

CEREBRAL PALSY IN CHILDREN: SUBTYPES, MOTOR FUNCTION AND ASSOCIATED IMPAIRMENTS; ADDIS ABABA, ETHIOPIA

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Supplement Information

1. Associated Impairments;

The associated impairments were investigated by the structured questionnaire with the caregiver and chart review which corresponds to the UNICEF/ Washington group child functioning module. These include;

- a. Intellectual disability: Care givers were asked if the child had any difficulty in understanding what he/she is told, Unable to learn things that other children of the same age could and if the child appeared mentally slow compared to other children.
- b. Behavioral abnormalities: Care givers were asked if the child had any kind of abnormal or uncontrollable behavior and if the child had been evaluated by a psychiatrist previously and the diagnosis of such children were confirmed by chart review however newly identified children were sent to psychiatrists for further evaluation.
- c. Speech difficulties: Care givers were asked if the child was able to speak or make appropriate sounds for age? Children who were nonverbal or lacking a recognizable vocabulary in the child's maternal language was considered as having a speech and language impairment irrespective of the possible etiology (e.g., motor or cognitive limitations)
- d. Feeding difficulties: Care givers were asked if the child could feed himself or herself, and if the child had any feeding problem. If the child has feeding problems, it was further identified if there was swallowing difficulties, regurgitation of feeds, tongue thrust, tonic bite, chewing difficulties, vomiting of feeds or drooling saliva.
- e. Seizures; Care givers were asked if the child had two or more afebrile seizures in the last 5 years that were spaced 24 hours apart and were unrelated to acute infection, metabolic disturbance, or drugs.
- f. Visual impairment: Care givers were asked if the child had difficulty in seeing during day or night. The eyes were also examined for eye contact and with torch light or bright object. Children with visual impairment were sent to Ophthalmologist for further examinations.
- g. Hearing impairment: Care givers were asked if the child had any hearing difficulties. The ears/ hearing were examined using clinical evaluation by observing the response of the child to a specific attention catching sound and calling his/her name from behind. Children with hearing impairment were sent to ENT unit for further examinations.

2. **Comparison Table**

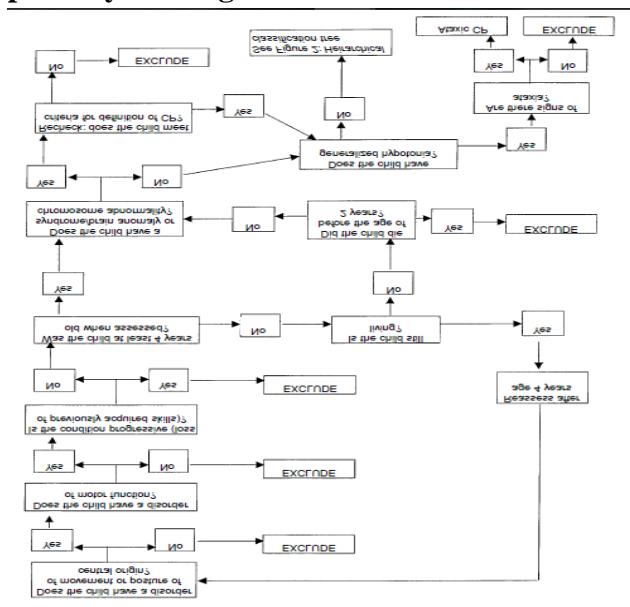
GMFCS level	Uganda		Bangladesh	Ethiopia	HICs
	2–5 years	6–17 years			
I–II	39%	72%	32%	13.8 %	65% ¹
III	24%	18%	22%	10.9 %	3% ¹
IV–V	36%	10%	47%	75.3 %	33% ¹
MACS level					
I–II	48%	77%	39%	13.8 %	59% ¹
III	3%	13%	18%	10.9 %	9% ¹
IV–V	48%	10%	44%	75.2 %	32% ¹
Intellectual disability					
Confirmed	45%	58%	39%	87.4 %	33–45% ^{1,2}
Unconfirmed	24%	13%			
Seizures					
Confirmed	30%	38%	23%	60.9 %	28–44% ¹⁻ ₃
Unconfirmed	15%	17%			
Speech					
Non-verbal	45%	37%	35%	95.4 %	49% ⁴
Hearing impairment					
Confirmed	3%	10%	10%	8.6 %	12% ²
Unconfirmed	18%	15%			
Vision impairment					
Confirmed	15%	10%	10%	24.7 %	17–35% ²
Unconfirmed	18%	23%			

