation

Eating & drinking



Read flashcard number 8 on feeding first. A person with CP can have difficulty controlling their tongue, chewing and closing the mouth. Feeding a person lying on his back this is dangerous with risk of choking and the person will learn one thing: trying to breath and not to choke. Feeding in a good position (see cards on sitting) will give the opportunity to (maybe) learn to chew, the person is sitting and seeing much more, and it is easier to communicate with someone sitting up compared to someone lying on his/her back. If the person can move their hands purposefully, practice with the person to eat by himself. This will not happen in one day. It takes time. Coach the person and caregivers how to practice themselves over the course of a few weeks or months, depending on the learning and physical skills.

Technique of eating hand-over-hand

This means guiding the hand of the person that is eating or drinking. Gradually decrease the amount of support you are giving. If possible, practice in front of a mirror so that the person sees the movement he/she makes. This can support the person learning how to do the movement and repeat next time by themselves.

Technique of jaw and lip support







Actions to take



- As with ALL people, follow good hygiene practices for food preparation and feeding.
- Make sure the diet is balanced, and extra high in nutrients (for health) and calories (for strength).
- Give smaller meals more often (for example 3 main meals and 2-3 snacks) (meals should not last for more than 30 minutes or else the person will get too tired and not be able to chew or swallow).
- Position: support the person in upright position with the chin slightly down (use a special seat if needed and possible). Provide jaw and lip support if needed (see picture at the bottom left).
- Make sure the food is of a smooth texture and with no bits in it if the person chokes easily with other types of food, even in a good position.
- Use good utensils: small plastic cup & small plastic spoon.
- If a person cannot feed themselves, feed sensitively: small mouthfuls, slowly, watching & pausing. NO FORCE.
- Communicate with the person in a positive manner. Tell when the spoon is coming before putting in the mouth.
- Give the person at least 1 liter (5 cups) of water per day.
- There are different techniques to practice this:

Technique of an adapted spoon or cup try out spoon with different sizes and handles that the person can (learn to) hold. You can thicken the handles for easier grip with old clothes (braided for firmer hold), attaching a piece of wood or object to the handle. If the person has difficulty holding on to the person for a longer while, you can make a handled like the picture, to attach the spoon to the hand.





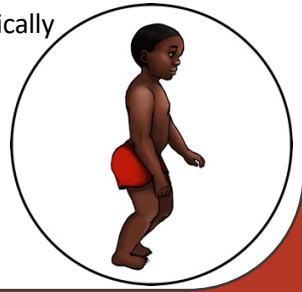
Card 22

Activities and Participation

Moving in and outside the house

Depending on the severity of CP people with CP will be able to become independent in walking (mild CP), need an assistive device for moving around (moderate CP) or will always be dependent in moving (severe CP). Before a child can walk, they need to have reasonable control of their head, they need to be able to sit without help, and to be able to keep their balance while standing. If they can sit without assistance by age 2, their chances of walking may be good – although other factors may affect this. Around two years old most typically developing children can walk.





Actions to take

- Always stimulate the child to help and do as much as possible by herself. This person take more time, but every time this is an opportunity for the person to learn and develop.
- When you pick up the person e.g. from the bed or the floor: always ask him to reach out with the arms, or to come and roll a little nearer to you.
- When the person for example goes to the toilet, let him stand/walk (with support) if possible.
- Let the person help wherever possible with transfers and moving from one place to the other. This is many times a day 'therapy'.
- All people need to be physical active to develop and to stay healthy, also people with CP.









Mild CP

Children with mild CP can (learn) to walk, but usually will stumble or fall more easily. They will be later in development of walking and running.





Actions to take

- Help the child in learning to roll, crawl, stand and walk from an early age. Look at the development milestones to see the sequence of development: www.cdc.gov/ncbddd/actearly/milestones/index.html
- You can practice standing at a table or chair.
- Stimulate the child who can already walk to:
  - walk stairs (if safe and under supervision first)
  - play with a ball (football, or throwing and catching balls)
  - balancing on a 'line of feet' on the floor

Moderate CP alternative mobility





Moderate CP

Children with moderate CP will be able to be independent in moving around with assistive devices (in accessible places), like a walker or a wheelchair. Most of them will need a wheelchair for longer distances. Milestones like rolling, crawling, changing positions, standing and walking with assistive devices will be reached late and could remain difficult. Walking could remain difficult for example on uneven surfaces and support of a person or assistive device might be needed here.





Actions to take

- Always stimulate the person to move and help doing those activities!
- Help the child in learning to roll, crawl, stand and walk from an early age. Look at the development milestones to see the sequence of development: www.cdc.gov/ncbddd/actearly/milestones/index.html.
- Use every opportunity to let the child move by himself with your support or of an assistive device like a walker.
- If the child can walk while holding your two hands, try out a walker, so he can learn to become move independently.
- Look where to put rails and handles in or outside the house or make parallel bars from wood to practice walking.
- There are different ways to move that you can explore, for example using wheel boards, wagons, wheelchairs, special walkers and hand-pedal tricycles.

Card 23

Activities and Participation

Card 24

Activities and Participation

Severe CP

A person with CP on a mat on the floor or in a special chair does not move around and gets less opportunities to interact with others so little spontaneous learning is present. People with severe CP will need support to moving around. If walking is not possible, aim for other important goals such as moving together, being moved, stimulate to move the arms and legs in different ways and changing positions regularly. They can join, learn and enjoy life in other ways.







