



## Guide to Working with Children with Cerebral Palsy for Community Rehabilitation Workers

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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.



# About this Manual

What is it?	A manual about children with cerebral palsy (CP), aged 0-6 years old.
Who is it for?	You! This is a <b>work manual</b> for Amar Seva Sangam (ASSA) community rehabilitation workers (CRWs) who work with children with CP in the Tirunelveli district.
When and where can it be used?	It can be used anywhere and anytime during your work day!
Why should ASSA CRWs use it?	This manual can be a helpful reference when working with children with CP. You can bring it in the community with you if you ever have any questions about what CP is or what therapy to provide to children with CP.
How do I use this manual?	Pick and choose which sections you would like to use in the field. The 3 sections include: (1) Introduction to CP: this section introduces CP, explaining causes and types; (2) Treatments for CP: this section provides specific therapy treatments for specific activities; and (3) Looking to the future: this section describes resources for the growing child with CP.

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# 1.1 What is cerebral palsy (CP)?

Cerebral means *brain* and palsy means *impairment in body movement control*.<sup>1</sup>

Definition of CP = Brain disorder that affects the body's nervous and muscular systems.<sup>1</sup>

CP is a **static** disorder, which means it does not progress<sup>1</sup>; however, it does remain with the person from infancy into adulthood, and motor impairments may change as the adult ages<sup>2</sup>. The impairments usually manifest before the age of 5<sup>3</sup> and they can occur before (***prenatal***), during (***perinatal***) or after birth (***postnatal***)<sup>2</sup>.

There are 4 main types of CP<sup>1,3</sup>:




<b>Spastic CP</b> 	<b>Dyskinetic or Athetoid CP</b> 	<b>Ataxic CP</b> 	<b>Mixed CP</b>
Jerky movements and stiff muscles  Most common type of CP  Occurs in 70-80% of all CP cases	Uncontrolled and spontaneous movement  Occurs in 10-20% of all CP cases	Sense of balance is impaired and depth perception is impaired as well	Depending on brain damage, children may have symptoms from more than one type of CP  Most common = Spastic CP and dyskinetic CP

*NOTE. Characteristics of each type are explained in the following sections.*

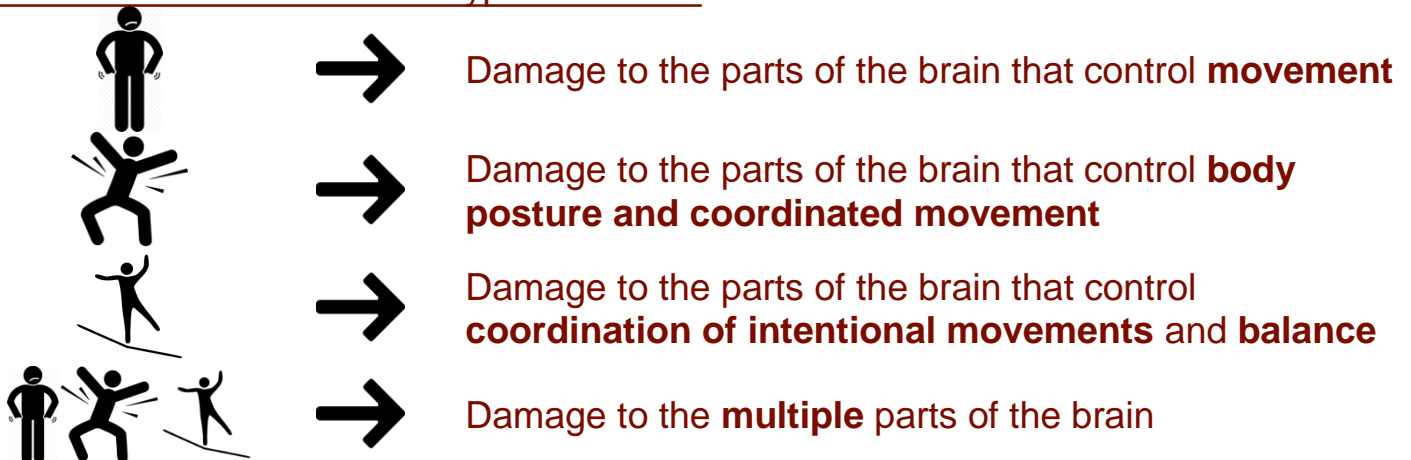


# 1.2 What causes CP?

The main cause for CP is **physical damage to a developing brain**<sup>1</sup> however, multiple risk factors contribute to this damage<sup>2,3</sup>. Damage can occur before birth around the time of birth or after birth as illustrated in the table below<sup>1,2</sup>:

<b>Prenatal Risk Factors</b> (occurring <i>before</i> birth) 	<ul style="list-style-type: none"> <li>• Baby with genetic disorder</li> <li>• Mother's health factors (e.g. stress, exposure to damaging drugs)</li> <li>• Placenta does not provide sufficient nutrients or oxygen to developing child</li> <li>• Growth factors limit fetal development</li> <li>• Mother and child's RH blood type are not compatible</li> </ul>
<b>Perinatal Risk Factors</b> (occurring <i>around</i> the time of birth) 	<ul style="list-style-type: none"> <li>• Issues relating to premature birth (e.g. brain hemorrhage)</li> <li>• Mother who has had multiple births</li> <li>• Baby born with low birth weight</li> <li>• Prenatal conditions (e.g. maternal diabetes causing pre-eclampsia around the time of birth)</li> </ul>
<b>Postnatal Risk Factors</b> (occurring <i>after</i> birth) 	<ul style="list-style-type: none"> <li>• Jaundice that is severe or not treated immediately</li> <li>• Infections to the baby's central nervous system (e.g. meningitis)</li> <li>• Transfer of alcohol or drugs to the baby through breastfeeding</li> <li>• Lack of oxygen during birth process (<i>hypoxic ischemic encephalopathy</i>)</li> <li>• Trauma during birth or shortly after</li> </ul>







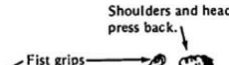
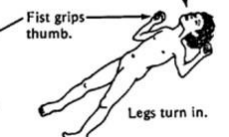

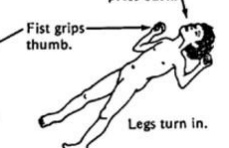






What causes the 4 different types of CP<sup>2,3</sup>?



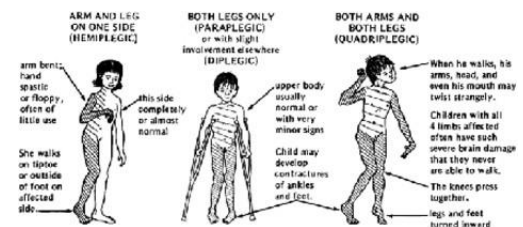
### DID YOU KNOW...

- CP is rarely caused by genetics and is not contagious<sup>1</sup>.
- CP is not caused by witchcraft or a curse<sup>5</sup>.
- Adults with CP can have children who may not have CP<sup>6</sup>.
- Most CP cases (70-80%) occur before birth<sup>2</sup>.

# 1.3 What does CP look like<sup>1,2,3?</sup>

<p><b>SPASTIC CP</b>  <i>Jerky movements and stiff muscles</i></p> 	<p>Affected muscles resist passive range of motion (PROM), have increased deep tendon reflexes and are hypertonic. Intentional movements are not coordinated and are weak.</p> <p>Can affect limbs in different ways:</p> <ul style="list-style-type: none"> <li>• <b>Diplegic:</b> Both legs affected more than arms</li> <li>• <b>Quadraplegic:</b> Whole body affected (all 4 limbs and torso)</li> <li>• <b>Hemiplegic:</b> One side of the body affected (arm and leg)</li> <li>• <b>Triplegia:</b> Three limbs affected</li> <li>• <b>Double hemiplegic:</b> Both sides affected (sometimes arms or legs significantly more affected)</li> </ul>	<p>When you try to stand the child the legs often stiffen or cross like scissors.</p>  <p>Less commonly the head and shoulders may stiffen forward . . .</p>  <p>The child who learns to walk may do so in a stiff, awkward position, with the knees pulled together and bent. Feet often turn in.</p>  <p>... or the arms may stiffen straight across the body, with the head pressed back.</p>  <p>This arm may stiffen straight out.</p>  <p>Head twists to one side.</p>  <p>Shoulders and head press back.</p> <p>Fist grips thumb.</p>  <p>Legs stiffen and knees press together.</p>  <p>This arm stiffens bent.</p>  <p>Legs turn in.</p> <p>6</p>
<p><b>DYSKINETIC or ATHETOID CP</b>  <i>Uncontrolled and spontaneous movement</i></p> 	<ul style="list-style-type: none"> <li>• Unpredictable movements of the body, especially in the arms, hands, torso and face</li> <li>• Proximal extremities and trunk = Slow, squirming movements</li> <li>• Distal extremities = Abrupt, jerky movements</li> </ul> <p>Distress or emotional tension may cause symptoms to be more severe; however, these movements disappear during sleep.</p>	<p>poor balance</p>  <p>arm and hand movement</p>  <p>This child has severe athetosis.</p> <p>Typical athetoid arm and hand movements may be as a regular shake or as sudden 'spasms'. Uncontrolled movements are often worse when the child is excited or tries to do something.</p> 
<p><b>ATAXIC CP</b>  <i>Balance and depth perception is impaired</i></p> 	<ul style="list-style-type: none"> <li>• Movements are unsteady and shaky</li> <li>• Handling small objects may produce tremors</li> <li>• Walking is unsteady, with wide-based gait pattern</li> <li>• Rapid or fine movements are difficult</li> </ul>	 <p>To keep her balance the child with ataxia walks bent forward with feet wide apart. She takes irregular steps, like a sailor on a rough sea or someone who is drunk.</p>
<p><b>MIXED</b></p>	<p><i>Clinical presentation of mixed CP will vary from child to child depending on extent of brain damage and combination of types of CP.</i></p>	

CP typically affects the body in three distinct patterns shown to the right<sup>6</sup>:





# 1.4 Problems associated with CP

Problems associated with CP will differ from child to child and manifest in different ways. Children aged 0-6 years old may have one, all or a combination of the following problems<sup>2,3,6,7</sup>:

Activities of Daily Living (ADLs)	<ul style="list-style-type: none"><li>• Limitation of functional activity</li><li>• Feeding</li><li>• Dressing (e.g. buttoning)</li><li>• Sleep disturbances</li><li>• Handling and manipulating toys</li><li>• Toileting</li><li>• Walking</li><li>• Handwriting and fine motor skills</li></ul>
Cognitive	<ul style="list-style-type: none"><li>• Intellectual disability</li><li>• Impairment in concentration</li><li>• Impairment in memory</li><li>• Difficulty learning information related to sensory impairments (i.e. with hearing and seeing)</li></ul> <p><i>NOTE. Problems with cognition may impact the child's understanding of therapy when you are with them.</i></p>
Communication	<ul style="list-style-type: none"><li>• Speech problems</li><li>• Difficulty understanding language and processing its meaning</li><li>• Impairment in understand directions</li></ul> <p><i>NOTE. Problems with communication may impact the process of therapy.</i></p>
Psychosocial	<ul style="list-style-type: none"><li>• Anxiety and frustration</li><li>• Becoming dependent on the caregiver</li><li>• Lower self-esteem</li><li>• Restless behaviour</li></ul>

## DID YOU KNOW...

- Children with CP who appear to have an intellectual disability may understand more than you think<sup>6</sup>.

# 1.4 Problems Associated with CP

Physical <sup>2,3,6,7</sup>	
<ul style="list-style-type: none"><li>• Abrupt movements</li><li>• Ataxia</li><li>• Attention problems</li><li>• Auditory impairment</li><li>• Fatigue or becoming tired easily</li><li>• Fluctuating muscle tone (i.e. hypertonicity at times and hypotonicity at others)</li><li>• Hypertonicity (tight resting muscles)</li><li>• Hypotonicity (loose or flaccid resting muscles)</li><li>• Impaired control of bladder muscles → Urinary incontinence and bowel dysfunction</li><li>• Limited body awareness</li><li>• Movement in one muscle group is unwillingly transferred to another group of muscles</li><li>• Persistent infantile reflex, preventing mature reflex patterns</li><li>• Poor balance</li><li>• Poor bilateral coordination</li><li>• Poor visual motor coordination</li><li>• Scoliosis of the spine</li><li>• Seizures</li><li>• Shaky tremor</li><li>• Spasticity (tight muscles when moved)</li><li>• Stiff joints</li><li>• Unable to lift head upright</li><li>• Unable to roll prone</li><li>• Unable to sit independently</li><li>• Unable to lie down from sitting</li><li>• Unable to crawl</li><li>• Unable to stand independently</li><li>• Unable to walk independently</li><li>• Unable to run</li><li>• Unintentional movements</li><li>• Visual skills impaired</li></ul>	<p><i>Specific to lower extremity:</i></p> <ul style="list-style-type: none"><li>• Crouched or crossed legged gait or walking on the toes</li><li>• Hemiplegia causing one foot to drag on the floor</li></ul> <p><i>Specific to the upper extremities:</i></p> <ul style="list-style-type: none"><li>• Difficulty with fine motor movements</li><li>• Hand-eye coordination difficulties</li><li>• Impaired ability to recognize objects by touch</li><li>• Impaired touch perception</li><li>• Inability to bring hands together at midline</li><li>• Limitation of forearm movement</li><li>• Limitation of finger extension</li><li>• Poor finger coordination</li><li>• Poor grip strength</li><li>• Poor pinch grip</li><li>• Poor wrist movement</li><li>• Poor hand manipulation</li><li>• Poor manipulative hand skills</li><li>• Poor weight bearing in forearm</li></ul> <p><i>Specific to the mouth/oral function:</i></p> <ul style="list-style-type: none"><li>• Biting</li><li>• Blowing</li><li>• Chewing</li><li>• Drooling</li><li>• Dysphagia (difficulty swallowing)</li><li>• Gastroesophageal reflux</li><li>• Impaired oral-motor movements due to complications (e.g. temporomandibular joint contractures)</li><li>• Sucking</li><li>• Swallowing</li><li>• Tongue movement</li></ul>

## DID YOU KNOW...

- Children with CP who experience hemiplegia may not attend to sensation on one side of their body including their visual field<sup>4</sup>.

# 1.5 ASSA Screening Tool

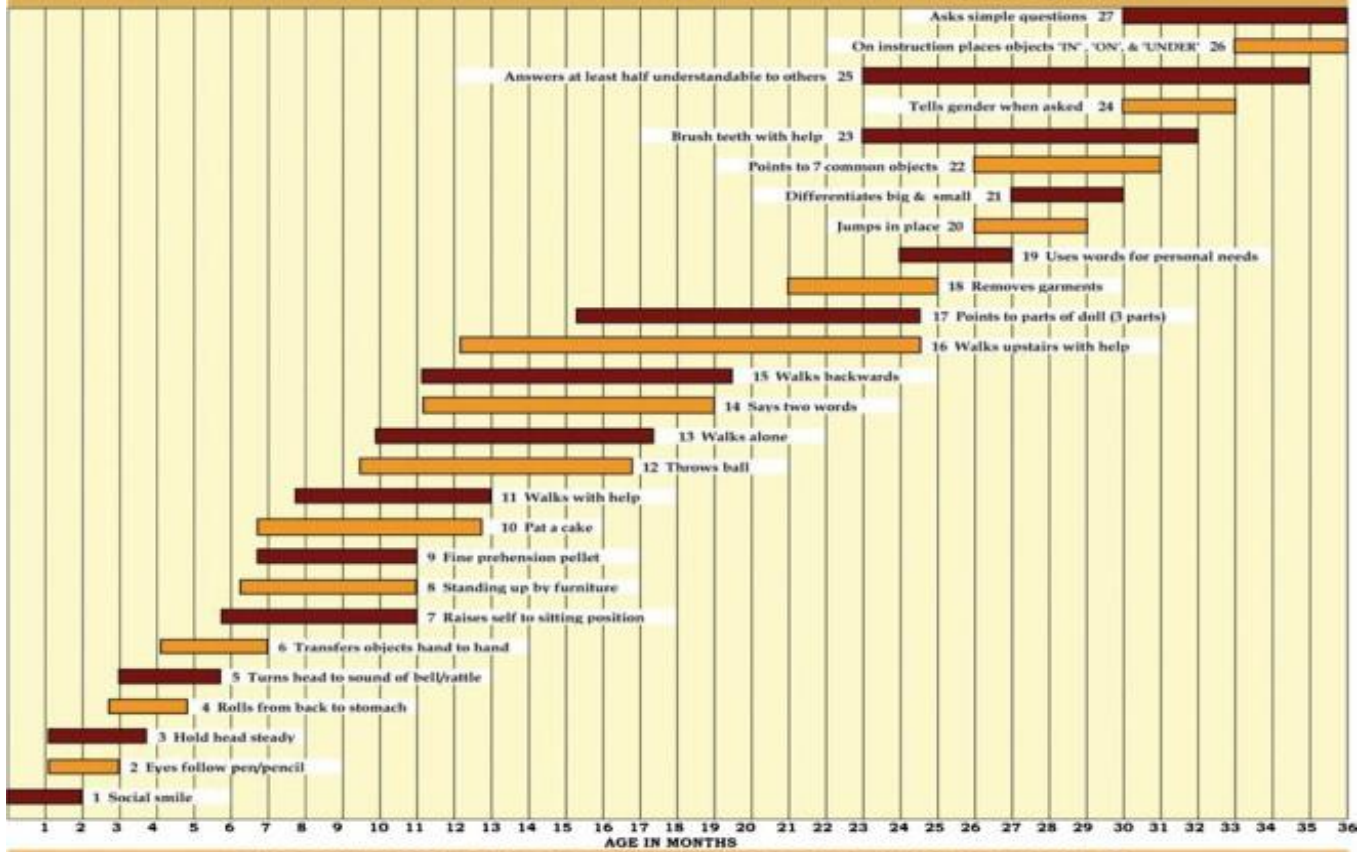
One way to determine if a child is at risk for CP is to check if they are meeting the *developmental milestones* for their age. As children age, they develop particular **physical, mental** and **social** skills in a specific sequence<sup>6</sup>. However, children with CP may not attain these developmental milestones like other children and may require assistance from the village based rehabilitation team to attain them.<sup>6</sup>

To check if a child is meeting their developmental milestones, you can use the developmental screening tool used by ASSA staff shown on the following pages.



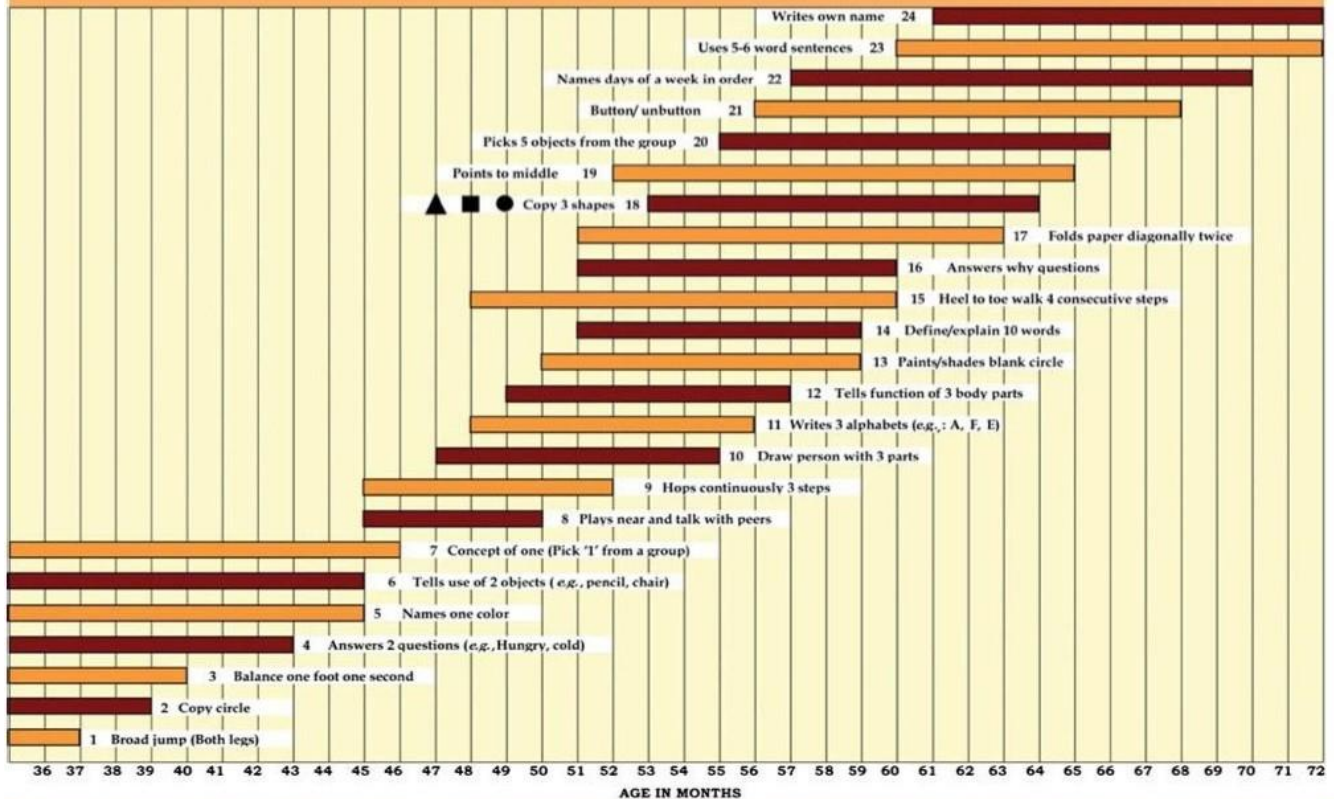


## TRIVANDRUM DEVELOPMENTAL SCREENING CHART (TDSC) 0-3 YEARS



CHILD DEVELOPMENT CENTRE (CDC), MEDICAL COLLEGE, THIRUVANANTHAPURAM  
 MKC Nair, Harikumaran Nair, Babu George, Suma N, Neethu C & CDC-NRHM- Childhood Disability Project Team

## TRIVANDRUM DEVELOPMENTAL SCREENING CHART (TDSC) 3 – 6 YEARS



CHILD DEVELOPMENT CENTRE (CDC), MEDICAL COLLEGE, THIRUVANANTHAPURAM  
 MKC Nair, Harikumaran Nair, Babu George, Neethu C, Suma N & CDC-NRHM-Childhood Disability Project Team

# 1.6 Rights of Persons with Disabilities

Children with cerebral palsy are persons with disabilities who should be afforded the **same opportunities** and **inclusion in society** as children without disabilities. India has ratified UNCRPD (United Nations Convention on Right of Persons with Disabilities, 2006) and The Rights of Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 2016 follows the UNCRPD guidelines. “

The convention lays down the following principles for the empowerment of persons with disabilities.

1. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”; <sup>10(p. 1-2)</sup>
2. “Non-discrimination”; <sup>10(p. 1-2)</sup>
3. “Full and effective participation and inclusion in society”; <sup>10(p. 1-2)</sup>
4. “Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity”; <sup>10(p. 1-2)</sup>
5. “Equality of opportunity”; <sup>10(p. 1-2)</sup>
6. “Accessibility”; <sup>10(p. 1-2)</sup>
7. “Equality between men and women”; <sup>10(p. 1-2)</sup>
8. “Respect for the evolving capacities of children with disabilities, and respect for the right of children with disabilities to preserve their identities” <sup>10(p. 1-2)</sup>

**PWD ACT, 1995**  
**THE PERSONS WITH DISABILITIES**  
(EQUAL OPPORTUNITIES, PROTECTION OF RIGHTS AND FULL PARTICIPATION ACT, 1995)

PUBLISHED IN PART II, SECTION 1 OF THE  
EXTRAORDINARY GAZETTE OF INDIA  
MINISTRY OF LAW, JUSTICE AND COMPANY AFFAIRS  
(Legislative Department)

New Delhi, the 1st January, 1996/Pousa 11, 1917 (Saka)

The following Act of Parliament received the assent of the President on the 1st January, 1996, and is hereby published for general information:- No.1 OF 1996

[1st January 1996]

An Act to give effect to the Proclamation on the Full Participation and Equality of the People with Disabilities in the Asian and Pacific Region.

WHEREAS the Meeting to Launch the Asian and Pacific Decade of Disabled Persons 1993-2002 convened by the Economic and Social Commission for Asia and Pacific held at Beijing on 1st to 5th December, 1992, adopted the Proclamation on the Full Participation and Equality of People with Disabilities in the Asian and Pacific Region;

AND WHEREAS India is a signatory to the said Proclamation; AND WHEREAS it is considered necessary to implement the Proclamation aforesaid.

Be it enacted by Parliament in the Forty-sixth Year of the Republic of India as follows:-

- [Chapter I Preliminary](#)
- [Chapter II The Central Coordination Committee](#)
- [Chapter III The State Coordination Committee](#)
- [Chapter IV Prevention And Early Detection Of Disabilities](#)
- [Chapter V Education](#)
- [Chapter VI Employment](#)
- [Chapter VII Affirmative Action](#)
- [Chapter VIII Non - Discrimination](#)
- [Chapter IX Research And Manpower Development](#)
- [Chapter X Recognition Of Institutions For Persons With Disabilities](#)
- [Chapter XI Institution For Persons With Severe Disabilities](#)
- [Chapter XII The Chief Commissioner And Commissioners For Persons With Disabilities](#)
- [Chapter XIII Social Security](#)
- [Chapter XIV Miscellaneous](#)

**K. L. MOHANPURIA**  
*Secy. to the Govt. of India*

9 - The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995

भारत का राजपत्र  
The Gazette of India

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No. 59] NEW DELHI, WEDNESDAY, DECEMBER 28, 2016/PAUSHA 07, 1938 (SAKA)

इस भाग में निम्न सूची संकेत दी जाती है जिससे कि यह अध्याय संकेतक के साथ में रखा जा सके।  
Separate paging is given to this Part in order that it may be filed as a separate compilation.

MINISTRY OF LAW AND JUSTICE  
(Legislative Department)

New Delhi, the 28th December, 2016/Pousha 17, 1938 (Saka)

The following Act of Parliament received the assent of the President on the 27th December, 2016, and is hereby published for general information:—

**THE RIGHTS OF PERSONS WITH DISABILITIES ACT, 2016**  
(No. 49 of 2016)

[27th December, 2016]

An Act to give effect to the United Nations Convention on the Rights of Persons with Disabilities and for matters connected therewith or incidental thereto.

WHEREAS the United Nations General Assembly adopted its Convention on the Rights of Persons with Disabilities on the 13th day of December, 2006;

AND WHEREAS the aforesaid Convention lays down the following principles for empowerment of persons with disabilities:—

- (a) respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- (b) non-discrimination;
- (c) full and effective participation and inclusion in society;
- (d) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

10 – Rights of Persons with Disabilities Act 2016

# 1.7 Role of Therapy

Cerebral palsy is a **lifelong, permanent condition** that cannot be cured<sup>1</sup>. Therapy is immensely beneficial for children who have CP because it can help them **regain some function, manage symptoms, and optimize abilities**<sup>1</sup> with the parts of the brain that are not damaged<sup>6</sup>. While



improving physical function of children with cerebral palsy can be helpful for certain symptoms (i.e. contractures), new approaches for treatment focus on **quality of life, social participation, sustained health, independence and function**<sup>1,3,4</sup>. New approaches also encourage multidisciplinary teams with members from different fields<sup>1</sup>, including physiotherapy, occupational

therapy, speech and language therapy, special education and community rehabilitation. Family members are also considered part of the rehabilitation team, as they hold valuable knowledge about their children<sup>1</sup>.



Please refer to the table below for a description of roles of each therapy team member<sup>6,11,12,13</sup>:

Team Member	Role
Community Rehabilitation Worker	<ul style="list-style-type: none"> <li>• Makes regular visits in the community</li> <li>• Provides assistance to the family and child, as well as suggestions for optimal functioning</li> <li>• Performs exercises and activities delegated by other therapists</li> <li>• Teaches the family exercises and activities they can do at home</li> </ul>
Occupational Therapist	<ul style="list-style-type: none"> <li>• Helps to improve function in ADLs</li> <li>• Uses exercises to increase strength, endurance and range of motion</li> <li>• Modifies the environment to accommodate the child</li> <li>• Adapts or changes the activity/task to suit the needs of the child</li> <li>• Helps to improve fine motor abilities</li> </ul>
Physiotherapist	<ul style="list-style-type: none"> <li>• Prescribes and supports repetitive passive/active range of motion exercises</li> <li>• Provides passive, static, gentle stretches</li> <li>• Prescribes exercises to improve balance, posture, gait pattern, etc.</li> </ul>
Social Worker	<ul style="list-style-type: none"> <li>• Works with the child and the family to coordinate access to and information on community services</li> <li>• Helps with advocating for the child in the community</li> <li>• Facilitates support groups for caregivers of children with disabilities</li> </ul>
Special Educator	<ul style="list-style-type: none"> <li>• Helps the child with learning, including reading, writing and picture recognition</li> <li>• Helps the child prepare for successful schooling</li> </ul>
Speech Language Pathologist	<ul style="list-style-type: none"> <li>• Helps to regain function for eating, drinking and communicating</li> <li>• Leads exercises in which children repeat after the therapist</li> <li>• Prescribes and guides mouth exercises to loosen oral muscles</li> </ul>



## 1.8 Importance of involving Parents/caregivers

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Why is it importance to involve caregivers in therapy?



1) CAREGIVERS ARE EXPERTS. Families and caregivers of a child with CP know the child best, including his/her struggles, strengths and preferences<sup>1,6</sup>. The CRW and caregiver can then work together, providing information and support to one another to best care for the child<sup>6</sup>.



2) CAREGIVERS CAN CONTINUE THERAPY AT HOME. CRWs can teach caregivers therapy practices to do with patients when the CRW is not present<sup>6</sup>. Educating parents is a good way to encourage activities of daily living in children with CP, because parents are with their children on a daily basis<sup>14</sup>. Prevention of secondary issues (e.g. contractures) is also an advantage of caregivers continuing therapy<sup>6</sup>. Once they are familiar with therapy, caregivers can then share what they have learned with other caregivers<sup>11</sup>.



3) CAREGIVERS ARE CLIENTS TOO. When working with a child for therapy, a CRW is also working with the family/caregivers that support them – this is called “Family Centred Care (FCC)”. FCC involved partnership and collaboration between caregivers and the CRW<sup>15</sup>. Practicing FCC can help decrease anxiety and depressive symptoms in parents, and can increase the wellbeing of both parents and children<sup>15</sup>.

How do I interact with caregivers?

- ❖ Share information about the therapy with the caregivers<sup>15</sup> as this will increase their confidence.<sup>11</sup>
- ❖ Actively involve them in the therapy<sup>15</sup> by asking the caregivers their perspective on the child and their concerns.<sup>11</sup>
- ❖ Give step-by-step instructions when sharing information, so as not to overwhelm them.<sup>11</sup>
- ❖ Respect their needs and desires.<sup>15</sup>
- ❖ When teaching therapy, give them reassurance that they are doing well.<sup>11</sup>
- ❖ Provide support to caregivers in any form.<sup>15</sup>

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# 2.1 Dressing



**Dressing** requires both fine and gross motor skills and patterns to complete<sup>1</sup>. It is important to increase the child's independence, giving the child more time to play and socialize<sup>2</sup>!



## *Developmental Milestones regarding dressing*

Age	Dressing <sup>1,3</sup>
0-1 years	<ul style="list-style-type: none"><li>• The child offers little or no help</li></ul>
1.5 years	<ul style="list-style-type: none"><li>• Begin to assist with dressing by taking off shoes and socks</li><li>• Holds arms and legs out for dressing, pushes arms and legs through sleeves and pants</li></ul>
2 years	<ul style="list-style-type: none"><li>• Able to remove loose clothing</li></ul>
3 years	<ul style="list-style-type: none"><li>• Able to put on loose clothing</li></ul>
4 years	<ul style="list-style-type: none"><li>• Able to do large buttons</li><li>• Able to do zippers</li><li>• Able to put on socks</li><li>• Able to identify front and back of garments</li></ul>
5 years	<ul style="list-style-type: none"><li>• Can dress unsupervised – can tie and untie knots but needs help with difficult steps</li></ul>
6 years	<ul style="list-style-type: none"><li>• Can tie shoelaces, adjust sandals and do buttons on back</li></ul>

## Problems that may affect dressing in children with CP

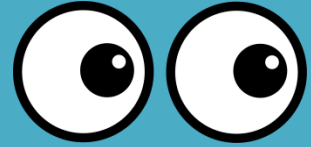
- Limited range of motion of upper extremities<sup>4</sup>
- Poor body positioning and posture<sup>2</sup>
- Poor coordination of hand functions<sup>2</sup>
- Poor motor control<sup>2</sup>
- Poor sensory, perceptual and cognitive abilities<sup>2</sup>



# Interventions

## Before you get started:

Observe the child's movements and ability to complete dressing activities<sup>2</sup>. Separate each task into easy steps.



Step 1



Step 2



Step 3



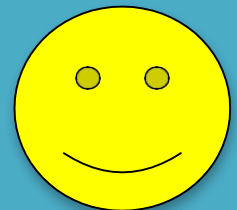
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## Backwards chaining:

Use backwards chaining when teaching a child to dress him or herself. Backwards chaining is a teaching method where you complete all of the steps of a task except for the last step. The child then completes the last step and receives praise and encouragement when he/she does so successfully. Once this is achieved, you should start the process again and have the child complete the last two steps. Continue this pattern. This type of teaching allows the child to experience early success in the task<sup>1,5</sup>.

## *Exercises for Dressing*

Encourage the child to participate in activities he/she likes to do to increase upper extremity ROM and function<sup>4</sup>.



3

Aim to improve hand function (strength, grip, handling of objects) through puzzles, plasticine/play dough, painting, or stringing beads<sup>2</sup>.

Improve balance through the following activities: swinging, sitting on a stool, kicking a ball, riding a rocking horse, throwing objects, walking on a tightrope, and rolling back and forth on a log or therapy ball<sup>2</sup>.



## Sequencing and Supporting Dressing

- When the child is first learning to dress him/herself, start with undressing because it requires fewer action sequences and perceptual skills<sup>2,6</sup>
- Use play for motivation – make dressing fun<sup>2</sup>!
- Use repetition, cueing, clear instructions, and sufficient time to practice dressing at home<sup>2</sup>



7

- Use visual cues like pictures or pointing<sup>2</sup>
- Help the child dress, using passive movements and saying the steps out loud<sup>2,3,6,7</sup>
- Give the least amount of support needed<sup>7</sup>
- Encourage the child and reward them when they are successful<sup>7</sup>
- Dress the affected side first<sup>3,7</sup>



7

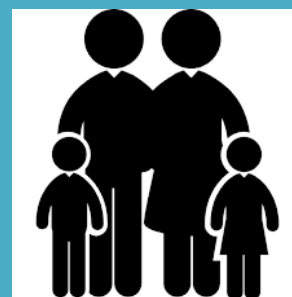


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## Changing the Dressing Environment

### Involving Family members:

- Include siblings and parents in therapy<sup>4</sup>
- Teach siblings about CP and dressing. Provide suggestions for motivating their sibling using repetition, rewards, demonstration, chaining (see backwards chaining on previous page), imitation, bargaining, challenging and, praise. This can also help to bond family



members<sup>4</sup>

- Structure the environment for practice<sup>2</sup>:
  - Quiet space with few distractions
  - Familiar setting
  - Appropriate seating if available

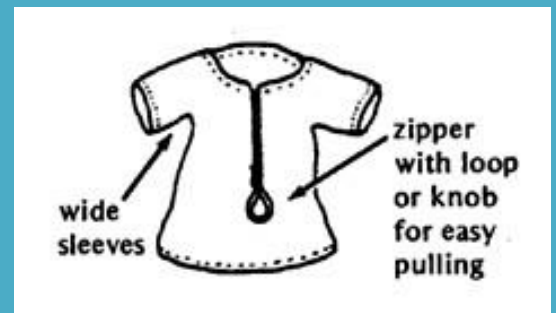


### Adaptive Clothing:

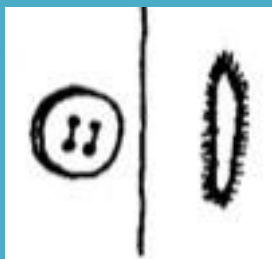
- Use simple clothing that is easy to put on and take off<sup>2,3,6</sup>
- Examples:
  - wide collars on shirts
  - front openings on clothes
  - zippers
  - elastic waists
  - large buttons
  - loops on zippers
  - loops on pants to pull up
  - reminders on front of clothing or different colored shoes
  - shoes with:
    - velcro
    - loop at back of heel
    - wide openings for foot



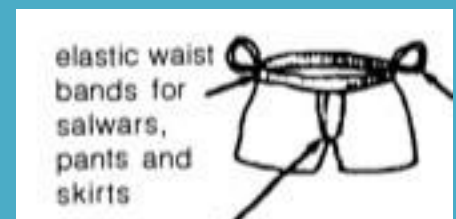
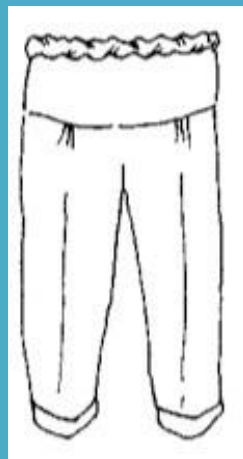
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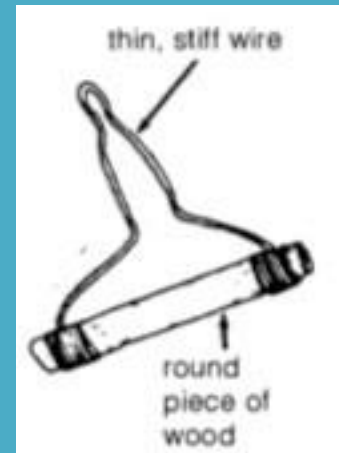
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### Assistive Devices:

- Make a stick with a hook at the bottom for pulling on pants<sup>3</sup>



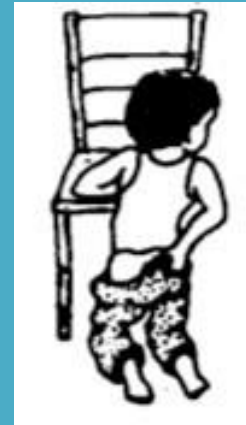
- Make a button hook tool to help with putting on buttons<sup>3</sup>



### Dressing Procedures for Common Clothing Items<sup>6</sup>:

#### *Positions for Dressing in pants or a skirt-*

- Have the child stand up while holding something, if possible
- Seat the child with his/her back against the wall for support
- Have the child lie down on his/her side and turn from side to side to remove/put on bottoms





## *Removing a shirt:*

- Have the child sit in a supported position (on a chair or against the wall)
- Show the child how to:
  1. pull the collar of the shirt up with his/her unaffected hand
  2. bend his/her head forward and remove strong arm first
  3. shake the shirt off of the other arm

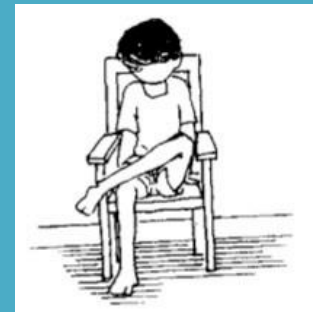
## *Putting on a shirt:*

- In a supported position, show the child how to:
  1. put his/her affected arm in the sleeve first
  2. pull the shirt up on his/her arms
  3. bend his/her head forward to pull the shirt overhead



## *Putting on shoes:*

- Have the child sit on a chair with a backrest and armrests, or cross-legged on the floor
- Bring one foot up at a time, close to the body



3

\*\*\*Please find new picture of child putting on shoe with 1 leg over the knee!

## *Positioning for Dressing<sup>2,7</sup>:*

*Caution: Never leave a child in the same position for the whole day. It is best to change positions. If you are unsure what is a safe position, consult with a specialist.*

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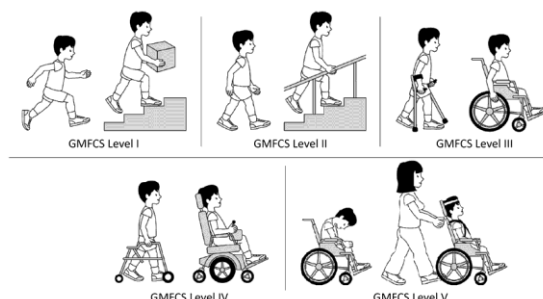
## 2.2 Mobility

**Mobility** is an important activity of daily living because it allows the child to navigate different environments (e.g. home, school, work, village, etc.). Often, children with CP have difficulties with mobility because of motor impairments, and these difficulties hinder their physical development and engagement in daily activities<sup>1</sup>. Some children with CP can walk independently, and others need assistive devices and other adaptations to help maximize independence in their environments<sup>2</sup>.



**Gross Motor Function Classification System (GMFCS):** The GMFCS is a tool that describes the levels of gross motor function of children with CP, specifically in the realm of mobility (seated, walking and wheeled mobility). It helps determine whether the child requires or would benefit from assistive devices for mobility<sup>3</sup>.