3. Data Collection Tools

I; selection of cases to be included on the study

Code number _____ Date ____/____/____

Please use the following SCPE decision tree to decide on inclusion of the child to the study NB; if the child was already diagnosed with CP but excluded according to this decision tree please notify the consultant neurologist and the primary investigator.



Go to the next page for children included on the study based on the decision tree consent

የጥናቱ የመረጃ እና ስምምነት ሰነድ

ይህ የምረጥ እና የገምገማዎች ስነድ በጥቃት አጋጣሪ ሁኔታዎች የሚታወቁ በእርግጥና ወቂት ወይም በወላይ ገዢ በተከከለ የአቶምና ጉዳት ምክንያት ስውነታዎችን የሚዘገበ ቅጋር የለበችው ሆኖም ለይ የለውን የንግድ አይነት የእንቅስቃሴ አባማቸውን የሚከተሉት ቅጋርዎን በተመለከተ ለሚደረግ ቅጽ ተከተል::

የጥናቱ መንገድ አሰጣ ጽኑ አለማ

የጥናቱ አላማ በእርግኩና ወቻት ወይም በውላድ ገዢ በተከሰተ የእናምድ ጉዳት ጥናኝና ስዕስት ተመለቻቸውን የሚዘገብ ችግር
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በሚለያቸው አስፈላጊው ሁኔታ እና ከተኞል እናነፃረገለቸው ለማድረግ ነው::

ከእርስ ባን ይጠበቃል

እዴ/እዴ+ በጥናቱ እንዲሰተኞ ከፌቀዬ ስለ የሚሆበሩች እና ማኅ ሆኖ ሁኔታ መረጃ ይሰጣል::

በተናቸው ላይ በመስተቀምኔያዥ ስምምነት አገልግሎት

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የተናቀቁ የተሰጠፈዎችን መረጃዎች ሆነ ማንኛው በሚሰጥር የሚጠበቅ ይሆናል በመሆኑም የተሰጠፈው ስም በተናቀቁ መጠይቷል እና አይነተትም::

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የጥናት ቤትም

ከዚህ ቅናት የሚገኘው መረጃ በተቀር አገበበ ሆነታቸል የሚታከማ በእርግዥና ወቂኑ ወይም በዋላ ይገኘበት የአዲምና የኩና ማስተካከለ ስለሚገኘው የሚገኘው ቅናት የሚገኘው የሚያስረዳው ሁኔታ እና አነስተኛ ለማስኬድል ይመለሳል::

በጥናቱ ወቂት ተያያዥ በኋላት

የኢትዮጵያ

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०८:

ଶବ୍ଦମୂଳ:

Φγ:

ቀና ተማሪዎች፡ ፧/፪ አለማኑስ ታሪ

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አ.ማድ: selidoc2@gmail.com

III. Study Questionnaire

Title of the Research – Cerebral Palsy in children aged 2 – 18 years attending follow up at the Pediatric Neurology Clinic; clinical subtypes, motor function and co-morbidities

Instructions – Please take your time to carefully complete the information below.

