

Caring for Children with Developmental Disabilities



A Guide for Parents living in low-resource settings

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RANGOONWALA FOUNDATION

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MAITS regards this manual as a work in progress. We are aware that further edits are necessary and that more illustrations would be helpful. We welcome feedback and suggestions which will contribute to the next edition, and would be grateful if you would complete the feedback form and return it by email to info@maits.org.uk.

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Cerebral Palsy Nepal

About the Guide

This resource is to be used by staff working with parents to promote the development and independence of their child with neurodevelopmental disabilities (mainly cerebral palsy, intellectual disability and autism).

Staff using the Guide should already have attended training on how to work with this client group and be in contact with local therapy services if they exist, in order to make referrals and obtain supervision for their work with these children and families. Training can be provided by MAITS or other local agencies.

Neurodevelopmental disabilities (NDD) are functional limitations in a child's abilities resulting from disorders or injuries to the developing brain. They are usually identified in infancy or childhood when the individual is unable to achieve developmental milestones or when there is a lack of function in one or multiple 'domains'. Developmental domains include cognition (thinking and reasoning), motor performance, vision, hearing, speech, and behaviour. NDD may lead to limited participation in daily life including in school, employment and leisure. For ease, we use the term 'developmental disabilities' interchangeably with 'neurodevelopmental disabilities'.

In line with current thinking, this resource places the emphasis on promoting activity and participation in a child's daily life activities rather than therapies that try to fix 'the problem' (Skelton and Rosenbaum, 2010). As such, this Guide provides ideas on how to support the child during activities of daily living – taking particular account of their physical and communication abilities and needs – and does not include hands-on rehabilitation techniques that focus on specific impairments. It does however provide guidance on overall management and prevention of further disability.

Staff working with families have a special and unique role in providing guidance and direction on how to build a child's knowledge and skills towards living an active life in their own environment. The Guide has been designed to be used as the basis of a programme, facilitated by the family worker, in which the parents are supported to identify functional goals for their child and to identify the strategies to achieving these e.g. The parent wants child to self-feed. The worker and parent discuss what level of independence in self-feeding might be achieved through providing physical support to the child and try out the best ways to optimise this (e.g. through improved seating, providing hand-over-hand support, and using modified utensils that the child can grasp more easily). The Guide does not prescribe goals and strategies to achieving them, as it is recognized that every child and family will be unique. Instead, the child and their family are supported, through discussion and pictorial aids, to find solutions that work for them. This requires a higher level of skill (and therefore training) of the family worker who will be using problem-solving, solution-focused techniques, involving the parents and their knowledge of the child as much as possible, and introducing graded support to enable progress to be achieved.

In line with Best Practice & Evidence-Based Practice, the model incorporates the following principles: It is child and family-centred, holistic, goal-centred and individually tailored, promotes function and participation before impairment-focused interventions, and involves and empowers the parents. These principles are being applied using simple, low cost methods that are applicable to the local setting.

It is also recommended that this individual family approach is accompanied by the organisation of parent support groups. It should be noted that for children with mild difficulties (i.e. Level I in this manual), the main focus of the family worker should be to promote inclusion of the child in mainstream activities and services.

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Depending on the age of the child (infant – child – teenager), the focus of support should be different. The Guide is divided up according to age groups and details of the priorities for the child at each stage of development are provided at the beginning of every section.

Apart from implementing strategies to support the child during activities of daily living, helping the child to learn through play is an essential part of their development. Ideas on this are also given throughout the Guide.

The International Classification of Function (ICF), developed by the World Health Organisation (WHO) provides a useful framework (see diagram below) to highlight the difficulties that a child with disability faces in growing up in a challenging environment. This model is used internationally, from North to South.

