



How do I care for a child with cerebral palsy? - Manual for Parents

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Enabling Inclusion through Early Intervention (EI) Programme



AMAR SEVA SANGAM



Amar Seva Sangam (ASSA) is a premier organisation in the field of disability management focusing on rural areas, located in Ayikudy Village in Tenkasi District of Tamil Nadu. Our approach is to establish a centralised resource center to act as a catalyst for change in the development of children and adults who are differently abled and intellectually challenged. We do this by involving the village community in the process. This mission of ASSA is to establish a Valley for the Disabled, whereby persons with physical / intellectual challenges live in a pro-active society where equality prevails irrespective of physical, intellectual or other challenges with the rest of the society. It is a futuristic vision whereby Amar Seva Sangam plays the role of an enabling agent to provide persons with physical / intellectual challenges "equality of status, equality in opportunities and equality in access".

Amar Seva Sangam (ASSA) was established by Mr. Ramakrishnan, in the International year of the Disabled to cater to disability management focusing on rural areas.



S. Ramakrishnan, Founder President

S. Ramakrishnan, while in his 4th year engineering, injured his spine while attending the last round of Naval officers' selection test and became a quadriplegic. He established ASSA in 1981, the year for the Disabled and named it after his Doctor and mentor Air Marshal Dr. Amarjit Singh Chahal of Defence hospital. **Padma Shree awardee** S.Ramakrishnan is the President of ASSA.



S. Sankara Raman, Secretary

S. Sankara Raman, a Chartered Accountant and a wheel chair user, affected by muscular dystrophy joined ASSA in 1992. He is the Secretary of ASSA. Along with Mr. Ramakrishnan, they have built a **Valley for the Differently Abled** in a 30 acre land

at Ayikudy, as a Rehabilitation and Development Centre and developing models for self-help initiatives by integrating individuals with disabilities within society for improved living conditions. In 2020, he established Amar Seva Global, a social enterprise focused on spreading Amar Seva's Enabling Inclusion program globally.





What is Development Delay ?

Skills such as taking a first step, smiling for the first time, and waving "bye-bye" are called developmental milestones. Children reach milestones in how they play, learn, speak, behave, and move (for example, crawling and walking). Children develop at their own pace. However, when developmental milestones are not met by a certain expected age, it is called "developmental delay". Early stimulation and intervention can help children reach these milestones.

What is Development Disability?

Developmental disabilities are a group of conditions due to an impairment in physical, learning, language, social or behavioral areas. These conditions begin during a child's developmental period, may impact day-to-day functioning, and can last throughout a person's lifetime. According to the WHO, "If children with developmental delays are not provided with appropriate early intervention, their difficulties can lead to lifetime consequences, increased poverty and profound exclusion".

What is Early Intervention?

Interventions promoting child development should address physical, social, emotional, language, and cognitive areas of development. Services targeting these domains of development are termed, "Early Intervention therapy" and can encompass physical therapy, occupational therapy, speech-language therapy and special education. Early Intervention has a significant impact for children who have delayed development in physical, cognitive, emotional, sensory, behavioural, social and communication domains of development. With quality early intervention services, children can reach their potential, live a meaningful life and integrate into their communities.



Enabling Inclusion Programme

Amar Seva Sangam's Enabling Inclusion programme uses community rehabilitation workers to provide early intervention services to children in their own homes or in community centres by connecting these community workers with rehabilitation specialists (physiotherapists, occupational therapists, speech therapists, trainers and special educators) through the use of the award winning Enabling Inclusion (EI) app. The program has proven to improve outcomes for children with disabilities and their family members and has allowed many children to reach their potential.





