Cerebral Palsy Road Map:

What to Expect as Your Child Grows

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To help you understand what having cerebral palsy means for your child, Gillette Children's created the Cerebral Palsy Road Map. This publication will show you how Gillette's providers can help meet your child's needs.

Every child with cerebral palsy possesses a unique combination of strengths and challenges. This guide will enable you to navigate through your child's experience with cerebral palsy. We hope it will encourage conversations among patients, families and health care providers.

What Is Gillette?

Gillette Children's is a specialty hospital based in St. Paul, MN. Every day Gillette grows its clinical expertise, medical research and advocacy network to ensure its patients live a life defined by their dreams, not their diagnosis.

Gillette offers comprehensive, coordinated care that can reduce the effect of cerebral palsy on people's lives. Because we see the full spectrum of cerebral palsy, from mild to severe, all patients benefit from an unmatched depth of experience, no matter their complexity. Our medical and rehabilitation specialists work closely with patients, families, and primary care providers to develop treatment plans that meet families where they are on their care journey.

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What Is Cerebral Palsy?

Cerebral palsy is a condition caused by an injury to the brain before, during, or shortly after birth. The brain injury often alters bone and muscle growth. It can restrict movement and affect posture.

Associated problems can include difficulties with sensation, perception, cognition, communication, and behavior. Epilepsy and secondary musculoskeletal problems also might occur.

Although cerebral palsy can't be cured, treatments can help ease symptoms and improve your child's abilities.

How to Use This Guide

You can use the information in the Cerebral Palsy Road Map to understand how recommended evaluations and interventions might help your child. The guide is organized by age group, Gross Motor Function Classification System (GMFCS) level, and eight conditions or areas that affect your child's life.

Classification systems help describe the nature of a condition and predict someone's current and future needs. Gillette's health care providers use the GMFCS to describe gross motor abilities (movement from place to place) of people who have cerebral palsy. This system focuses on tasks such as walking, maintaining balance or crawling, which require the use of large muscle groups. For specific details about GMFCS, see Appendix 1. Your health care provider will help you understand how the classification system applies to your child.

Standing up and walking are skills children learn throughout early childhood and continue to improve upon as they grow older. These movements rely on using large muscle groups and moving the whole body. We recognize that a child's gross motor abilities depend on age, especially during infancy and early childhood. For that reason, the information in this guide is divided into four age groups:

● **Infant and Toddler (0 to 3)**
● **Early Childhood (4 to 6)**
● **Middle Childhood (7 to 12)**
● **Adolescence (13 to 18)**

We recommend that you look through the information in your child's age group, then decide with your health care provider which of these conditions or areas apply to your child:

- Mobility
- Musculoskeletal
- Communication and Cognition
- Feeding and Nutrition
- Social/Emotional Development and Behavior
- Self-Care and Daily Living Skills
- Sensory Functions
- Recreation and Fitness

Within each age group, you'll also find a list of the key providers your child might see at Gillette. Your provider will discuss which evaluations and interventions might be appropriate for your child.

Movement and Posture Concerns

Because cerebral palsy is a disorder of movement and posture, children who have cerebral palsy will typically have one or more of the following:

Abnormal Muscle Tone

- Spasticity: Muscles in legs and arms are extremely tight, resist movement and tend to spasm (a sustained muscle contraction or sudden movement). The tightness usually increases when people try to move quickly.
- Rigidity: Muscles in legs and arms are extremely tight and resist movement, regardless of how quickly or forcefully a person moves.
- Hypotonia: Arms and legs seem floppy and don't resist movement (low muscle tone).

Involuntary Movement

- Ataxia: Problems with balance and unsteady, shaky movements or tremors.
- Athetosis: Slow, continuous, uncontrolled extra movements, particularly in the arms, hands, feet and around the mouth. Such movements might be worse when a child attempts to move, but they also can occur when a child is at rest.
- Chorea: Random, involuntary, and often continuous movements of arms and legs that might make a child appear fidgety.
- Dystonia: Muscle activity that often causes twisting or repetitive movements or abnormal postures.

A diagnosis usually is based on the parts of the body affected:

- Diplegia: Both legs are the primary body parts affected. A person might have some difficulties with arm or hand movements.
- Quadriplegia: Both arms, both legs and the trunk of the body are affected. The muscles of the neck, face, mouth, and throat can also be involved.
- Hemiplegia: The arm and leg on one side are the primary body parts affected. (See below for more about hemiplegia.)

See Page 31 for a full glossary of definitions.

Hemiplegia

Hemiplegia is the most common form of cerebral palsy in children who were not born prematurely. It is often caused by a stroke. People with hemiplegic cerebral palsy have impaired movement of the leg, arm and trunk on one side of the body. Treatments for a child with hemiplegia will differ from those for a child who is affected on both sides of the body.

For most children with hemiplegia, the arm is more involved than the leg, and the wrist and hand are more involved than the shoulder. The impairment of the elbow varies. Similarly, children will likely have more difficulties with the ankle and foot than with the hip or knee. Children with significant hand impairment will likely need intensive therapy to improve function. Children with hemiplegia consistently do better on evaluations of leg movement (lower extremities) and poorer on assessments related to their arms (upper extremities) and school abilities.

Children with hemiplegic cerebral palsy might:

- Walk at a later age and have challenges with balance and/or walking endurance. However, they typically walk without using a walking aid.
- Struggle with fine motor skills and self-care activities including writing, dressing and grooming.
- Have weakness and/or stiffness in the muscles on the side of the body that is involved.
- Have other movement disorders.
- Experience seizures, depending on the portion of the brain that was damaged or the part of the brain that was injured.
- Experience cognitive challenges such as learning disabilities. This is more prevalent in children who have seizures.

Possible Treatments

Health care providers might recommend that a child with hemiplegic cerebral palsy:

- Wear splints or braces to stretch the muscles and/or improve function of the arm and hands.
- Take medicines (usually injections) to reduce muscle tightness in specific muscles of both the upper and lower extremities.
- Have orthopedic surgery to prevent or correct bone and/or muscle deformities and improve use of legs and arms.
- Take medicines to manage movement disorders, seizures and learning difficulties.
- Participate in rehabilitation therapies such at physical therapy, occupational therapy or speech therapy.

Classification Systems

Health care providers use a variety of assessment tools and classification systems when making a cerebral palsy diagnosis and treatment plan.

Gross Motor Function Classification System (GMFCS)

Gillette Children's health care providers use the Gross Motor Function Classification System (GMFCS) to describe the abilities of people with cerebral palsy. GMFCS classifications emphasize a person's ability to move on his or her own (self-initiated movement) with a focus on sitting, walking and wheeled mobility. The distinction between levels is based on abilities, the need for assistive technology (including walkers, crutches or wheeled mobility) and—to a lesser extent—quality of movement.

Gillette uses the GMFCS to focus on abilities. We look at how people perform in the home, at school and in community settings rather than on what they can do in the best possible circumstances. The levels help us classify conditions; they don't indicate a prognosis. As children mature, their GMFCS levels might change. Review the GMFCS in Appendix 1.

Manual Ability Classification Systems (Mini-MACS and MACS)

Some of our Gillette therapists and other health care providers use the Manual Ability Classification Systems (Mini-MACS and MACS) to discuss how people with cerebral palsy use their hands to handle objects in daily activities. Objects included are relevant and age-appropriate for the children, used when they perform tasks such as eating, dressing, playing, drawing or writing. The Mini-MACS is for children 1-4 years of age. The MACS is for children 4-18 years of age. For more information, see Appendix 2.

Communication Function Classification System (CFCS)

Gillette uses the CFCS is to classify the everyday communication performance of an individual with cerebral palsy into one of five levels. The CFCS focuses on activity and participation levels as described in the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF).

Gillette care teams work with families to evaluate the overall effectiveness of a person's communication performance based on how they usually take part in everyday situations requiring communication, rather than their best capacity. These everyday situations may occur in home, school, and the community. For more information on CFCS, see Appendix 3.

Eating and Drinking Ability Classification System (EDACS)

The Eating and Drinking Ability Classification System (EDACS) helps Gillette providers classify how individuals with cerebral palsy eat and drink in everyday life. The distinctions between the different levels in the EDACS are based upon functional ability, the need for adaptations to the texture of food and drink, the techniques used and some other features of the environment. It classifies overall performance in eating and drinking, which includes both motor and sensory elements. The current version of EDACS describes the eating and drinking abilities of children with cerebral palsy beginning at age 3. See Appendix 4.

Age Groups

The information in this guide is divided into these age groups:

- 🟦 **Infant and Toddler (0 to 3)**
- 🟪 **Early Childhood (4 to 6)**
- 🟥 **Middle Childhood (7 to 12)**
- 🟧 **Adolescence (13 to 18)**

We recommend that you look through the information in your child's age group. Your health care providers will discuss which potential evaluations and/or interventions might be appropriate for your child.