Level <sup>4</sup>	Description of functional activity <sup>4</sup>
Level I	<ul style="list-style-type: none"><li>Walks without limitations; performs gross motor skills like running and jumping, but speed, balance and coordination may be impaired</li></ul>
Level II	<ul style="list-style-type: none"><li>Walks with limitations; this includes walking for long distances, walking in crowds and/or confined spaces, and walking on uneven surfaces, inclines, or stairs</li></ul>
Level III	<ul style="list-style-type: none"><li>Walks using a hand-held mobility device; walks on even surfaces-- indoors and outdoors-- with an assistive device; may use manual wheelchairs for long distances</li></ul>
Level IV	<ul style="list-style-type: none"><li>Self-mobility (independent mobility) with limitations; may use powered mobility or require assistance from a caregiver; may walk short distances with a mobility device, but relies primarily on wheeled mobility</li></ul>
Level V	<ul style="list-style-type: none"><li>Transported in a manual wheelchair; has no means of independent mobility and relies on caregiver for all transportation needs.</li></ul>



# Problems that may affect mobility in children with CP

## CP specific symptoms that impact mobility<sup>1</sup>:

- Spasticity<sup>1</sup>
- Muscle paresis<sup>1</sup>
- Impaired muscle control<sup>1</sup>
- Muscle weakness



## Posture and stability:

- Difficulty maintaining postural stability when standing, sitting, lying down, etc.<sup>5</sup>

## Mobility specific problems:

- Unable to crawl<sup>6</sup>
- Unable to stand independently<sup>6</sup>
- Unable to walk independently<sup>6</sup>
- Unable to run<sup>6</sup>
- Limited when walking up stairs<sup>7</sup>

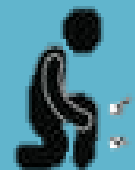


## Interventions

### *Exercises to Help Mobility*

When a child with CP does not move or use his/her limbs often, muscles become weak and joints become stiff. This decreases the child's range of

motion, causes deformities, and prevents the child from using his/her limbs properly. Exercises can help to improve muscle strength, increase range of motion, and reduce joint stiffness. These changes may improve the child's function and ability to participate in different activities<sup>8</sup>.



## How often to do the exercises and when to start:

- Do the exercises 2 times per day<sup>8</sup>
- Start the exercises when the child is young, to reduce the impact of the disability on the body<sup>8</sup>
- Be careful and gentle when doing the exercises<sup>8</sup>

## How long to continue ROM exercises:

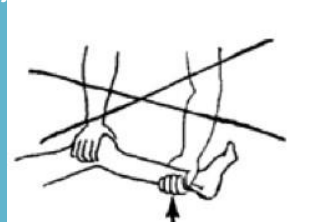
- Incorporate the exercises into the child's daily routine and throughout his/her life, as this will enable function in his/her daily life.<sup>8</sup>



## IMPORTANT FOR EXERCISES

- Move the joint slowly and gently<sup>8</sup>
- Stretch the joint as far as possible, but do not force it as that may cause pain<sup>8</sup>
- Do not perform exercises on joints that are already floppy (non spastic) as this could cause more injury<sup>8</sup>

**CAUTION:** It is important to **protect the joint**, as some exercises can hurt weak joints. Hold the limb both above and below the joint to support it as much as you can<sup>8</sup>.



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*Example:* To protect the knee joint, put one hand on the thigh and one hand on the tibia (do not place one hand on the knee).

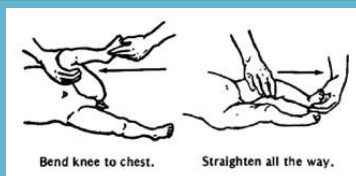
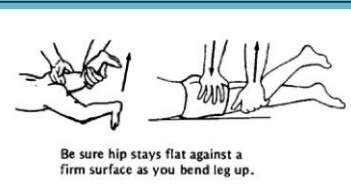
## Exercises for lower extremity (hips, legs, knees, ankles and feet)<sup>8</sup>

### Hip Exercises

*Straighten the hip:* Place child on his/her stomach on a flat and comfortable surface; place one hand on the buttocks and use the other hand to lift the thigh slowly and gently<sup>8</sup>.

*Bending the hip:* bend the knee up to the chest and then straighten the leg down<sup>8</sup>.

### Exercises



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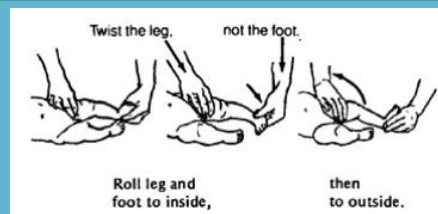
## Hip Exercises

## Exercises

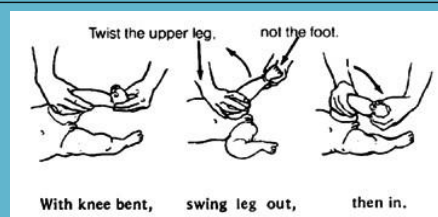
*Spread the hips:* gently and softly open the hips as far as you can by moving the leg out to the side<sup>8</sup>.



*Twist the hip (keeping leg straight):* twist the leg only, and roll the leg and the foot to the inside and then the outside<sup>8</sup>.



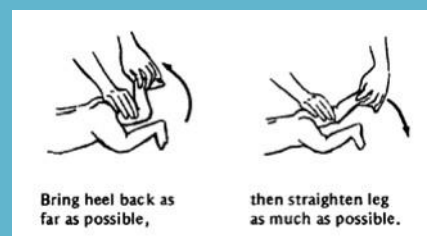
*Hip Rotation:* rotate the hip, keeping the leg bent<sup>8</sup>.



## Knee exercises

## Exercises

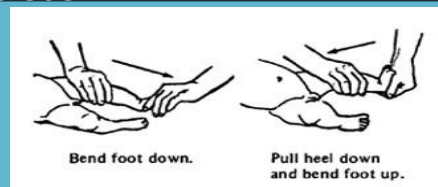
*Place child on his/her stomach:* bring the heel back and then straighten the leg<sup>8</sup>.



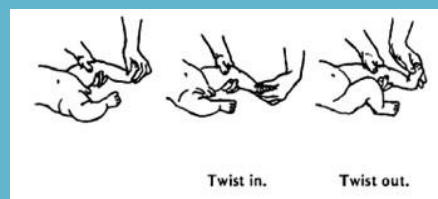
## Ankle exercises

## Exercises

*Bring the ankle and foot up and down:* bend the foot down and gently pull heel down and bend foot up<sup>8</sup>.



*Ankle twisting:* gently and slowly twist the ankle in and out<sup>8</sup>.



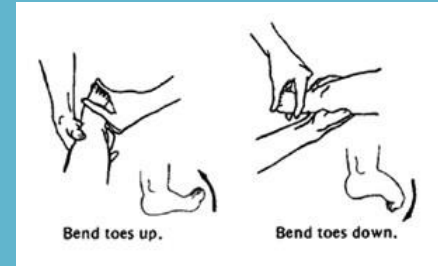
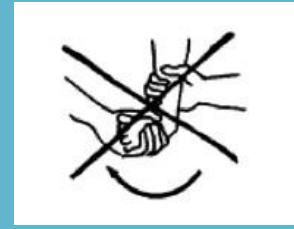
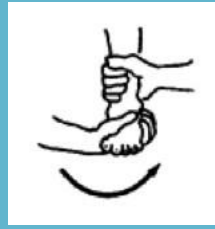
## Feet and Toe Exercises

Bring or bend the foot to outside (place on hand on top of the ankle and the other on top of the joint)<sup>8</sup>.

**CAUTION:** Do not bring or bend the foot towards the inside. This could cause injury<sup>8</sup>.

*Toes:* Bring toes up and down to stretch them out<sup>8</sup>.

## Exercises



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### Suggestions for CRWs teaching exercises to parents:

- Show and explain how to perform the exercise to the parents (show pictures, demonstrate exercises, practice with the parent etc.)
- Have the parent practice the exercise so that they can do them at home daily
- These passive exercises improve joint mobility and flexibility of muscles, but may not promote developmental milestones. To promote motor development, we need to facilitate training.

## *Encouraging Mobility through Physical Support*

### Picking up & carrying a child with CP (when independent mobility is not possible)

It is important to handle a child who has CP with care, as poor handling can impact the child's development, cause contractures or deformities, and even make it increasingly difficult for the parent to pick up, carry and handle the child<sup>9</sup>.

#### Tips for picking up a child with CP

1. Bend your knees<sup>9</sup>
2. Keep back straight<sup>9</sup>
3. Place one foot slightly in front of the other<sup>9</sup>
4. Hold child close to your body<sup>9</sup>
5. Lift using leg muscles (not back muscles)<sup>9</sup>
6. As the child grows, ask for help to lift<sup>9</sup>
7. If lifting with another person, count to 3<sup>9</sup>

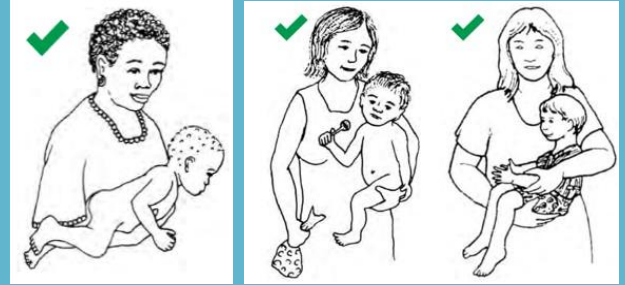
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**CAUTION:** Bending forward with legs straight can cause injury and severe pain to the back. This is especially true if you are picking up the child several times during the day.

### Tips for carrying a child with CP:

1. Keep child's body upright<sup>9</sup>
2. Keep child's hips and knees a little bent<sup>9</sup>
3. Keep child's knees separated<sup>9</sup>
4. Child's arms can hold onto the carrier or can<sup>9</sup> be free for handling objects<sup>9</sup>



9

**CAUTION:** Avoid letting the child's head fall back unsupported. This is unsafe for the neck, and the child cannot see. The child's body becomes stiff, and his/her arms and hands are not free to handle objects.

### Crawling (independent or assisted):

- To encourage lifting of the head and head control<sup>8</sup>:
  - When child is lying on his/her stomach, attract the child's attention to an object<sup>8</sup>.
  - Place a "wedge" made from blankets and pillows under the child's torso to promote head lifting<sup>8</sup>.
  - When child is lying on his/her back, pull the child up gently by the *upper* arms until his/her head lifts a bit, then lay the child down again<sup>8</sup>.



8

**CAUTION.** Do not pull the child up by the hands if the child's head hangs a lot. The head must be supported if this is the case.

- To encourage rolling:
  - When child is lying on his/her stomach, move a toy from side to side and the child should turn his/her head and shoulders to follow it<sup>8</sup>.
  - Encourage the child to reach sideways for the toy, then move the toy upwards so that the child twists onto his/her side and back<sup>8</sup>.



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- To encourage creeping:
  - When child can lift his/her head, place the child on their hands and knees, support his/her feet, and place a toy just out of reach<sup>8</sup>.



**CAUTION.** Sometimes with children with CP, supporting the feet may cause legs to stiffen and straighten, and should therefore be avoided<sup>8</sup>.

8



- Lift the hips if the child has trouble bringing the legs forward<sup>8</sup>.

8



- Supported crawling:

- Hold up a child with a towel and encourage him/her to crawl. As the child gains strength, gradually support him/her less and less. Moving the child from side to side will help him/her shift weight from one side of the body to the other side. Placing an object or toy in front for the child to reach will further encourage crawling motions<sup>8</sup>.



- Place the child on his/her stomach over your knee. Slowly move the knee up and down, and sideways, and encourage the child to take one hand off the ground at a time<sup>8</sup>.



- Place child over a log or bucket to promote weight bearing on the hands and straight elbows. Push down on shoulders and release a few times<sup>8</sup>.

- Arm crawling (pelvis and leg off the ground)<sup>8</sup>.

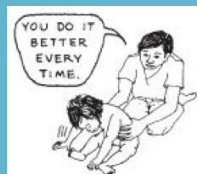


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## Balance

- Hold the child above the hips and gently rock him/her from side to side, and forward and backwards<sup>8</sup>.

8



- Put the child on a tiltboard or a ball; hold the child above the hips and slowly tip the board from side to side. Encourage the child to catch him/herself with his/her hands. When the child's balance improves, gradually move your hands from the hips to the thighs, so he/she depends less on your support<sup>8</sup>.



8



- Position the child on his/her hands and knees and have him/her hold one leg or one arm off the ground, shifting weight back and forth<sup>8</sup>.

8



## Standing

- Hold the child loosely under the arms and gently tip from side to side and forward and backward. Allow the child to come back into a straight position<sup>8</sup>.
- **IMPORTANT:** Hold the child under the arms or at the waist depending on the child's capacity to weight bearing.
- The child can practice standing balance using a stool or a chair and practice sitting to standing<sup>8</sup>.
- The child can stand on one leg and reach for objects<sup>8</sup>.

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## Walking

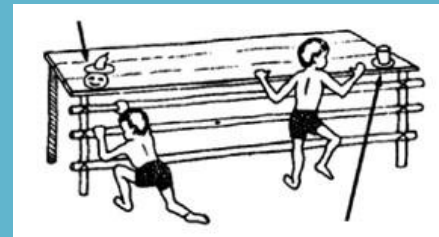
- When the child starts standing, support the hips. Spread the feet apart to form a wide base<sup>8</sup>.
- As the child gains some balance, you can provide light support at the shoulders<sup>8</sup>.
- The child can hold on to an object (e.g. stick or hose) to challenge his/her balance.
- Have the child step up and down from a stool<sup>8</sup>.



8

## Sit-to-stand

- To encourage transferring from sitting to standing, place a toy on the edge of a table and encourage the child to stand using the side of the table (as shown in the picture)<sup>8</sup>.
  - **CAUTION.** Supervision is required for this exercise.



8

## Supported walking

- Tie a cloth loosely around the chest, and walk behind the child<sup>8</sup>



# Environmental Changes to Support Mobility

Assistive devices and adaptations to help with mobility in different environments:

*Parallel bars:* These bars help children with CP to practice balancing and walking. Some parallel bars are adjustable to meet the height of the child using them<sup>8</sup>.



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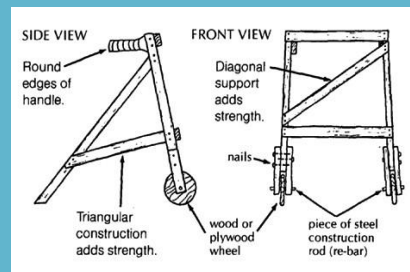
*Walker or Pushcart:* can provide balance support when the child is walking, to increase the child's independence<sup>8</sup>.

- A walker without wheels is very stable but more difficult to move<sup>8</sup>.



8

- A walker with two wheels in the front offers some stability and is easy to move<sup>8</sup>.



8

- When a child has enough **arm strength** and **good control of his/her posture and body**, use a low walker<sup>8</sup>.
- When a child has **weaker elbows, impaired balance, and/or impaired body control**, use a higher walker with armrests<sup>8</sup>.

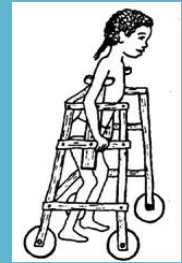


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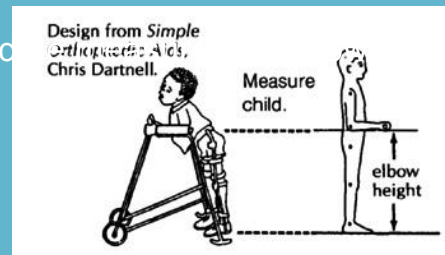
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- walker with 3-4 wheels is easy to move but can roll from under the child<sup>8</sup>.
  - When a child has **weaker legs** and **impaired balance**, add underarm crutches to the walker for more support and safety when walking<sup>8</sup>.



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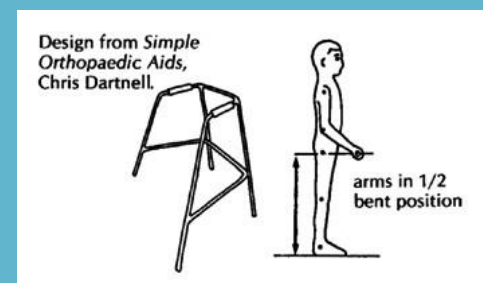
- A walker made of iron with armrests should be measured for the child<sup>8</sup>.



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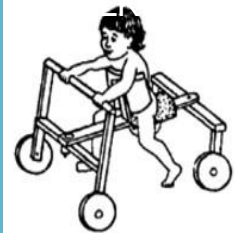

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- A simple walker made of iron without armrests should be measured at the hand level when the arm is slightly bent<sup>8</sup>,



8

Other devices like cart walkers, roller seats, tricycle walkers, saddle-type walkers, and spider walkers can be used to **keep the child's legs separated**, and to encourage **independent walking, sitting, and standing**<sup>8</sup>.

CART WALKER <sup>8</sup>	ROLLER SEAT AND	SPIDER WALKER <sup>8</sup>	SADDLE-TYPE WALKER <sup>8</sup>
			

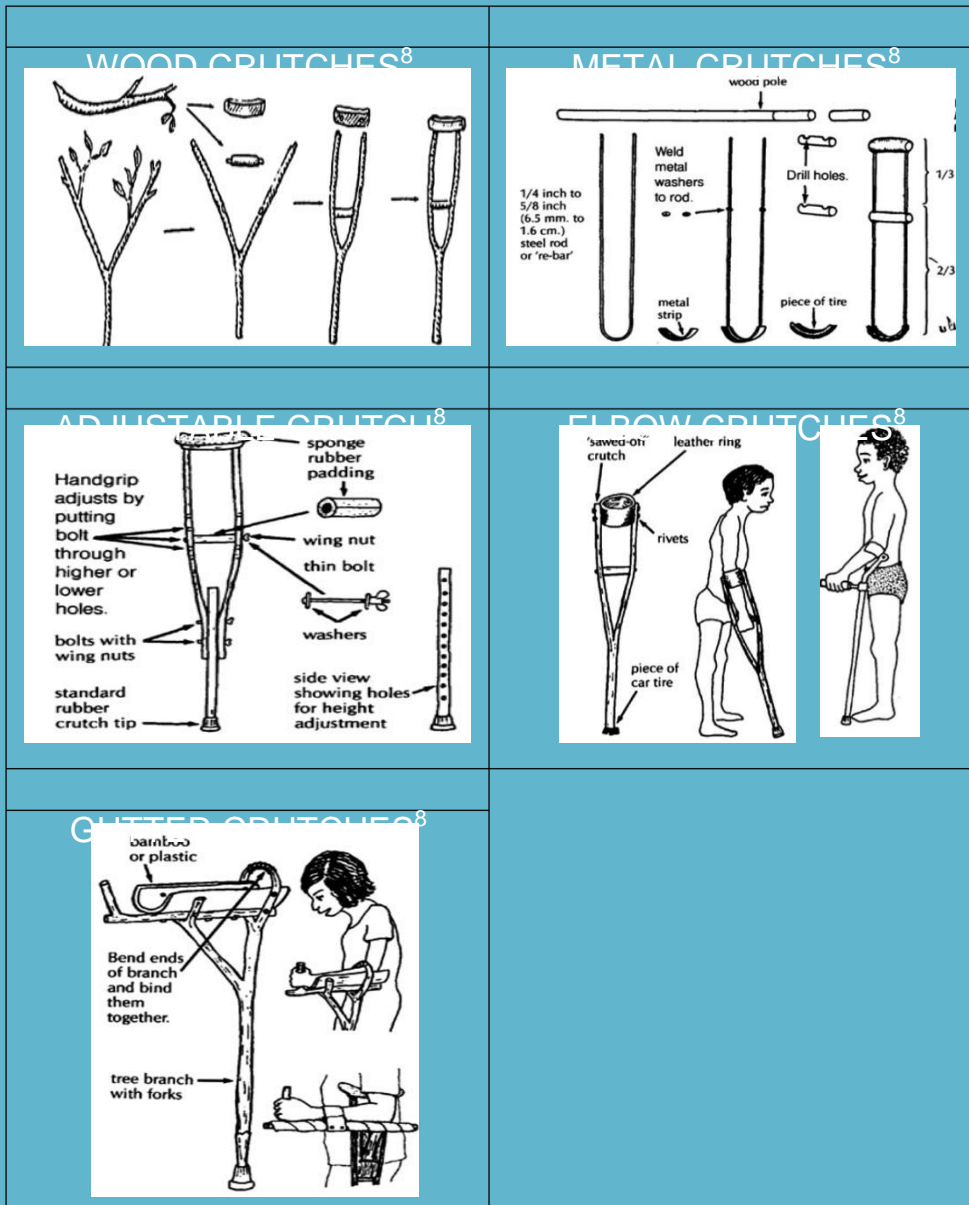
**CAUTION:** All walkers and push devices must be solid enough to support the child.

A caregiver should assist or supervise the child when he/she is walking (standing beside or behind them).