Code number _____ Date ____/____/____

Part I – Socio-demographic Data of child

1. Age in completed years and months _____
2. Sex; _____
3. Birth order: _____
4. Family size _____
5. Address (region) _____
6. Religion: _____
7. Child's level of education
 - a. . No schooling
 - b. Nursery
 - c. Primary School (grades 1-8)
 - d. Secondary school
8. Has the child ever repeated grade? _____
9. What is the child's average performance score in class
 - a. Top ten
 - b. 1st quarter
 - c. 2nd quarter
 - d. 3rd quarter
 - e. 4th quarter
 - f. Last ten

Part II–Family and Primary caregivers' information

1. Who is the primary caregiver? If not parents, state why _____
 - a. Mother
 - b. Father
 - c. Both parents
 - d. Adult relative
 - e. Non relative adult
 - f. Orphanage
2. What is the marital status of parents?
 - a. Single parent
 - b. Married
 - c. Divorced
 - d. Widowed (specify the deceased)
3. Primary caregiver's highest level of education –**Mother** _____, **Father** _____, **Other** _____
 - a. Illiterate
 - b. Can read and write
 - c. Primary (attended grades 1-8)
 - d. Secondary (attended grades 9-12)
 - e.College(certificate/diploma/1stdegree/Master/MD/PhD)
4. Primary caregiver's occupation (**Mother**) _____ (**Father**) _____ (**Other**) _____ and Monthly income _____
5. Monthly income (as perceived by primary care giver to support the family):
 1. Partially Adequate income
 2. Inadequate income
6. Number of child death in home if any? If yes, what was the age and cause of death?
 - a. Age _____ suspected cause of death _____
 - b. Age _____ suspected cause of death _____
 - c. Age _____ suspected cause of death _____

Part III. Medical history

1. At the time of child conception/birth, was mother taking alcohol?
 - a. Yes
 - b. no
 - c. don't know
2. If yes to no 7, specify years of taking alcohol_____ . Type of alcohol_____ . Volume of alcohol_____
3. When the mother was pregnant with the child, did she have ANC follow up?
 - a. Yes
 - b. no
 - c. don't know
4. Any complications during ANC _____
5. Where was the child born?
 - a. Home
 - b. Hospital
 - c. Health center
 - d. Other, specify _____
6. Was it a single birth?
 - a. Single birth
 - b. Twins
 - c. Triplets
 - d. More
7. Was the baby born at term (between 37-42 weeks or at about 9 months)?
 - a. Yes
 - b. No, >3 weeks early
 - c. No, > 2 weeks late
8. Was there prolonged rupture of membranes (>18 hours) before delivery?
 - a. Yes
 - b. no
 - c. Don't know
9. How long was the labour?
 - a. <24 hours
 - b. >24 hours
 - c. No labor, C-Section
 - d. Unknown
10. Was there any complication during labor and delivery?

11. Did the baby cry immediately after birth?
 - a. Yes
 - b. No, but in <5 min after >5 minutes
 - c. No, Unknown
12. Was the baby resuscitated with bag and mask at birth?

13. Was the baby admitted to hospital care at birth (NICU). If yes, specify why

14. What was the birth weight? _____
15. Did the child have any of these conditions from birth to one month of age?

	Condition	Response
1	Seizures	
2	Infection	
3	Trouble feeding	
4	Meningitis	
5	Deep jaundice	
6	Severe diarrhea	
7	Difficult breathing	
8	Tetanus	

16. Growth and development:

- a. Compared with his/her peers did your child have any difficulty or delay while growing up?
- b. Delay in sitting?
- c. Delay in standing?
- d. Delay in walking?
- e. Difficulty in walking/ moving limbs?
- f. Difficulty in seeing during day or night?
- g. Difficulty in hearing?
- h. Unable to speak/ make appropriate sounds for age?
- i. Difficulty in understanding what he/she is told?
- j. Unable to learn things other age mates can?
- k. Appears mentally slow compared to other children his/her age?
- l. Other problem?, describe.....