Infant and Toddler (0 to 3)

Infant and Toddler (0 to 3)

Level	Mobility	Musculoskeletal
	Your child might be:	Your child might be:
I	• Moving in and out of sitting positions without help • Able to balance while sitting and using both hands to play • Crawling on hands and knees • Pulling to stand • Taking steps while holding on to furniture, caregivers • Walking unassisted by 24 months old; starting to prefer to move around by walking	• Able to control movement of nonimpaired limbs and of hip and knee of involved leg(s), but struggling with moving toes, foot and ankle of involved leg(s) • Experiencing tightness in forearm muscles (if hemiplegia is present) • Experiencing toe-walking or in-toeing
II	• Able to get in and out of sitting positions on own • Having difficulty with balance while sitting and using both hands to play • Rolling, belly-crawling, or crawling on hands and knees • Pulling to stand and cruising by holding on to furniture • Walking using an assistive device	• Able to control movement of nonimpaired limbs and of hip and knee of involved leg(s), but struggling with moving toes, foot and ankle of involved leg(s) • Experiencing tightness in forearm muscles (if hemiplegia is present) • Experiencing toe-walking, in-toeing or scissoring gait. • Demonstrating a preference for non-involved arm or hand (if hemiplegia)
III	• Rolling, belly-crawling or crawling and hands and knees • Needing help to sit; if sitting on own, usually prefers “w-sitting” because it leaves hands free to play with toys • Pulling to a stand and cruising short distances by holding on to furniture • Walking with a mobility device, such as walker with help to steer and turn	• Having problems controlling movement in arms and legs, including hips • Experiencing increased tightness in legs (which might occur with other movement disorders such as athetosis or dystonia) • Experiencing toe-walking, in-toeing, scissoring or stiff knees • Experiencing poor pelvis positioning and hip instability • Demonstrating a preference for non-involved arm or hand (if hemiplegia)
IV	• Rolling or belly-crawling to move around • Using hands for support to sit without equipment • Using supportive equipment to sit and/or stand	• Struggling to control movement of legs because of impairment with legs, including hips • Struggling to control movement of arms • Experiencing leg and arm spasticity, but legs likely more involved • Experiencing other movement disorders (athetosis or dystonia) • Experiencing muscle contractures that restrict range of motion * Experiencing hip subluxation/dislocation, long bone torsion or foot deformities
V	• Having difficulty controlling head and trunk in most positions • Using supportive equipment to sit or stand • Moving around only with assistance or adaptive equipment, including powered wheelchair	• Unable to control movement of arms and legs • Experiencing leg and arm spasticity, with legs likely more involved (except in hemiplegia where the arm is often more involved) • Experiencing muscle contractures that restrict the range of motion of the joints, especially in legs • Experiencing hip subluxation/dislocation and/or foot deformities

Level	Communication and Cognition	Feeding and Nutrition
	Your child might be:	Your child might be:
I-II	• Cooing, babbling and using words; using 3-word sentences by age 3 • Turning to sounds and voices • Starting to understand, follow directions • Reaching, grasping, using gesture or pointing to get attention, to show what you named or show what they want • Paying attention to books, showing interest in other children • Showing affection and communicating with a variety of emotions	• Transitioning gradually from breast milk or formula to solid foods • Transitioning from bottle to cup and self-feeding • Having difficulty gaining weight
III-IV	• Experiencing slow speech development • Requiring support such as pictures, gestures and signing • Needing assistance to listen and make choices • Experiencing a delay in learning and reasoning skill development • Having difficulty being understood by unfamiliar listeners and some familiar listeners	• Experiencing a delay in self-feeding • Struggling with feeding if experiencing oral muscle weakness, tightness and incoordination • Having difficulty gaining weight • Experiencing constipation, especially when mobility and/or diet are limited • Needing to eat certain types of foods or use specific strategies to eat safely
V	• Using eye contact, eye gazing and facial expressions to communicate • Experiencing slow speech development • Difficult to understand • Requiring support such as pictures, gestures and signing • Needing assistance to listen and make choices • Experiencing a delay in learning and reasoning skill development	• Unable to eat foods with particular textures • Experiencing constipation, especially when mobility and/or diet are limited • Experiencing choking or reflux • Having difficulty controlling head and body postures that might affect chewing and swallowing

Infant and Toddler (0 to 3) continued

Level	Social/Emotional Development and Behavior	Self-Care and Daily Living Skills	Sensory Functions	Recreation and Fitness
	Your child might be:	Your child might be:	Your child might be:	Your child might be:
I	• Smiling, interacting with family members and peers • Crying easily when frustrated • Relying on caregivers to maximize physical comfort and provide support during medical procedures; using child life specialists when needed • Experiencing a delay in social skill development • Having emotional or behavioral challenges	• Maintaining a sitting position for feeding • Feeding self (holding a bottle) at 6 months old (extra support or positioning might be needed) • Needing assistance to unfasten clothing, but able to remove clothing • Pushing arms and legs through clothing to get dressed/undressed • Beginning to assist with washing hands and body • Beginning to assist with simple chores around the house (picking up toys, putting clothes in basket) at 2 to 3 years old	• Experiencing normal hearing and vision (screening is essential) • Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes • Struggling with speech development (hearing assessment is essential)	• Interacting with cause-and-effect toys (anything that makes a sound or movement based on a child's action) • Bouncing, climbing, swinging and sliding
II-III	• Smiling, interacting with family members and peers • Crying easily when frustrated • Relying on caregivers to maximize physical comfort and provide support during medical procedures; using child life specialists when needed • Experiencing a delay in social skill development • Having emotional or behavioral challenges	• Struggling to coordinate actions of both hands (such as holding a bottle) • Using additional caregiver support when getting dressed and undressed • Engaging in simplified or modified chores (pushing toy to spot, picking out clothes to wear through gesture or verbalization)	• Experiencing normal hearing and vision (screening is essential) • Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes • Having difficulty fixing on and following something with the eyes (cortical vision impairment) • Struggling to hear nearby sounds (hearing assessment is essential) • Struggling with speech development (hearing assessment is essential) • Experiencing distress from ordinary stimuli, especially sounds or things that they touch (sensory integration disorder)	• Interacting with cause-and-effect toys (anything that makes a sound or movement based on a child's action) • Initiating bouncing, climbing, swinging and sliding but needing assistance
IV-V	• Smiling, interacting with family members and peers • Crying easily when frustrated • Relying on caregivers to maximize physical comfort and provide support during medical procedures; using child life specialists when needed • Experiencing a delay in social skill development • Having emotional or behavioral challenges	• Needing complete positioning assistance from caregivers for feeding and dressing • Using adaptive seating systems for toileting and bathing in order to stay in a safe sitting position • Using a sleep system or positioning device to support proper alignment during sleep as indicated	• Experiencing normal vision and hearing (screening is essential) • Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes • Having difficulty with fixing on and following something with the eyes (cortical vision impairment) • Struggling to hear nearby sounds (hearing assessment is essential) • Experiencing distress from ordinary stimuli, especially sounds or things that they touch (sensory integration disorder) • Preferring to look at certain colors, movement or light	• Interacting with cause-and-effect toys (anything that makes a sound or movement based on a child's action) • Enjoying bouncing and swinging; unable to initiate movements

Infant and Toddler (0 to 3) continued

Level	Evaluations and Assessments	Interventions	Care Team Key providers are in bold.
	Your care team might recommend:	Your care team might recommend:	
I	• Physical examination, medical history and developmental assessments of mobility, communication and fine motor skills (functional status) • Imaging studies, such as an MRI or CT scan, to determine the cause of cerebral palsy or area of injury to the brain • X-ray of pelvis at 12 months of age and at age 3 to look for subluxation/dislocation • Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing and pain • Genetic evaluation • Appointments with key providers every 3 months or so • Diagnostic evaluation by pediatric neurology	• Treatments to improve mobility, communication and fine motor skills, and to prevent or correct deformity • Medicine to reduce tightness/spasticity, such as botulinum toxin • Management of associated conditions, such as seizures • Physical, occupational, and speech and language therapy • Collaboration with your school district or early intervention services • Orthotics to maintain alignment and provide stability to a joint (usually for feet/ankles and hands/wrists) • Child life support during procedures • Social work help with resources, grief	Adaptive Equipment Specialist/Vendor of Medical Equipment Audiologist Child Life Specialist **Developmental and Behavioral Pediatrician** Gastroenterologist Geneticist Neuropsychologist Nurse Nurse Practitioner Orthotist Pediatric Endocrinologist Pediatric ENT **Pediatric Neurologist** Pediatric Neurosurgeon Pediatric Orthopedist **Pediatric Rehabilitation Medicine Physician** Psychologist/ Psychotherapist Pulmonologist Sleep Health Specialist Social Worker Therapeutic Recreation Specialist **Therapists –** **Occupational Therapist** **Physical Therapist** **Speech and Language Pathologist**
II-III	• Physical examination, medical history and developmental assessments of mobility, communication and fine motor skills (functional status) • Imaging studies, such as an MRI or CT scan, to determine the cause of cerebral palsy or area of injury to the brain • X-ray of pelvis at 12 months of age and every 6 to 12 months thereafter to look for subluxation/dislocation • Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing, and pain • Genetic evaluation • Appointments with key providers every 3 months or so • Diagnostic evaluation by pediatric neurology	• Treatments to improve mobility, communication and fine motor skills, and to prevent or correct deformity • Medicine to reduce tightness/spasticity, such as oral muscle relaxants, botulinum toxin, or phenol • Management of associated conditions, such as seizures • Physical, occupational, and speech and language therapy • Collaboration with your school district or early intervention services • Orthotics to maintain alignment and provide stability to a joint (usually for feet/ankles and hands/wrists) • Adaptive equipment for mobility (such as a walker) and positioning (such as a car seat) • Child life support during procedures • Social work help with resources, grief	
IV-V	• Physical examination, medical history and developmental assessments of mobility, communication and fine motor skills (functional status) • Imaging studies, such as an MRI or CT scan, to determine the cause of cerebral palsy or area of injury to the brain • X-ray of pelvis at 12 months of age and every 6 to 12 months thereafter to look for subluxation/dislocation • Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing and pain • Genetic evaluation • Appointments with key providers every 3 months or so • Diagnostic evaluation by pediatric neurology • May need VFSS or FEES to assess safety of swallow for eating by mouth	• Treatments to improve mobility, communication and fine motor skills, and to prevent or correct deformity • Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures • Physical, occupational, and speech and language therapy • Collaboration with your school district or early intervention services • Orthotics to maintain alignment and provide stability to a joint (usually for feet/ankles and hands/wrists) • Equipment for bathing • Adaptive equipment for mobility and positioning such as a stroller, wheelchair, stander or gait trainers • Child life support during procedures • Social work help with resources, grief • Equipment, treatments or modifications to reduce aspiration, address swallowing problems, control saliva, etc.	