## Crutches and elbow crutches:

- Many different materials and shapes of crutches exist :<sup>8</sup>
  - Wood crutches
  - Metal crutches
  - Adjustable crutches
  - Elbow crutches
  - Gutter crutches



**IMPORTANT:** Measuring the crutch for every child is very important. When being used, the crutch should allow<sup>8</sup>:

- Elbows to be bent so that the arms can lift the body when walking;
- Comfort in the hands; and

- 3 inches of space between the underarm and the top of the crutch to avoid pressure<sup>8</sup>.

**IMPORTANT:** It is important to teach the child to put weight on their hands, NOT their underarms<sup>8</sup>.

*Canes and walking sticks:*

- Many different forms and types of materials exist :<sup>8</sup>
  - Straight poles
  - Canes made from trees
  - Canes with height adjustable tubes
  - 3 or 4 footed canes to provide maximum stability

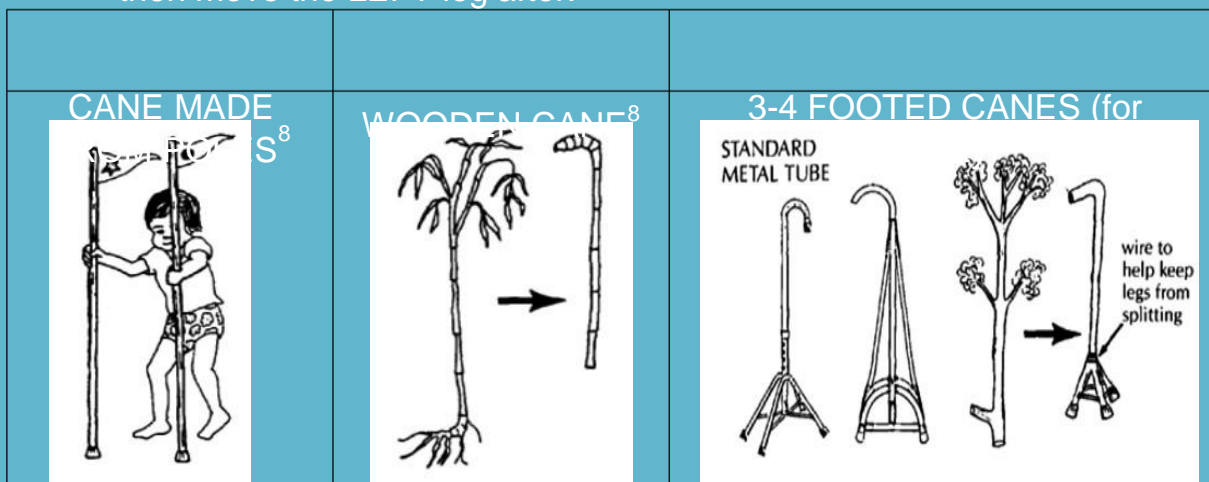
**NOTE.** It is helpful to have the end of the cane made with a non-slip material like **rubber** to avoid falls and make them safer to use<sup>8</sup>.

How to properly use a cane for walking and climbing stairs:

- **Walking:** Make sure the child using one cane only is holding the cane on the good (uninjured) side of his/her body. When the child is walking, have him/her move his/her injured side and the cane at the same time.
- **Going Up Stairs:** When the child is going up stairs, he/she should move the good side first and then move his/her injured side with the help of a cane.
- **Going Down Stairs:** When the child is going down stairs, he/she should put the cane on the first step, move the injured side first, and then move his/her good side down.





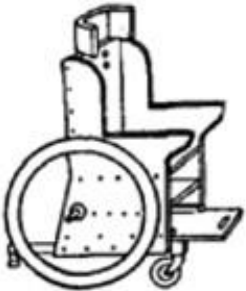

**EXAMPLE:** Child with CP with injured **RIGHT (injured) leg.**

- Walking: child should hold his/her cane in the LEFT hand.
- Going Up Stairs: child should move the LEFT leg first and then move the **RIGHT leg (injured) after.**
- Going Down Stairs: child should move the cane and **RIGHT leg (injured) first** and then move the LEFT leg after.



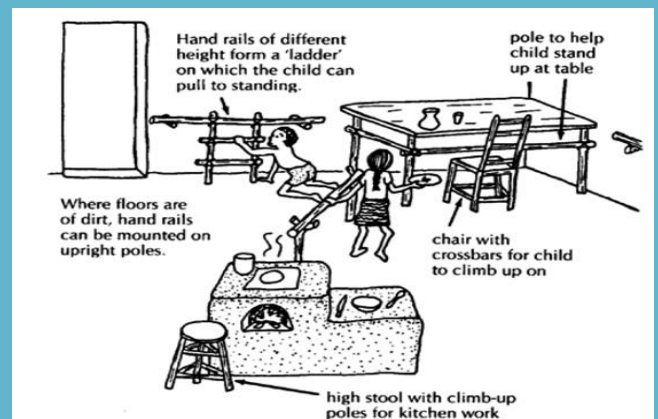
*Wheelchairs:*

- Wheelchairs are other assistive devices to support mobility in children with CP<sup>8</sup>.
- Wheelchairs come in different shapes, sizes, materials, features and adaptations, depending on the needs of the child<sup>8</sup>.
- They require a very specific assessment of the child's needs by a skilled professional, such as a physiotherapist or occupational therapist<sup>8</sup>.
- Refer to "Positioning" Section to learn how to properly position a child in a wheelchair<sup>8</sup>!
- Examples of wheelchairs<sup>8</sup>:

HEALTHLINK WOODEN WHEELCHAIR <sup>8</sup>	RE-BAR AND WOVEN PLASTIC WHEELCHAIR <sup>8</sup>	SQUARE METAL TUBE WHEELCHAIR <sup>8</sup>
		
WHEELCHAIR WITH LYING BOARD <sup>8</sup>	PLYWOOD FRAME WHEELCHAIR <sup>8</sup>	METAL TUBE FOLDING WHEELCHAIR <sup>8</sup>
		

*Adaptations at home<sup>8</sup>:*

- To increase the child's mobility in his/her home, it is important to include solid objects around the house that the child can hold onto while walking and moving. These include tables, stools, and/or handrails made from wood.



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10. London School of Hygiene & Tropical Medicine (LSHTM). (n.d.). Getting To Know Cerebral Palsy. Retrieved on June 17, 2017 from <http://disabilitycentre.lshtm.ac.uk/files/2013/06/Getting-to-know-cerebral-palsy-v1-lowres.pdf>



## 2.3 Feeding



**IMPORTANT:** Always consult with a speech specialist, occupational therapist (OT), or medical doctor before changing the texture of the food you give your child, before recommending oral-motor exercises or before recommending food supplementations. If possible, have a feeding expert assess the child first.

**Feeding** is a process that requires the coordination of muscles and sense<sup>1</sup>. Feeding includes chewing, ingestion, swallowing and digestion<sup>2</sup>

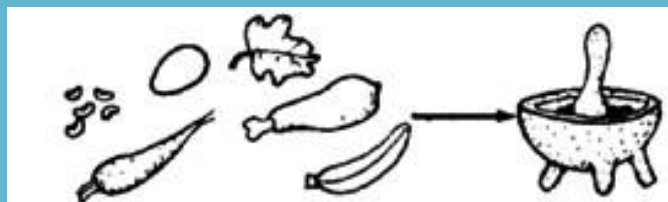
### Why is proper feeding important?

- For the child's growth and strength<sup>2, 3</sup>
- To make the feeding process easier for parents<sup>2, 4</sup>
- To help the child gain independence in feeding and build social relationships with others<sup>2</sup>
- To ensure the child receives proper nutrition and hydration<sup>3</sup>
- To build healthy family relationships<sup>2</sup>
- To promote good quality of life for the child and his/her family<sup>5</sup>

### *Developmental Milestones regarding feeding*

Age	Feeding <sup>6</sup>
0-6 months	<ul style="list-style-type: none"><li>• The child drinks breast milk or formula</li></ul>
6-8 months	<ul style="list-style-type: none"><li>• The child continues breastfeeding</li><li>• The child can begin to eat other foods like juices, mashed fruits and vegetables, mashed, boiled and skinned lentils, oatmeal, rice, etc.</li></ul>
8-12 months	<ul style="list-style-type: none"><li>• The child should be eating the same food as the rest of the family</li><li>• If the child still has trouble with liquids and solids, the solids can be mashed up</li></ul>

Note: Children under the age of 12 months should be fed 5 times a day because their stomachs are smaller





# Problems that may affect feeding in children with CP

## *Problems with feeding:*

- Choking and/or aspiration of food<sup>1, 3, 4, 5, 7, 8, 9, 10, 11</sup>
- Vomiting<sup>1, 3, 5, 9, 10, 11, 12</sup>
- Difficulty with chewing<sup>3, 5</sup>
- Poor appetite<sup>9, 12, 13</sup>
- Refusal of new or old foods<sup>10, 12, 13</sup>
- Picky eating (refusal to eat certain foods)
- Swallowing problems and/or refusing to swallow<sup>3, 11, 12, 13, 14</sup>
- Drooling<sup>9, 11, 14</sup>
- Gagging<sup>9</sup>
- Difficulty speaking<sup>9</sup>
- Coughing<sup>1, 11, 14</sup>
- Difficulty coordinating the tongue and the swallowing muscles
- Jaw contractures<sup>1</sup>
- Crying
- The child is unable to feed him/herself<sup>3, 10, 11</sup>
- Problems with sucking<sup>11</sup>
- Cry/extensor dystonia during feeding<sup>11</sup>
- Difficulty controlling the head and maintaining posture<sup>3</sup>
- Difficulty closing the mouth<sup>3</sup>

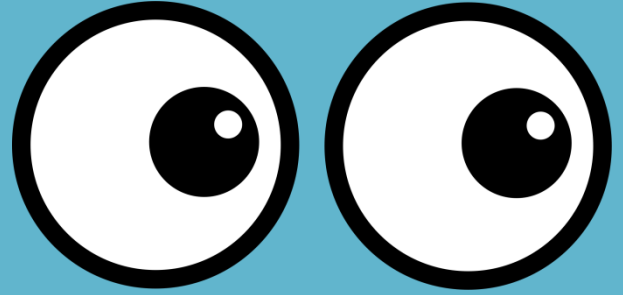
## *Consequences of feeding problems:*

- Dysphagia
- Lung problems and infections<sup>1, 4, 7, 9, 10, 11</sup>
- Gastroesophageal reflux and gastrointestinal functioning problems<sup>2, 7, 9, 10</sup>
- Dehydration<sup>2, 8, 11, 15</sup>
- Malnourishment
- Long and stressful feeding times<sup>3, 4, 5, 8, 12, 13, 14, 15</sup>
- Caregiver stress/burden
- Decrease in child's health<sup>2</sup>
- Child dependence on caregiver<sup>2</sup>
- Constipation<sup>3</sup>

# Interventions

Before we begin it is important to:

- Observe the caregiver/parent feeding the child to identify the problems or issues<sup>10</sup>
- Observe the child's positioning when he/she is sitting<sup>1, 10</sup>
- Obtain a food intake history (what the child eats). Ask questions about what the child eats (texture), how long it takes to feed them and what are the interruptions during feeding? Etc.<sup>7, 10</sup>
- Measure improvements by weighing the child



Considerations to help the caregiver with feeding the child<sup>4</sup>:

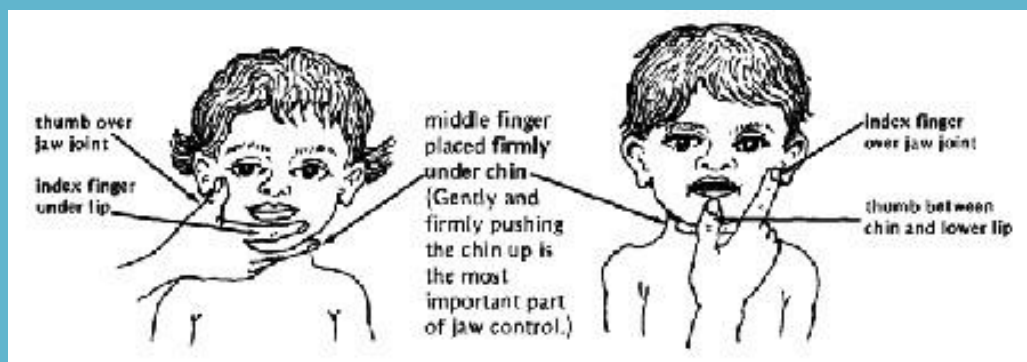
- Have a few therapy sessions on feeding
- Demonstrate to the caregiver the proper way to feed
- Consider providing low-cost materials or showing the parent what they should get and where (e.g. supportive seat, spoon, cup etc.)
- Use different ways to educate caregivers about feeding:
  - Oral education/Presentation
  - Paper handouts/copies
  - Videos
  - Demonstrations



## Exercises to support feeding

**Caution: Always consult a medical doctor, speech specialist or OT who have experience in feeding before recommending exercises!**

- **Massage:** Massage can help with closing the lips, moving the tongue from side to side, stop tongue thrusting, decrease touch hypersensitivity and help with chewing<sup>5, 17</sup>. The steps to proper massage include:
  - massaging the upper and lower gums from front teeth to the back (near the molar teeth), and
  - rolling thumb on the cheek (back and front), use middle and index fingers on lips and proceed to close the mouth and raise it from the throat.
- **Jaw control:** Exercises to do before feeding the child, to help with drooling and choking<sup>6</sup>. To complete the jaw control exercise:
  - place hand on child's face
  - use thumb or index finger to stabilize jaw joint
  - use other fingers to firmly push up the chin



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### Oral sensorimotor exercises<sup>1, 2, 7, 10, 13</sup>

Complete the following exercises for 5 to 7 minutes **before** feeding using small pieces of food especially for children with a history of choking.

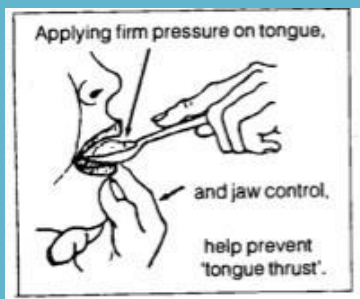
**CAUTION:** Be careful when performing the exercises and consult with language specialists before recommending or implementing these exercises.

- **Chewing exercise:** Place a chew tube or a clean soft cotton cord in the molar area (back of the mouth) and move tube from one side to the other. Increase the hardness of the material as the child's chewing improves<sup>5,6</sup>.

- *Tongue exercises demonstration:*
  - Demonstrate and practice tongue exercises such as:
    - moving the tongue forward
    - twisting the tongue and making circles with the tongue
    - touching the tongue to the tip of the nose
    - touching the top and the bottom of the mouth with tongue, and
    - touching the inside of teeth with the tongue<sup>17</sup>
- *Improve biting:* Demonstrate biting to the child, and then place food in front of child's teeth and assist him/her to initiate the bite<sup>17,18</sup>.
- *Improve sucking:* Demonstrate to the child the action of sucking, and ask him/her to imitate you<sup>17</sup>
- *Improve swallowing:* Press the child's lips together and train the child to move the food with their tongue<sup>17</sup>
- *Improve blowing:* Demonstrate blowing by using bubbles and soapy water. Ask the child to blow the bubbles<sup>17</sup>



- *To prevent tongue thrusting:* Apply firm pressure on top of tongue when feeding child with a spoon and use jaw control exercises mentioned above<sup>6</sup>



**IMPORTANT:** Do not scrape the spoon on the child's teeth.

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### Before mealtime:

- Give the child some choice of different foods and notice when the child is hungry. Have pictures of food for the child point to the one he/she likes if he/she has difficulty speaking<sup>18</sup>.



## Feeding Interventions for mealtime

- **IMPORTANT:** Before feeding, the caregiver and child's hands as well as the utensils should be washed with soap<sup>3</sup>.



**IMPORTANT:** Ask for the advice of a medical doctor, speech specialist or OT before recommending that the caregiver adjust a child's food consistency or change his/her caloric supplementation.

### During mealtime:

- Place the food in front of the child (bring spoon to the front of the child) and wait for him/her accept the spoon before placing it into his/her mouth. Sit in front of the child for floor sitting<sup>3, 6, 18</sup>.
- Place the food at the corner of the lips and back to the molar area during every meal. This will inhibit abnormal reflexes<sup>5</sup>.
- Feed the child when they are ready for the next mouthful. Take rest as needed and stop when the child is tired<sup>3</sup>



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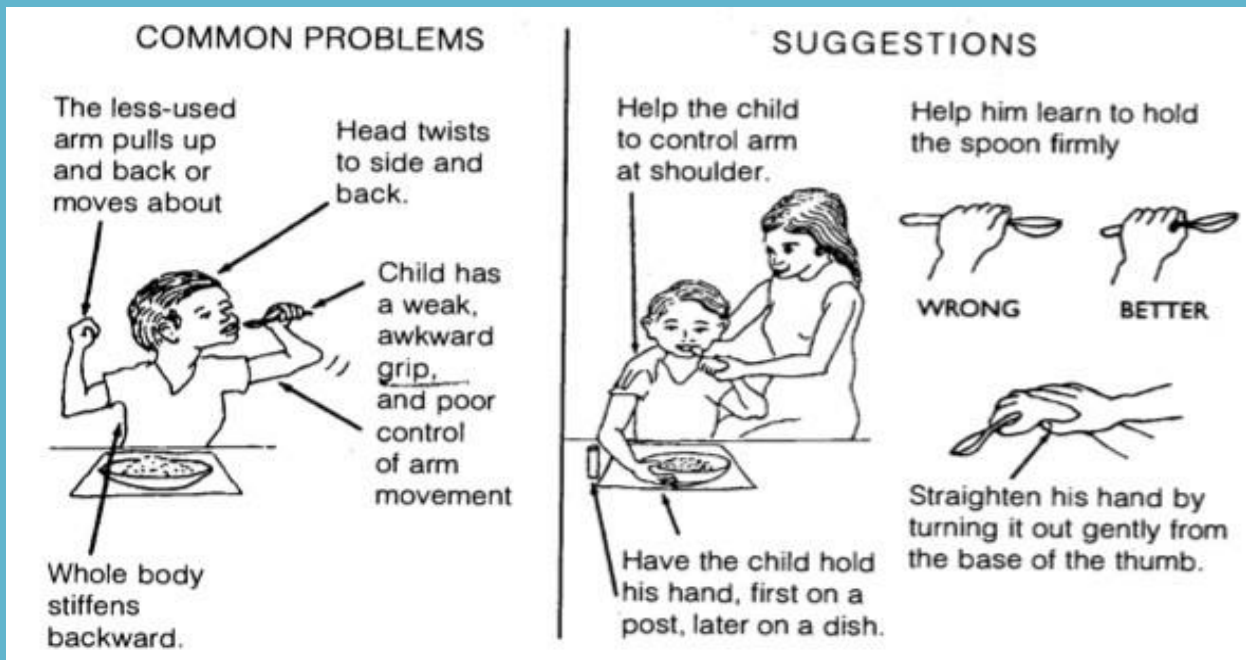


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### ***Independent eating for the child<sup>6, 18</sup>:***

- Sit behind the child and place your hand over the child's hand and help bring the food to their mouth
- Gradually help a little bit less to support the child's independence
- Reward each feeding success with words or clapping
- Continue these steps until the child does it on their own





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- Reward the child with verbal encouragement, toys or videos when they demonstrate good feeding behaviors<sup>1,18</sup>
- Interact with the child and talk to him/her while eating<sup>3</sup>
- Be patient with feeding and try to make mealtime fun<sup>3,6</sup>.



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- Allow the child to eat with the right or left hand<sup>18</sup>.
- Consider feeding child with a spoon instead of his/her hands<sup>18</sup>.
- Continue to feed the child even if they are turning their head away or crying for 1 minute. Stop and wait for the child to turn back to the food, and continue<sup>12</sup>.

- If the child is not cooperating during feeding take away social attention and toys<sup>1</sup>
- Have small and frequent meals 5 times a day for 15 minutes<sup>3,4,8,12,13</sup>

### **After mealtime:**

- Have the child rinse his/her mouth with a little bit of water after the meal<sup>18</sup>.
- Give the child small sips of water during the day<sup>3</sup>.

## Home and Equipment Interventions for feeding

### Positioning tips for feeding:

1, 4, 8, 10

- Ensure good positioning and physical support during mealtimes
- Keep the child's neck and trunk stable, allow their neck to move a little bit forward or place the child in a reclined position that is well supported<sup>2, 15</sup> (limited evidence)
- Proper positioning: sitting position with the body tilted 60–90°, head in neutral position, with the arms and legs supported. This is good for effective and safe eating<sup>5</sup>.



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### Feeding positions for different ages and abilities:

#### Positioning for breastfeeding:

- Feed the baby in your lap in a seated position with the child's head bent forward slightly. Hold the child's shoulders forward, hold his/her chest and keep his/her knees bent<sup>6</sup>.



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Positioning the child on lap:

- Use your arm to support the child's head and neck and have him/her sit on your leg, not lying down<sup>18</sup>.