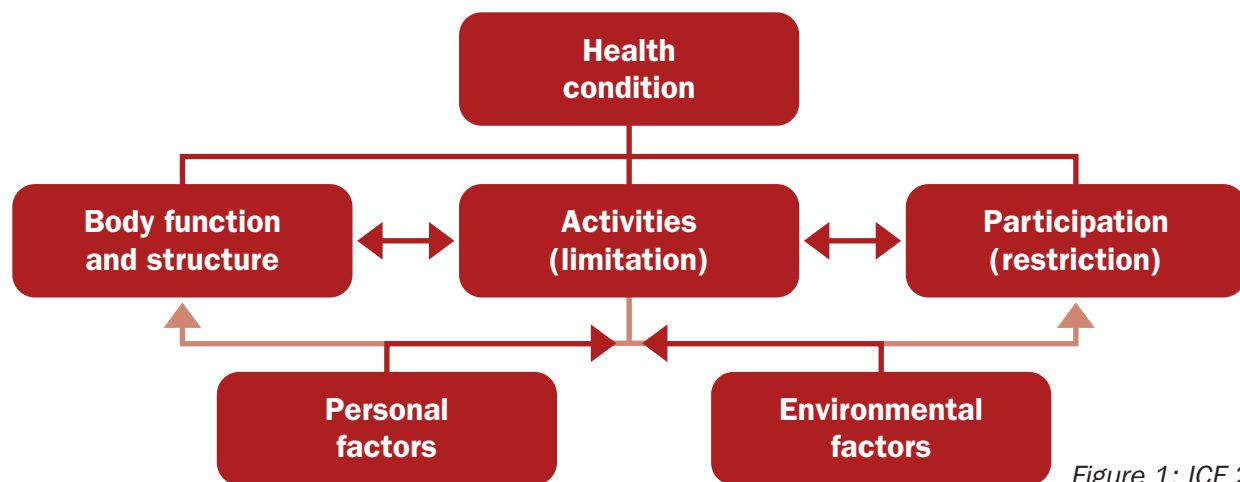


Figure 1: ICF 2002

Around the world, there has been an increasing awareness that a child or adult with a disability will be confronted not only with their personal health condition, but that their activities and ability to participate are limited by the acceptance and understanding of their disability by their family and community. This often leads to rejection and isolation, in addition to limited access to support and services, such as work places, schools or rehabilitation centres.

This Guide provides practical information which can directly impact on the daily life of a child with disabilities and their carers and is one way in trying to achieve the rehabilitation guidelines set by UNICEF and WHO (2012).

Although the Guide does not directly address other conditions such as progressive neuromuscular conditions or disability caused by diseases or accidents affecting mobility alone (e.g. Polio, landmine accidents etc.), it contains a lot of relevant information that can be used in all areas, such as working towards independence and building up a child’s daily living skills, which is the main focus of the Guide.

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Part 1:

Background Information

Working with Parents

Some parents will have great difficulty accepting that their child has disabilities and be experiencing a sense of 'grief'. Others less so. There may also be an increased burden of care, financial demands and less time for other members of the family and possible.

The following diagram outlines common concerns expressed by parents:

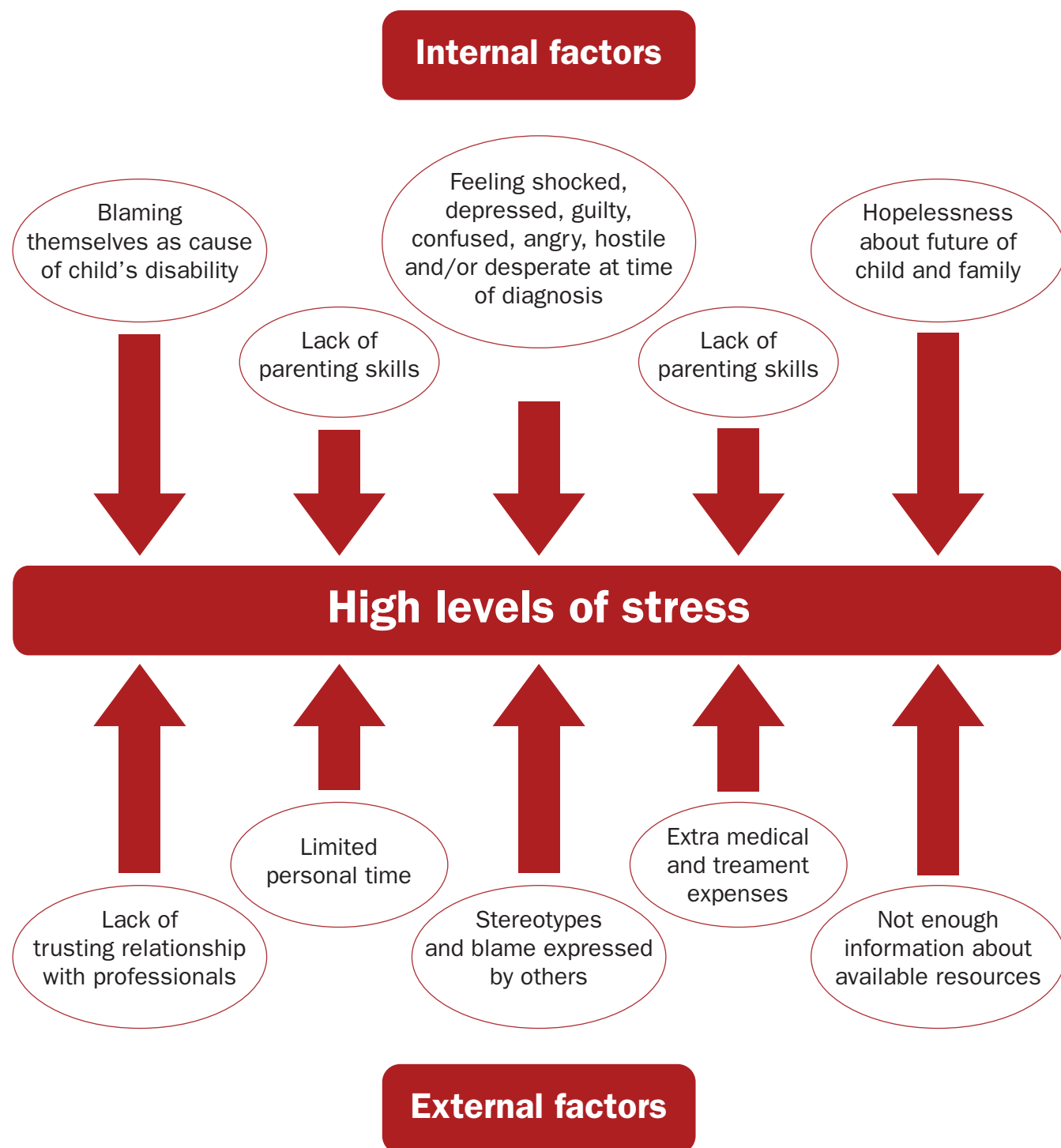


Figure 3: Common concerns expressed by parents. (Ergüner-Tekinalp and Akkök, 2004; Gettinger and Guetschow, 1998; Goddard, Lehr, and Lapadat, 2000; Heiman, 2002)

When working with parents, it is important to:

- **Reassure parents that the type of emotions they experience may be intense and overwhelming, but they are normal and acceptable.**
- **Encourage parents to learn to be patient with their child, themselves, their family and the entire process.**
- **Encourage parents to begin afresh; to tell themselves they have a whole future ahead with worthy things to do. There will be challenges ahead but also hope.**
- **Focus on the needs of the child.**
- **Try to encourage realistic expectations of the child at the same time as promoting a positive attitude towards the child.**
- **Emphasize the strengths of the carers and the child.**
- **Help parents to value their child by encouraging them to.....**
 - **learn to accept their child for who he/she is**
 - **identify their child's strengths and not only his/her difficulties**
 - **acknowledge their child as an individual with thoughts and feelings**
 - **focus on the present instead of the future**
 - **focus on things that can be controlled instead of those that can't be controlled**
- **Encourage carers to seek and build support networks and to look for help from others outside the family with caring for their child.**
- **Use counselling skills to support the family – listening, empathy etc.**
- **Develop a contract of work.**
- **Keep all information confidential.**

Understanding Cerebral Palsy

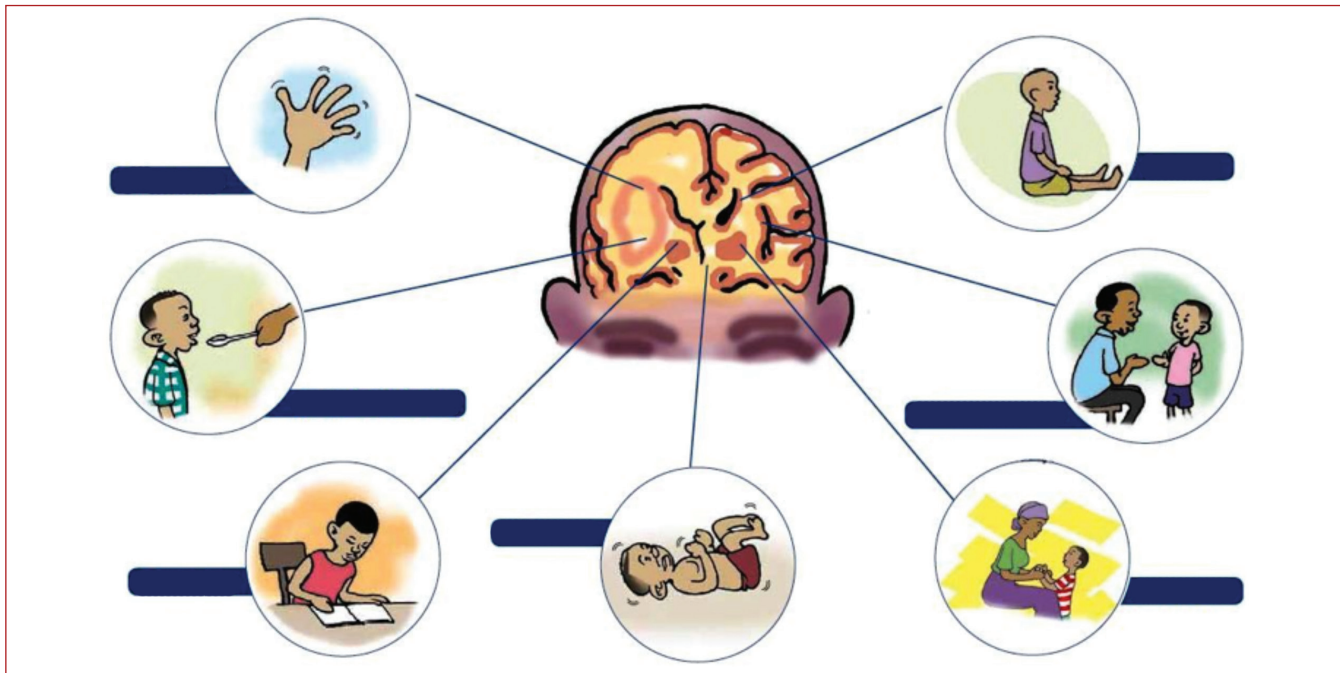


Diagram from CBM International 2012, *How can you help your child with cerebral palsy (flipchart)* available at <http://www.cbm.org/Publications-252011.php>

What is cerebral palsy?