Content

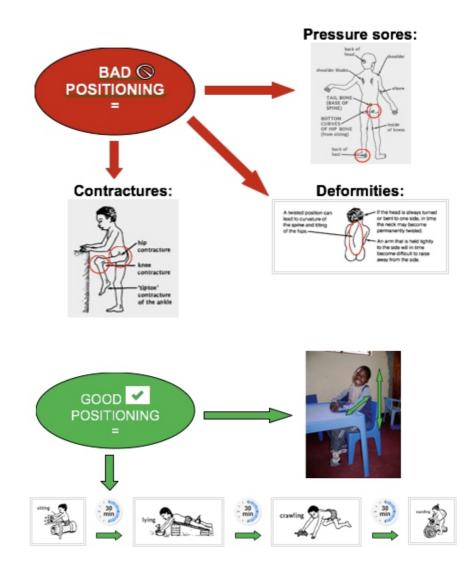
- 1. Introduction to Cerebral Palsy -
- 2. Positioning and handling
- 3. Mobility
- 4. Dressing
- 5. Feeding
- 6. Toileting
- 7. Play
- 8. Speech and Communication





Positioning

Positioning is the way your child sits, stands and lies down. Good positioning is very important

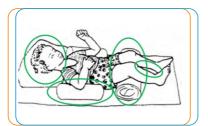






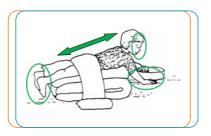


GOOD



Lying on Stomach

GOOD







BAD 🚫





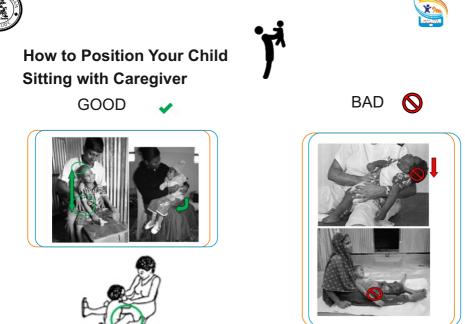
GOOD





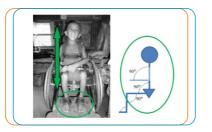
Switch sides every 30 minutes.





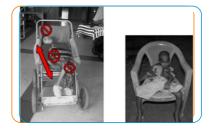
Sitting in a Wheelchair or Chair

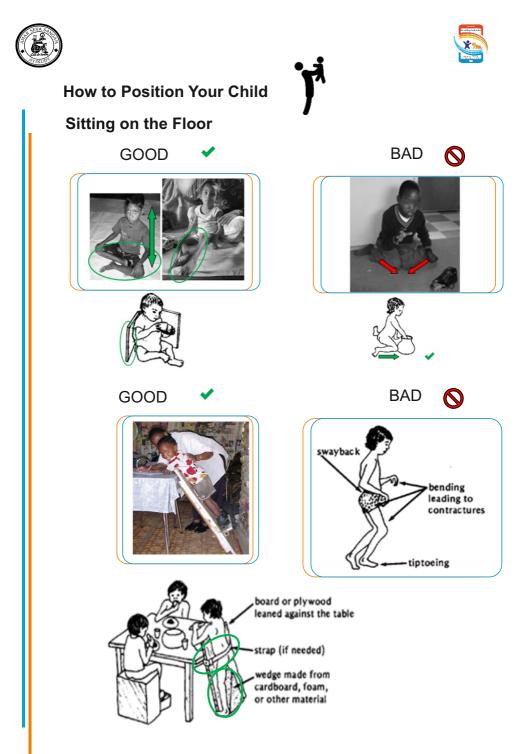
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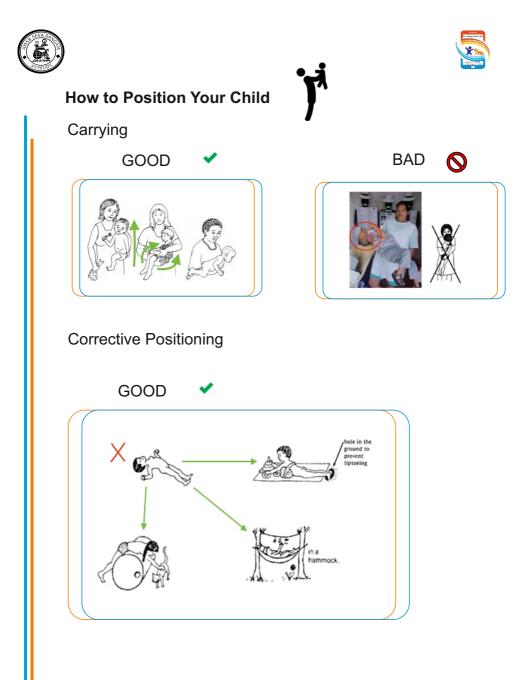