Early Childhood (4 to 7)

Early Childhood (4 to 7)

Level	Mobility	Musculoskeletal
	Your child might be:	**Your child might be:**
I	• Moving up and down from the floor and in and out of a chair without using hands for support • Walking long distances outdoors and on uneven surfaces • Climbing stairs • Starting to run and jump	• Having problems controlling movement of toes, foot, and ankle of the involved leg(s) • Experiencing spasticity/contracture of calf muscles • Experiencing toe-walking or in-toeing • Experiencing tightness in forearm muscles (if hemiplegia is present) • Experiencing foot issues, such as flatfoot or high-arched foot
II	• Sitting in a chair and using both hands without assistance • Moving from the floor or a chair to standing while using a stable surface to push or pull on • Walking indoors without an assistive device, but unable to walk long distances, run and jump • Climbing stairs while holding on to a railing	• Having problems controlling movement of toes, foot, ankle and knee of involved leg(s) • Experiencing increased muscle tone/tightness in many leg muscles (calf, knee and inner thigh) • Experiencing toe-walking, in-toeing or scissoring gait. • Experiencing tightness in forearm muscles (if hemiplegia is present) • Experiencing foot issues, such as flatfoot or high-arched foot • Demonstrating a strong preference for non-involved arm or hand (if hemiplegia)
III	• Walking indoors with an assistive device; using a wheelchair outdoors or for long distances • Able to get into and out of a chair using a stable surface to push or pull on • Needing pelvic or trunk support when sitting in a chair in order to use hands for play • Standing from a sitting position with use of arm support • Climbing stairs or walking on uneven surfaces with help from an adult	• Having problems controlling movement in arms and legs, including hips • Experiencing increased tightness in legs (which might occur with another movement disorder, such as athetosis or dystonia) • Experiencing toe-walking, in-toeing, scissoring or stiff knees • Experiencing poor pelvis positioning and hip instability • Demonstrating a strong preference for non-involved arm or hand (if hemiplegia)
IV	• Moving into and out of sitting using a stable surface to pull up on or with help from an adult • Sitting on own but needing extra body or trunk support in order to use hands for play • Walking short distances with walker or gait trainer with or without adult help • Using a manual wheelchair or power wheelchair to go long distances	• Struggling to control movement of legs (including hips) and arms • Experiencing spasticity of legs and arms; legs likely more involved • Experiencing muscle contractures that restrict the range of motion • Experiencing other movement disorders (athetosis/dystonia) • Struggling to stand and walk • Experiencing hip subluxation/dislocation, long bone torsion or foot deformities • Developing a spinal deformity, such as scoliosis or kyphosis
V	• Needing caregiver to help with changing positions • Experiencing difficulty sitting on own and controlling head and body posture in most positions • Using supportive equipment for sitting or standing • Moving around only with extensive mobility equipment and physical assistance	• Struggling to control movement of legs (including hips) and arms • Experiencing muscle contractures with spastic muscles, especially in legs • Experiencing hip subluxation/dislocation, foot deformities or pelvic obliquity (tilt) • Developing a spinal deformity, such as scoliosis or kyphosis • Experiencing difficulty with controlling head

Level	Communication and Cognition	Feeding and Nutrition
	Your child might be:	**Your child might be:**
I-II	• Communicating effectively with familiar and unfamiliar listeners, may communicate slower • Carrying out multistep directions • Communicating independently to a variety of people in a variety of settings • Using language to recite ABCs, colors, etc. • Using 4- to 6-word sentences, asking who and why questions, telling simple stories • Starting and continuing social interactions • Demonstrating generally typical language skills and intellectual development • Having attention problems • Able to express needs and wants through speech/gesture/facial expression	• Feeding themself • Needing supervision during meals
III-IV	• Experiencing a delay in learning and reasoning skill development • Having attention problems • Needing support to communicate with unfamiliar listeners and sometimes familiar listeners • Able to attract attention of a familiar person to interpret communication	• Struggling with feeding if oral muscles are uncoordinated, weak or tight • Having difficulty gaining weight • Unable to eat foods with particular textures • Having constipation, especially when mobility and/or diet are limited
V	• Needing communication assistance in many situations, especially with unfamiliar people and environments • Communicating routine needs and wants to familiar people • Accepting, rejecting/refusing and/or protesting choices through body movements, facial expressions or vocalizations • Responding to familiar voices and sounds with body movements, facial expressions or vocalizations • Anticipating activities, routines • Needing support to learn language concepts, recite ABCs, colors, etc.. • Needing support to start and continue social interaction • Experiencing a delay in learning and reasoning skill development	• Experiencing difficulty feeding and swallowing • Having difficulty gaining weight • Experiencing or at risk for choking or aspiration • Experiencing reflux • Having constipation, especially when mobility and/or diet are limited

Early Childhood (4 to 7) continued

Level	Social/Emotional Development and Behavior	Self-Care and Daily Living Skills	Sensory Functions	Recreation and Fitness
	Your child might be:	**Your child might be:**	**Your child might be:**	**Your child might be:**
I	• Aware of differences between self and others • Needing to be with caregivers as much as possible • Feeling self-conscious • Having attention problems • Easily frustrated and emotionally reactive • Socially immature or prefer the company of younger children • Needing help regulating behavior • Needing support to initiate and maintain social interaction • Having difficulty making friends	• Feeding self in most situations; having challenges when in stressful situations, such as an unfamiliar environment • Dressing self if able to use hands during daily activities • Learning from repetition of movements necessary for dressing (such as holding with one hand and pulling or pushing with the other hand) • Washing hands and face, bathing body, brushing teeth, toileting, and washing hair • Increasing number of chores and responsibilities at home and school	• Experiencing normal hearing and vision (screening is still essential) • Experiencing strabismus, or eye muscle imbalance, (also known as crossed eyes or lazy eyes) • Struggling with speech development (hearing assessment is essential)	• Participating in imaginative play • Starting to share, engage and interact with children of the same age • Interacting with hands-on toys, riding toys and action games • Hopping, skipping, jumping, throwing and catching • Seeking play options that offer a sense of independence • Attempting to throw and catch larger, light-weight objects with assistance
II-III	• Aware of differences between self and others • Needing to be with caregivers as much as possible • Feeling self-conscious • Having attention problems • Easily frustrated and emotionally reactive • Socially immature or prefer the company of younger children • Needing help regulating behavior • Needing support to initiate and maintain social interaction • Having difficulty making friends	• Using alternative strategies and adaptations or assistance with self-care skills • Using adapted feeding utensils, needing help with cutting or serving food • Learning from practicing dressing skills in many different settings • Dressing self if able to maintain sitting balance and trunk control • Struggling with fasteners such as snaps, zippers and buttons • Needing assistance with washing hands and face, bathing body, brushing teeth, toileting, and washing hair • Increasing number of chores and responsibilities at home and school with use of adaptations as needed	• Experiencing normal hearing and vision (screening is still essential) • Experiencing strabismus, or eye muscle imbalance, (also known as crossed eyes or lazy eyes) • Having difficulty fixing on and following something with the eyes (cortical vision impairment) • Struggling to interpret visual information as it relates to space, i.e. puzzles, writing (visual-spatial learning disability) • Struggling to hear nearby sounds (hearing assessment is essential) • Struggling with speech development (hearing assessment is essential) • Experiencing decreased sensation in respective arm, hand or leg • Experiencing distress from ordinary stimuli, especially sounds or things that they touch (sensory integration disorder)	• Participating in imaginative play • Starting to share, engage, interact with children of the same age • Interacting with hands-on toys, riding toys and action games • Struggling with activities that require fine motor skills, such as crafts or board games • Attempting hopping, skipping and jumping, but might not be fully successful • Seeking play options that offer a sense of independence • Attempting to throw and catch larger, light-weight objects with assistance
IV-V	• Demonstrating disruptive and uncooperative behaviors • Withdrawing from others • Easily frustrated, emotionally reactive, and demonstrating poor social skills • Needing support to initiate and maintain social interaction • At risk for self-injurious behaviors or aggressive behaviors	• Using adaptive tools to get food on a spoon, moving food towards mouth, or making similar motions to attempt to assist with feeding • Eating best with highly motivating foods that are easier to manage (such as foods that stick to a spoon, like pudding) • Using a communication device or switches to tell caregivers what foods he or she likes or dislikes • Needing assistance to use fingers for feeding • Doing simple dressing tasks on own (such as removing a hat), but dependent for most dressing tasks • Needing assistance with washing hands and face, bathing body, brushing teeth, toileting, and washing hair • Increasing number of chores and responsibilities at home and school based on ability	• Experiencing normal hearing and vision (screening is still essential) • Experiencing strabismus, or eye muscle imbalance, (also known as crossed eyes or lazy eyes) • Having difficulty fixing on and following something with the eyes (cortical vision impairment) • Struggling to interpret visual information as it relates to space, i.e. puzzles, writing (visual-spatial learning disability) • Struggling to hear nearby sounds (hearing assessment is essential) • Experiencing distress from ordinary stimuli, especially sounds or things that they touch (sensory integration disorder) • Experiencing significant sensory impairments with sight, hearing, smell, touch, taste or spatial awareness • Preferring to look at certain colors, movement or light	• Starting to share, engage, interact with other children • Interacting with cause-and-effect toys (anything that makes a sound or movement based on a child's action)