Actions to take

- If possible, use a walker to support the child moving inside the house with your help. This will keep his body in a better position and better condition.
- Ensure that the person is in a good position, preferably sitting, and being able or helped to look around, to keep the head up and interact with people around them.
- Let the person help you, even if only a little, when changing position, dressing etc. Trying to do these activities will keep his body in better condition and make caring easier for you.
- A standing frame might help if a person cannot stand themselves. The frame helps stretching the muscles and preventing joints from becoming stiff.





Card 25

Activities and Participation

Self-care

The child with CP will become an adult with CP. Help the child become an adult who can live with their disability and be as independent as possible. Most important is that the caregivers and other family members learn not to do everything for the person. Families can do a lot to help their children or family members carry out activities and participate happily in daily life. Even children with severe CP can often learn important basic skills. Maybe not the entire activity, but they might be able to help with parts which is good for the muscles to become and stay strong and active.



Actions to take

- Go through the activities in a normal day and see where the person can do parts of tasks or entire tasks themselves.
- When you dress the child: ask him to help (lifting the leg, changing position, reaching out the arm).
- Help the child just enough so that they can learn to do more for themselves. For example, if the child is beginning to hold up their head, and to take things to their mouth, instead of always feeding them yourself, look for ways to help your child begin to feed themselves.
- Try out some of the techniques on this card together with the caregiver and coach the person and caregiver how to do this themselves on a daily basis, embedded in their daily routine. These techniques apply to different types of activities. You can replace the activities below with others you are working on.
- From easy to difficult, you can gradually build skills such as in dressing: cooperating in dressing, removing loose clothes, putting on loose clothes, managing fasteners, little help, tying shoes or sandals.

See the next page for a description of some techniques for how to do this.



Card 26

Activities and Participation

Hand over hand

Put you hand over the hand of the child to guide the movement of washing the body.



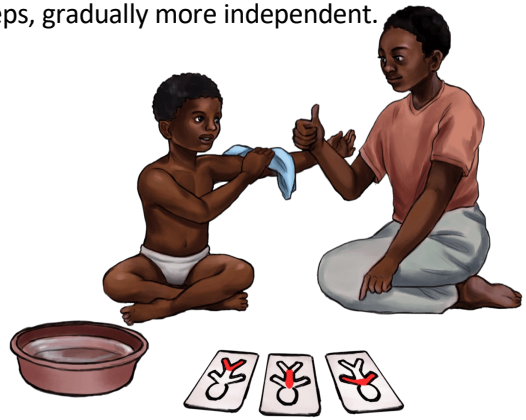
Mirror

Brush teeth in front of a mirror for the child to see their movements, while supporting the body.



Drawings to show sequence

Make drawings that show the steps of washing the body. Let the child follow the steps, gradually more independent.



Clothing ready in a row

Put the clothes in front of the child while sitting in the corner of the room. Help with words and if needed physically if child gets stuck.



Helping aids

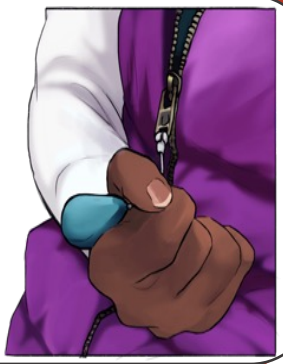
If handling the clothes is difficult, talk with a therapist to see if you can make small, low cost helping aids such as a key chain on the zipper to pull down and up easier, adapted cup or bottle.











Card 27

Activities and Participation

Learning

Learning takes place in daily life, at home, the community or at school/ day-care centre. A person with CP, staying at home or in one place, gets less opportunities to learn and practice by seeing, hearing and doing. Learning will not take place spontaneous if no opportunities are provided to learn. If the child cannot move around him/herself, they will stay most of the time in one place and deprived from learning opportunities through people around them. Parents and siblings are often very busy with other activities and often do too many things for the person instead of involving the person and do things with him.

A lot of 'spontaneous' learning takes place when moving around, playing, singing, chatting; such as in a school. When moving around, a person will see, hear and experience much more compared to a person who is dependent on others and only stays inside the house. A child without disability has lots of opportunities to learn and to repeat again and again, which will improve the abilities of the person. Repetition, stimulation and being appraised are important to develop their full potential.

A person with CP usually gets much less practice, even though more practice is needed because of the disability. It can be much faster to dress the person with CP but supporting and teaching the child to do the activity him/herself will help improve hand skills, balance, understanding what's first in an activity and what's next.
Often the caregivers do too much because it is faster, but maybe also because they think the person will not be able to learn. But learning, even if only small steps, is important for their development and their well-being. Providing children opportunities to learn by moving (even if it is stimulating to move the hands through play) and participating needs to start as young as possible.

Many children with CP in low-resource settings do not go to school because the parents believe this is not possible or they are afraid their child will not be accepted. The school may also refuse to accept them because they are disabled, cannot move around, concentrate well or because they might need support to go to the toilet. With the right support from other people and/or assistive devices, like a wheelchair or walker, going to school or a daycare centre could be possible.