- Cerebral palsy is a condition that affects muscle control and movement.
- It is usually caused by an injury to the brain before, during or after birth.
- Often the cause is not known.
- Signs of cerebral palsy may not be identified at birth but usually become obvious when the child does not achieve age appropriate skills e.g. when a child cannot hold their head up by themselves by six months or is unable to roll over to sit by eight months.
- There is no cure for cerebral palsy, but appropriate advice can help individuals with cerebral palsy to become more independent.

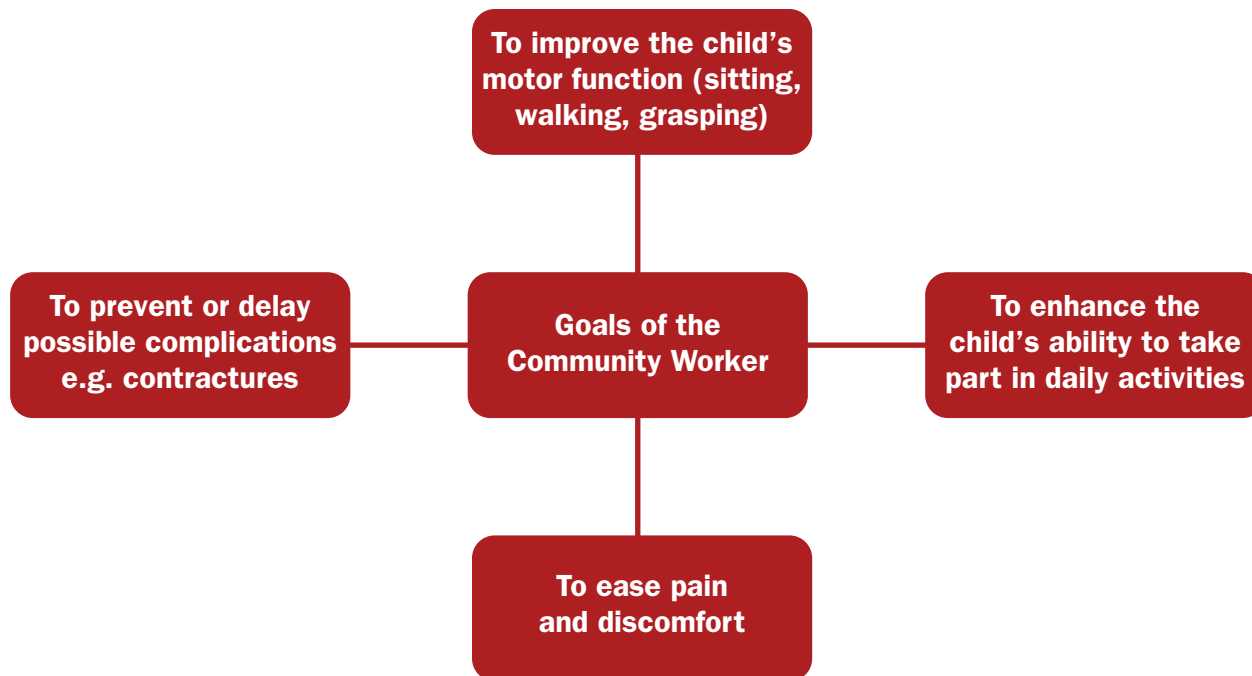
Some possible causes

These may occur by themselves or in combination with each.

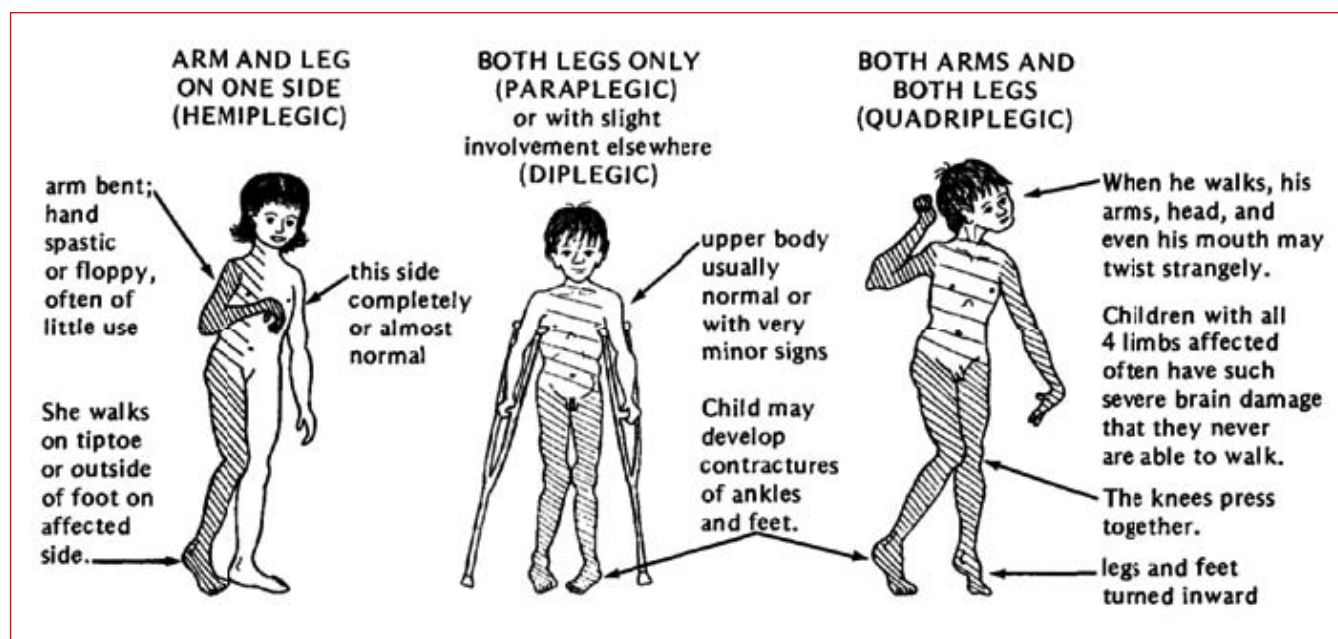
Before birth	During birth	After birth
Infection in the mother during early pregnancy Abnormal brain development	Difficult birth Premature birth Very low weight at birth	Brain infection Malaria Head injury