17. Immunization History:

- a. Is immunization completed? _____
- b. If no, what doses are missing? _____

16. Was the child breast fed exclusively the 1st 6 months ?

- a. yes
- b. No, specify what was initiated_____

17. At what age in months was solid food introduced_____ , how often is the child fed within 24 hours_____

18. Can the child feed himself or herself?

- a. Yes, skillfully
- b. No, must be fed
- c. Yes, but unskilled (i.e. like a baby)
- d. unknown

19. At what age did child start to finger feed himself or herself?

- a. By 7mo
- b. By 1 year
- c. After 1 year
- d. After 2 years
- e. Not yet
- f. Unknown

20. If child has a feeding problem, which one (s)

- a. Swallowing difficulties
- b. Regurgitation of feeds
- c. Tongue thrust
- d. Tonic bite
- e. Chewing difficulties
- f. Vomiting of feeds
- g. Drooling saliva=6

21. Has the child ever been hospitalized ?_____

If yes, what was the reason for the most recent 3 admissions? Please describe:

(i)_____

(ii)_____

(iii)_____

22. Is the child taking any medication? _____

If YES, which drugs? Why
?_____

23. Is there any alternative/traditional medicine this child is taking? _____ If Yes, specify _____

24. Has the child ever been diagnosed with the following conditions;

	CONDITION	RESPONSE
1	Epilepsy?	
2	Attention Deficit Hyperactivity disorder?	
3	Hearing Impairment?	
4	Visual Impairment?	
5	Autism?	
6	Speech and Language impairment?	
7	Behavioural impairment?	
8	Mental illness?	
9	Cerebral Palsy?	

25. Are there any other illnesses that have been diagnosed in NAME's family members? _____

If yes (specify

illness) _____

Thank you!!

IV. CEREBRAL PALSY CLINICIAN'S ASSESSMENT QUESTIONNAIRE

Please carefully use the following assessment steps (adapted from SCPE) together with a quick neurological examination to decide whether the child has CP.

Code no _____ Date ____/____/____

NB; We are using the SCPE consensus definition of cp which consists the following 5 elements to define CP. Check this elements as you proceed with your clinical assessment to diagnose CP. According to SCPE, in order to define a disorder as CP, it should consist of the following five key elements:

1. It is permanent but not unchanging;
2. It involves a disorder of movement and/or posture
3. It involves a disorder of motor function;
4. It is due to a non-progressive interference/lesion/abnormality;
5. This interference/lesion/abnormality is in the developing/immature brain

Anthropometry

1. Weight __ Kg , W/A _____
2. Height/Length __ cm , H/A _____
3. Occipital-frontal head circumference __ cm, Hc/A _____
4. Mid Upper Arm Circumference (MUAC) __ cm,
5. W/H _____
6. BMI _____

Clinical examination

Vitals (i) Pulse rate..... (ii) Temp..... (iii) Respiratory rate.....
 Gross and fine motor classification; see at the end of the questionnaire
 GMFCS – E & R ;
 Level I MACS ; Level I

Level II	Level II
Level III	Level III
Level IV	Level IV
Level V	Level V

A. Observe the child in any comfortable position he/she may adopt and **check for abnormal involuntary movements**. If present place a (Tick) and if absent place a (Cross) as appropriate.

	At rest	With excitement or goal-directed movement
1. None		
2. Short jerky		
3. Slow and writhing (chorea)		
4. Tremor		
5. Flexor and extensor spasms		
6. Other please describe (tics, myoclonus, dystonia)		

B. Examine **muscle tone** in each limb and **tick one box** for each limb. Test **tendon reflexes** in each limb and **tick one box** for each limb.

	Right Upper limb	Left Upper limb	Right Lower Limb	Left Lower limb
1. Normal tone				
2. Increased tone				
3. Decreased tone				
4. Varying increased/decreased				
5. Normal tendon reflexes				
6. Increased tendon reflexes				
7. Decreased tendon reflexes				

C. Test for **clonus** and look for **contractures** and investigate **muscle size/volume**. (If present place a **tick one box** for each limb if absent in any limb place a **in the box**.)