Early Childhood (4 to 7) continued

Level	Evaluations and Assessments	Interventions	Care Team Key providers are in bold.
	Your care team might recommend:	Your care team might recommend:	
I	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • X-ray of pelvis at age 5 • Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing and pain • Appointments with key providers every 6 months to monitor development, reduce deformities • Spasticity management with gait analysis and physical therapy to assess muscle tone • Referrals to psychology/neuropsychology for learning or behavior problems • Meeting with a social worker for mental health support and resources	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures or ADHD • Physical, occupational, and speech and language therapy • Selective dorsal rhizotomy surgery or orthopedic surgery • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation	Adaptive Equipment Specialist/Vendor of Medical Equipment Audiologist Child and Adolescent Psychiatrist Child Life Specialist **Developmental and Behavioral Pediatrician** Gastroenterologist Geneticist Neuropsychologist Nurse Nurse Practitioner Orthotist Pediatric Endocrinologist Pediatric ENT **Pediatric Neurologist** Pediatric Neurosurgeon Pediatric Orthopedist **Pediatric Rehabilitation Medicine Physician** Psychologist/Psychotherapist Pulmonologist Sleep Health Specialist Social Worker Therapeutic Recreation Specialist **Therapists – Occupational Therapist** **Physical Therapist** **Speech and Language Pathologist**
II-III	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • X-ray of pelvis every 6 to 12 months • Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing and pain • Appointments with key providers every 6 months to monitor development, reduce deformities • Spasticity management with gait analysis and physical therapy to assess muscle tone • Referrals to psychology/neuropsychology for learning or behavior problems • Meeting with a social worker for mental health support and resources	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures or ADHD • Physical, occupational, and speech and language therapy • Selective dorsal rhizotomy surgery or orthopedic surgery • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation therapies • Adaptive equipment for mobility (walker or a wheelchair) and positioning • Alternative or augmentative communication devices or methods	
IV-V	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • X-ray of pelvis every 6 to 12 months • Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing and pain • Appointments with key providers every 6 months to watch development, reduce deformities • Spasticity management to assess muscle tone • Referrals to psychology/neuropsychology for learning or behavior problems • Meeting with a social worker for mental health support and resources • Evaluation for assistive technology devices, such as power mobility or augmentative and alternative communication devices • May need VFSS or FEES to assess safety of swallow for eating by mouth	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Intrathecal baclofen pump to reduce spasticity • Management of associated conditions, such as seizures • Physical, occupational, and speech and language therapy • Orthopedic surgery to correct a hip dislocation or other deformities • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation therapies • Adaptive equipment for mobility (gait trainer or wheelchair) and positioning (car seat) • Adaptive seating, with support as needed • Equipment for bathing and/or toileting • Van for transportation • Alternative or augmentative communication devices or methods • Equipment, treatments or modifications to reduce aspiration, address swallowing problems, control saliva, etc.	

Middle Childhood (8 to 12)

Middle Childhood (8 to 12)

Level	Mobility	Musculoskeletal
	Your child might be:	Your child might be:
I	• Walking wherever he or she wants to go, including on uneven surfaces, on slopes or in crowds • Going up and down stairs and curbs without needing to hold a handrail or caregiver's arm • Running and jumping, but with limitations in speed, balance and coordination • Participating in physical activities and sports	• Having problems controlling movement of toes, foot and ankle of the involved leg(s) • Experiencing spasticity/contracture of calf muscles • Experiencing toe-walking or in-toeing • Experiencing tightness in forearm muscles (if hemiplegia is present) • Experiencing foot issues, such as flatfoot or high-arched foot
II	• Walking on own without walking aids • Having difficulty walking on uneven surfaces, on slopes or in crowds and may use an assistive device for safety • Climbing stairs using railing or assistance • Having limited ability to run and jump • Using wheeled mobility for longer distances, outdoors and in the community	• Having problems controlling movement of toes, foot and ankle of the involved leg(s) • Experiencing increased muscle tone/tightness in leg muscles (calf, knee, inner thigh) • Experiencing toe-walking, in-toeing or scissoring gait. • Experiencing tightness in forearm muscles (if hemiplegia is present) • Experiencing foot problems (flatfoot or high-arched foot) • Experiencing long bone torsion of thigh/leg bones, knees and feet that don't align • Demonstrating a strong preference for non-involved arm or hand (if hemiplegia)
III	• Walking with an assistive device indoors and using wheeled mobility for long distances and outdoors • Climbing stairs using railing or assistance • Using adaptations, such as a manual wheelchair, to participate in physical activities and sports • Requiring hands on support surface or assistance for sit to stand and floor to stand transfers	• Having problems controlling movement in arms and legs, including hips • Experiencing increased tightness in legs, along with other movement disorders, such as athetosis or dystonia • Experiencing toe-walking, in-toeing, scissoring or stiff knees • Having poor pelvis positioning, hip instability • Experiencing long bone torsion of thigh/leg bones, knees and feet that don't align • Demonstrating a strong preference for non-involved arm or hand (if hemiplegia)
IV	• Able to get around at home, at school and in the community on own using a powered wheelchair or using a manual wheelchair with help • Walking short distances with a gait trainer and assistance • Requiring physical assistance for transfers • Rolling or crawling to get around at home • Sitting with adaptive seating	• Having problems controlling movement in arms and legs, including hips • Experiencing spasticity of both the legs and arms (legs likely more involved) • Experiencing muscle contractures with growth • Experiencing other movement disorders (athetosis/dystonia) • Experiencing hip subluxation/dislocation, long bone torsion and foot deformities • Experiencing spinal deformity
V	• Having difficulty controlling head and body posture in most positions • Using a manual wheelchair to get around with assistance or a powered wheelchair with extensive modifications to get around without help • Requiring total assistance for transfers • Experiencing limited ability to get around • Needing a supportive chair to be positioned comfortably	• Having problems controlling movement in arms and legs, including hips • Experiencing spasticity and or other movement disorders (athetosis/dystonia) in both legs and arms (legs likely more involved) • Experiencing muscle contractures with growth, especially in the legs • Experiencing hip subluxation/dislocation, long bone torsion and foot deformities • Experiencing spinal deformity or pelvic obliquity (tilt)

Level	Communication and Cognition	Feeding and Nutrition
	Your child might be:	Your child might be:
I-II	• Using language to learn • Using stories to describe, contrast and compare • Communicating by speaking and writing • Using complex language structures • Having generally typical language skills and intellectual development • Having attention or processing speed problems • Easily overwhelmed • Struggling to manage expectations • Experiencing learning or memory challenges • Needing more time for effective communication	• Feeding themself • Learning how to cook • Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)
III-IV	• Using language to learn • Carrying out multistep directions • Using stories to describe, contrast and compare • Communicating by speaking and writing • Using complex language structures • Having attention or processing speed problems • Experiencing learning or memory challenges • Experiencing delayed intellectual development like difficulty comprehending or difficulty problem-solving • Struggling with speech and writing • Using technology to communicate more independently • Easily overwhelmed • Struggling to manage expectations	• Struggling with feeding if oral muscles are uncoordinated, weak or tight • Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth) • Unable to eat foods with particular textures • Having constipation, especially when mobility and/or diet are limited
V	• Needing assistance in many situations, especially with unfamiliar people and environments • Demonstrating speech and muscle coordination problems that affect communication • Using speech, gestures, facial expressions or augmented or alternative communication devices • Having attention or processing speed problems • Experiencing learning or memory challenges • Experiencing delayed intellectual development like difficulty comprehending or difficulty problem-solving	• Having difficulty feeding and swallowing • Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth) • Experiencing or at risk for choking or aspiration • Experiencing reflux • Having constipation, especially when mobility and/or diet are limited • Gaining too much weight due to an inactive lifestyle