Card 28

Activities and Participation

Actions to take

Help the child, to be able to go to school, learn, play with friends and move around the school. Work with the caregivers, teachers and head teachers to address the following:

1. All children want to be able to reach school: provide children with a disability (adapted) transport to school.
2. All children want to be able to enter and pass through the school: school buildings, furniture and grounds need to be accessible for children with a disability.
3. All children want to be able to visit the restroom: restrooms at every school need to be adapted for children with a disability.
4. All children want to receive 'honest' education: lessons and rules need to be adapted for children with a disability.
5. All children want to play: enable children with a disability to participate in sports and games at school.
6. All children want friends: teach children how they can be there for children with a disability.
7. All children want parents to help: stand up as parents for children with a disability.
8. All children want good guidance: train teachers how they can better council children with a disability.
9. All children have to be able to perform the activities in school. Sometimes assistive devices are needed such as adaptive chairs or materials like an adapted pen.
10. all children want positive attention: acknowledge their hard work and praise their effort.
11. All children want to just be a kid: provide opportunities to develop their potential and enjoy life.



Card 29

Activities and Participation

Community activities

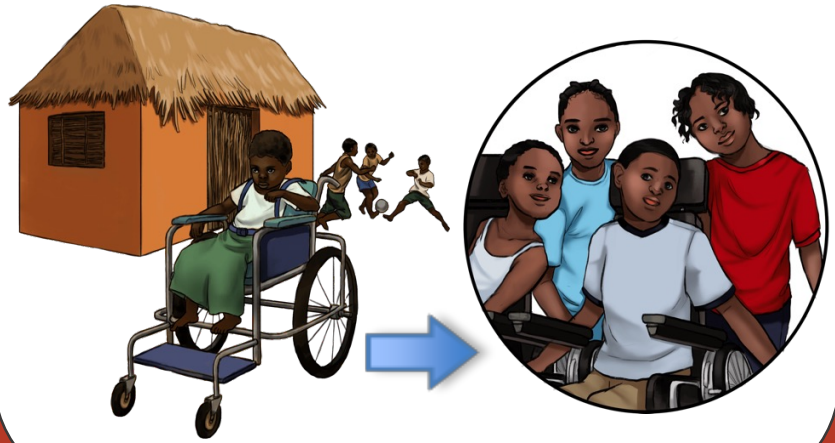
Every child needs to interact in all settings to learn and enjoy life – at home, in the community and at school. Participation in daily life is important for the development of the persons' motor and social skills, for learning and future work skills. Active participation is needed for developing social networks and a feeling of belonging and well-being.

Often people with a disability are kept or stay inside the house out of fear for stigma, caregivers not having time, materials such as a wheelchair or knowledge how to involve the person in daily life. Participation in the family and community is important for good health, social interaction and support and learning. With support everybody can be included in activities.

Actions to take

- Together with physical support to participate, social barriers also need to be tackled and fieldworkers can have an important role in doing this.
- It is important that the child is included in all social activities within the family and community.
- Provide the person and their family with ideas and materials to be able to join activities inside and outside the house of example play with friends or going to church. Arrange a (wheel)chair or mobility device suitable for the person, practice moving around (if possible), find games or activities the person can join and enjoy.
- Involve family, community members and peers in these activities to understand how to include the person in activities, physically, socially and interactive.

Children with CP are also often excluded from social activities in the community or with friends. A child with CP may need help getting to a friend's house or physical support to play with other children.



- Include peers in activities. Explore and enjoy together.





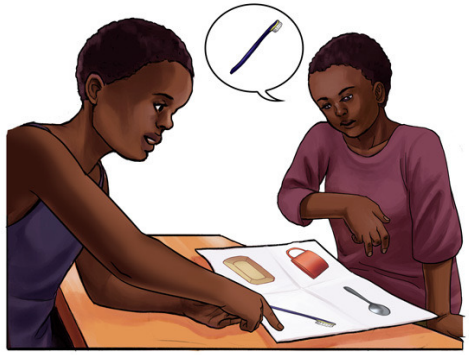




Personal factors:

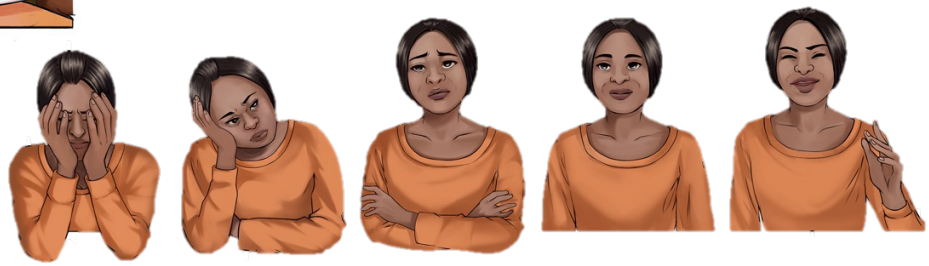
Information and

Actions to take











Card 30

Personal Factors

Personal wishes and needs

Every person has wishes and needs, with or without disability. Also when a person cannot speak or doesn't seem aware, that person has needs. Everyone has the right to well-being. These wishes and needs have to be taken into account when discussion priorities for intervention, setting goals and actions.

Actions to take

- When talking with families, always include the person it is about.
- When a person cannot speak, use alternative ways (see 'communication' in the previous cards) and observe body language and facial expression when talking with the person and the caregivers.