	Right Upper limb	Left Upper limb	Right Lower Limb	Left Lower limb

1. Clonus present				
2. Contractures present				
3. Muscle atrophy present				

D. Gait and posture pattern. Place a ✓ tick in the appropriate boxes

1. No gait problem, walks fluently	
2. Gait functional but non-fluent	
3. Abnormal gait reducing mobility; crouched gait	
4. Asymmetric gait	
5. Walking aids regularly used	
6. No independent walking	
7. Can sit independently	
8. Can sit only with support	
9. Cannot sit	

E. Upper Limb Function. Place a ✓ tick in the appropriate boxes

	Right Upper Limb	Left Upper Limb
1. Moves limb well. No apparent problem		
2. Can perform finger-nose according to age		
3. Can perform alternating hand movements		
4. Can perform “piano-playing-in-air”		
5. Can reach and grasp objects according to age		
6. Prefers using either the right or left hand		
7. Able to eat self with either hand		
8. Can use both hands at same time (bimanual skills)		
9. Can put on vest or T-shirt without help		
10. Physically incapable of putting on vest or T-shirt and unable to feed self with either hand		

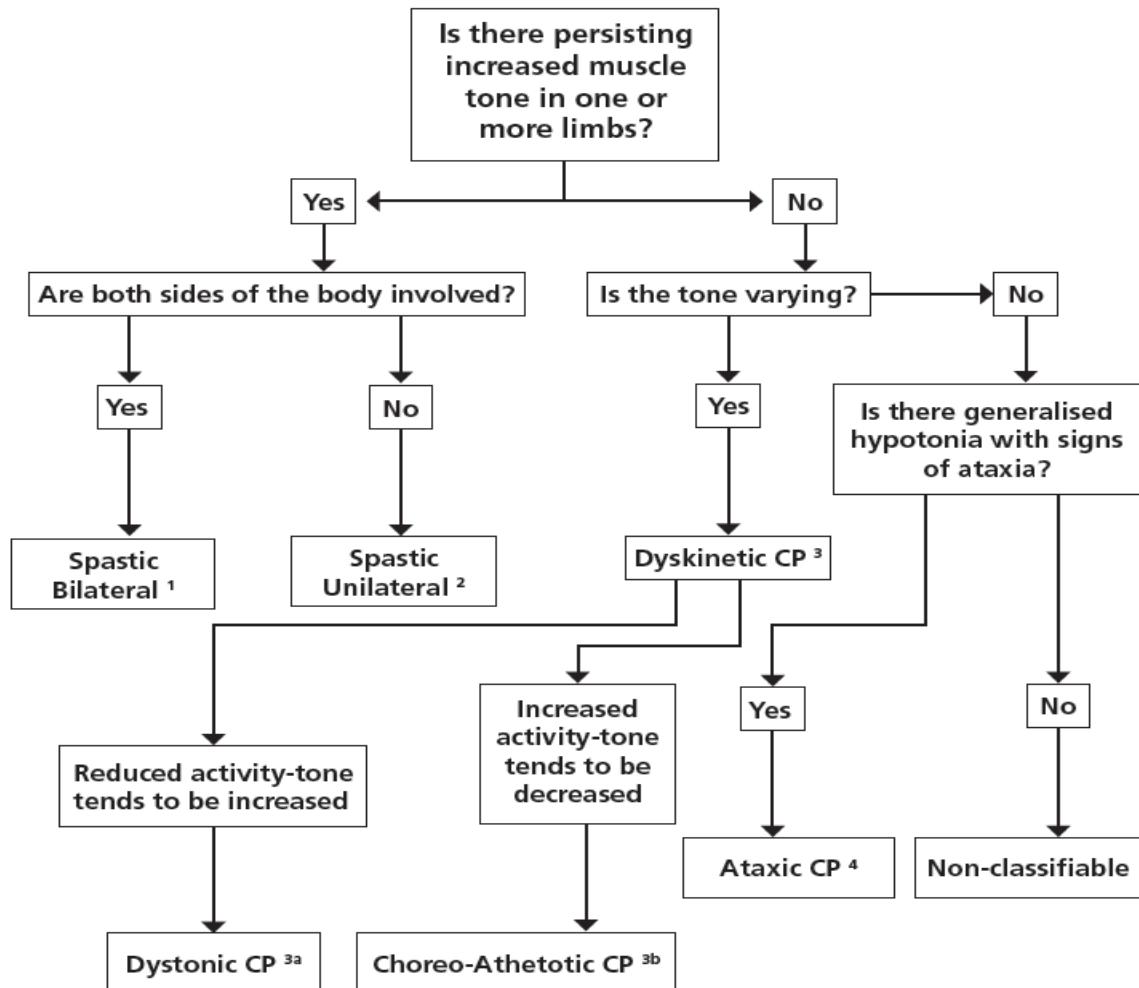
F. Distribution of Symmetric/Asymmetric Limb involvement: ✓ Tick as appropriate.