Middle Childhood (8 to 12) continued

Level	Social/Emotional Development and Behavior	Self-Care and Daily Living Skills	Sensory Functions	Recreation and Fitness
	Your child might be:	Your child might be:	Your child might be:	Your child might be:
I	• Focusing on facts versus abstract thoughts • Aware of individual differences and that the condition is not reversible • Starting a grieving process • Having attention problems • Easily frustrated and emotionally reactive • Demonstrating poor social skills and difficulty making friends • Socially immature or prefer the company of younger children • Struggling to understand social cues • Needing help managing behavior and emotional reactions	• Doing many self-care skills, such as dressing and eating on own • Needing more time than peers to learn skills (such as zipping coat, managing backpacks, or changing clothes quickly for activities, such as swimming lessons) • Increasing number of chores and responsibilities at home and school • Beginning to explore personal interests for potential later work opportunities	• Experiencing normal hearing and vision (screening is still essential) • Experiencing difficulties with speech or language abilities (hearing assessment is essential)	• Participating in supportive play that includes cooperation and compromise • Identifying preferences for specific sports, types of music, books and movies • Playing team and competitive sports, perhaps with adaptive equipment and modified participation • Seeking play options that offer a sense of independence
II-III	• Focusing on facts versus abstract thoughts • Aware of individual differences and that the condition is not reversible • Starting a grieving process • Having attention problems • Easily frustrated and emotionally reactive • Demonstrating poor social skills and difficulty making friends • Socially immature or prefer the company of younger children • Interpersonally vulnerable • Struggling to understand social cues • Needing help managing behavior and emotional reactions	• Needing assistance with cutting food • Eating food independently if the environment is arranged to meet needs • Needing assistance with positioning if he or she is struggling with using one hand to hold clothing, while using the other to push or pull through sleeves • Increasing number of chores and responsibilities at home and school with adaptations as needed • Beginning to explore personal interests for potential later work opportunities	• Experiencing normal hearing and vision (screening is still essential) • Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes • Experiencing difficulty with fixing on and following something with the eyes (cortical vision impairment) • Struggling to interpret visual information as it relates to space, i.e. puzzles, writing (visual-spatial learning disability) • Struggling with speech development (hearing assessment is essential) • Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder) • Not using involved arm because of sensory issues • Experiencing decreased sensation in respective arm, hand or leg	• Participating in supportive play that includes cooperation and compromise • Identifying preferences for specific sports, types of music, books and movies • Struggling with activities that require fine motor skills, such as crafts or board games • Playing team and competitive sports using adaptive sports equipment and with modified participation • Seeking play options that offer a sense of independence
IV-V	• Easily frustrated and emotionally reactive • Demonstrating poor social skills • Demonstrating disruptive and uncooperative behaviors • Withdrawing from others • At risk for self-injurious behaviors or aggressive behaviors	• Needing adequate posture support to use hands while eating • Requiring total assistance from caregivers to complete feeding and dressing tasks • Learning parts of some dressing skills, such as offering a hand or foot when getting clothes or shoes on • More likely to have casts and/or braces due to increased stiffness in muscles • Increasing ability to make choices and direct cares as appropriate • Beginning to explore personal interests for potential work or community engagement opportunities	• Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes • Experiencing difficulty with fixing on and following something with the eyes (cortical vision impairment) • Struggling to interpret visual information as it relates to space, i.e. puzzles, writing (visual-spatial learning disability) • Struggling with speech development (hearing assessment is essential) • Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder) • Experiencing significant sensory impairments with sight, hearing, smell, touch, taste or spatial awareness • Not using involved arm because of sensory issues • Preferring to look at certain colors, movement or light	• Playing with hand-over-hand assistance • Socializing and interacting through adapted programs and camps • Interacting with cause-and-effect toys (anything that makes a sound or movement based on child's action) • Identifying preferences for specific sports, types of music, books and movies • Using highly adapted sport options that provide hand-over-hand or full assistance

Middle Childhood (8 to 12) continued

Level	Evaluations and Assessments	Interventions	Care Team Key providers are in bold.
	Your care team might recommend:	Your care team might recommend:	
I	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • Clinical examination of hips, possibly with an X-ray • Screening of vision, hearing, growth, nutrition, bone health, bowel, bladder, sleep, swallowing and pain • Appointments with key providers every 6 to 12 months to monitor development, reduce deformities • Evaluation of muscle tone and spasticity • Referrals to psychology/neuropsychology for learning or behavior problems • Meeting with a social worker for mental health support and resources	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures or ADHD • Physical, occupational, and speech and language therapy • Selective dorsal rhizotomy surgery or orthopedic surgery to correct skeletal deformities • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation	Adaptive Equipment Specialist/Vendor of Medical Equipment Audiologist Child and Adolescent Psychiatrist Child Life Specialist Developmental and Behavioral Pediatrician Gastroenterologist Geneticist Neuropsychologist Nurse Nurse Practitioner Opthalmologist Orthotist Pediatric Endocrinologist Pediatric ENT **Pediatric Neurologist** Pediatric Neurosurgeon Pediatric Orthopedist **Pediatric Rehabilitation Medicine Physician** Psychologist/ Psychotherapist Pulmonologist Sleep Health Specialist Social Worker Therapeutic Recreation Specialist **Therapists –** **Occupational Therapist** **Physical Therapist** **Speech and Language Pathologist**
II-III	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • X-ray of pelvis at 8 to 10 years of age and every 12 months until skeletal maturity • Screening for spinal deformity • Screening of vision, hearing, growth, nutrition, bone health, bowel, bladder, sleep, swallowing and pain • Appointments with key providers every 6 to 12 months to monitor development, reduce deformities • Evaluation of muscle tone and spasticity • Referrals to psychology/neuropsychology for learning or behavior problems • Meeting with a social worker for mental health support and resources	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures or ADHD • Physical, occupational, and speech and language therapy • Selective dorsal rhizotomy surgery or intrathecal baclofen pump • Orthopedic surgery to correct skeletal deformities • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation therapies • Adaptive equipment for mobility (walker or a wheelchair) • Alternative or augmentative communication devices or methods • Bracing to control a spinal deformity	
IV-V	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • X-ray of pelvis at 8 to 10 years of age and every 6 to 12 months until skeletal maturity • X-ray of spine • Screening of vision, hearing, growth, nutrition, bone health, bowel, bladder, sleep, swallowing and pain • Appointments with key providers every 6 to 12 months to monitor development, reduce deformities • Evaluation of muscle tone and spasticity • Referrals to neurodevelopmental pediatrics/psychology/neuropsychology for learning or behavior problems • Meeting with a social worker for mental health support and resources • May need VFSS or FEES to assess safety of swallow for eating by mouth	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures • Physical, occupational, and speech and language therapy • Intrathecal baclofen pump to reduce spasticity • Orthopedic surgery or bracing • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation • Adaptive equipment for mobility (gait trainer, stander, car seat or wheelchair) • Adaptive seating, with support as needed • Equipment for bathing and/or toileting • Modifications to your child's home or school environment • Alternative or augmentative communication devices or methods • Equipment, treatments or modifications to reduce aspiration, address swallowing problems, control saliva, etc.	

Adolescence (13 to 18)

Adolescence (13 to 18)

Level	Mobility	Musculoskeletal
	Your child might be:	Your child might be:
I	• Walking wherever he or she wants to go, including on uneven surfaces, on slopes or in crowds • Going up and down stairs and curbs without needing to hold a handrail or caregiver's arm • Running and jumping, but with limitations in speed, balance and coordination • Participating in physical activities and sports	• Having problems controlling movement of toes, foot and ankle of the involved leg(s) • Experiencing spasticity/contracture of calf muscles • Experiencing toe-walking or in-toeing • Experiencing tightness in forearm muscles (if hemiplegia is present) • Experiencing foot problems (flatfoot or high-arched foot)
II	• Walking on own without walking aids • Having difficulty walking on uneven surfaces, on slopes or in crowds and may use an assistive device for safety • Climbing stairs using railing or assistance • Having limited ability to run and jump • Using wheeled mobility for longer distances, outdoors and in the community	• Having problems controlling movement of toes, foot and ankle of the involved leg(s) • Experiencing increased muscle tone/tightness in leg muscles (calf, knee, inner thigh) • Experiencing toe-walking, in-toeing or scissoring gait • Experiencing tightness in forearm muscles (if hemiplegia is present) • Experiencing foot problems (flatfoot or high-arched foot) • Experiencing long bone torsion of thigh/leg bones, knees and feet that don't align • Demonstrating a strong preference for non-involved arm or hand (if hemiplegia)
III	• Walking with an assistive device indoors and using wheeled mobility for long distances and outdoors • Having difficulty walking on uneven surfaces, on slopes or in crowds and may use an assistive device for safety • Climbing stairs using railing or assistance • Using adaptations, such as a manual wheelchair, to participate in physical activities and sports	• Having problems controlling movement in arms and legs, including hips • Experiencing increased tightness in legs, along with other movement disorders, such as athetosis or dystonia • Experiencing toe-walking, in-toeing, scissoring or stiff knees • Having poor pelvis positioning, hip instability • Experiencing long bone torsion of thigh/leg bones, knees and feet that don't align • Demonstrating a strong preference for non-involved arm or hand (if hemiplegia)
IV	• Able to get around at home, at school and in the community on own using a powered wheelchair or using a manual wheelchair with help • Walking short distances with a gait trainer and assistance • Requiring physical assistance for transfers • Rolling or crawling to get around at home • Sitting with adaptive seating	• Having problems controlling movement in arms and legs, including hips • Experiencing spasticity of both the legs and arms (legs likely more involved) • Experiencing muscle contractures with growth • Experiencing other movement disorders (athetosis/dystonia) • Experiencing hip subluxation/dislocation, long bone torsion and foot deformities • Experiencing spinal deformity
V	• Having difficulty controlling head and body posture in most positions • Using a manual wheelchair to get around with assistance or a powered wheelchair with extensive modifications to get around without help • Requiring total assistance for transfers • Experiencing limited ability to get around • Needing a supportive chair to be positioned comfortably	• Having problems controlling movement in arms and legs, including hips • Experiencing spasticity and or other movement disorders (athetosis/dystonia) in both legs and arms (legs likely more involved) • Experiencing muscle contractures with growth, especially in the legs • Experiencing hip subluxation/dislocation, long bone torsion and foot deformities • Experiencing spinal deformity or pelvic obliquity (tilt)