Social skills and boundaries

Social skills include being able to manage yourself, being self-aware, being aware socially of the people around you, being able to make decision in an appropriate manner, solve problems and skills in relationships. Social skills are needed in different areas of life such as at home, friends, school, work, when meeting people and having a love life when grown older. One of the things that is needed is personal space and understanding when just talking or touching is appropriate. Knowing when you can trust a person. When a person has a disability intellectually or is not used to connecting with people, it might be difficult to develop social skills and understand social boundaries. This is important to prevent unwanted contact.

Actions to take

- Discuss with the person, the caregivers and family how to teach the person social skills if this is a challenge. This does not mean, it is a challenge for all people with CP.
- Talk to the person and caregivers to identify any difficulties. Is there a difficulty in understanding physical and social boundaries or is it difficult for a person to protect oneself, for example when a person is home alone and doesn't have the social or physical capacity for self-protection.



Card 31

Personal Factors

Mental support

Many factors may affect the person with CP and his/her family emotionally. They usually experience different stages of emotional distress, that can repeat every time they have to adjust their expectations about the person's life. This can result in feeling hopeless, depressed or sad. If you sense that there is depression which grows worse, refer to a specialist.

Depression is an illness characterized by persistent sadness and a los of interest in activities once enjoyed, accompanied by an inability to carry out daily activities that lasts for at least two weeks. It can lead to a variety of emotional and physical problems, such as loss of energy, a change in appetite, sleeping more or less, feelings of worthlessness and thoughts of self-harm or harm to the person with CP. In this case refer to a specialist immediately!

Actions to take

- Be sensitive to the stages of emotional distress and provide mental support and courage to hold on. Refer if needed!
- Provide the child and family practical and mental support for developing resilience and learning to live with their strengths and weaknesses and finding alternative ways to achieve their full potential.
- Listen to their stories, encouraging them to seek assistance from family and friends and provide a positive sense of the future.
- Make sure the person as well as the caregivers have some form of social support (e.g. from caregiver(s), family members, friends/peers, community members or other).
- Pay attention to whether the person or caregiver(s) shows signs of emotional distress (e.g. exhaustion, worry, depression, anger)



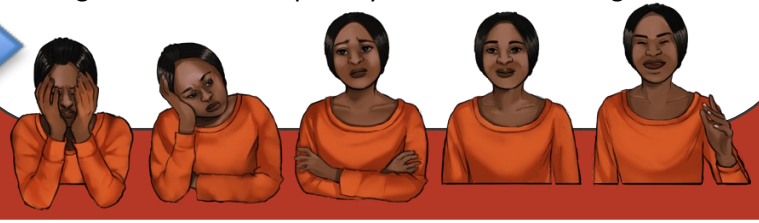
Caregivers role

The caregiver assisting the person with CP plays a crucial role in improving and maintaining quality of life. CP can vary from mild to severe. When a child has severe CP or CP and intellectual disability, more support is needed from caregivers. At all times, it is important to include the wishes and needs of the person with CP, but It is also important for the caregiver to be conscious of the following:

- The responsibility this entails in his/her life and where to find support.
- The impact of caregiving on the caregiver and prevent physical and mental overburden.
- The goals the caregiver wants to achieve or maintain for the person with CP.

Actions to take

- Coaching caregivers to understand what they can do in their daily life routines and in their skills as caregivers.
- Help to manage caregiver stress and/or fatigue.
- Avoid overprotecting the person with CP by not allowing him/her to use his/her full functional potential in daily life.
- Help the caregiver to find up-to-date information about CP and upgrade his/her knowledge and skills on how to take care of their child and stimulate development.
- Answer their questions.
- Provide realistic information on (re)habilitation outcomes.
- Include them in your interventions by making decisions together. This will improve your collaboration together.



Card 32

Personal Factors

Peer counseling

Peer counselling consists of emotional and practical support provided by people in similar situations, such as other caregivers of persons with CP. Peer counselling can be an asset to a caregiver that recently learned the child had CP or for youngsters with CP. Still, the peer counsellor should be aware that everybody has his unique coping style; experiences and practices can't just be replicated without adaptation to the person and the context. Peers can answer questions on how to take care of the child in daily life, share experiences, knowledge and skills. Peer support can be directed at the individual caregiver or person with CP as a "buddy", but also at caregivers in the form of family counselling, or as group counselling.



Learning your child has CP is a life-changing event for both the affected person and their family. They will most likely ask themselves why this misfortune overtook them. For these sort of questions, they may benefit from consultation with a religious leader – a priest, an imam, a rabbi- or from partaking in religious rituals. It is good to be aware that not only practical support is needed but also spiritual support.

Actions to take

- Be aware of what support is asked from and provided by traditional healers and that this does not do harm to the persons' body such as making burns or cuts to the back.
- Connect the caregivers to other caregivers or parent support groups. These groups can provide mental support but also livelihood support by organizing soft loan systems.



Behaviour

The brain damage may also affect behaviour and make it challenging for caregivers or health workers to understand what the child wants and needs. It needs to made sure first whether challenging behaviour is caused by difficulty expressing needs and wishes with words. If so, look at the flashcards about communication first.