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Positioning the child when sitting on the floor:

- When a child has good trunk control, sit him/her on the floor, against a wall and support his/her back and arms with a pillow. Place a small table in front of him/her for mealtimes<sup>18</sup>.



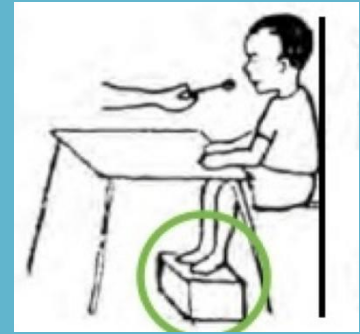
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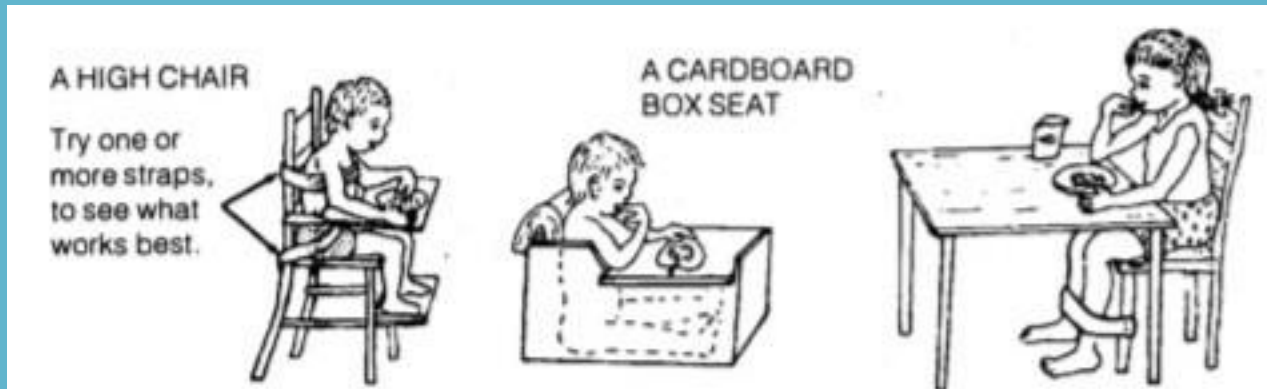
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Positioning the child in a chair:

- Place a table in front of the child and make sure the child is well seating in his/her chair. If the child cannot touch the ground when he/she is sitting, use a small stool or block of wood to support his/her feet<sup>18</sup>.



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If the child needs more support than a regular table and chairs, you may ask an OT for proper seating recommendations like the ones below:



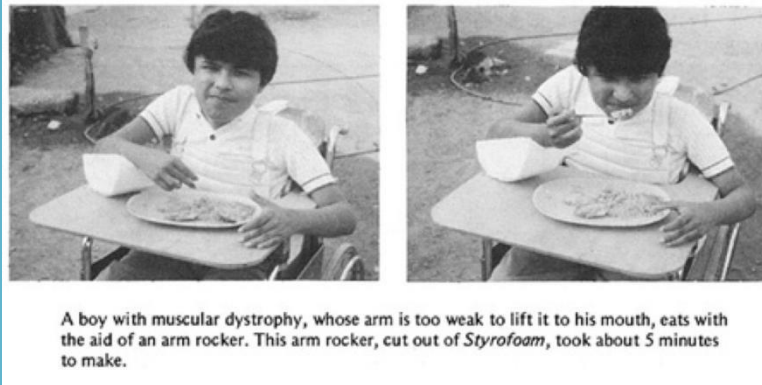
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### Positioning in a wheelchair:

- Make sure the child is sitting upright in the wheelchair (just like they do sitting in a chair)
- Suggest a wooden food tray to support the child's arms.
  - Attach 2 long pieces of wood with grooves to fit over the armrests of the wheelchair. If the tray falls, attach 2 hooks to each side of the tray, use string or fabric to attach the tray to the chair.
  - The tray should not be set too tight. The child must be comfortable in his/her chair<sup>18</sup>.



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### Positioning the child who may have lack of control of arms:

- Get the child to hold onto the edge of the table or onto pegs attached to the table to help with stabilizing his/her arms<sup>18</sup>

**IMPORTANT:** Do not strap or restrain the child's arm to the table

### Positioning after eating:

- After the child is done eating, keep him/her in an upright sitting position for 10-30 minutes to prevent choking<sup>3</sup>.

### Positioning for choking:

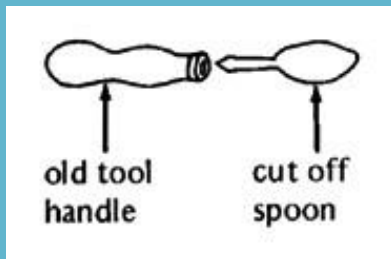
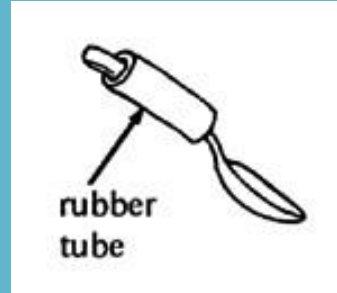
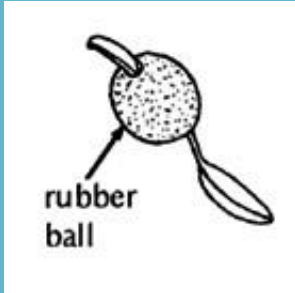
- If the child is choking on his/her food, bend his/her body downward and forward. **Do not tap the child on the back when they are choking**<sup>18</sup>.





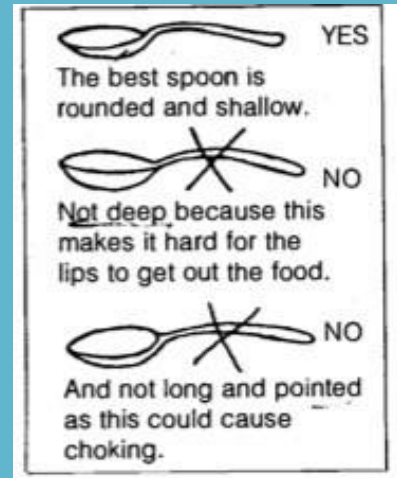
## Adaptive feeding equipment: 2, 3, 4, 6, 8, 13, 18

- **Cutlery and utensils** that are easier for the child to hold because the handle is larger



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- **Non-slip mats** underneath plates, bowls and slabs to keep them stable when the child is eating or the caregiver is feeding the child
- **Round shallow spoon** to facilitate eating and feeding
- **Nose cup** to help with drinking



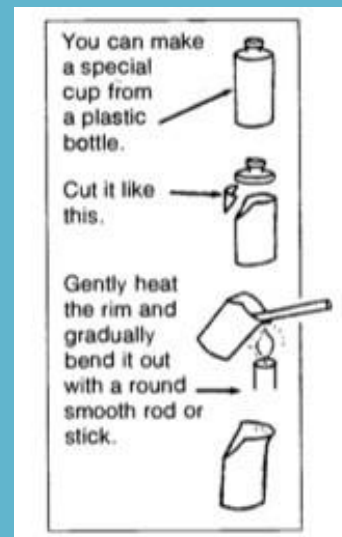
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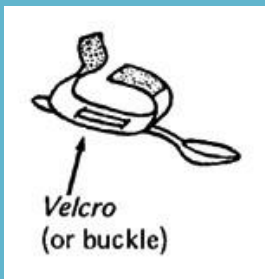


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- **Spoon with handle strap** (place strap loosely around the child's wrist)



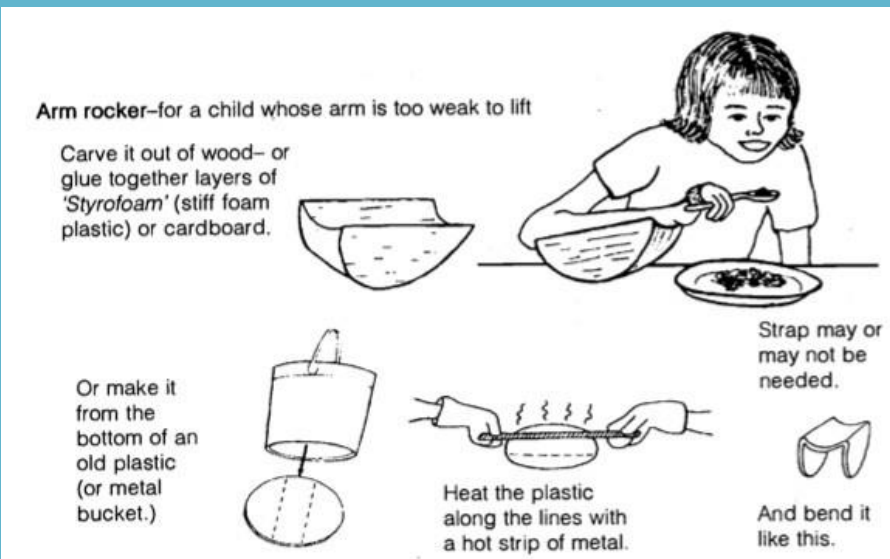
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- **Cup with 2 handles** for the child to easily grab



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- **Arm rocker:** When a child has lower arm strength, an arm rocker helps assist the hand in bringing utensils and foods to the child's mouth. The rocker can be made out of plastic, Styrofoam or block of wood<sup>6</sup>.



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**IMPORTANT:** Involving caregivers and siblings in feeding and feeding rehabilitation whenever possible is important to encourage the child with CP and help them with the activity of feeding<sup>11</sup>.



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# 2.4 Play

**Play** is a child’s main occupation, and it is enjoyable for the child because it offers freedom and choice to do the things he/she likes.<sup>1,2</sup> Play has been described as a right for every child, as it is necessary for development.<sup>1,3</sup> While children with disabilities often experience play differently from their peers, it is still an essential part of their lives and development.<sup>1,4</sup>



## Importance of Play:

Play is essential for a child’s physical, cognitive, and social/emotional development, and it is connected to a child’s health and quality of life.<sup>1</sup>

Area of Development	Benefits of Play
Physical 	<ul style="list-style-type: none"> <li>● Reaching, grasping <sup>5</sup></li> <li>● Motor control (small and large motor) <sup>5</sup></li> <li>● Balance, trunk control, coordination <sup>5</sup></li> <li>● Visual development <sup>6</sup></li> <li>● Muscle endurance, strength and energy <sup>6</sup></li> <li>● Promotes interaction with physical environment <sup>5</sup></li> </ul>
Cognitive 	<ul style="list-style-type: none"> <li>● Learning (colors, numbers, shapes, math concepts) <sup>1,5</sup></li> <li>● Use of senses <sup>7</sup></li> <li>● Motivation <sup>7</sup></li> <li>● Problem-solving <sup>8</sup></li> <li>● Flexibility and thought organization <sup>8</sup></li> <li>● Imagination and creativity <sup>5</sup></li> <li>● Brain development <sup>5</sup></li> </ul>
Socio-Emotional 	<ul style="list-style-type: none"> <li>● Self-efficacy and confidence<sup>1</sup></li> <li>● Exploration and mastery <sup>5</sup></li> <li>● Social participation and interaction with peers (e.g. sharing, taking turns, leadership) <sup>5,8</sup></li> <li>● Social roles <sup>8,9</sup></li> <li>● Emotional expression and regulation; communication <sup>10</sup></li> <li>● Language development <sup>8</sup></li> <li>● Play helps children to understand their culture-Eg: Traditional songs, stories, religion <sup>5</sup></li> </ul>

## Play and CP: Common Problems and Differences

A child with CP may experience more barriers to play compared to other children. Difficulties with physical functioning and manual ability skills might prevent him/her from participating in play activities, and affect his/her development. <sup>1,9</sup>

### Some common problems include:

- less spontaneous play <sup>8</sup>
- difficulty manipulating toys <sup>11</sup>
- decreased pretend or imaginary play <sup>8</sup>
- poor social interactions in play <sup>1</sup>



Children with CP can still enjoy a full play experience, if we expand the idea of play:<sup>1</sup>

1. **Vicarious play:** Children can experience and be engaged in play without physically participating in the activity. <sup>1</sup>



2. **Play through communication:**

- For a child with significant cognitive impairment, participating in playful conversation is a way of playing.
- For a child without cognitive impairments but who has severe CP, communication skills are main forms of play and they often use stories and role play. <sup>1</sup>



### **Parent Perspectives:**

You can build rapport with parents by understanding their perspectives. Often, parents prioritize their child's physical development and self-care activities and do not pay as much attention to play. <sup>1,9</sup> Since parents are responsible for supporting their child's therapy at home, <sup>12</sup> you can support a child's development by educating the parents on the importance of play, and providing them with ideas and strategies to support play in and out of the home.<sup>1</sup>





# The Role of Therapy in Play

Play is used in therapy as:

## 1. Treatment/intervention (way to develop skills)

- Eg: Catching a ball with two hands to develop bilateral hand use
- Giving the child a choice of play and leisure activities, to increase his/her motivation to engage in therapy <sup>13</sup>






## 2. Goal (to improve play occupation)

- Eg: Engaging the child in their environment <sup>13</sup>



## Tips for Using Play in Therapy <sup>5</sup>

### 1. Use sensory cues:

<p>Tactile Cues</p> 	<ul style="list-style-type: none"><li>• Use your hands to help the child move the toy</li><li>• Draw attention to the toy through light touch</li></ul>
<p>Verbal Cues</p> 	<ul style="list-style-type: none"><li>• Explain how to use the toy in words (e.g. “This cup is too big to fit in there; will the smaller cup work?”)</li><li>• Make the sounds of the toy (e.g. “vroom vroom” for a toy car)</li><li>• Use singing during therapy and games</li></ul>
<p>Visual Cues</p> 	<ul style="list-style-type: none"><li>• Show the child how to use the toy</li><li>• Point with your finger and hold the toy so the child can see it</li><li>• Use facial expressions (e.g. smiling) to engage the child</li></ul>

2. Let the child lead the play and you just observe and support if required
3. Use toys or activities the child likes
4. Use toys that are appropriate for the child's abilities (e.g. use larger beads if child can't string small beads)
5. Use chaining: this is a strategy to help a child learn an activity with many steps
  - a. *Forward Chaining*: Child does the first step and then you do the rest of the steps in the task. Once the child can do the first step, get the child to do the second step and so on. **Use forward chaining when child has difficulty with task sequences.**
  - b. *Backward Chaining*: The child completes the last step of the task and once he/she can do it successfully, the child tries the second to last step of the task, and so on. **Use backward chaining when child is easily frustrated or has poor confidence.**
6. Reward play behaviour
7. If child completes activity and engages with a toy reward the child immediately by clapping, smiling and saying “super” or “nallum” to encourage him/her. Repeat play activities during a session to promote learning

8. Keep therapy fun and positive!

## Play Therapy Interventions

### Exercises:

- **Twisting:**

- To help with muscle stiffness, swing the child's legs back and forth. Then, help him/her learn to twist his/her body and roll. Figure out games so that the child **wants** to twist, and does it without help.<sup>14</sup>

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- **Caution against massage:** In some countries, people use massage, or rubbing, to try to relax spastic muscles. **DO NOT MASSAGE SPASTIC MUSCLES** as massaging, pulling or pushing directly against spastic muscles causes more tightness.<sup>14</sup>

### Constraint-induced movement therapy (CIMT):

- This therapy is based on 2 principles: (a) constraint of the least affected arm and hand and (b) intensive and frequent training of activities with the affected arm and hand.<sup>15</sup>
- **Caution:** This type of therapy is very intense. It involves wearing a restrictive mitt for 90% of waking hours for 2 weeks, and participating in 6 hours of intensive therapy 5 days/week.<sup>15</sup> Speak with a specialist (such as a physiotherapist or an occupational therapist) and caregivers before attempting this treatment.

# Play Therapy Interventions

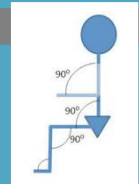
## Positioning for play:

**\* Note:** not all children will be able to stay in the following positions without some kind of support. Special chairs, tables, wedges, pads, or bags of clean sand may be needed to keep a good position.<sup>14</sup>

## Sitting:

Supported seating is very important! Often a child who cannot sit straight will have difficulty lifting his/her arms or manipulating objects, which affects play.<sup>5</sup>

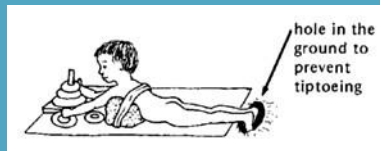
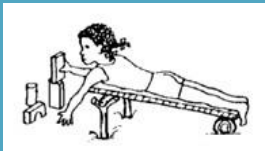
- Proper positioning:<sup>5</sup>
  - Head supported upright
  - Back straight
  - Elbows-hips-knees at 90°-90°-90°
  - Hands free and able to move to grasp objects
  - Legs apart
  - Sitting crossed legged can help support the child when sitting, but position should be changed regularly (every 30 minutes)



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## Lying Down:

- If the child does not have enough control to reach out when lying down, help position the child so he/she can lift his/her head using his/her arms.



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- If the child's head always turns to the same side, have the child lie so that he/she has to turn his/her head to the other side to see the action.<sup>14</sup>



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- If the child's body often arches backward, try positioning him/her to lie and play on his side.<sup>14</sup>



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- Position babies on their tummies to play if they are not able to crawl.<sup>5</sup>

# Play Therapy Interventions

## **Positioning for play (continued):**

*Note: not all children will be able to stay in the following positions without some kind of support. Special chairs, tables, wedges, pads, or bags of clean sand may be needed to keep a good position.<sup>14</sup>*

### Standing:

- Look for ways to provide standing support during play. A cart can provide the child with more balance and keep his/her arms straight.<sup>14</sup>



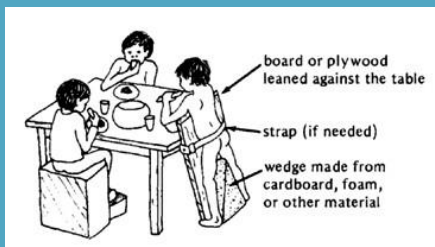
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- Two sticks can also help a child stand (first, hold the tops of the sticks, but let go as soon as possible and have the child hold them alone). It is important that the sticks are taller than the child.<sup>14</sup>

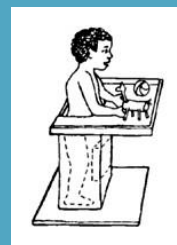


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- Even if a child will never stand or walk alone, using a standing frame helps prevent deformities. It also helps the leg bones grow and stay strong. Start using a standing frame at around 1 year old.<sup>14</sup>



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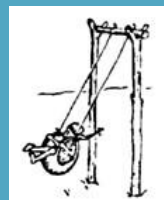
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### Positioning to reduce spasticity:

- Look for ways to decrease spasticity having the child bend forward, or over a barrel (or beach ball or big rock, etc.), or in a car tire swing.<sup>14</sup>



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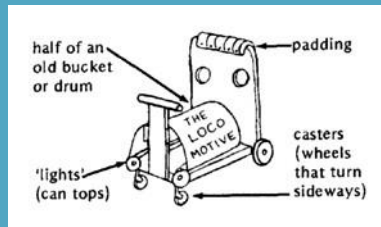


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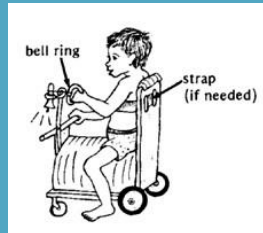
# Play Therapy Interventions

## Adaptive mobility during play:

- Find ways to help the child move around during play.<sup>14</sup>



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## Therapeutic games:

### Hand positioning:

- Sit the child on your belly with his legs spread, knees bent for support (if needed) and feet flat. As he/she begins to reach for his face, help his shoulders, arms, and hands take more natural positions (gently move the shoulders, arms and hands around).<sup>14</sup>
- Continue to encourage him/her to put his/her arms and body in more normal positions through play and *imitation*.<sup>14</sup>

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### Hand use:

- When the child is sitting, standing, lying, etc., in proper positions, encourage him/her to reach, touch, feel, and handle different objects and shapes; things that are big, small, hot, cold, sticky, smooth, prickly, hard, soft, thin, and thick.<sup>14</sup>

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### Crawling:

- When working on balance, use a tilt board or tipping surface and make the activity and playful to motivate the child.<sup>14</sup>

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# Play Therapy Interventions

## Adapting toys:

- Adaptive materials, such as velcro strips, can help the child hold the toy in order to play with it.<sup>10</sup>
- Toys can also be adapted by changing the weight, size, shape, texture, etc.<sup>10</sup>
- When the child is able to manipulate the toy by him/herself this can enhance his/her pretend behavior and influence his/her emotions.<sup>10</sup>

## Homemade therapeutic toys:

**Note:** All of the following toys can be made using different objects that are found in communities. Creating appropriate toys requires creativity and materials, which can be changed if they are not available in the community.