	YES	NO
1. Is there Right to Left asymmetry of tone or function?		
2. If yes; is right side worse?		
3. If yes; is left side worse?		
4. Are the upper limbs more affected than the lower limbs?		
5. Are the lower limbs more affected than the upper limbs?		

G. Making a Cerebral Palsy diagnosis:

Does this child have Cerebral Palsy? If Yes or Uncertain - proceed with **H** and subsequent examinations. If No - proceed with **I**.

H. If YES, use the classification tree below



Tick the appropriate box:

Spastic, bilateral:	2 limb involvement	<input type="checkbox"/>
	3 limb involvement	<input type="checkbox"/>
	4 limb involvement	<input type="checkbox"/>
Spastic, unilateral (hemiplegia):	Right sided	<input type="checkbox"/>
	Left sided	<input type="checkbox"/>
Dyskinetic:	Dystonic	<input type="checkbox"/>
	Choreo-athetotic	<input type="checkbox"/>
Ataxic		<input type="checkbox"/>
Unclassifiable		<input type="checkbox"/>

I. If NO , what are the alternative diagnoses? (Autism spectrum, Intellectual disability, ADHD, Hydrocephalus, Myelo-meningocele, Probable Genetic syndrome, Dysmeli, Poliomyelitis, Deafness, Speech and Language delay, etc)

1. _____ 2.
_____. 3.
_____. 4._____

Thank you

Gross Motor Function Classification System – Expanded and Revised (GMFCS – E & R)

BEFORE 2ND BIRTHDAY

LEVEL I:

- Move in and out of sitting.
- Floor sit with both hands free to manipulate objects
- Crawl on hands and knees, pull to stand and take steps holding on to furniture
- Walk between 18 months and 2 years of age without the need for any assistive mobility device.

LEVEL II:

- Maintain floor sitting but may need to use their hands for support to maintain balance
- Creep on their stomach or crawl on hands and knees.
- Infants may pull to stand and take steps holding on to furniture.

LEVEL III:

- Maintain floor sitting when the low back is supported
- Roll and creep forward on their stomachs.

LEVEL IV:

- Have head control but trunk support is required for floor sitting
- Can roll to supine and may roll to prone.

LEVEL V:

- Physical impairments limit voluntary control of movement
- Unable to maintain antigravity head and trunk postures in prone and sitting
- Require adult assistance to roll.

BETWEEN 2ND AND 4TH BIRTHDAY

LEVEL I:

- Floor sit with both hands free to manipulate objects.
- Movements in and out of floor sitting and standing are performed without adult assistance.
- Walk as the preferred method of mobility without the need for any assistive mobility device.