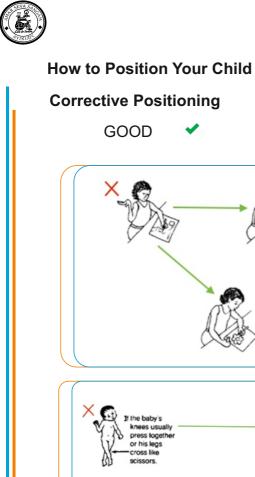
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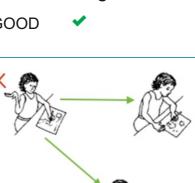


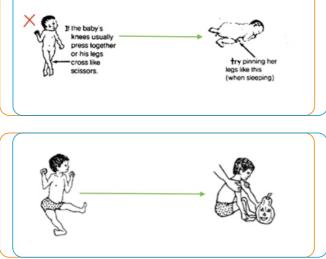
















Mobility

Mobility is how someone gets around their home, school, work, or village. Children with CP may have problems with moving around because of their disorder. These children may need help to walk or they may walk a bit differently than other children.



Exercises

How to help the child move around

Caution: Do these exercises after you have talked with ASSA staff and know it's safe

Important for exercises

- Move carefully and slowly
- Don't force body if it wont go
- Do not do exercises if floppy
- Stop if there's pain
- Don't hold on joint, hold on top and bottom

When to do exercises and for how long?

- Do exercises 2 times a day
- Try to include exercises into child's normal life and routine
- Have older siblings help do the exercises. Male sure they know ho to safely







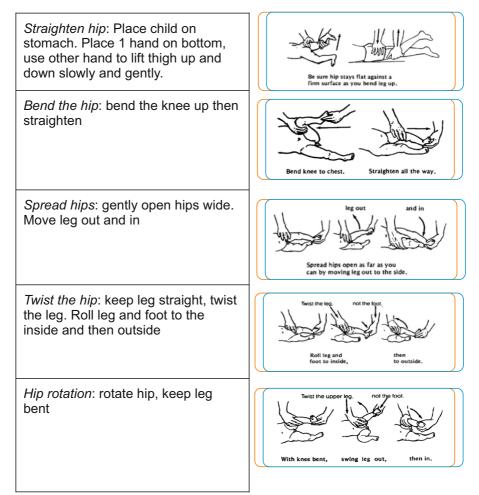






Hip Exercises

Picture

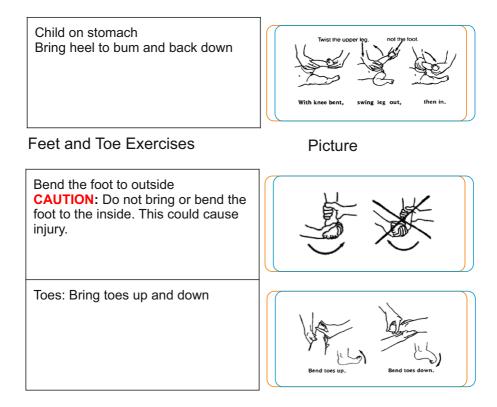






Knee exercises

Picture







Picking up and carrying a child with CP

Safe pickup for child and caregiver to not have an injury

How to pick up the child with CP:

- 1. Bend knees
- 2. Keep back straight
- 3. Place one foot a little in front of the other
- 4. Hold child close to your body
- 5. Lift using leg muscles not back muscles
- 6. When the child gets bigger, ask for help to lift

them

7. When two people are lifting the child, count to 3

DO NOT: bend forward with legs straight. This will hurt your back. DO NOT: pull up child by their arms with no



How to carry the child with CP:

- 1. Keep child's body upright
- 2. Keep child's hips and knees bent a little
- 3. Keep child's knees apart
- 4. Child can hold onto caregiver or hold toys











Crawling (alone or with help)

Improve neck and head control:

- Child on stomach, use toy so they can look up at
- Make a wedge out of blankets and pillows
- When child on back
- Pull child up gently by their arms until head hangs, then place child back down slowly

Help crawling:

- Hold child up with a towel
- Move child from side to side to help with body shifting
- Place toy in front of them for them to grab
- When the child gets stronger, use less help
- Place child on log or bucket with their arms straight this will help make arms stronger
- Gently push down on shoulders and let go.
- Do 3 times
- Place child on stomach on your leg
- Slowly move your knee up, down, left and right
- Child will use arms to catch body















For rolling and creeping:

- Child is laying on stomach, move toy for child to follow, touch it with hands
- Place toy just out of reach so child with try to get it
- Lift hips to help bring legs forward







Balance:

- Child is sitting on ground
- Gently move child from side to side and front to back
- Tell child to use arms to stop their body from falling over
- Place child on ball or log
- Rock child left and right, front and back
- Child on hands and knees
- Hold hips
- Child lift leg behind
- Child move back and forth
- Hold child if they fall
- When child is stronger, they lift one arm and one leg at a time (opposite) and reach for toy







Standing:

- Hold child loosely under arms and • gently move from side to side, front and back
- Child can practice using a stool or chair
- Child can practice standing on one leg and reaching for toy

Walking:

When child is standing, hold onto the hips

Sit - to - stand:

- Place a toy at the edge of a steady table
- Get child to stand up using edge of table
- Watch child as they do this



Tie a loose

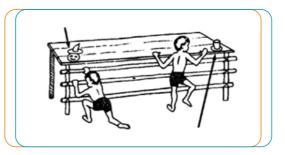
child

they get

stronger

cloth around

the chest and walk behind the





Spread feet to

form a wide base



Hold less when

the child gets

stronger









Have child step up

and down on small

stool



Children who need help to walk:

Parallel bars: A supported bar can help a child walk alone





Tricycles and rolling toys: If a child cannot walk, they can use a rolling toy or tricycle. As they get older, talk to ASSA about cane, walker or wheelchair





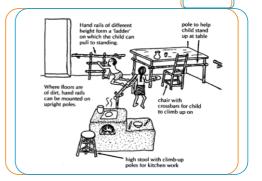
Canes:

How to use a cane for walking

- Hold cane in good (uninjured) side of body.
- When the child is walking, they move their
- injured side and the cane at the same time.

Adaptations at home:

- Include solid objects around the house the child can hold onto while walking and moving
 - \circ Tables
 - Handrails made out of wood
 - o Stools



- Remove garbage and small objects on the ground so the child does not trip
- If the child uses a rolling walker, toy or tricycle to get around, put a ramp made out of wood or concrete going into the house
- If a child crawls, put a mat on the floor for them to crawl on





Dressing

Caution: Do these exercises and activities after you have talked with ASSA staff and know it is safe.

How to position the child when dressing them:

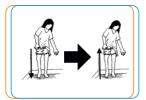


For children with stiff muscles who cannot dress themselves, lay child on back with pillows under head and knees OR over your lap.



For children who can dress themselves, they can lay down on their side, sit against a wall, sit comfortably, or hold onto something while standing.

How to help the child get dressed:



Teach undressing first.



Step 1 "One arm in"



Dressing should be done in the same location



Step 2 "Other arm in"



Home should be quiet for dressing child



Step 3 "Over the head"

Separate each task into smaller easy steps and say them out loud.







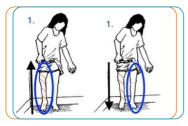
Use pictures and pointing





Complete all the steps for the child, then let the child complete the last step and praise them!

Give clear instructions and repeat them more than once.



Dress the side of the body that has the most disability first. Undress the side of the body that does not have disability.



Use rewards when child succeeds in dressing.

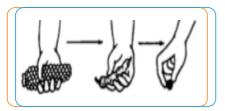


Family should dress with the child and learn about CP together.





Preparatory exercises for dressing:

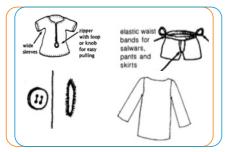


Child strengthen their hands for dressing by holding and squeezing small objects.

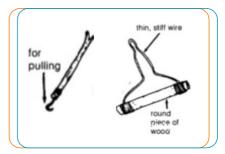


Improve balance for dressing by rocking the child from side to side on a log, ball or toy.