### Rattles <sup>7</sup>

Example(s)	
To make	<ul style="list-style-type: none"> <li>• See description in example</li> </ul>
To use	<ul style="list-style-type: none"> <li>• Hold near child's face and encourage him/her to look towards the sound and movement</li> <li>• Help child hold the rattle and move it to make noise (attach a string at the end of the rattle for the child to get it him/herself)</li> <li>• Practice holding and letting go</li> </ul>
Key development areas	<ul style="list-style-type: none"> <li>• Sound recognition, grasp</li> </ul>

### Mobiles <sup>7</sup>

Example(s)	
To make	<ul style="list-style-type: none"> <li>• Hang tinfoil, CDs, bottle tops, beads, bells, bright material, cardboard-- any shiny or eye-catching object that moves in the wind</li> </ul>
To use	<ul style="list-style-type: none"> <li>• Hang above child and encourage him/her to reach for the objects</li> </ul>
Key development areas	<ul style="list-style-type: none"> <li>• Sensory stimulation, tracking</li> </ul>

# Play Therapy Interventions

## Homemade therapeutic toys (continued):

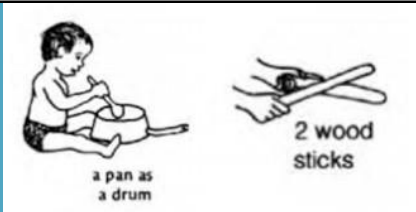
### Vision Box <sup>7</sup>

Example(s)	
To make	<ul style="list-style-type: none"> <li>• Attach no more than 3 shiny or colourful objects to the top of the box on the inside, hanging them so they move in the wind</li> </ul>
To use	<ul style="list-style-type: none"> <li>• The child lies on his/her back with head and upper body inside the box</li> <li>• The dark box with the shiny or coloured mobiles may help a child with vision difficulties to begin to train his/her eyes, as he/she watching the objects</li> </ul>
Key development areas	<ul style="list-style-type: none"> <li>• Sensory stimulation, tracking</li> </ul>

### Texture Bag/Box <sup>7</sup>

Example(s)	
To make	<ul style="list-style-type: none"> <li>• Gather pieces of material and objects with different colours and textures. Include hard, soft, scratchy, shiny, dull, noisy or quiet objects</li> </ul>
To use	<ul style="list-style-type: none"> <li>• Help the child feel the different textures by placing them on the inside and outside of his/her hand</li> <li>• Practice taking and giving objects to the child</li> </ul>
Key development areas	<ul style="list-style-type: none"> <li>• Sensory stimulation, fine motor</li> </ul>

### Drum <sup>7</sup>

Example(s)	 <p>The illustration shows a child sitting on the floor, using a pan as a drum. To the right, two wood sticks are shown with the text '2 wood sticks' below them. The text 'a pan as a drum' is written below the child's pan.</p>
To make	<ul style="list-style-type: none"> <li>• Use 2 wood sticks on any safe surface that makes noise</li> </ul>
To use	<ul style="list-style-type: none"> <li>• Help child hold the stick and drum, and work towards the child making sounds independently</li> <li>• Sing along, and have family members join in</li> </ul>
Key development areas	<ul style="list-style-type: none"> <li>• Cause and effect, sound recognition</li> </ul>

# Play Therapy Interventions

## Homemade therapeutic toys (continued):

### Push/Pull Rattle <sup>7</sup>

Example(s)	
To make	<ul style="list-style-type: none"> <li>• See description in example</li> </ul>
To use	<ul style="list-style-type: none"> <li>• Help/encourage child to hold the wire and push the toy forward and back</li> <li>• Encourage child to walk/crawl while pushing the toy</li> </ul>
Key development areas	<ul style="list-style-type: none"> <li>• Cause and effect, gross motor</li> </ul>

### In/Out Toy <sup>7</sup>

Example(s)	
To make	<ul style="list-style-type: none"> <li>• Place small items (seeds, bolts, match boxes, stones, small plastic cups or bottle tops) into a large container</li> </ul>
To use	<ul style="list-style-type: none"> <li>• Encourage child to pick up objects one by one, and take them in/out of the container</li> <li>• Encourage child to talk about what he/she is doing (e.g. “in” and “out,” naming objects)</li> <li>• <b>CAUTION: due to choking hazard, only use this toy with children over the age of 3 years</b></li> </ul>
Key development areas	<ul style="list-style-type: none"> <li>• Sensory stimulation, fine motor</li> </ul>

# Play Therapy Interventions

Other Musical Instruments <sup>7</sup>	
Example(s)	
To make	<ul style="list-style-type: none"> <li>• String bottle tops on a piece of wire; use the lid from a can, to create a tambourine</li> </ul>
To use	<ul style="list-style-type: none"> <li>• Help child hold and play instrument</li> <li>• Encourage child to move and shake his/her arm independently to make a noise</li> </ul>
Key development areas	Gross motor, cause and effect

Other Helpful Toys <sup>5</sup>	
Toy:	Key Areas of Development:

Clothes pegs



- Cause and effect
- Motivation
- Ordering
- Fine motor skills (reaching, grasping, pinching)
- Bilateral hand use
- Sharing and taking turns with others
- Imaginative and role play

Balloons



- Concepts: weight, colour, small/large, expanding/shrinking
- Tracking
- Bilateral hand use
- Grasping, reaching, throwing
- Taking turns with others (e.g. playing pass)
- Imitating friends

Beads



- Hand-eye coordination (threading string through hole in the beads)
- Sensory stimulation (colour, size, shape)
- Bilateral hand use
- Using different grasp patterns
- Problem-solving
- Counting

Bubbles



- Cause and effect
- Fine motor skills
- Hand-eye coordination for popping bubbles
- Taking turns with others

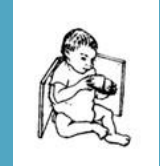
# Play Therapy Interventions

## Promoting Play in the Environment

- Look for simple ways to help the child stay and play using good positioning with the help of a caregiver.<sup>14</sup>



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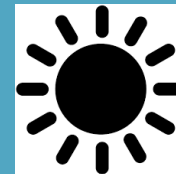
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- Use things in the environment (e.g. a table) to encourage specific movements during play. At the table, sit across from the child to have him/her reach forward for toys with both hands.<sup>14</sup>



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- Expose the child to a variety of environments to support development and sensory exploration. Take the child outside, where he/she can experience temperature, sunshine, wind, etc.<sup>5</sup>



- Take away distractions (e.g. TV, cell phone ringing) during therapy.<sup>5</sup>



- **Promote a play environment for everyone by:**
  - Sharing information from this manual with family, friends and coworkers.
  - Talking to siblings and other children to give them activities that they can do with the child with CP.
  - Adapting toys, games and activities to promote inclusive play.
  - Helping to set up a parent support group.
  - Working with a local teacher to teach students to better include students with disabilities in play.
  - Moving a child sitting in a chair or wheelchair closer to a group so they feel included.
  - Positioning your body so you can face the child in a chair or wheelchair, and so that he/she can easily see your face.<sup>5, 7, 14</sup>





# References

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# 2.5 Positioning

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**Positioning** is involved in all activities that a child will do during the day. The physical arrangement of a child's body and limbs can have a big impact on his/her functional abilities. Good positioning should be used at all times, to support the successful development of a child with CP.<sup>1,2</sup>



## Importance of Positioning:

### Good handling and positioning will:<sup>1</sup>

- makes daily activities like eating, drinking, playing and communicating **easier** and **safer** for the child
- makes it easier for **the caregiver** to care for the child, and
- help prevent disabling positions that lead to deformities of the body and limbs.

### General Positioning Guidelines:<sup>1,2</sup>

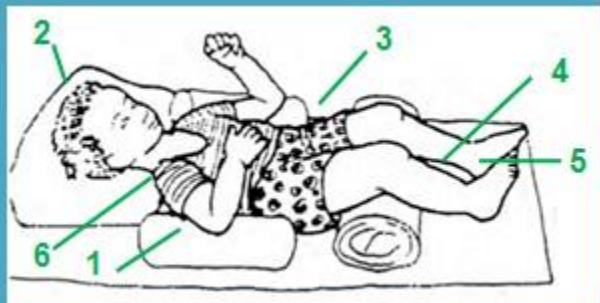
1. Learn how your child moves (e.g. loosen stiffness before moving)
2. Change the child's position often (every 30 minutes) -- this help avoid stiffness and pressure sores
3. Aim for the best possible positions
  - Head is straight up and down
  - Body is straight (not bent, bowed, or twisted)
  - Both arms are straight and kept away from the sides.
  - Both hands can be used, in front of eyes
  - Child bears weight equally on both sides of body (through both hips, both knees, both feet or both arms)



## Specific Positioning Guidelines for Children with CP

### Lying on Back

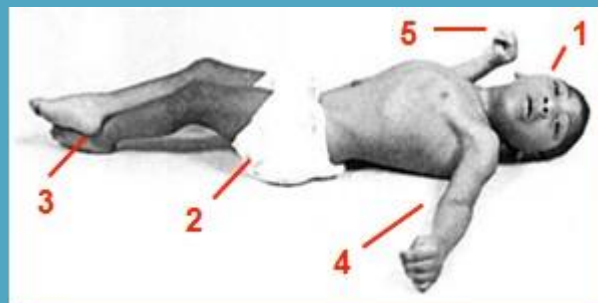
#### Good Positioning



1,2

1. Back straight with the sides supported using rolled towels
2. Head supported (on a pillow or towel) and comfortable
3. Bend hips to support the back relax stiffness in the legs; place support (e.g. towel) under knees to keep hips bent (not under feet)
4. Legs open and without touching (pillow between if needed)
5. Feet up (similar position to when standing) (if feet push down, look into ankle/foot orthosis)
6. Shoulders and arms forward and supported, to allow hands to open easily<sup>1</sup>

#### Things to Avoid



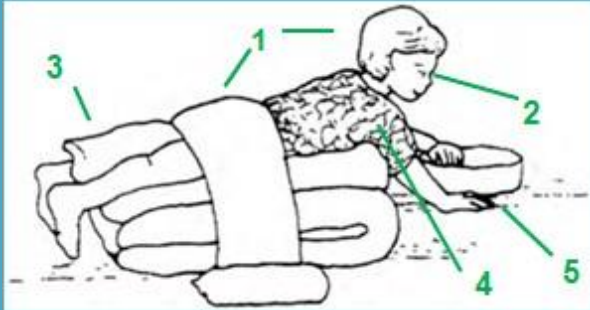
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1. Head pushed back and turned to one side.
2. Hips turning/twisting in, with legs crossing (scissor).
3. Feet pointing down (child can't get them flat if sitting)
4. Hands and arms away from body
5. Hands in a fist and closed<sup>1</sup>

## Specific Positioning Guidelines for Children with CP

### Lying on Stomach

#### Good Positioning



1, 2

1. Head and body in a straight line
2. Encourage child to lift head and look at something in front on the floor
3. Legs and feet straight (push down on her bottom and rock from side to side to strengthen the hips)
4. Arms in line with, or slightly in front of, shoulders (place pillow or towel right under the underarm/armpit)
5. If possible, encourage child to open his/her hands and gently push down on them <sup>1</sup>

**IMPORTANT:** this position may be good for some children but not for all. This requires you to try different positions to see which one is best for the child. <sup>1,2</sup>

#### Things to Avoid



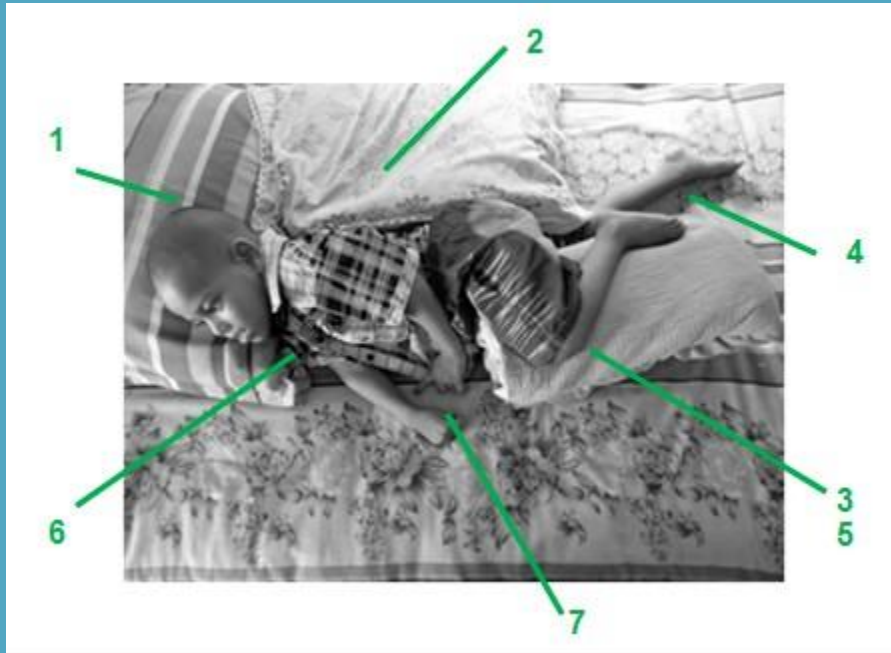
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1. Body posture is uneven, because head is turned to breathe
2. No muscle work
3. Child cannot see anything
4. Legs are crossed
5. Hands in a fist
6. Child is unable to move or do anything <sup>1</sup>

# Specific Positioning Guidelines for Children with CP

## Side-Lying

### Good Positioning



1. Head supported on pillow so the chin is level (in the middle, with head and back in a straight line)
2. Good support at child's back, from the top of the head to the feet
3. Bending one leg and keeping the other straight helps reduce stiffness in the legs.
4. Keep bottom leg straight
5. Top leg is bent at the knee, and is supported with pillows or blankets so the knee is at the same level as the hip – this is important to help prevent hip dislocation or injury
6. Child's lower shoulder and arm brought forward so they are not stuck underneath body
7. Keep both arms forward to bring child's hands together – encourage him/her to use hands by playing a game with him/her
8. During the day this position should be changed from one side to the other, or to another position every 30 minutes
9. This is also a good sleeping position <sup>1</sup>

## Sitting with Caregiver

### Good Positioning

### Things to Avoid





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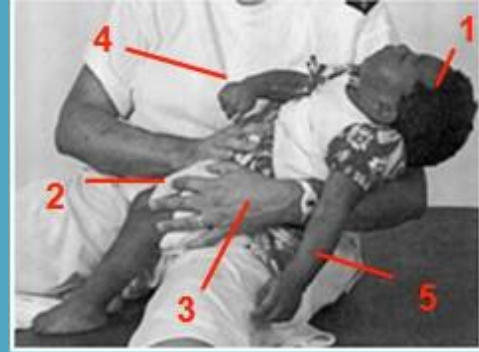
1. Child sitting up straight with the head and back supported
2. If child can hold head up, use your hands to support child's chest and/or hips so he/she stays up straight and control the head
3. Child should be working his/her muscles to move his/her body and keep it upright.
4. Bend hips to at least a right angle – this will help keep the child in a good position and help stop him/her from sliding off your lap
5. Child's shoulders should be slightly forward so that arms and hands are in front of his/her body, and he/she can use her arms and hands to play when sitting <sup>1</sup>

You can control the child's legs by placing each of his/her legs on either side of one of your own legs, like this:



2

This leaves your hands free to help him/her control and use his arms and hands. <sup>2</sup>



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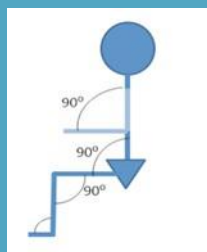
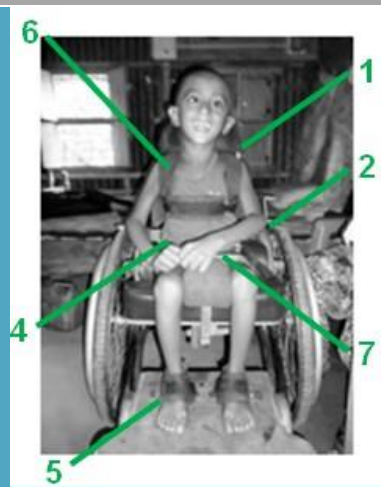
1. Head hanging backwards, or to one side, or just leaning against the caregiver
2. Child lying down, without sitting on his/her bottom
3. Hips are not bent
4. Child cannot use his/her hands when sitting
5. Arms are not helping the child to sit <sup>1</sup>



# Specific Positioning Guidelines for Children with CP

## Sitting in a Wheelchair or Chair

Good Positioning 



1 2

1. Back straight and head upright and supported if necessary
2. Buttocks all the way to the back of the chair
3. Arms-hips-knees at 90°-90°-90°
4. Lap strap, tightened firmly enough to stop child from sliding down in the chair
5. Legs and feet supported
6. Shoulders and arms supported slightly forward and in front of the body.
7. Hands free for the child to use <sup>1,2</sup>



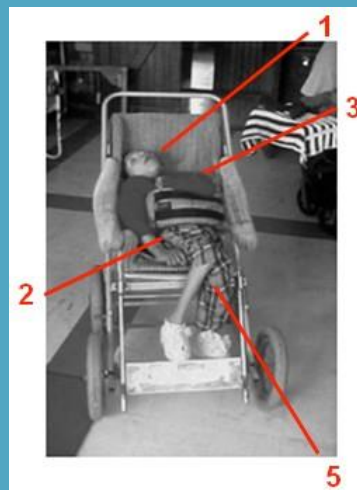
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Things to Avoid 



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1. Head pushing back and sliding out of the chair
2. Hips too straight and stiff
3. Shoulders unsupported, and are either pulling back, or pushed too far forward
4. Child leans sideways and is not stable
5. Twisting leg bones, may cause deformities and contractures <sup>1</sup>



1

# Sitting on the Floor

## Good Positioning



1. Follow other sitting guidelines (back and head straight, etc.)
2. Child can sit independently with legs crossed
3. He/she should sometimes sit with legs straight (not always bent), to avoid contractures <sup>1</sup>
4. Child's sitting position can be supported using special pillows, room corners, or other things in his/her environment. **An example of a supportive cushion is \_\_\_\_\_ [ASK SANKAR FOR INFO]**  
<sup>1,3</sup>



**NOTE:** Look for ways the child can sit with legs spread apart. Above, the pot or log keeps the knees apart. Holes for heels help too. <sup>2</sup>

## Things to Avoid



1. Avoid the "W" position:
  - a. This position can hurt the knees and hips of the child.
  - b. **However, if it is the only way that allows your child to be independent in sitting, then it should be supported, but do not let him/her sit in this position all the time. See "good positioning" for ways to improve this position.** <sup>1,2</sup>

## *Specific Positioning Guidelines for Children with CP*

### **Importance of Standing:**

Standing is essential for good physical development. Standing strengthens the hip joint, to avoid weakness, dislocation and pain as well as contractures and stiffness. A child who never stands has weaker bones that can break, and standing can help with breathing and blood circulation to make the bones stronger.<sup>1,2</sup>

### **The Benefit of Standing Frames:**

Many children with disabilities who are unable to stand spend their time lying or sitting. Without support, the child's stiff leg muscles prevent him/her from standing on flat feet with knees and hips straight. In a standing frame, the child is able to see the world differently, and they are able to engage and interact with friends. This offers broader stimulation for the child, and will contribute to social development and cognitive skills.<sup>1,2</sup>

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## *Specific Positioning Guidelines for Children with CP*

### **Standing Frames**

#### Good Positioning

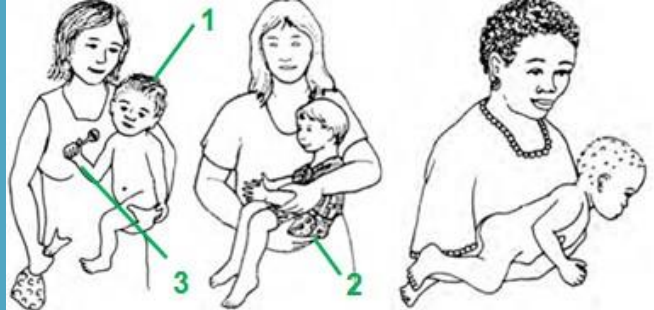
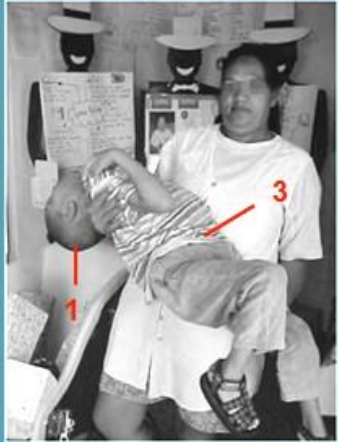