LEVEL II:

- Floor sit but may have difficulty with balance when both hands are free to manipulate objects.
- Movements in and out of sitting are performed without adult assistance.
- Pull to stand on a stable surface.
- Crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

LEVEL III:

- Maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting.
- Creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility.
- May pull to stand on a stable surface and cruise short distances.
- May walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

LEVEL IV:

- Floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support.
- Frequently require adaptive equipment for sitting and standing.
- Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

LEVEL V:

- Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures.
- Have no means of independent movement and are transported

BETWEEN 4TH AND 6TH BIRTHDAY

LEVEL I:

- Get into and out of, and sit in, a chair without the need for hand support.
- Walk indoors and outdoors, and climb stairs.
- Emerging ability to run and jump.

LEVEL II:

- Sit in a chair with both hands free to manipulate objects.
- Move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms.
- Walk without the need for a handheld mobility device indoors and for short distances on level surfaces outdoors.
- Climb stairs holding onto a railing but are unable to run or jump.

LEVEL III:

- Sit on a regular chair but may require pelvic or trunk support to maximize hand function.
- Move in and out of chair sitting using a stable surface to push on or pull up with their arms.
- Walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult.
- Frequently transported when traveling for long distances or outdoors on uneven terrain.

LEVEL IV:

- Sit on a chair but need adaptive seating for trunk control and to maximize hand function.
- Move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms.
- May at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces.
- Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

LEVEL V:

- Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures.
- Children have no means of independent movement and are transported.

BETWEEN 6TH AND 12TH BIRTHDAY

Level I:

- Walk at home, school, outdoors, and in the community.
- Walk up and down curbs without physical assistance and stairs without the use of a railing but speed, balance, and coordination are limited.
- Participate in physical activities and sports depending on personal choices and environmental factors.

Level II:

- Walk in most settings but may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects.
- Walk up and down stairs holding onto a railing or with physical assistance
- Children have at best only minimal ability to perform gross motor skills such as running and jumping hence necessitate adaptations to enable participation in physical activities and sports.

Level III:

- Walk using a hand-held mobility device in most indoor settings.
- When seated, children may require a seat belt for pelvic alignment and balance.
- Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface.
- When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance.
- Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV:

- Children use methods of mobility that require physical assistance or powered mobility in most settings.
- At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility.

Level V:

- Children are transported in a manual wheelchair in all settings.
- Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements.

BETWEEN 12TH AND 18TH BIRTHDAY

Level I:

- Youth walk at home, school, outdoors, and in the community.

- Able to walk up and down curbs without physical assistance and stairs without the use of a railing.
- Perform gross motor skills such as running and jumping but speed, balance, and coordination are limited.
- Participate in physical activities and sports depending on personal choices and environmental factors.

Level II:

- Walk in most settings.
- Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices.
- At school or work, youth may walk using a handheld mobility device for safety and may use wheeled mobility when traveling long distances.
- Walk up and down stairs holding a railing or with physical assistance
- Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III:

- Capable of walking using a hand-held mobility device.
- When seated, youth may require a seat belt for pelvic alignment and balance.
- Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface.
- At school, youth may self-propel a manual wheelchair or use powered mobility.
- Walk up and down stairs holding onto a railing with supervision or physical assistance.
- Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV:

- Wheeled mobility in most settings.
- Require adaptive seating for pelvic and trunk control.
- Physical assistance from 1 or 2 persons is required for transfers.
- Youth may support weight with their legs to assist with standing transfers.
- Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker.

Level V:

- Youth are transported in a manual wheelchair in all settings.
- Limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements

MACS ; Manual Ability Classification System for children with cerebral palsy

Level I. Handles objects easily and successfully

Level II. Handles most objects, but with somewhat reduced quality and/or speed of achievement.

Level III. Handles objects with difficulty.

Level IV. Handles a limited selection of easily managed objects in simple actions.

Level V. Does not handle objects and has severely limited