The role of the family worker is to dismiss fears, blame and superstition, that may be held by the family or the community, and to explain the child's disability by providing alternative explanations.

It is important to encourage support for the child in the following areas:



What does cerebral palsy look like?



Images from *Disabled Village Children*

Cerebral palsy can affect an individual in many different ways:

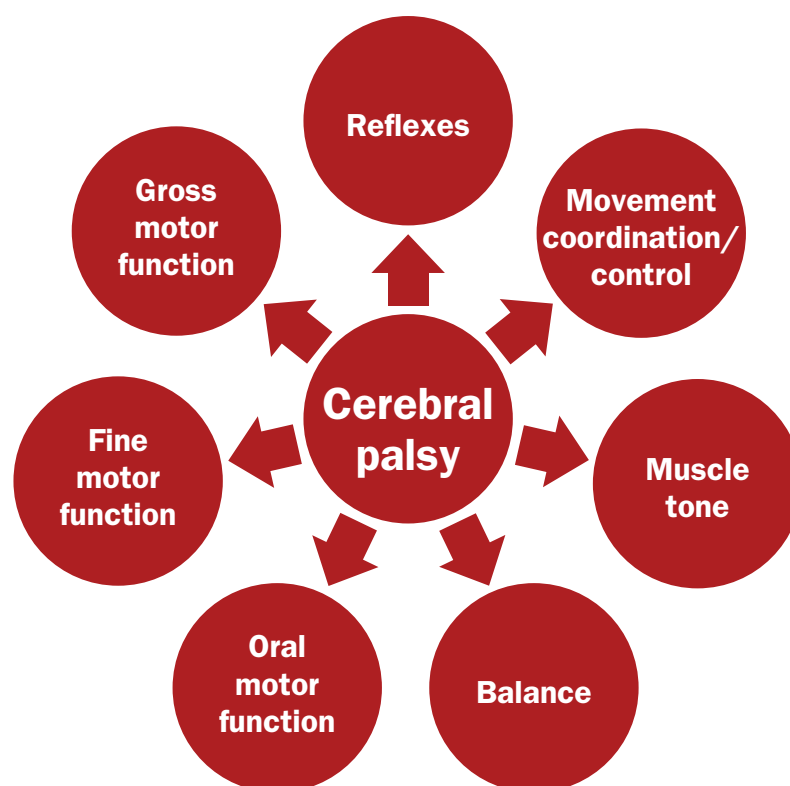
- A child with mild cerebral palsy may have some difficulties in moving but not require assistance, whereas another child with severe cerebral palsy may need daily and long-term assistance to perform daily living skills.
- Each child is unique and needs support – physically, mentally and emotionally – to allow them to reach their full individual potential.
- Each child needs to interact in all settings – at home with their family and friends, in school for education, and in the community to develop their social networks.
- As a child grows up into adulthood, a lot of help is often needed to maintain movement of the body and joints, and to maintain muscle strength.

It is important to work with the parent and the child to identify what the child can do and what he or she finds difficult and then help them to achieve their full potential.

Early support for a child with cerebral palsy can be effective in promoting the child's development and can reduce the complications, which appear as the child grows up.