#### Standing Frame #1:



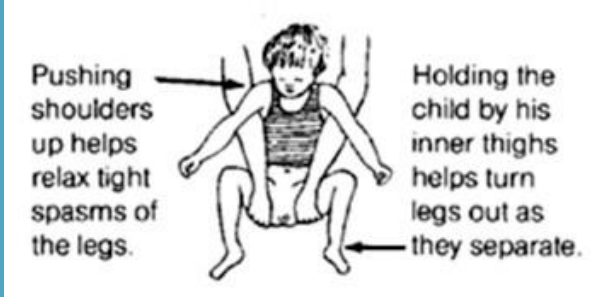

1. This is a simple piece of wood
2. Hips and knees are in a good position, helping to keep feet flat
3. Shoulders and arms are forwards
4. Child no longer needs to hold on for support, as balance is not difficult in this position
5. Hands are now free to do play, touch, etc.<sup>1</sup>

## Standing Frame #2:

1. Back is straight – if body leans to the left or right, put a rolled up towel on each side of the body in the frame
2. Hips are facing the front
3. Shirt is covering the tummy so skin is not touching the Velcro in front
4. Feet are firmly on the ground (including heels); toes are facing forward (if you can easily move the feet, the child is not putting enough weight on them. Loosen the frame, and let him/her fall more onto his/her feet before placing the child back in a standing position and close the frame.
5. **IMPORTANT:** If the child's feet are in a very poor position, he/she should only stand in the frame when he/she has been assessed for, and is using, orthotics
6. Arms should come forward onto the tray/table, which should be at about nipple height
7. It is good if the child pushes on his/her arms, or uses them to touch a toy or object on the tray.<sup>1</sup>

# Specific Positioning Guidelines for Children with CP

Carrying Positions	
Good Positioning	Things to Avoid
 <ol style="list-style-type: none"> <li>1. A more upright position will help the child to hold his/her head up and look around</li> <li>2. Use positions that keep the child's hips and knees partially bent and the knees separate</li> <li>3. The child can hold on with his/her arms or he/she can use arms or hands for playing</li> </ol>	  <ol style="list-style-type: none"> <li>1. Head falling back</li> <li>2. Child cannot see</li> <li>3. Body stiff and straight</li> <li>4. Arms and hands can't do anything</li> </ol>

Additional Carrying Strategies		
Good Positioning		
	<p>The child with severe spasticity who tends to straighten and arch backward</p>  <p>can be carried like this:<sup>2</sup></p> 	



# Specific Positioning Guidelines for Children with CP

## Additional Positioning Strategies

### Good Positioning

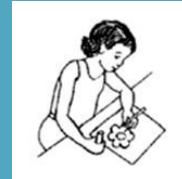
If the child's arm repeatedly bends up, encourage him/her to reach out and hold objects.<sup>2</sup>



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2



2

If the child bends backward a lot, he/she needs movements that bend his/her head, body, and shoulders forward.<sup>2</sup>

2

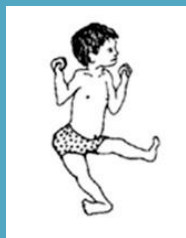


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2

If the child's legs stay apart, the buttocks sticks out, and shoulders are pulled back, sit the child with his/her body bent forward and legs together. Then bend his/her shoulders forward and turn them in.<sup>2</sup>



2



2

# Specific Positioning Guidelines for Children with CP

## Additional Corrective Positioning Strategies

### Good Positioning

If the child's body often arches backward, try the following positions:<sup>2</sup>



2

2



2

2

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2

If the child's legs come together and turn in, and his/her arms turn in, sit the child with legs apart and turned the legs out. Also lift the shoulders up and turn his/her arms out like this:<sup>2</sup>



2

2

2

### **NOTE:**

- For information about positioning during play, please refer to chapter # on play.
- For information about positioning during feeding, please refer to chapter # on feeding.

# References

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1. London School of Hygiene & Tropical Medicine (LSHTM). (n.d.). Getting To Know Cerebral Palsy. Retrieved on June 17, 2017 from <http://disabilitycentre.lshtm.ac.uk/files/2013/06/Getting-to-know-cerebral-palsy-v1-lowres.pdf>
2. Werner, D. (1987). *Disabled Village Children. A Guide for Community Health Workers, Rehabilitation Workers, and Families*. Hesperian Foundation, PO Box 1692, Palo Alto, CA 94302.
3. **ASSA cushion resource from Sankar.**



Children use language and communication for different reasons. These include:

- Communicating what they need and want<sup>1</sup>
- Communicating to gather information<sup>1</sup>
- Communicating to create relationships with others (i.e. friends, siblings, family members)<sup>1</sup>
- Communicating to share information and messages with people (i.e. brothers and sisters)<sup>1</sup>



## Speech/Communication and Children with CP

For children with CP, physical and cognitive impairments affect their ability to communicate with others.<sup>1,4</sup>

Why is communication more difficult for children with CP?:

- **Difficulty understanding** the information received. This may be caused by visual (eye) or auditory (ear) difficulties. Due to impairments at the level of the brain, it may be more difficult for children to understand what they have heard and seen<sup>5</sup>.
- **Cognitive problems** (intellectual disabilities), which impact how the child processes information and expresses him/herself<sup>5</sup>.
- **Oromotor problems** that involves the tongue and mouth. This can physically affect the child's ability to communication and speak<sup>5</sup>.
- Increased **muscle tone and spasticity**, which can impact the child's ability to make gestures and signs, or point to different things to communicate<sup>5</sup>.

**IMPORTANT:** Communication issues will vary depending on the child, the CP diagnosis and the signs and symptoms of the child<sup>5</sup>.

# Specific problems that may affect speech and communication in children with CP

## Speech problems:

**Dysarthria** is a motor disorder that affects speech in children with CP.<sup>1,4,6,7</sup> Specifically, dysarthria will impact:

- Producing speech
- Respiration
- Articulation
- Intonation
- Resonance

**Speech impairments** include<sup>1,4,6</sup>:

- Shallow breathing when the child is speaking
- Low pitched voice
- Low intonation (no variation in intonation)
- Low articulation
- Abnormal resonance



Spastic and dyskinetic types of CP can affect the child's speech. Dysarthria is often found in children with dyskinetic CP (vs spastic CP)<sup>1,6</sup>.

## Communication problems:

When the child has motor impairments, this can impact:

- Ability to produce speech<sup>1</sup>
- Ability to make facial expressions<sup>1</sup>
- Ability to perform gestures and body movements<sup>1</sup>
- Ability to communicate altogether<sup>1</sup>



## Cognitive problems relating to speech:

- Language development and language delays of children with CP can result or be impacted by cognitive difficulties or decreased socialization and experience within their everyday environments<sup>1</sup>

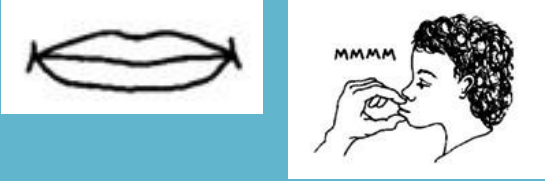
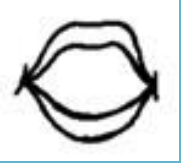

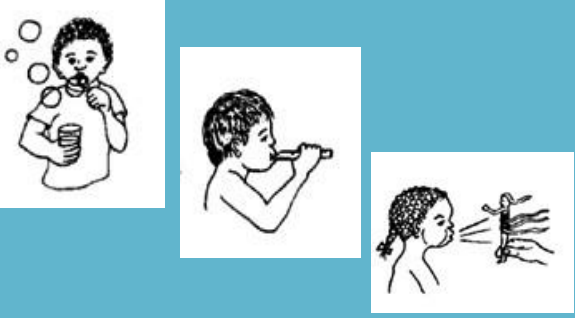
## Social & interpersonal problems due to speech and communication problems:<sup>6,8,9</sup>




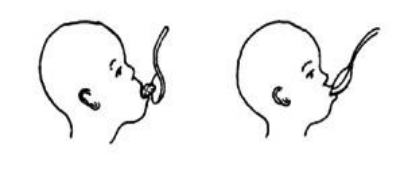
- Social and educational isolation because the child cannot communicate with people around him/her (i.e. parents, friends, siblings etc.)
- Decreased social participation in school, home and community environments. This increases the risk of lower education levels and unemployment.



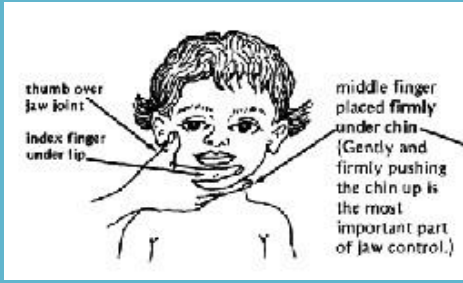
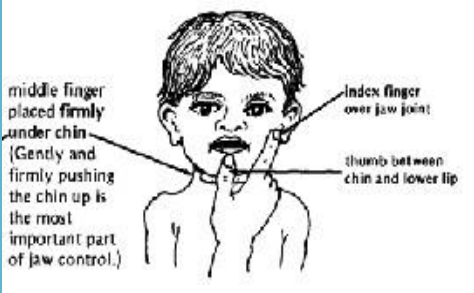


## Exercises to prepare oral muscles:

Exercises for mouth, tongue and lips	Exercise
<p>Press lips together and say “mmm.” If it is difficult for the child to keep his/her lips together the lips can be held shut by the child or caregiver. <sup>2</sup></p>	<p style="text-align: right;">2</p> 
<p>Make a circle with mouth like an “O.” <sup>2</sup></p>	<p style="text-align: right;">2</p> 
<p>Make a big smile by stretching the mouth and saying “eee.” <sup>2</sup></p> <p>Other easy sounds to make are: “ah” “ay” “ee” “aw” “o” “p” “b” “t” and “d.” <sup>2</sup></p>	<p style="text-align: right;">2</p> 
<p>Blow soap bubbles, blow pieces of paper off a table, or practice blowing into a whistle to work on the mouth muscles. <sup>2</sup></p> <p><b>CAUTION:</b> In some children with CP, blowing bubbles could increase the uncontrolled tightening of the muscles or twisting of the mouth. If so, it is better not do these exercises. <sup>2</sup></p>	<p style="text-align: right;">2</p> 

Exercises for drooling and strengthening of mouth, tongue and lips	Exercise
Gently tap or stroke the child's top lip and/or lightly press on the bottom lip a few times. <sup>2</sup>	 <span style="float: right;">2</span>
Gently use two fingers to stretch the lips, which strengthens the lip muscles. This can support the strengthening of the lips muscle to help the child close his/her mouth. <sup>2</sup>	 <span style="float: right;">2</span>
Parents can try putting some honey or another sweet substance on the top and bottom lips, and encourage the child to lick it off. This will help with strengthen the child's tongue and lips. <sup>2</sup>	 <span style="float: right;">2</span>
Parents can try putting sticky food on a spoon and encouraging the child to lick it off. This too can help strengthen the child's tongue and lips. <sup>2</sup>	 <span style="float: right;">2</span>

**CAUTION:** Some children with CP may not have much tongue control, and their tongues may naturally push forward. If that is the case, avoid all exercises that involve licking lips or a spoon.

Exercises for jaw control	Exercise
<p><i>Jaw control exercises when sitting <b>beside</b> the child:</i> <sup>2</sup></p> <ol style="list-style-type: none"> <li>1. Place thumb over jaw joint</li> <li>2. Put index finger under the lip</li> <li>3. Place middle finger under the chin</li> <li>4. Push the chin up</li> <li>5. Keep head straight</li> <li>6. When the child is speaking, apply firm, gentle and continuous pressure</li> </ol>	<p style="text-align: right;">2</p> 
<p><i>Jaw control exercises when sitting in front of the child:</i> <sup>2</sup></p> <ol style="list-style-type: none"> <li>1. Place the index finger over jaw joint</li> <li>2. Place the thumb between the chin and lower lip</li> <li>3. Place the middle finger placed under the chin</li> <li>4. When the child is speaking, apply firm, gentle and continuous pressure</li> </ol>	<p style="text-align: right;">2</p> 

Positioning to practice exercises for mouth, tongue and lips:

- It is best to sit in front of the child so they can see your lips and face.
- Demonstrate the movement of mouth, lips and tongue so that the child can imitate them.
- Imitate and repeat the sounds that the child makes to have the child copy them and repeat them.
- Practice the exercises during the day.



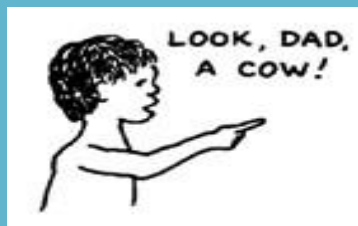
**IMPORTANT:** Do not go too fast and be patient to avoid overwhelming the child.

## Promoting Speech Through Activity

To help support the child's communication development, you must be able to recognize the different ways children can communicate. It is especially important that the caregivers are aware of their child's communication strategies, because that may help them understand their child's needs<sup>6</sup>.

### Different forms of communication in children:

- *Sounds, gestures and facial expressions:* Children may use signs, gestures or facial expressions to communicate. Some children may also have signs, gestures, movements etc., that are specific to them and that they use with their family and friends<sup>10</sup>.



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**IMPORTANT:** It is important to try and understand what the gestures, signs, movements, and facial expressions mean, and to encourage the child to use them to support their development.

- *Pointing (eyes or hand), showing, and touching:* Some children will use their eyes, hands or fingers to point, touch, or lean towards different objects. This is a way of communicating what he/she wants. Encourage the child to use pointing and touching to communicate, in order to gain independence in communication (LSHTM, n.d; Pennington, 2008)<sup>5</sup>.



2

### Children with CP and MR or ID: <sup>2</sup>

- Some children with CP and MR or ID, may have trouble speaking and communicating or may not be at the same developmental level as other children who are the same age.

**IMPORTANT:** Even if the child cannot speak or communicate, he/she may still understand information and conversations.

## Helping with communication for children with CP and MR or ID: <sup>2</sup>

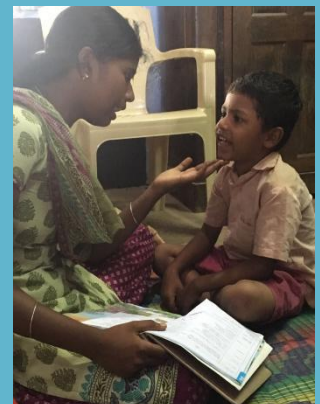
- Speak to the child during the day using clear and simple words, because the child may be able to listen and start understanding. Speak to the child when bathing, dressing, playing, cooking, etc.
- Encourage the child when they imitate sounds, words, gestures, actions etc.
- Encourage siblings to speak and talk to the child using simple words or sounds.
- Siblings can also encourage the child to imitate their sounds and gestures.



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## Speech exercise for saying and pronouncing words<sup>5</sup>:

- *Before starting the speech exercise:*
  - Find a quiet room to get the child's attention.
  - Sit in front of the child, so that he/she can see your face and lips when you speak. This is important because listening and understanding come before speaking.
  -
- *During speech exercise* <sup>5</sup>:
  - Start using words that the child knows already (use words from books, school books, tablet pictures etc.).
  - Have the child say the word out loud first (example: good morning).
  - Do not correct the child; simply repeat the word with the right pronunciation.
  - Sound out every syllable (example: good... mor... ning), and then say the word or phrase all together (example: good morning).
  - Have the child sound out every syllable (example: good... mor... ning) and then put them all together (example: good morning).
  - Repeat the word a few times and encourage the child ("Super").







## Different forms of AAC (applicable to VBR and children with CP)

*Communication Boards:* A communication board has many symbols and pictures of things that a child recognizes in his/her daily life. To communicate, he/she can point, reach, look at the pictures on the board to communicate with people around him/her<sup>11,12</sup>.

**IMPORTANT:** It is important to see if the child is able to understand the pictures, and is able to point, touch, gesture, or look at the pictures to communicate with parents, siblings, friends, and others.

- *Communication Book:* This is a book with many symbols and pictures displayed on the pages. Some symbols and pictures are placed in categories (example: food, animals, dressing, body etc.) to help the child better understand them<sup>6</sup>. Pictures and symbols can be added to the book very easily as the child learns new words and ideas.



**CAUTION:** For some children and caregivers, the communication book can be too difficult to carry around, and they may find that it takes a long time to search the pages. This is something to discuss with the child and parent.

### **IMPORTANT INFORMATION ABOUT AAC DEVICES:**

- *Conflict when communicating with others:* At times, the child may not have enough time to communicate using their devices, as those around them have continued to speak. The child can then become removed from the conversation around him/her<sup>10</sup>.
- *Caregiver attitudes towards AAC:* Some parents may not completely understand the technology and its benefits for their child. This can influence their attitudes toward using the AAC system at home<sup>10</sup>.
- *Barriers to using AAC:*
  - Frustration when using AAC can affect when the caregiver and child use it in the home (example: it takes too much time to use, it's difficult to transport, etc.)<sup>4</sup>.
  - Negative attitudes or stigma from the community can impact the use of the AAC device by child and its family<sup>4</sup>.

- Children and caregivers must be open to using the AAC device.
- Providing information to the caregivers and children about the different options for AAC devices is very important.
- Supporting the children and caregivers in using the AAC device is very

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## 2.7 Toileting

**Toileting** is an important activity of daily living, especially for young children<sup>1</sup>. However, for children with CP, toileting independently or with assistance can be a challenge. Rehabilitation and adaptations are helpful to support toileting and increased independence in children with CP<sup>2,3</sup>.

### *Developmental Milestones for toileting*

Age	Toileting
2.5 years	<ul style="list-style-type: none"><li>• Child can pull down pants with help for dressing and toileting</li><li>• Child can pull down and pull up pants with help for dressing and</li></ul>
toileting 3 years	<ul style="list-style-type: none"><li>• Child typically shows some readiness to practice toileting because he/she has improved control of bladder and bowel</li></ul>
4.5 years	<ul style="list-style-type: none"><li>• Child can usually toilet independently</li><li>• It is important to remember that this may be different for children, as some children need more time to achieve toileting</li></ul>

### Problems that may affect toileting in children with CP

#### **(1) Problems with upper extremity (hands, wrists, arms etc.):**

- Poor weight bearing in forearm<sup>4</sup>
- Abnormal muscle tone and posture instability<sup>5</sup>
- Weakness in shoulders<sup>5</sup>
- Fine motor and precision difficulties<sup>6</sup>
- Weak pinch grasp



#### **(2) Problems with lower extremity (hips, legs, ankles, feet):**

- Impaired gait<sup>6</sup>
- Unable to sit independently<sup>4</sup>
- Unable to stand independently<sup>4</sup>
- Unable to walk independently<sup>4</sup>
- Postural instability and poor balance (lying, sitting, and standing)<sup>5,7,9</sup>
- Impaired balance and



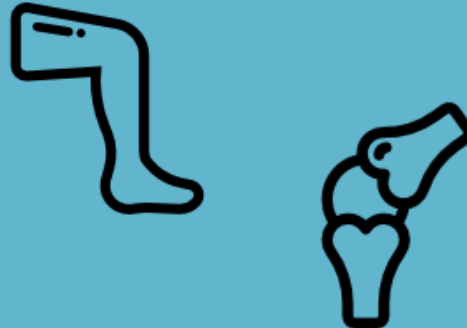
**(3) Common urinary/digestive problems in children with CP:**

- Bowel dysfunction
- Urinary incontinence due to impaired control of bladder muscles<sup>9</sup>
- Toilet training was not given



**(4) Problems due to spasticity:**

- Muscle pain/spasm<sup>11</sup>
- Difficulty with transfers<sup>11</sup>
- Poor positioning when sitting<sup>11</sup>
- Difficulty standing and walking<sup>11</sup>
- Contractures (leading to joint deformity)<sup>11</sup>
- Joint dislocation<sup>11</sup>
- Bone deformity<sup>11</sup>
- Decreased functional independence<sup>11</sup>



**What is spasticity?**  
 Spasticity is muscle stiffness and tightness from muscle contraction; it occurs due to injuries to the brain or spinal cord. Spasticity in a child with CP may cause pain to the child, disturb his/her sleep, and affect his/her functioning in daily activities<sup>12</sup>.

## Toileting Interventions

### *Exercises for Toileting*

The following exercises can be completed during the day to stretch the limbs, muscles and joints necessary for toileting.

**Exercises for balance and stability**

***Sitting (with assistance):*** When the child is sitting down, hold him/her above the hips and gently push him/her from side to side and backwards and forwards, so that the child learns to catch him/herself with the support of his/her arms. This will be useful for independent or assisted toileting, as y and bance are needed when sitting or squatting<sup>21</sup>.

**Exercise**



## Exercises for balance and stability

## Exercise

**Using a tiltboard or ball:** If the child falls over when he/she is sitting up, you can help the child develop the use of his/her arms when balancing. Put the child on a tiltboard or ball, hold his/her hips, and slowly tip the board from side to side. Encourage the child to catch him/herself with a hand<sup>21</sup>.



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**Squatting:** Encourage the child to squat down for approximately 5 minutes or less, with his/her back and hips supported to keep a straight position. This may help positioning for using a squat toilet<sup>21</sup>.