Level	Communication and Cognition	Feeding and Nutrition
	Your child might be:	Your child might be:
I	• Using language to learn • Using stories to describe, contrast and compare • Communicating by speaking and writing • Using complex language structures • Having generally typical language skills and intellectual development • Having attention problems or processing speed problems • Easily overwhelmed • Struggling to manage expectations • Experiencing learning or memory challenges • Needing more time for effective communication	• Feeding themself • Learning how to cook • Having difficulty gaining weight
II-III	• Using language to learn • Carrying out multistep directions • Using stories to describe, contrast and compare • Communicating by speaking and writing • Using complex language structures • Having attention or processing speed problems • Experiencing learning or memory challenges • Experiencing learning disabilities or delayed intellectual development like difficulty comprehending or difficulty problem-solving • Struggling with speech and writing • Using technology to communicate more independently • Easily overwhelmed • Struggling to manage expectations	• Struggling with feeding if oral muscles are uncoordinated, weak or tight • Having difficulty gaining weight • Unable to eat foods with particular textures • Having constipation, especially when mobility and/or diet are limited
IV-V	• Needing assistance in many situations, especially with unfamiliar people and environments • Demonstrating speech and muscle coordination problems that need communication • Using speech, gestures, facial expressions or augmented or alternative communication devices • Having attention or processing speed problems • Experiencing learning or memory challenges • Experiencing a delay in intellectual development like difficulty comprehending or difficulty problem-solving	• Having difficulty feeding and swallowing • Having difficulty gaining weight • Experiencing or at risk for choking or aspiration • Experiencing reflux • Having constipation, especially when mobility and/or diet are limited • Gaining too much weight due to an inactive lifestyle

Adolescence (13 to 18) continued

Level	Social/Emotional Development and Behavior	Self-Care and Daily Living Skills	Sensory Functions	Recreation and Fitness
	Your child might be:	Your child might be:	Your child might be:	Your child might be:
I	• Focusing on facts versus abstract thoughts • Aware of individual differences and that the condition is not reversible • Starting a grieving process • Having attention problems • Easily frustrated and emotionally reactive • Demonstrating poor social skills and difficulty making friends • Socially immature or prefer the company of younger children • Struggling to understand social cues • Needing help managing behavior and emotional reactions • Needing education and support to understand safe and positive relationships, personal space and boundaries.	• Needing support with feminine or masculine hygiene tasks (shaving, cleanliness) • Demonstrating interest in dating and intimacy • Completing many chores and increasing responsibilities at school/work to prepare for adulthood • Practicing directing personal care attendants if those are needed	• Experiencing normal hearing and vision (screening is still essential) • Experiencing difficulties with speech or language abilities (hearing assessment is essential)	• Participating in supportive play that includes cooperation and compromise • Identifying preferences for specific sports, types of music, books and movies • Playing team and competitive sports, perhaps with adaptive equipment and modified participation • Seeking play options that offer a sense of independence
II-III	• Focusing on facts versus abstract thoughts • Aware of individual differences and that the condition is not reversible • Starting a grieving process • Having attention problems • Easily frustrated and emotionally reactive • Demonstrating poor social skills and difficulty making friends • Socially immature or prefer the company of younger children • Interpersonally vulnerable • Struggling to understand social cues • Needing help managing behavior and emotional reactions • Needing education and support to understand safe and positive relationships, personal space and boundaries	• Needing support with feminine or masculine hygiene tasks (shaving, cleanliness) • Demonstrating interest in dating and intimacy • Completing adapted chores and increasing responsibilities at school/work to prepare for adulthood • Practicing directing personal care attendants if those are needed	• Experiencing normal hearing and vision (screening is still essential) • Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes • Experiencing difficulty with fixing on and following something with the eyes (cortical vision impairment) • Struggling to interpret visual information as it relates to space (visual-spatial learning disability) • Struggling with speech development (hearing assessment is essential) • Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder) • Experiencing decreased sensation in respective arm, hand or leg	• Participating in supportive play that includes cooperation and compromise • Identifying preferences for specific sports, types of music, books and movies • Struggling with activities that require fine motor skills, such as crafts or board games • Playing team and competitive sports using adaptive sports equipment and with modified participation • Seeking play options that offer a sense of independence
IV-V	• Easily frustrated and emotionally reactive • Socially immature or prefer the company of younger children • Interpersonally vulnerable • Demonstrating poor social skills • Demonstrating disruptive and uncooperative behaviors • Withdrawing from others • At risk for self-injurious or self-damaging behaviors and aggression • Needing education, support and supervision for safe relationships, personal space, and boundaries	• Needing support with feminine or masculine hygiene tasks (shaving, cleanliness) • Demonstrating interest in dating and intimacy • Practicing directing personal care attendants • Communicating future hopes and dreams	• Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes • Experiencing difficulty with fixing on and following something with his or her eyes (cortical vision impairment) • Struggling to interpret visual information as it relates to space (visual-spatial learning disability) • Struggling with speech development (hearing assessment is essential) • Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder) • Experiencing significant sensory impairments with sight, hearing, smell, touch, taste or spatial awareness • Experiencing decreased sensation in respective arm, hand or leg • Preferring to look at certain colors, movement or light	• Playing with hand-over-hand assistance • Socializing and interacting through adapted programs and camps • Interacting with cause-and-effect toys (anything that makes a sound or movement based on child's action) • Identifying preferences for specific sports, types of music, books and movies • Using highly adapted sport options that provide hand-over-hand or full assistance

Adolescence (13 to 18) continued

Level	Evaluations and Assessments	Interventions	Care Team Key providers are in bold.
	Your care team might recommend:	Your care team might recommend:	
I	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • Clinical examination of hips, possibly with an X-ray • Screening of vision, hearing, growth, nutrition, bone health, bowel, bladder, sleep, swallowing and pain • Evaluation of muscle tone and spasticity • Appointments with key providers every 6 to 12 months to monitor and evaluate development • Referrals to psychology/neuropsychology for learning or behavior problems • Meeting with a social worker for mental health support and resources • Discussing transition to adult care • Planning for housing, work, safety, relationships and skill building with social work	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures or ADHD • Physical, occupational, and speech and language therapy • Selective dorsal rhizotomy surgery or orthopedic surgery to correct skeletal deformities • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation	Adaptive Equipment Specialist/Vendor of Medical Equipment Audiologist Child and Adolescent Psychiatrist Child Life Specialist Developmental and Behavioral Pediatrician Gastroenterologist Geneticist Neuropsychologist Nurse Nurse Practitioner Orthotist Pediatric Endocrinologist Pediatric ENT **Pediatric Neurologist** Pediatric Neurosurgeon Pediatric Orthopedist **Pediatric Rehabilitation Medicine Physician** Psychologist/ Psychotherapist Pulmonologist Sleep Health Specialist Social Worker Therapeutic Recreation Specialist **Therapists –** **Occupational Therapist** **Physical Therapist** **Speech and Language Pathologist**
II-III	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • X-ray of pelvis at 8 to 10 years of age and every 12 months until skeletal maturity • Screening for spinal deformity • Screening of vision, hearing, growth, nutrition, bone health, bowel, bladder, sleep, swallowing and pain • Evaluation of muscle tone and spasticity • Referrals to psychology/neuropsychology for learning or behavior problems • Appointments with key providers every 6 to 12 months to monitor and evaluate development • Meeting with a social worker for mental health support and resources • Discussing transition to adult care • Planning for housing, work, safety, relationships and skill building with social work	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures or ADHD • Physical, occupational, and speech and language therapy • Intrathecal baclofen pump to reduce spasticity • Orthopedic surgery to correct skeletal deformities • Correction of recurrent deformities due to growth spurts • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation • Adaptive equipment for mobility (walker or a wheelchair) • Alternative or augmentative communication devices or methods	
IV-V	• Ongoing assessments of mobility, communication and fine motor skills (functional status) • X-ray of pelvis at 8 to 10 years of age and every 6 to 12 months until skeletal maturity • X-ray of spine • Screening of vision, hearing, growth, nutrition, bone health, bowel, bladder, sleep, swallowing and pain • Evaluation of muscle tone and spasticity • Referrals to psychology/neuropsychology for learning or behavior problems • Appointments with key providers every 6 to 12 months to monitor and evaluate development • Meeting with a social worker for mental health support and resources • Discussing transition to adult care • Planning for housing, work, safety, relationships and skill building with social work • May need VFSS or FEES to assess safety of swallow for eating by mouth	• Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol • Management of associated conditions, such as seizures or ADHD • Physical, occupational, and speech and language therapy • Intrathecal baclofen pump to reduce spasticity • Orthopedic surgery to correct skeletal deformities • Correction of recurrent deformities due to growth spurts • Orthotics to maintain alignment and provide stability to a joint • Collaboration with your school district • Child life support during procedures and rehabilitation • Adaptive seating and mobility (gait trainer, stander, manual or powered wheelchair) • Modifications to your child's home or school environment • Alternative or augmentative devices or methods • Equipment treatments or modifications to reduce aspiration, address swallowing problems, control saliva, etc.	