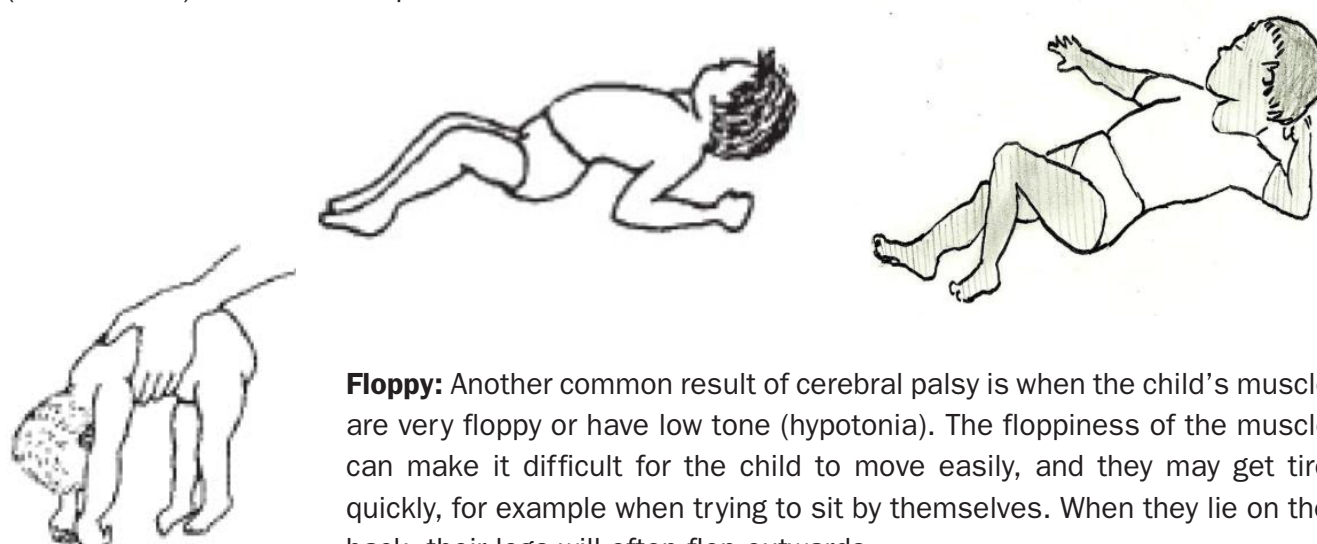
Understanding movement and function for a child with cerebral palsy

Depending on the type of cerebral palsy, a child will have problems in one or more of the following areas:



A. Muscle tone

Some children have **muscle stiffness**, or 'increased muscle tone'. This is called hypertonia. This causes part of the body to be rigid, or stiff. Movements are slow and awkward. Often the position of the head triggers strange positions of the whole body. The stiffness increases when the child is upset or excited, or when their body is in certain positions. **The pattern of stiffness varies greatly from child to child and they have no control over these movements.** Muscle stiffness is the most common way that individuals are affected by cerebral palsy. It may result in stiff joints (contractures) and abnormal posture.



Floppy: Another common result of cerebral palsy is when the child's muscles are very floppy or have low tone (hypotonia). The floppiness of the muscles can make it difficult for the child to move easily, and they may get tired quickly, for example when trying to sit by themselves. When they lie on their back, their legs will often flop outwards.

It is important to recognize the problems that the abnormal tone is causing and find solutions through good handling, positioning, posture and communication to help the child carry out their daily routine.

B. Movement problems

It is common for a child with cerebral palsy to experience difficulty in moving. There are different types of movement problems, as follows:

- **Spastic movements** – This is when the muscles are too tight, resulting in muscle spasms, scissoring of the leg and uncontrolled movements (clonus). **Ataxic movements** – This is when there is poor coordination and balance, making it difficult to carry out tasks such as walking, brushing teeth, buttoning coats, tying shoes, and writing. The individual is very unsteady on their feet or when he is trying to carry out any movement.
- **Athetoid or dyskinetic movements** – This is caused by changing muscle tone causing uncontrolled, sometimes slow, writhing movements which can worsen with stress.
- **Dystonic movements** – This is when the individual's movements cause spasms or continuous contractions of the muscles.

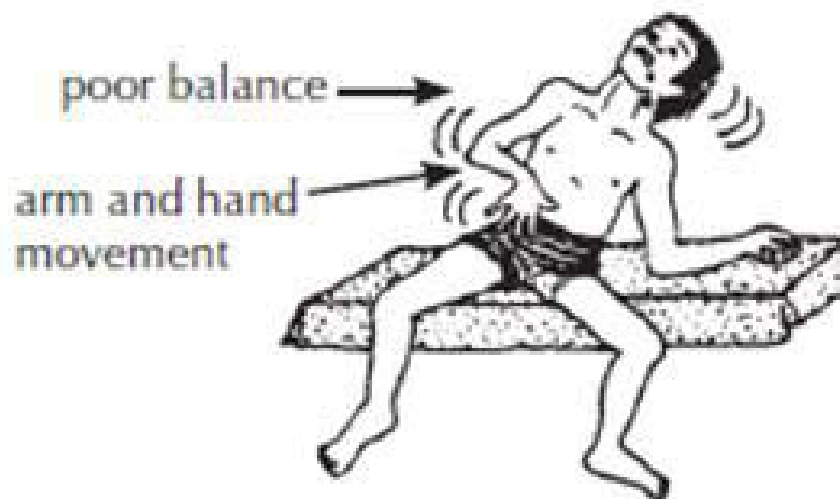


Image from Disabled Village Children

The lack of control is often seen in the way a child walks, such as toe-walking, walking with a scissor gait, dragging the feet and moving with a stiff posture.