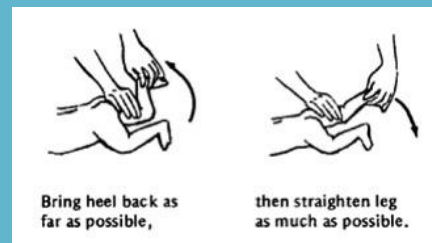
## Exercises

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## Exercises for lower extremity

### Knee:

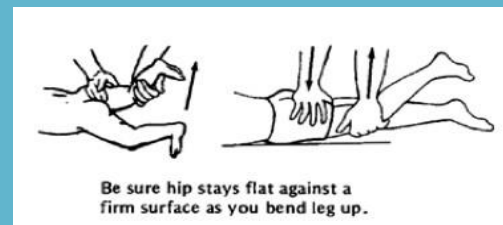
- **Child lying on stomach:** bring heel back as far as possible and strengthen the leg<sup>21</sup>.



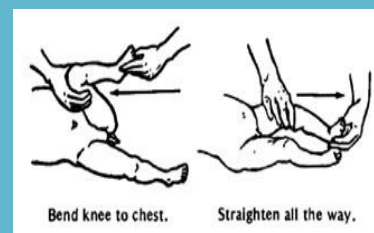
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### Hip:

- **Straighten:** Have child lie on stomach on a flat surface. Place one hand on buttocks and with the other hand lift up the thigh (slowly and gently)<sup>21</sup>.
- **Bend:** bend the knee to the chest and then straighten all the way<sup>21</sup>.



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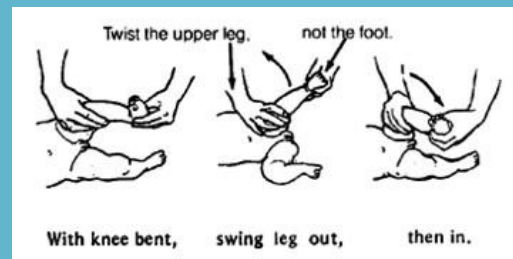
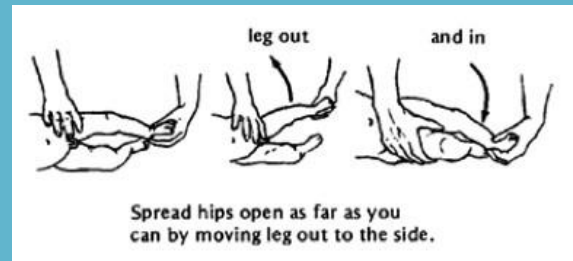


## Exercises for lower extremity

## Exercises

### Hip:

- **Spread:** spread the hips open as far as possible by moving the leg out to the side<sup>21</sup>.
- **Hip Rotation** (leg bent): rotate the hip, keeping the leg bent<sup>21</sup>.

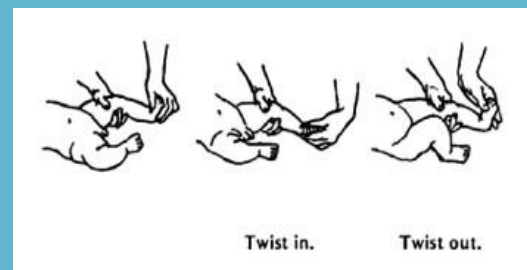
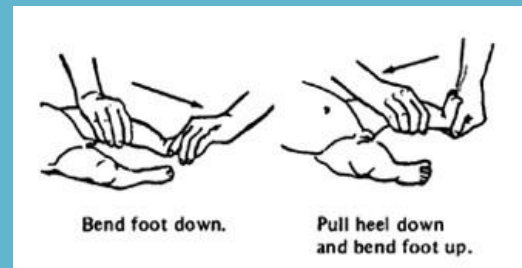


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### Ankle

- **Ankle and foot up and down:** Bend the foot down, pull the heel down, and bend the foot up. This will help the foot stay flat while the child is toileting<sup>13</sup>.

- **Ankle twisting (in and out)**<sup>15</sup>

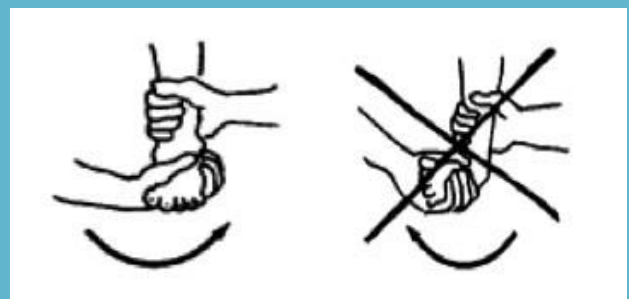


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### Feet:

- You can do exercises to help the foot bend out<sup>13</sup>.

**CAUTION:** Do not do exercises that bend the foot in.

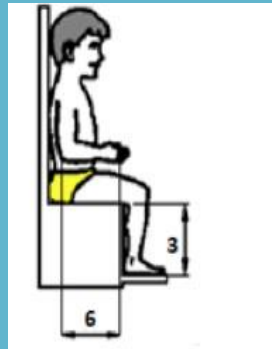
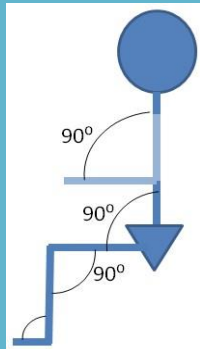




## Adaptations to Support Toileting

### Positioning for toileting on toilet:

- To sit in a safe position, it is important to keep the back straight and head up (if possible). A child with abnormal muscle tone should have his/her pelvis in a neutral position (not tilted or angled) and have his/her hips, knees, and ankles at 90-degree angles<sup>8,13</sup>.



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- When toileting, have the child lean his/her chest and abdomen forward so that his/her hips are flexed a bit more than 90 degrees. This can help with elimination of the bladder and bowels. This positioning will also help relax the abdominal muscles and reduce spasms<sup>8,15,16,17</sup>.
- Provide the child with a stool or step to support his/her feet when sitting. When the knees are higher than the hips, this can help with elimination of urine and bowels, as it relaxes the abdominal muscles<sup>8,15</sup>.



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### Modeling and demonstrating toileting:

- It is important to encourage the child when you are assisting or helping with toileting<sup>18</sup>.
- Model the proper positioning<sup>18</sup>.
- Provide the child with pictures of all the steps needed to complete toileting. This can help the child imagine the steps before doing them. Make sure the pictures match the child's ability level<sup>19</sup>.
- Steps include: (1) pull pants down or lift skirt (with or without help); (2) transfer or position body on the toilet or squat toilet; (3) use bucket or spray rod to wipe or clean him/herself; and (4) pull pants up or bring skirt down (with or without help).

### Clothing to help make toileting easier:

- Using velcro (not buttons) and elastic waistbands on pants, can make it easier for the child to remove his/her clothes quickly.

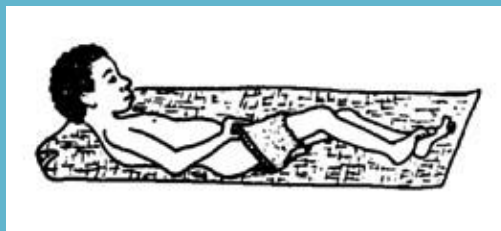


- Use loose fitting clothes that can be taken off easily, especially for children who have trouble pulling down pants and undergarments<sup>9,21</sup>.
- Have a large zipper for a child to easily grip and pull up or down<sup>5,9</sup>.



### Positioning to put clothes on and off after toileting:

- For a child with CP, it may be easiest to lie down on a clean mat when putting pants on or off<sup>21</sup>.



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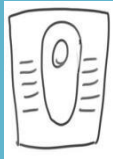
- The child could also transfer or be moved back to his/her chair, bed, wheelchair etc., to re-dress<sup>22</sup>.



# Equipment to Support Toileting

## Different toilet options and types for children <sup>21</sup>

- Squat toilet<sup>21</sup>



- Western toilet<sup>21</sup>



- Plastic potty seat (place in a box with a rod if the child needs postural support) <sup>21</sup>

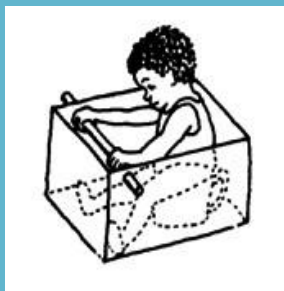


- Bowl<sup>21</sup>



## Modified toilets

- *Sitting frame (box) for bowl or potty/toilet seat:* Children who have difficulties with posture, balance, independent sitting etc. may benefit from a sitting frame around a bowl or potty. Adding a rod at the front of the box allows the child to hold on and remain stable when sitting down<sup>21</sup>.



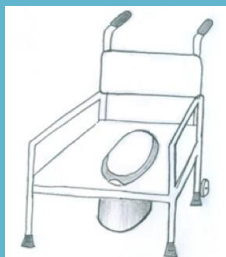
- *Modified chair or commode:* This is a chair with a hole in the seat, placed over a squat toilet or bucket. This offers good positioning and stability for the child who is unable to squat and needs to sit. The chair can be removed when the child is not using it<sup>2,21,23</sup>.



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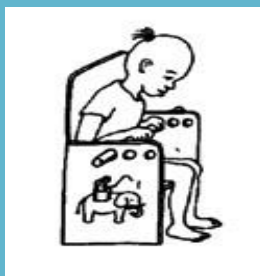
**IMPORTANT:** If the child's feet do not reach the floor, add a small stool or other flat surface under his/her feet for good positioning<sup>8</sup>.



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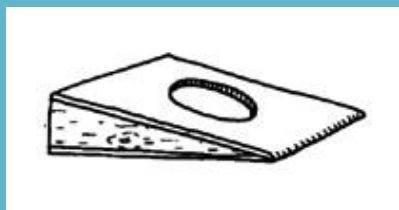
**CAUTION:** When making the modified toilet, it is important to ensure that the child is properly positioned to avoid increases in spasticity, contractures and deformities. The chair/commode should sit on a flat surface to avoid falling over<sup>2</sup>.

- Consequences of poor seated position can also include: poor posture, back and neck pain, tension in muscles, etc.<sup>2</sup>
- *Modified wooden seat with wooden rod:* Similar to the modified chair, the wooden seat is placed on top of the toilet or squat toilet. The wooden rod offers the child somewhere to place his/her hands when seated, and this is helpful for children with spasticity and low balance<sup>21</sup>.



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- *Wedge-shape toilet bedpan:* This toilet is useful for children who may not be able to stand, sit or squat independently. The child slides onto the wedge (feet first) from the bottom. This may be done with help or independently, but a pillow or sheet should be placed under the child's head for safety and support<sup>21</sup>.



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- *Caregiver support:* For children with severe CP who are unable to sit independently, placing a bowl or pot between the mother's knees and having her support the child during toileting can be helpful. The child's shoulders should be kept forward, his/her hips should be bent, and his/her knees should be separated<sup>21</sup>.

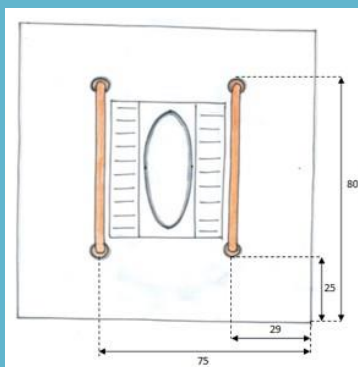


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#### Additional Equipment:

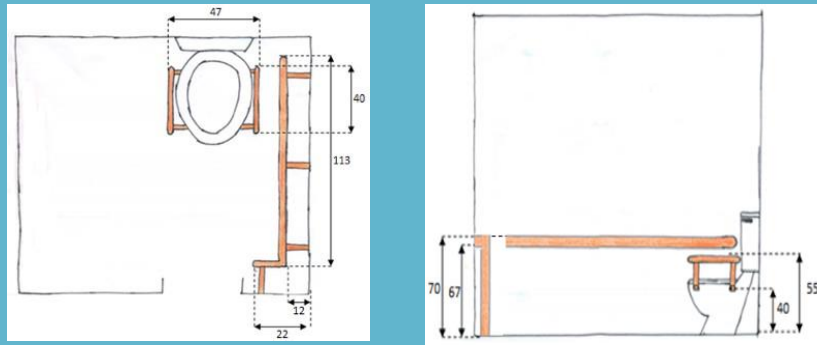
##### *Grab Bars/Rails:*

- *Squat toilet rails:* Place a rail on either side of the squat toilet. This will offer the child some support and stability when he/she is squatting down<sup>14,18</sup>.



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- *Western toilet rails:* Place one vertical rail at the toilet entrance for children to use to enter the restroom and pull him/herself up. Place one horizontal rail along the wall of the restroom to support the child as he/she walks or crawls to the toilet and sits on the toilet <sup>14,22</sup>.



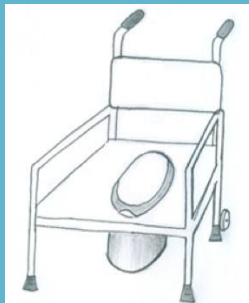
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- *Supporting for squat toilets:* Some children with CP could benefit from having something to hold when squatting, for added support. Encourage the child to reach their shoulders and arms forward to hold a stabilizing device or object (i.e. stool, chair, posts, pole, etc.) <sup>8,21</sup>.



21

- *Armrests:* Adding armrests to a toilet can offer support to the arms, wrists and hands when the child is moving on and off the toilet. Armrests can also be a part of the toilet frame (see the Modified Toilets section)<sup>7</sup>.



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- *Contoured seat:* Placing a contoured seat on top of the toilet seat can help stabilize the pelvis and promote the 90°-90°-90° position when the child is toileting<sup>8</sup>.



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#### Modified washing techniques after toileting:

- When the child is sitting on the modified chair, commode or stool, bring a bucket of water or hose to meet the genital area between the legs. It is much easier to wash between the legs from the front<sup>23</sup>.
- Have the child hold a cup of water with one hand and practice splashing the water between the legs. After splashing, the child can use the same hand to clean him/herself<sup>23</sup>.
- A sponge attached to the hose can be used to wash in between the legs. Use water from a bucket beside the toilet to soak the sponge<sup>23</sup>.
  - **CAUTION:** It is very important to clean the sponge after every use for good hygiene and health<sup>23</sup>.
- A water bottle can be used by the child clean him/herself. Having a bottle that can easily open at the top is very useful<sup>18</sup>.



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## 3.1 Supporting Caregivers Through Mental Health Considerations



Caregivers caring for children with CP experience:

- significantly more stressful life events than people who do not care for a child with a disability<sup>1</sup>
- low quality of life and some mental health issues such as depression<sup>2</sup>
- lower levels of self-mastery than people who do not care for a child with a disability<sup>1</sup>

What can CRWs do?	What can caregivers do?
<ul style="list-style-type: none"><li>• Educate the family on CP and information related to therapy and caring for the child - perhaps in a workshop or meeting format<sup>3</sup><ul style="list-style-type: none"><li>• <i>NOTE. ASSA's Women and Community Awareness programs are great recommendations for caregivers!</i></li></ul></li><li>• Get to know the family's natural coping mechanisms and incorporate them into therapy<sup>3</sup></li><li>• Facilitate a parent to parent counseling program, in which caregivers of children with CP exchange information and offer support and guidance<sup>4</sup></li><li>• Inform families of support groups run by social workers from ASSA</li></ul>	<ul style="list-style-type: none"><li>• Maintain a healthy diet<sup>5</sup></li><li>• Take rest and maintain consistent sleep schedule<sup>5</sup></li><li>• Seek assistance when needed<sup>5</sup></li><li>• Express frustrations productively<sup>5</sup></li><li>• Reframe or change the way you think about your child to be more positive and meaningful<sup>6</sup></li><li>• Establish and maintain a large family support network<sup>1</sup></li><li>• Foster a sense of self-mastery, self-esteem, and self-efficacy<sup>1,2</sup></li></ul>





## 3.2 Training Related to Special Education



It is important that children with disabilities obtain an education to secure employment later in life, as most children with disabilities cannot obtain work that requires much physical labour<sup>7</sup>.

### **Children with CP can obtain an education by:**

1. Attending regular school with other children<sup>7</sup>
  - a. CRWs can speak with teachers to advocate for the child and arrange appropriate accommodations within the school environment (e.g. providing adapted writing tools for classroom writing, quiet space to work, etc.).
2. Receiving tutoring at home (one-on-one education) from peers and/or special education specialists<sup>7</sup>
3. Attending ASSA's Centre for Special Education or ASSA's Integrated Schools

Choosing a school for a child with disabilities to attend is a very important decision. Admission for children with disabilities and do the reasonable accommodation to promote learning is the responsibility of school management. Some schools are more accommodating than others with regards to children with disabilities. It is important for CRWs and the caregivers to speak with different schools, school staff, other rehabilitation team members and the child about which school would be most appropriate. Some children with mental retardation (MR) may participate very well in regular schools, while other children with MR may not – the decision should be made by considering the individual child and his/her needs.<sup>7</sup>





## 3.3 Vocational Training



ASSA has a vocational training centre on campus, in which persons with disabilities can receive skill- and job-related training for future employment<sup>9,10</sup>.

Training programs focus on:

- computer programming, information and technology
- tailoring
- cell phone and small appliance repair
- fabrication of orthotics
- handicrafts, toys and painting
- typewriting
- gold appraiser training
- notebook making and binding

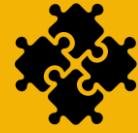
Some units at ASSA will even employ participants of the vocational training program once they have completed their training<sup>9,10</sup>. CRWs can educate caregivers of the many vocational training possibilities at ASSA, as potential options for their children in the future.







## 3.4 Integration into Society



The success of a child with CP integrating into society will depend on how family members, friends and community members treat and engage with the child. Children with disabilities deserve the same rights and opportunities as children without disabilities, however this belief may not be present in all communities or families. Treatment and attitudes towards children with disabilities will therefore vary greatly depending on the belief system of the people around them.<sup>7</sup>

### Suggestions to help integrate children into society

- Share what you have learned from this manual with your friends and family
- Suggest that parents and children attend the ASSA awareness training programs
  - **Community Awareness Program**: ASSA staff offer educational information to community members on various disabilities.
  - **Students Awareness Program**: ASSA staff visit schools in the community and educate students on various disabilities.
  - **Women Awareness Program**: ASSA staff offer educational information to women in the community on various disabilities that are most relevant to women's issues and women's health.
- Advocate for the child to have access to services and encourage participation
- Become familiar with accessible places in your community and share and inform family members of disability-friendly locations
- Plan outings ahead of time
- Encourage caregivers to take the child into the community
- Encourage children without disabilities to play with, interact with and learn about children who do have disabilities<sup>7</sup>
- Recognize and highlight the child's strengths<sup>7</sup>







## 3.5 Other ASSA Resources



The following resources are offered through ASSA and may be beneficial to children with CP and their families/caregivers<sup>10,11</sup>:

<b>Centre for Special Education</b>	The centre is a school for children with intellectual disabilities/MR where they can work with special educators, teaching assistants and therapists in an academic setting. Staff and volunteers help the child engage in school activities by providing accommodations, modifications and assistive devices to help them learn in the best way possible.
<b>Early Intervention for Children with Delayed Development (Age 0-5)</b>	Children with developmental delays are offered physiotherapy, occupational therapy, speech therapy and sensory integration therapy services early in their life to help them achieve developmental milestones and participate in important activities such as feeding.
<b>Medical Treatment Unit/Outpatient Physiotherapy Unit</b>	Physiotherapy, occupational therapy and speech therapy services are offered to children and adults of all ages with varying disabilities. Services will help with client rehabilitation.
<b>Home for Disabled Children</b>	Children with varying disabilities living at ASSA, attending the school on campus and receiving rehabilitation services.
<b>Integrated Schools</b>	Children with disabilities attend school with children without disabilities.



## 3.6 Other Resources & Contact Information

There are multiple schemes that families with children with disabilities can apply for through the Government of Tamil Nadu<sup>12</sup>. Schemes are sums of money (loans?) that families can receive from the government for economic support to help them pay for services and anything they may need help with. If the family is interested in learning more about schemes or applying for a scheme, let them know that they can contact their local district rehabilitation officer:

**Designation:** District Disabled Rehabilitation Officer (i/c), Thirunelveli.  
STD Code: 0462

**Address:** District Rehabilitation Centre, Colony, Palayamkottai Thirunelveli 627 007

**Office phone number:** 2553157

**Office fax number:** 2554190

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Other contacts that may be of use to you as you work in the community	
<b>Amar Seva Sangam</b>	Sulochana Gardens Post Box No. 001 10/02/163, Tenkasi Road, Ayikudi, Tirunelveli Dt., Pin: 627852 Tamil Nadu, India Phone: 91-4633-249170 / 249180 Mob: 99444 59170
<b>Emergency</b>	Call 112 to speak to an operator about your emergency (e.g. child choking, unresponsive child)
<b>Suspicion of child abuse</b>	Call Childline 1098



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