Glossary

This glossary will help you better understand terms associated with your child's diagnosis. When words in the definitions are italicized, those words are defined elsewhere in the glossary.

Abduction – Outward movement of a leg or arm away from the body.

Adduction – Inward movement of a leg or arm toward the body.

Ankle foot orthosis (AFO) – A brace that surrounds the ankle and at least part of the foot; used to control the position and motion of the ankle, compensate for weakness or correct deformities.

Aspiration - The entry of secretions or food into the airway.

Assessment (or evaluation) – Process to determine a child's strengths and weaknesses; includes testing and observations performed by a team of specialists.

Assistive technology – Equipment, such as walkers and crutches, used to compensate for weakness or balance in order to accomplish a particular task, such as walking.

Ataxia – A condition in which damage to the brain results in an unbalanced way of walking (gait); can affect movement, speech, eye movements and the ability to swallow.

Athetosis – Having uncontrolled writhing movements caused by damage to the brain.

Augmentative communication – Use of nonspeech techniques, such as signs, gestures, or pictures, to supplement speech.

Bilateral – Relating to both sides of the body.

Bony deformity – Abnormality in the bone, often caused by the pressure of imbalanced muscles on a growing skeleton.

Brain stem – Portion of the brain between the **cerebellum** and the spinal cord.

CT (computerized axial tomography) scan – X-ray procedure that uses a computer to combine many X-ray images, creating cross-sectional views and three-dimensional images of the inside of the body.

Cavus – Deformity in which the arch of the foot is abnormally high; usually associated with hindfoot varus—a type of deformity where the heel turns inward.

Cerebellum – Part of the brain that helps coordinate muscle activity and control balance.

Cerebral palsy – Movement and posture disorder resulting from nonprogressive damage to the brain.

Cognitive impairment – Problem with one's ability to think and/or learn.

Congenital – Condition present at or before birth.

Contracture – Shortening of muscle fibers, which causes a restricted **range of motion**.

Contraction – Momentary tightening or shortening of muscles.

Cortical visual impairment – Total or partial blindness resulting from injury to the brain's visual centers; although the eyes can pick up visual information, the brain cannot process and interpret it.

Craniofacial – Pertaining to the skull and the bones of the face.

Crouch gait – Type of walking characterized by a bent posture amongst the hip, knee, and ankle joints (sagittal plane); makes it difficult for a child to maintain upright posture.

Development – Process of growth and learning during which a person acquires skills and abilities.

Developmental disability – An **impairment** beginning before age 18 that is likely to continue indefinitely and that causes a substantial disability.

Developmental milestone – Developmental goal, such as sitting or using two-word phrases, which health care providers use to measure developmental progress over time.

Diplegia – Type of **cerebral palsy** in which spasticity primarily affects the legs.

Dystonia – Sustained muscle **contractions** that cause slow, rhythmic twisting movements or abnormal postures.

Epilepsy – A recurring condition in which abnormal electrical charges in the brain cause seizures.

Equinus – Walking on toes because the calf muscles are shortened or contracted.

Expressive language – The ability to use gestures, words and written symbols to communicate.

FEES test Flexible Endoscopic Evaluation of Swallowing - A FEES test is a procedure used to assess swallowing actions. During the procedure, a speech-language pathologist (SLP) passes a thin, flexible instrument through the nose to evaluate parts of the throat during swallow.

Femoral bone (femur) – The long, heavy bone connecting the knee to the hip.

Femoral torsion (femoral ateversion) – Inward twisting of the femur so that the knees and feet turn inward.

Fine motor – Relating to the use of the small muscles of the body, such as those in the face, hands, fingers, feet and toes.

Flexion – Bending of joints.

Floppy – Having weak posture and loose movements.

Foot drop (drop foot) – General term for difficulty lifting the front part of the foot while walking; people with the condition might drag the front of the foot on the ground when they walk.

Foot orthosis – A brace that supports the foot but does not extend above the ankle.

Forefoot – Front third of the foot.

Gait analysis – The use of computers to measure joint motion, force production, muscle activity and sometimes energy exertion when walking.

Gastroesophageal reflux – Condition in which stomach contents are forced back into the esophagus and sometimes the mouth.

Gross motor – Relating to the use of the large muscles of the body, such as those in the legs, arms and abdomen.

Hemiplegia – A type of **cerebral palsy** in which either the right or left side of the body is affected; the face or trunk can be affected as well.

High tone – Tightness or **spasticity** of the muscles.

Hindfoot – Back third of the foot.

Hip dislocation – Occurs when the head of the thighbone (femur) slips out of its socket in the pelvis.

Hip subluxation – Incomplete or partial dislocation of the hip joint.

Hypertonia – Increased tension or spasticity of the muscles (high tone).

Hypotonia – Decreased tension of the muscles (low tone).

Individualized Education Program (IEP) – Written plan that describes what services a local school has promised to provide.

Impairment – Decrease in strength, dexterity or ability to use a leg, arm or other body part.

Impaired coordination and balance – Interruption in equilibrium responses and balance mechanisms as a result of damage to the central nervous system.

In-toeing – Walking with the feet turned in (internally rotated).

Intrathecal baclofen pump – A device that is surgically placed under the skin to dispense baclofen into the fluid-filled areas around the spinal cord (known as the intrathecal space) to reduce spasticity. If the catheter is advanced into a patient's brain, the baclofen is dispensed into a fluid-filled area known as the intraventricular space.

Inversion – When a part of the body turns in.

Knee ankle foot orthosis (KAFO) – Long leg brace of lightweight plastic, with hinges at the knee joint, which supports the entire leg.

Kyphosis – A round-back (hunchback) deformity of the upper spine.

Learning disability – Difficulty processing information in one or more academic areas (reading, writing or math), which interferes with school performance or everyday tasks that require reading, writing, or math skills.

Lever arm dysfunction (LAD) – A bone deformity preventing the muscles that cross or are attached to that bone from functioning normally.

Long-leg sitting – Sitting with legs extended in front of the body.

Long bone torsion – The twisting of the thigh or legbone(s) either outward or inward, which occurs during growth.

Loss of selective motor control – Disruption of the timing, intensity, duration and coordination of voluntary muscle control.

Low tone – Decreased muscle tone.

Lower extremities – Legs.

Manual Ability Classification System (MACS) – One way through which health care providers discuss how people with cerebral palsy use their hands to handle objects in daily activities.

Malrotation – Abnormal rotation of a bone that changes the way the muscles are attached.

Midfoot – Middle third of the foot.

Midline – Imaginary reference line down the center of the body, separating left from right.

Motor delay – Slower than normal development of movement skills.

Motor patterns – Ways in which the body and limbs work together to make sequenced movement.

Magnetic resonance imaging (MRI) scan – Medical technique used to see the details of structures inside the body.

Muscle tone – Amount of tension or resistance to movement in a muscle.

Neuroleptic – Medicine that produces changes in the way the nervous system functions.

Neuromotor – Involving both the nerves and the muscles.

Oral motor – Relating to the movement of muscles in and around the mouth.

Orthopedic – Relating to the bones, joints or muscles.

Orthoses – Lightweight devices, made from plastic, leather or metal, which provide stability at the joints or passively stretch the muscles.

Osteotomy – Surgery to cut and realign a bone.

Pes valgus – Foot abnormality in which the foot is flat and the back of the foot is turned outward.

Physical therapy – Evaluation and treatments aimed at helping people improve gross-motor skills, strength and balance. Therapists also recommend, create and customize adaptive equipment, such as power or manual wheelchairs, walkers, and standers.

Posture – Positioning or alignment of the body.

Quadriplegia – Type of cerebral palsy in which the whole body is affected.

Range of motion (ROM) – Degree of movement present at a joint.

Rhizotomy (full name: selective dorsal rhizotomy) – Neurosurgical procedure involving the cutting of selected nerves in the spine to reduce spasticity in muscle groups.

Rigidity – Extremely **high muscle tone** in any position, combined with very limited movements; muscle resistance occurs throughout the entire **range of motion**.

Scissoring gait – Crossing legs when standing or being held upright; legs appear to cross each other in a scissors-like movement when walking.

Scoliosis – An abnormal side-to-side curvature of the spine when viewed from the back or front.

Seizure – Involuntary movement or changes in consciousness or behavior brought on by an abnormal burst of electrical activity in the brain.

Selective dorsal rhizotomy – See Rhizotomy.