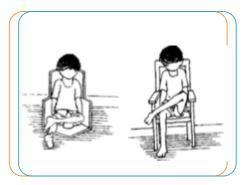
Adaptions in dressing and use of assistive devices



Clothing should be easy to put on and take off.



Sticks with a hook can help pull up pants and doing up buttons.



To put on shoes, child should sit and cross his/her leg over the other.

For the child to be independent and to make friends

Why is good feeding important? For a strong, healthy and happy

For happy and healthy families

How to help a child with feeding:

Preparatory Exercises:

Caution: Do these exercises and activities after you talked to ASSA staff and know it is safe.

Massage:

Feeding

child

- Massage gums moving fingers front and back
- Roll thumb on cheek front and back, two fingers on lips to close mouth and lift up

Jaw control:

- Do before eating •
- Put hand on child's face
- Use thumb or finger to hold jaw
- Use other fingers to push chin up

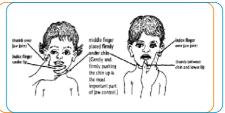
















Chewing and biting:

- Use chew tube or clean cotton cord
- Soak it in tasty food
- Put in back of mouth
- Move tube to both sides
- Show the child how to bite

Tongue exercises:

- Sit in front of child and show same movements
- Stick tongue out
- Twist tongue
- Make circles with tongue
- Touch teeth with tongue
- Put honey on lips and get child to lick off

Swallowing: Press child's lips together

Sucking:

- Show child how to suck
- Practice with a straw

Blowing:

- Show the child how to blow bubbles
- Ask child to blow bubbles
- Show the child how to blow a whistle
- Ask the child to blow a whistle

Stop tongue thrusting:

- Do this if child's tongue goes out a lot
- Use spoon
- Put spoon on tongue and press down
- Do not scrape spoon on teeth

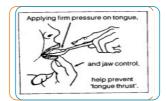
















Mealtime tips

Give child choice of what to eat

- Show picture of food and ask child to point
- Ask child to say what they would like





Give child small sips of water during the day

Wash hands! Important: Wash your hands, child's hand and spoon before eating

Food placement

- Sit in front of child
- Wait for child to be ready for next spoonful
- Place food at corner of mouth
- Take rest if child is tired



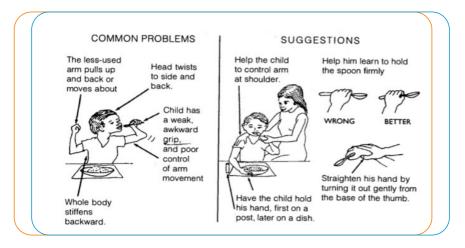






Help child eat him/herself:

- Sit behind child
- Use hand over hand to bring food to mouth
- Use less help each time the child gets stronger
- Clap and say "super" when child does well
- Continue steps each meal until child does on their own





Small meals 5 times a day for 15 minutes



After eating:

- Rinse child's mouth out with water
- Have child sit up for 10-30
 minutes after eating to prevent
 choking







Positions:

- Keep child supported during meals
- Keep the child's head, neck, body stable
- Do not let child's head and neck be floppy



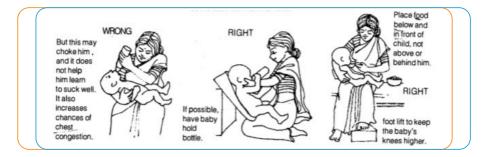
Positions for breastfeeding:

- Feed baby in lap while sitting
- Keep child's head bent forward a little
- Hold child's shoulders forward
- Hold child's chest
- Keep knees bent



Positions for child on lap:

- Use your arm under child's head and neck
- Have child sit on your leg
- No lying down during eating







Positions when sitting on floor:

- When child has stronger body they can sit up
- Child sit on floor
- Child sit with back on wall
- Child sit with pillow behind them
- Small table in front of child

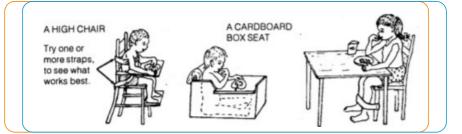


Position for child in a chair:

- Put table in front of child
- Make sure height of table is good for child
- If child's feet do not touch ground, use small stool or block of wood underneath