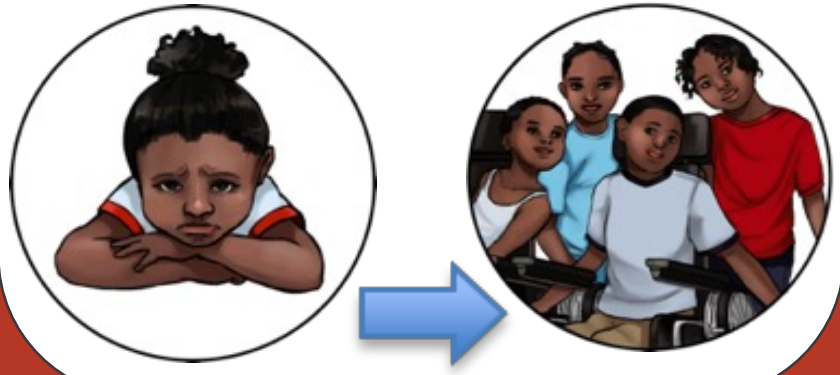
Sudden changes of mood from laughing to crying, becoming frightened, fits of anger, and other difficult behaviour may be present just like with typically developing people. This may partly be due to the child's frustration at not being able to do what he wants with his body. Some people may need a lot of help and patience to overcome their fears and other challenging behaviour.



Actions to take

- Find out the causes of behaviour you don't understand:
  - Ask the caregivers, they know their child best.
  - Does the person have difficulty communicating needs and wishes and being understood by people?
  - Observe closely during daily routines what the cause could be.
  - Is the person not feeling well, in pain, afraid, angry?
  - Is there too much noise, light or movement around the person?

- Try out and evaluate which adjustments have a positive effect:
  - Making your actions and movements more predictable by saying what you will do before doing it.
  - Involve the person in activities by letting them point at what first and next, give people influence and autonomy in what is happening.
  - Finding out and use this as an entry point what the child likes e.g. sounds, songs, movements, types of appraisal like high five.
  - Take your time to connect to the person.
  - See communication techniques if needed.

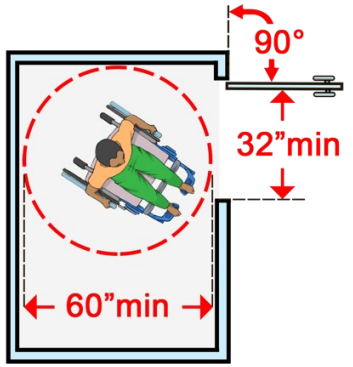


Card 33

Personal Factors

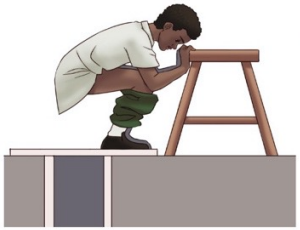














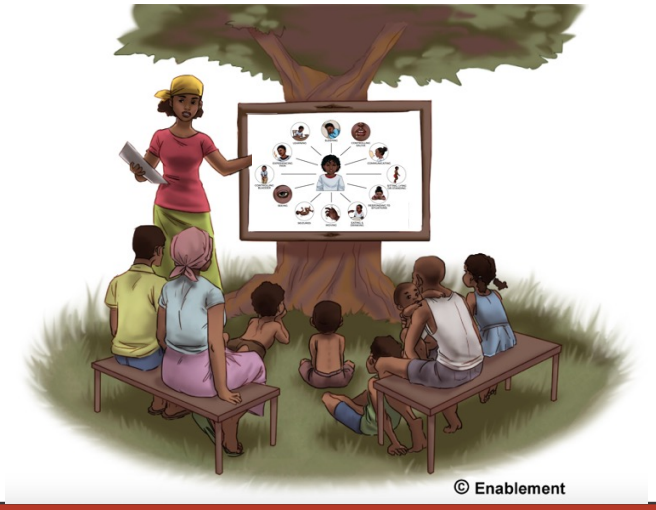
Environmental factors:

Information and

Actions to take









Safety

People with disability might be at risk for abuse and safeguarding needs to have important attention. Especially girls with a disability are at risk due to not always being able to protect themselves and beliefs that are harmful for safeguarding. Abuse can have many shapes: neglect (caregivers not being able to provide in the child's needs or protection from dangerous situations), physical abuse, psychological or emotional abuse and sexual abuse.

It is important that this issue is addressed within the community alongside creating awareness for the convention on the rights of people with disabilities. Safety is not only about identifying possible abuse, but also teaching a person to understand social and physical boundaries. When a person does not have a lot of contact with other people for example, it might be difficult to understand what is 'normal' in terms of these boundaries. On the other hand, many people with disabilities can and want to have a healthy love life.

Actions to take

- Create awareness in the community on the rights of people with disabilities and the need for protection against abuse.
- Be aware for signs and symptoms of abuse. Teach caregivers these signs and symptoms.
- Teach children and adults with CP about self-protection, justice and how to speak up, if possible, for their rights.
- Being able to protect oneself is important, for example by learning to express yes/no and understanding boundaries.



Livelihood

Taking care of a person with a disability can bring about extra costs such as for treatment, hospital consultations, assistive devices and other, especially for single mothers. In addition, having to visit health clinics, hospitals and rehabilitation centres regularly will prevent from being able to work and hence loss of income.