It is important to help the parent to observe and identify the problems that the child's movement coordination and control are causing, and find solutions through good handling, good sitting position and standing posture to help the child carry out their daily routine.

C. Reflexes

Reflexes are involuntary movements that the body makes in response to a stimulus. Some reflexes help and protect the child during the early days of life, but disappear at predictable stages of development as the child grows. These are called primitive reflexes.

In children with cerebral palsy, these primitive reflexes often persist when in other children they would have already disappeared. This adds to the child's difficulties in carrying out functional activities such as sitting, walking and eating. For example, a persistent bite reflex will make eating and drinking more difficult.

It is important to teach the parent good handling, positioning and postural support to reduce these reflexes.

D. Posture

A child's posture should develop symmetrically, however children with cerebral palsy often have an asymmetrical posture, which means that the right and left limbs will not mirror one another.

It is important to promote symmetrical positioning and posture in order to help the child develop and carry out their daily routine.



E. Balance

Children with cerebral palsy may have a difficulty maintaining their balance. They often need to use their hands more than typically developing children, as they learn to sit, rise from a sitting position, and begin crawling or walking.

It is important to observe the child and if needed, help the child to develop the use of their hands to improve their strength, coordination and balance to carry out an activity.

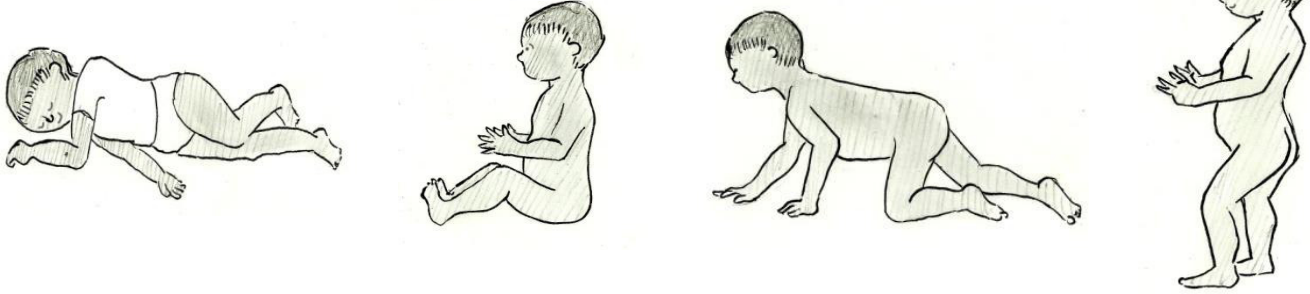


F. Gross motor function (movements of the large muscle groups)

Children with cerebral palsy often have impaired or delayed ability to make large movements such as turning or rolling over, sitting, standing, crawling and walking independently.

It is important to encourage the child with mild difficulties to follow the usual developmental milestones (see chart on child development). If, however, the child has severe difficulties, encouraging the normal progression of milestones is not helpful, and instead it is more appropriate to help the child find an alternative solution towards functional goals.

Significant milestones of gross motor function include:



1. Rolling (6 months)
2. Sitting up (8 months)
3. Crawling (10 months)
4. Standing, Balancing, Walking (12-18 months)

G. Fine motor function (hand function)

Children with cerebral palsy often have difficulties in grasping small objects, holding objects between the thumb and forefinger, and setting objects down gently.

It is important to observe the child and identify the developmental milestone and then encourage them to do new, functional gross and fine motor activities.

H. Oral motor function (movement of the lips, tongue and swallowing)

A child with cerebral palsy often has difficulty in using their lips, tongue and jaw.

This affects:

- Speaking
- Chewing
- Swallowing

Speaking: Children with cerebral palsy may learn to talk or communicate at different rates. Children with milder difficulties generally follow the same pattern of communication development, but other children who may have more significant oro-motor difficulties may always communicate largely through their actions and using non-verbal means, which needs to be interpreted by other people who know them well.

It is important to help the child and family to find methods of communicating non-verbally, using gestures, pictures and symbols when talking is not clear enough.

Eating and drinking: Feeding difficulties caused by an inability to chew and swallow are common in children with cerebral palsy. They may involve choking, coughing, gagging and vomiting on food and/or drink. A child with a poor swallowing abilities will also drool since they are unable to effectively swallow the saliva that they are producing.

It is important to observe the way the child is being fed or is feeding themselves. The mother may need help to position the child well, help them feed themselves or adjust the way she feeds the child according to their needs.

Other associated conditions

Sensory difficulties

Some children with cerebral palsy have visual and/or hearing impairments. They may also have difficulty understanding shapes and judging the distances between objects that they can see.

Intellectual and/or behavioural difficulties

A child with cerebral palsy may also have intellectual difficulties. They may have problems with their attention levels and their behaviour may be difficult to manage. Sometimes children with cerebral palsy appear to have an intellectual disability when they do not in fact have one, but the physical problems they have can make them seem less intelligent.