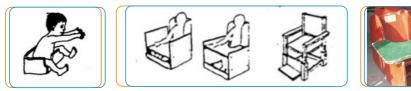






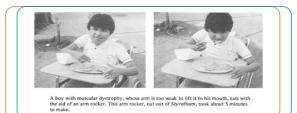


If child needs more support, ask ASSA staff about making seat like below:



Positioning in a wheelchair:

- Child sits up in wheel chair like normal chair
- Wooden tray attached for eating
- Ask ASSA staff how to make it



Position for little arm control:

- · Child sit in chair
- Child holds onto edge of table or table peg

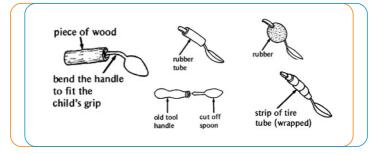
Position for choking:

- If child is choking, bend body forward
- Do not tap the child on the back when they are choking



Feeding equipment:

Use utensils that are easy to hold







Sticky mats under plates, bowls and slabs Round, shallow spoon Adapted nose cup





Spoon with handle wrapped around the wrist

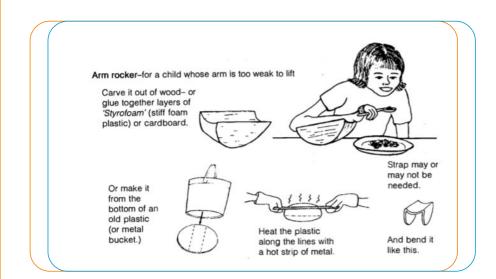
Cup with 2 handles





Arm rocker

- Make for child with weak arms
- Make out of plastic, Styrofoam or block of wood.



Be involved!

- Participate in the child's therapy with the CRW
- Involve the child's brothers and sisters







Toileting

Helping your child with toileting

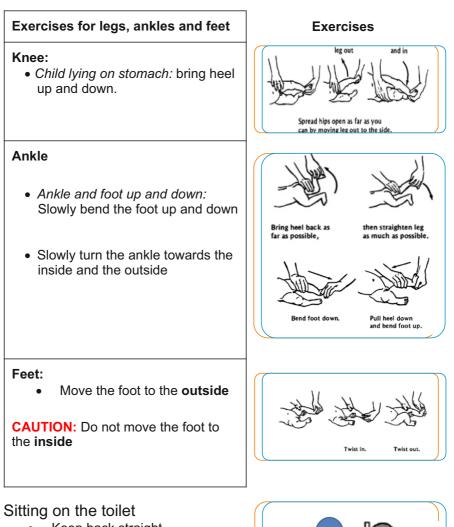
Exercises:

Do these exercises during the day to stretch the body and stiff muscles. This can help your child with toileting.

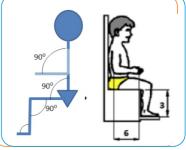








- Keep back straight
 - Keep head up
 - Keep hips, knees and ankles at a 90-degree angle







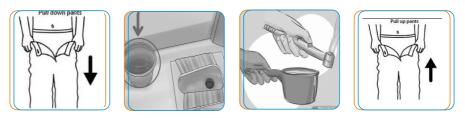
When your child is sitting or squatting, he/she should lean forward. Use a small stool for your child to place his/her feet when they are sitting.



Demonstrations for toileting:

Show your child pictures of the steps for toileting:

- 1. Pull pants down or lift skirt (with or without help)
- 2. Transfer or place body on the toilet or squat toilet
- 3. Use bucket or spray rod to clean yourself
- 4. Pull pants up or bring skirt down (with or without help)



Clothing to help make toileting easier:

• Use Velcro (not buttons) and elastic waistbands on pants so clothes are easy to take off





- Bigger clothes are also easy to take off
- Larger zipper on clothes can help your child remove his/her clothes







Putting clothes on and off after toileting:

- Lying down can help your child put his/her pants on and take them off
- Sit in chair to put clothes on if your child has trouble with balance





Different toilets









SQUAT TOILET

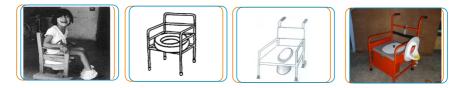
WESTERN TOILET

PLASTIC POTTY

BOWL OR POT

Adapted toilets

- *Sitting box with bowl or seat:* Helps your child with posture and stability when sitting
- Chair or commode: chair with hole in the seat. Place on top of squat toilet so your child can sit by him/herself.