Some disabled people's organisations or parent support groups have soft loan systems which makes it possible for the caregivers to create a business near the house where they can also take care of their child.





Actions to take

- Check whether the person with the disability or caregiver is employed and/or has enough financial support to afford basic needs for the household.
- Together with the caregiver discuss the actions that are needed and related costs. If this is beyond the financial capacity of the family, encourage and help them to explore possibilities for financial support from the local community such as churches, international organisations (INGOs), income generating activity programs, micro credit programs or soft loan systems.

Card 34

Environmental Factors

Card 35

Environmental Factors

Attitudes

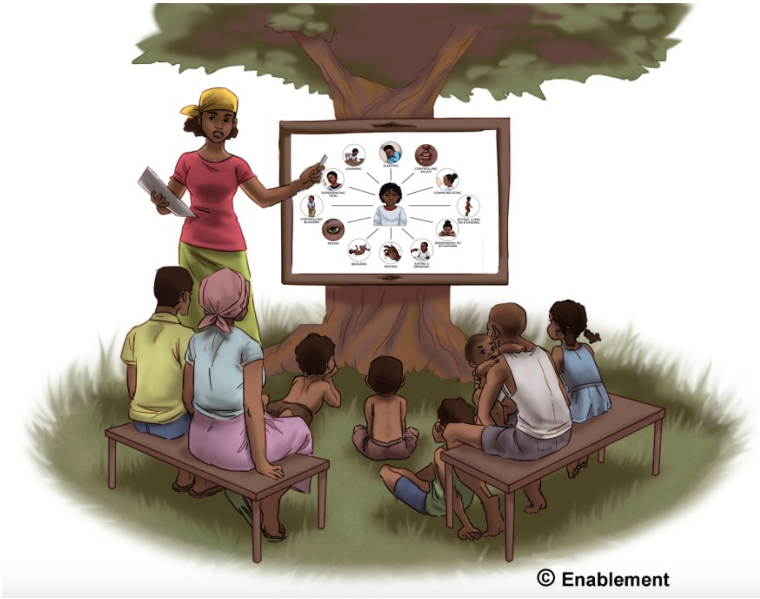
Within a family or the community, negative attitudes can exist towards CP but also towards caregiver(s) for example if the person is not progressing. Even being blamed by fieldworkers for this lack of progress exists whom might think the child will develop well if the mother is doing more exercises.

The mother is often blamed by family for having a child with a disability resulting in being abandoned, lack of support by family members or family not paying attention to the person with CP. Sometimes caregivers and their child are refused in the bus, being treated as having a contagious condition. Some beliefs can bring about positive results in including a person within the community. Others are harmful resulting in exclusion from the community. It can cause a person with CP difficulty finding a job but can also make them strong community, members speaking up for rights of everyone. Some persons and caregivers become strong, motivated fieldworkers, helping other people with disabilities and their family.



Actions to take

- You must change your approach if you see no progress. Never blame the mother! Did you push too much? Did you not have the whole picture of the environment? Where your goals not SMART? Go over your ABCs (see Rehab Cycle: acute, barriers, capacity – development).
- Some children, with severe CP may show little or no progress and the mother realizes the child will always be dependent on her. This can frustrate or frighten her. She needs more support how to make taking care easier for her and still give the child love and quality of life.
- Check whether there are social barriers preventing the person and/or caregiver(s) from accessing public places. For example, out of fear to be stared at or not being accepted.
- Pay attention to the child's, caregiver(s)'s and community members' perceptions of disabilities. Talk with family and community members to create awareness.



Card 36

Environmental Factors

Accessibility

Home modifications might be needed if a person cannot walk easily or not at all. With some creativity (and sensitivity), a lot can be modified to achieve temporary or permanent solutions. A ramp might have to be put in if there are differences in the height of surfaces within or around the house. Additionally, the person might benefit from handles being attached, for example to doorways and near the toilet, to support moving in and outside the house and maintaining balance whilst doing an activity.

What applies for the home, also applies for school. Make every effort to ensure the child attends school and that the school is inclusive (adapted to the needs of all learners, including children with disabilities).

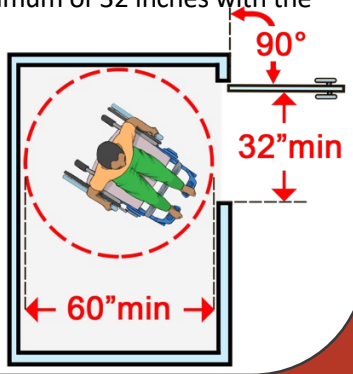
Actions to take

- Check whether there are physical barriers preventing the person from moving around in or accessing the house, neighbourhood or public places. For example big rocks in the road and differences in height when accessing a building.
- Consult a therapist if you believe modifications to the house need to be made.



Possibilities for home modifications

- Establish ramps where there are steps. The international standard for slopes is 1:14. This means that for every 14 centimetres travelled horizontally, the ramp rises 1 centimetre.
- Ensure sufficient turning space (minimum of 60 inches) for the wheelchair user to rotate on the spot.
- Doorways should be wide enough (minimum of 32 inches with the door open to 90 degrees) to pass with the wheelchair and doors light enough to open and close from sitting position in the wheelchair.
- Tables and kitchen sink should prefereably be wheelchair accessible and cupboards within reach of the wheelchair user.