Epilepsy

Many children with cerebral palsy have epileptic fits, or seizures, and this can delay their development. If a child is falling to the floor, shaking or lying still and not aware of their surroundings and then recovers, this may be a fit and which needs medical help.

It is important to find out the most useful way to support the family and the child with cerebral palsy. You may be the child's first friend and if you are not sure what to do, start by playing and talking to the child to build up a relationship. Then it is easier to start to use the information here, as you can work together to help the child develop and to learn new skills with the aim of them becoming more independent.

Understanding Intellectual Disability

What is an intellectual disability?

Children with intellectual disabilities find it harder to learn new skills than other children of the same age. This may include learning to eat and drink, learning physical skills (e.g. jumping, climbing), learning play skills, understanding what other people say and learning to talk, learning to read and write and learning to do things for themselves (self-care skills).

The range and degree of difficulty will vary from child to child. This is also influenced by the support available to the child and the opportunities for stimulation and schooling.

Some children with intellectual disabilities have additional difficulties which can make it harder for them to learn. These may include:

- Difficulties with vision and hearing
- Physical difficulties (e.g. cerebral palsy)
- Epilepsy
- Behavioural difficulties
- Eating and drinking difficulties
- Social communication difficulties

What causes intellectual disability?

Most often there is no known cause, although common causes are similar to those for cerebral palsy.

What can a child with intellectual disabilities achieve?

Each child is different, however with support and stimulation many children with intellectual disability can:

- Learn to communicate their needs in some way
- Learn to be quite independent in self-care activities (e.g. bathing, dressing, eating)
- Attend school (mainstream or special school, depending on the needs of the child)
- Help with domestic or work activities in some way
- Be as much a part of his or her family and community as any other child

Communication development and the child with intellectual disabilities

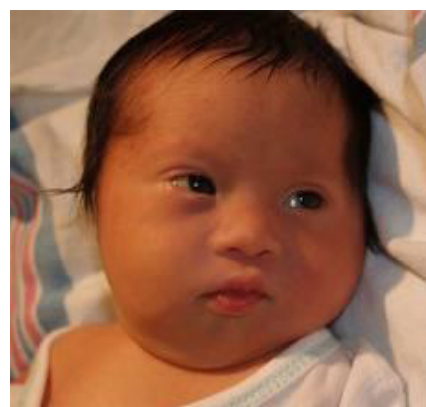
Children with intellectual disabilities learn to talk and communicate at different rates. Children with milder difficulties generally follow the same pattern of communication development as other children, but some may always communicate largely through their actions, which needs to be interpreted by other people who know them well.

A special note about Down syndrome

Down syndrome is a special kind of intellectual disability that results from a genetic change in the child before birth.

Children with Down syndrome will have a mild, moderate or severe intellectual disability. They tend to have particular facial features which include:

- A small head
- A flat bridge of the nose
- A small mouth which causes the tongue to seem larger
- Small ears and hands
- Upward slanting eyes
- Fine straight hair



Children with Down syndrome may also have the following:

- A heart defect
- Difficulties with digestion
- Problems with their thyroid hormones which may affect their energy levels
- A visual impairment (many need to wear glasses to see well)
- A hearing impairment (often due to infections in the ears)
- Weak, floppy muscles which delay their sitting, crawling and walking, and make their speech unclear

Children with Down syndrome require careful monitoring of their general health by a doctor.

Understanding Children on the Autism Spectrum

What is the autism spectrum?

These children are different in the following main ways:

- How they respond, interact and communicate with others
- The range of interests they have, which tends to be very narrow
- How they experience what they see, hear, touch, taste and smell

Children who do not fit the full 'profile' of autism, or who have not been fully assessed for autism by a specialist, are often described as having social communication difficulties.

What does it look like?

- Autism presents itself differently in different children. Some children have a complete lack of interest in communicating with others, use very little or no eye contact, and often prefer to spend time on their own. These children may not use words to speak, or use very few words. Other children may have delayed speech, an awkward manner of interacting with others and may prefer to spend their time with adults and older children (rather than children of their own age).
- Because of their narrow area of interest, these children often play with toys in an unusual manner (e.g. just spinning the wheels of a toy car or lining up blocks instead of making something with them). They do not play 'pretend' games and may also have a need for rigid routines, which when disturbed can cause tantrums.
- These children often experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colour. This too may mean that they behave unexpectedly when exposed to stimuli which bother them.

What causes autism?

The cause of autism is not known, although some families may have an increased risk. What we do know is that each child with autism is unique; some children will grow up to live relatively independent lives and others may have accompanying intellectual disabilities and need lifelong support.

What can a child with social communication difficulties or autism achieve?

Understanding the individual needs of the child with autism and supporting their unique difficulties can help them to achieve the following:

- Learn to communicate their needs in some way
- Learn to be as independent as possible in activities of bathing, dressing, eating and generally caring for himself or herself
- Attend school (mainstream or special school, depending on the needs of the child)
- Help with domestic or work activities in some way
- Be as much a part of his or her family and community as any other child