IMPORTANT: The chair/commode should sit flat on the floor so your child does not fall.









Wooden seat with pole: Wooden seat on top of the toilet or squat toilet. The pole should be held by your child to be safe and stable on the seat.



Wedge-shape toilet: This toilet helps children who cannot stand, sit or squat. The child may need some help from caregiver for this toilet.



Caregiver support: Place a bowl or pot between parents' knees and sit child on the bowl or pot. Good for children who cannot sit by themselves

Armrests: Armrests help your child sit on the toilet or move on and off the toilet

Contoured seat: A seat placed on the toilet helps your child stay stable when toileting

Equipment:_Bars or rails:

- Squat toilet rails: Add 2 bars on both sides of the squat toilet. Child holds onto bars.
- Supports squat toilets: Your child can use a small chair, stool or table to hold when Squatting







Play

Children with disabilities often experience play differently from other children, but play is still an important part of their lives.

Why is Play Important?

Play helps a child's physical, mental, and social development. Children who play have greater health and happiness.



How Can Children with CP Play?



Direct play

Tips for Play:



Play through watching



Play through communication







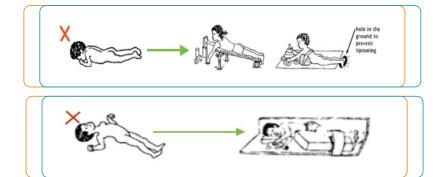
Positioning for Play:

1. Sitting:

- Back and head straight
- Legs apart
- Hands free to move

2. Lying Down:





3. Standing:

• Important to stand



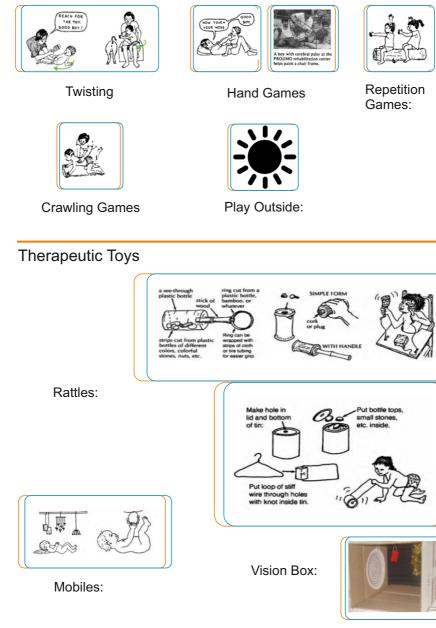
4. Moving Around:







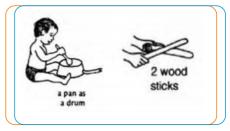
Ideas for Play:





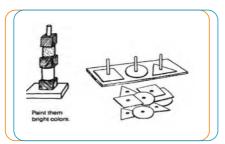






Texture Bag/Box





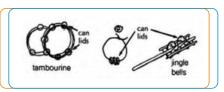
Stacking Poles



Clothes Pegs



Balloons



Other Musical Instruments



Beads



Bubbles





Speech & Communication

Communication is information and messages shared between different people.

Speech is the use of words to communicate thoughts, ideas, etc.

Children use language and communication to:

- tell others what they need or want
- talk with others (e.g. friends, siblings, family members) and give them information

Interventions

Exercises for making sounds and speaking:







Exercises for mouth, tongue and lips

Lips together and say "mmm"

Make a circle with mouth like an "O"

Make a big smile by stretching the mouth and saying "eee"

Blow bubbles, pieces of paper off a table or practice blowing into a whistle **CAUTION:** If your child has CP be careful that this exercise does not make his/her mouth muscles more tight

















Exercises for drooling, mouth, lips and tongue:

Exercises for drooling, mouth, lips and tongue:

Tap or touch your child's top lip and press on the bottom lip a few times

Use 2 fingers to stretch the lips to make the mouth stronger

Put some honey or another sweet liquid on the top and bottom of your child's lips and get him or her to lick it off

Try putting sticky food on a spoon and ask your child to lick it off









Exercises for the jaw:

Exercises for the jaw:

Jaw control exercises when **sitting beside** your child

- 1. Place thumb on the cheek
- 2. Put 2nd finger under the lip
- 3. Place 3rd finger under the chin
- 4. Push the chin up
- 5. Keep head straight
- 6. When your child is speaking, apply gentle pressure









Exercises for the jaw control

Exercises for the jaw control

Jaw control exercises when **sitting in front** of your child

- 1. Place the 2nd finger over the cheek
- 2. Place the thumb between the chin and lower lip
- 3. Place the 3rd finger under the chin
- 4. When your child is speaking, apply gentle and continuous pressure





Practicing the exercises

- 1. Sit in front of your child
- 2. Show your child the movements with the mouth, lips and tongue so they can imitate you
- 3. Repeat the sounds your child makes
- 4. Practice exercises during the day



IMPORTANT: Do not got too fast and be patient when your child is practising the exercises

How children communicate:

• **Sounds, gestures and facial expressions:** Child can use signs, gestures, body movements, or facial expressions to communicate.



IMPORTANT: Try and understand what the gestures, signs, movements, and facial expressions mean and encourage your child to use them.





• **Pointing, showing and touching:** Children can use their arms, hands, fingers, and eyes, to point or touch things to communicate different messages.



Children with CP and Mental Retardation (MR) or Intellectual Disability (ID)

• Some children with CP, MR or ID, can have trouble speaking and communicating

IMPORTANT: Even if your child cannot speak or communicate, he/she can understand information,



Helping your child communicate:

- Speak to your child during the day using simple words
- Encourage your child when they imitate sounds, words, gestures or actions
- Encourage brothers and sisters to speak and talk to your child



Speech Exercises

- 1. Sit in a quiet room in front of your child
- 2. Practice saying words your child knows
- 3. Ask your child to repeat the word out loud
- 4. Don't correct your child, just repeat the word correctly
- 5. Encourage your child (ex: "Super")
- 6. Provide your child with some rest during the exercises

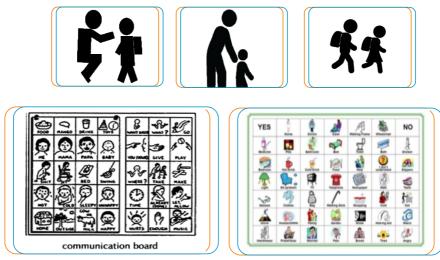






Supporting your child in the community:

• Tell people you trust about the needs of your child so they can help (teachers, siblings, friends, community rehabilitation worker etc.).



Communication Boards: A board with pictures to help your child communicate



Communication Books: Abook with pictures to help your child communicate





Looking to the future

Taking Care of Yourself

Caring for a child with a disability is very hard work and takes more time than a child without a disability. It is important for you to stay healthy so you can care for your child in the best way possible!









Ask for help when you need it



Be frustrated in a healthy way



Look for good things and strengths of the

child



Lean on family and friends for support



Have confidence in yourself







School

The child can attend school in a number of ways:

- 1) Attend regular school with other children and with the help of CRWs
- 2) Tutoring at home
- 3) Attend ASSA Centre for Special Education
- 4) Attend ASSA Integrated Schools



Vocational Training

When the child grows up, they may be eligible to attend ASSA's vocational training centre to receive skill- and job-related training for future employment.



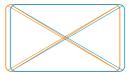


The child in the community

To help the child be included in society:

- Share what you have learned from this manual with friends and family!
- Encourage the child as well as children who do not have disabilities to play together.
- Focus on the child's strengths
- Attend ASSA's Awareness Programs to gain more knowledge on how to care for a child with disabilities.









ASSA Resources



Centre for Special Education



Early Intervention for Children with Delayed Development (Age 0-5)



Medical Treatment Unit/Outpatient Physiotherapy Unit



Home for Disabled Children

Integrated Schools



Enabling Inclusion through Early Intervention (EI) Programme

https://earlyintervention.amarseva.org/



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