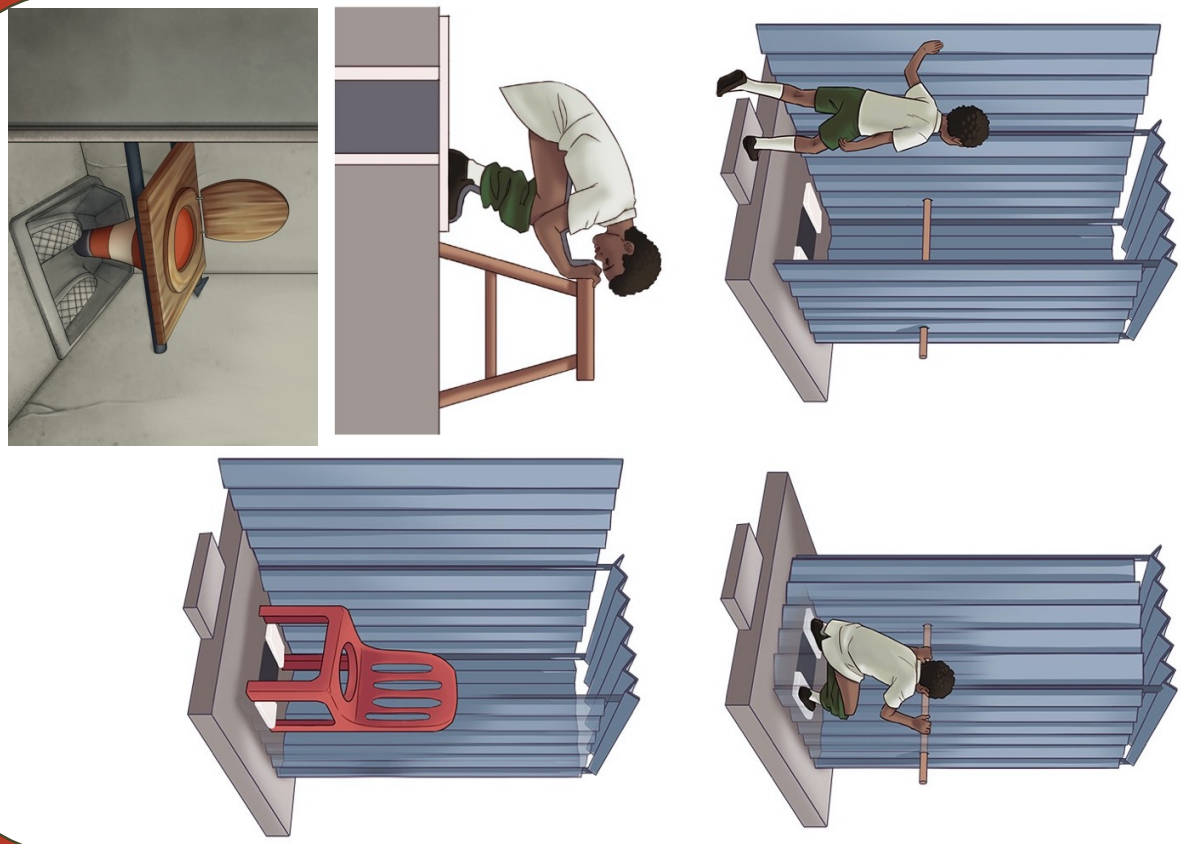
Possibilities for bathroom modifications

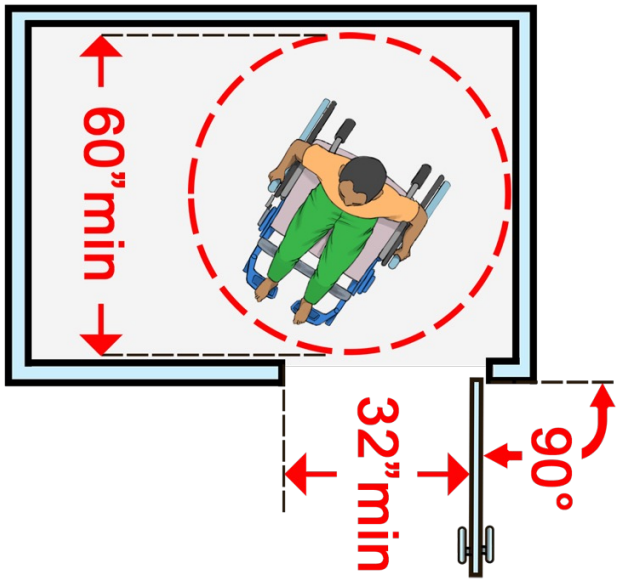
- Have sufficient space (minimum of 59 inches) in front of the toilet/commode for a safe transfer. The same between the sink and the wall (minimum of 60 inches).
- Level the toilet/commode where possible to align with the height of the wheelchair.
- Install grab rails alongside and behind the toilet from wood.
- Use a plastic chair if needed over flat toilets.
- See next page for larger pictures of modifications to the house and bathroom.



Environmental Factors

Card 37







Card 38

Environmental Factors

Assistive devices

Assistive devices have a great effect on being able to perform activities and participate in daily life. When you observe the person has activity limitations, consider if adapting daily materials can support the activity. You can also choose to refer to an organization that provides assistive devices, especially large devices like a wheelchair, supportive seat or walker.

There are several types of devices and adaptations. These devices can help children to:

- move around
- eat by themselves or make feeding easier
- communicate
- go to school
- play by themselves
- play with their friends
- or become more independent

Actions to take

- Refer to an orthopaedic technician or physiotherapist when:
  - The family does not have but needs an assistive device for the child.
  - The child is always crying when placed in the assistive device.
  - The child cannot sit or stand up straight in the assistive device.
  - The assistive device is too small.
  - The assistive device is broken.
  - The family has but does not use the assistive device: find out first why.

Throughout these flashcards, information and pictures have been given and shown of some of these devices and their use. Check the different cards to see how they can be made and used.

People with CP that have difficulty walking could benefit from a wheelchair or walker to move around. People who need support sitting upright can benefit from special seats. It is important to remember that the child needs to change their position regularly to avoid stiffness and pressure sores, and so must not sit in the same seat / or wheelchair all day. The seat on all CP wheelchairs should be designed to prevent skin problems, maintain posture and enhance independent mobility and functioning.

Besides mobility devices, there are also **assistive devices** to support self-care activities such as eating & drinking, and learning. These devices can improve playing, doing parts of or entire self-care activities, participating in social activities and much more.



Card 39

Environmental Factors

Network of stakeholders

You don’t have to do everything alone. Unity among a network of organisations and specialists is needed to help a family in the best way. It requires working together, being connected, informing each other and asking for advice.

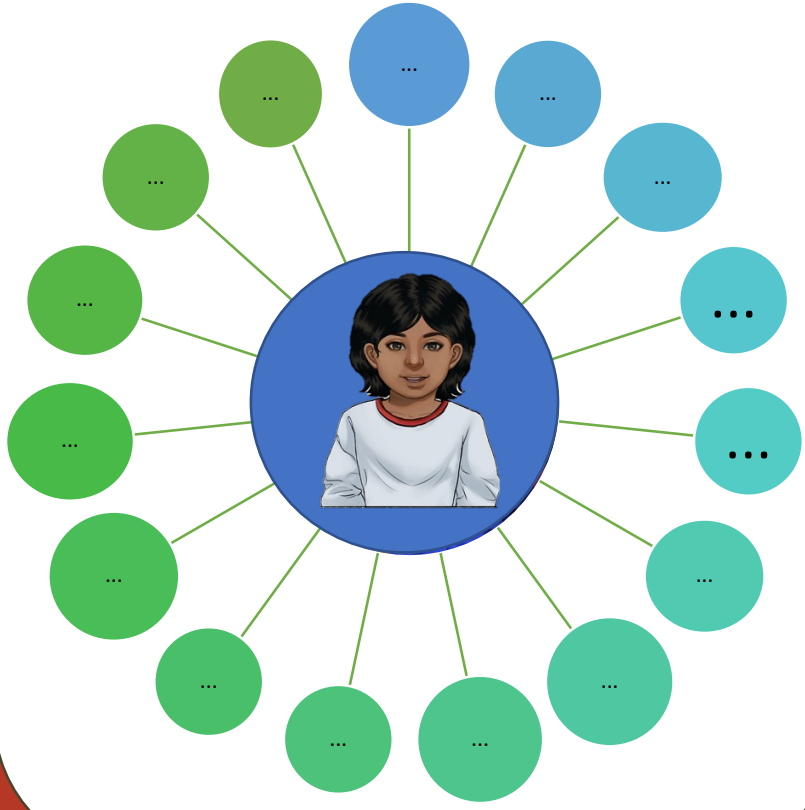
It may be very well that you won't be able to help the child and his/her family yourself. That could be for various reasons for example:

- You may not have the right expertise,
- You or your organisation may not have the means to assist for example assistive devices.
- Other interventions may be needed than those that your organisations offer. For example, the family may be very poor, and you may need to refer to a social work department or poverty alleviation programme for assistance.
- The child may need medical attention, for example medication.



Actions to take

- Please develop a list of local organisations and persons to refer to. Make your own address book and share or exchange with colleagues.
- Always make sure you refer in time and to the right person or organisation! Think of the ABCs (see Rehab Cycle: acute, barriers, capacity – development).
- You can think of finding these persons for your list: family, elders, CBR worker, specialist doctors, therapists, local leaders, suppliers and so on. Which people are involved depends on the area you work and live in. Get to know them and inform them about the process of the child wherever needed.



Card 40

Colophon

The content of these Flashcards was made with the support of:

- Children, caregivers and CBR workers from around the world
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- Angelique Kester
- Roelie Wolting
- Marian Fransen
- Maria Njeri
- Mel Adams
- Wouter de Groote

CONTACT INFORMATION

Enablement

Antonie van Leeuwenhoekweg 38 A16

2408 AN Alphen aan den Rijn

The Netherlands

Phone: +3172 499 940

E-mail: info@enablement.nl

Website: www.enablement.eu

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Enablement

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IFSBH

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Karunafoundation – Saving children from disability, one by one

Koninklijke Kentalis

LIGHT FOR THE WORLD

Norges Handikapforbund

NLR

PLAN INTERNATIONAL

Sightsavers

VRHL

Card 41

Colophon

When drafting the content of these Flashcards, these resources were particularly helpful:

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