Sensory integration – Ability of the central nervous system to process and learn from sensations such as sight, touch, sound, smell, taste and movement.

Sensory integration disorders – Central nervous system has difficulty handling information from the senses (sight, touch, sound, smell, taste and movement).

Selective motor control – Ability of the brain to selectively control and coordinate the muscles during activities such as walking, running and reaching for an object.

Speech and language pathology – Services that focus on improving speech and language skills, as well as on improving oral motor abilities (swallowing).

Spasticity – Increased muscle tone (stiff muscles) and a wide range of involuntary muscle spasms (sustained muscle contractions or sudden movements) that result in difficulty moving.

Stimulus – Physical object or environmental event that could affect behavior.

Strabismus – Lack of coordinated eye movement, resulting in crossing and/or wandering eyes.

Subluxation – Partial dislocation of a joint.

Tactile – Relating to touch or the sense of touch.

Toe walking – Walking with the foot and ankle in a toe-down position.

Triplegia – Involvement of both legs and one arm.

Upper extremities – Arms.

VFSS Videofluoroscopic Swallow Study - A VFSS is an imaging procedure, also known as a modified barium swallow, used to assess swallowing. During the procedure, a speech-language pathologist (SLP) will evaluate the mouth and throat during swallow.

Visual-spatial learning disability – Inability to make sense of what one sees; difficulty recognizing complex shapes like letters/numbers, remembering visual patterns, and organizing objects in space (such as understanding a map).

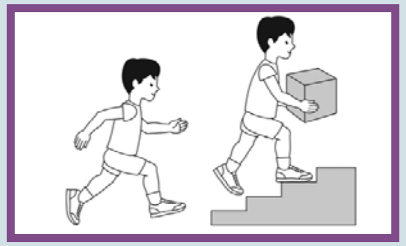
Weakness – Inability to exert as much force with one's muscles as would be expected given the person's general physical fitness.

W-sitting – A sitting position where a person's legs form a "W" shape on the floor (knees bent, legs rotated and facing away from the body).

Appendix 1

Gross Motor Function Classification System (GMFCS)

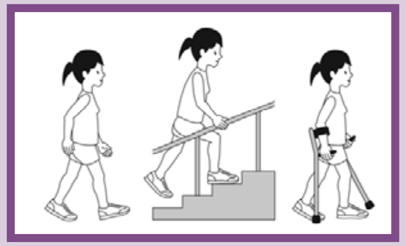
I



Walks without limitations.

- Walks at home, at school, outdoors and in the community.
- Climbs stairs without using a railing.
- Performs skills such as running and jumping, but lacks speed, balance and coordination.

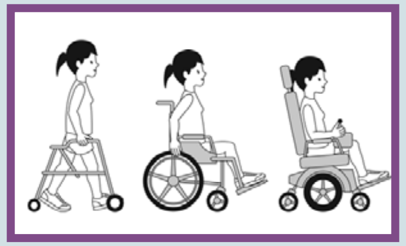
II



Walks with limitations.

- Walks in most settings.
- Climbs stairs holding on to a railing.
- Experiences difficulty walking long distances and balancing on uneven surfaces, on inclines, in crowded areas or in confined spaces.
- Walks with physical assistance, using a mobility device or wheeled mobility over long distances.
- Has minimal ability to perform skills such as running and jumping.

III



Walks using a hand-held mobility device.

- Walks using a mobility device in most indoor settings and for shorter distances.
- Climbs stairs holding on to a railing with supervision or assistance.
- Uses wheeled mobility when traveling long distances.
- Uses arms and hands, or feet, to propel the wheels of a wheelchair (self-propels) for shorter distances.

IV

Moves by himself or herself with limitations; might use power mobility.

- Requires physical assistance or power mobility in most settings.
- Walks for short distances at home with physical assistance or uses power mobility or a body support walker.
- Uses a manual wheelchair or power mobility at school, outdoors and in the community.

V

Needs to be transported in a manual wheelchair.

- Needs to be transported in a manual wheelchair in all settings.
- Has limited control of head and trunk posture in most positions.
- Has limited ability to control leg and arm movements.

GMFCS – E & R, Palisano, Rosenbaum, Bartlett & Livingston, 2007 UCP - My Child Without Limits – Illustrations by Matthew Heern.

Appendix 2

Mini Manual Ability Classification System (Mini-MACS) Ages 1-4

Level I: Handles objects easily and successfully.

The child may have a slight limitation in performing actions that require precision and coordination between the hands but they can still perform them. The child may need somewhat more adult assistance when handling objects compared to other children of the same age.

Distinctions between Levels I and II:

Children in Level I may have slightly more difficulty handling items that require good fine motor skills compared to children without disabilities of the same age.

Children in Level II handle essentially the same objects as children in Level I, but they may encounter problems performing tasks and/or take longer to perform them, so they often ask for help. Functional differences between hands may cause performance to be less effective. They may need more guidance and practice to learn how to handle objects compared with children in Level I.

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

Some actions can only be performed and accomplished with some difficulty and after practice. The child may try an alternative approach, such as using only one hand. The child need adult assistance to handle objects more frequently compared to children at the same age.

Distinctions between Levels II and III:

Children in Level II can handle most objects, though they may take longer and do so with somewhat less quality, and they may need a lot of guidance and practice to learn how to handle objects.

Level III children manage to use easily handled objects but often need help placing objects in an easy position in front of them. They perform actions with few subcomponents. Performance is slow.

Level III: Handles objects with difficulty.

Performance is slow, with limited variation and quality. Easily managed objects are handled independently for short periods. The child often needs adult help and support to handle objects.

Distinctions between Levels III and IV:

Children in Level III manage to use easily handled objects independently for short periods. They perform actions with few subcomponents, and the actions take a long time to perform.

At best, children in Level IV can perform simple actions such as grasping and releasing easily handled objects that are offered in an adapted position. They need constant help.

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

The actions are performed slowly, with exertion and/or random precision. The child needs constant adult help and support to handle objects.

Distinctions between Levels IV and V:

Children in Level IV perform individual actions with a very limited selection of objects and need constant help.

At best, children in Level V perform simple movements in special situations. For example, they can press a simple button or hold single, simple objects.

Level V: Does not handle objects and has severely limited ability to perform even simple actions.

At best, the child can push, touch, press, or hold on to a few items, in constant interaction with an adult.

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Contributers: Ann-Marie Öhrwall, Ulla Wahlström, Åsa Persson-Annersten.

Manual Ability Classification System (MACS) Ages 4-18

Level I: Handles objects easily and successfully.

At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

Distinctions between Levels I and II:

Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control, or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

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

Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

Distinctions between Levels II and III:

Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

Level III: Handles objects with difficulty; needs help to prepare and/or modify activities.

The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

Distinctions between Levels III and IV:

Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

Level IV: Handles a limited selection of easily managed objects in adapted situations.

Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity

Distinctions between Levels IV and V:

Children in Level IV perform part of an activity, however, they need help continuously. Children in Level V might at best participate with a simple movement in special situations, e.g. by pushing a button or occasionally hold undemanding objects.

Level V: Does not handle objects and has severely limited ability to perform even simple actions.

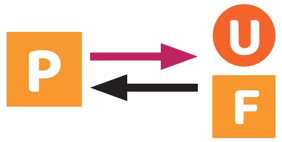
Requires total assistance.

Eliasson AC, Krumlinde Sundholm L, Rösblad B, Beckung E, Arner M, Öhrvall AM, Rosenbaum P. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability Developmental Medicine and Child Neurology 2006, updated 2010.

Appendix 3

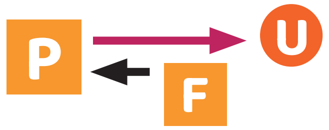
Communication Function Classification System (CFCS)

Level I - Effective Sender and Receiver with unfamiliar and familiar partners.
The person independently alternates between sender and receiver roles with most people in most environments. The communication occurs easily and at a comfortable pace with both unfamiliar and familiar conversational partners. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.



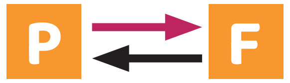
The difference between Levels I and II is the pace of the conversation. In Level I, the person communicates at a comfortable pace with little or no delay in order to understand, compose a message, or repair a misunderstanding. In Level II, the person needs extra time at least occasionally.

Level II - Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners. The person independently alternates between sender and receiver roles with most people in most environments, but the conversational pace is slow and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstanding are often repaired and do not interfere with the eventual effectiveness of the person's communication with both unfamiliar and familiar partners.



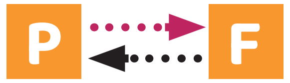
The differences between Levels II and III concern pace and the type of conversational partners. In Level II, the person is an effective sender and receiver with all conversational partners, but pace is an issue. In Level III, the person is consistently effective with familiar conversational partners, but not with most unfamiliar partners.

Level III - Effective Sender and Receiver with familiar partners.
The person alternates between sender and receiver roles with familiar (but not unfamiliar) conversational partners in most environments. Communication is not consistently effective with most unfamiliar partners, but is usually effective with familiar partners.



The difference between Levels III and IV is how consistently the person alternates between sender and receiver roles with familiar partners.In Level III, the person is generally able to communicate with familiar partners as a sender and as a receiver. In Level IV, the person does not communicate with familiar partners consistently. This difficulty may be in sending and/or receiving.

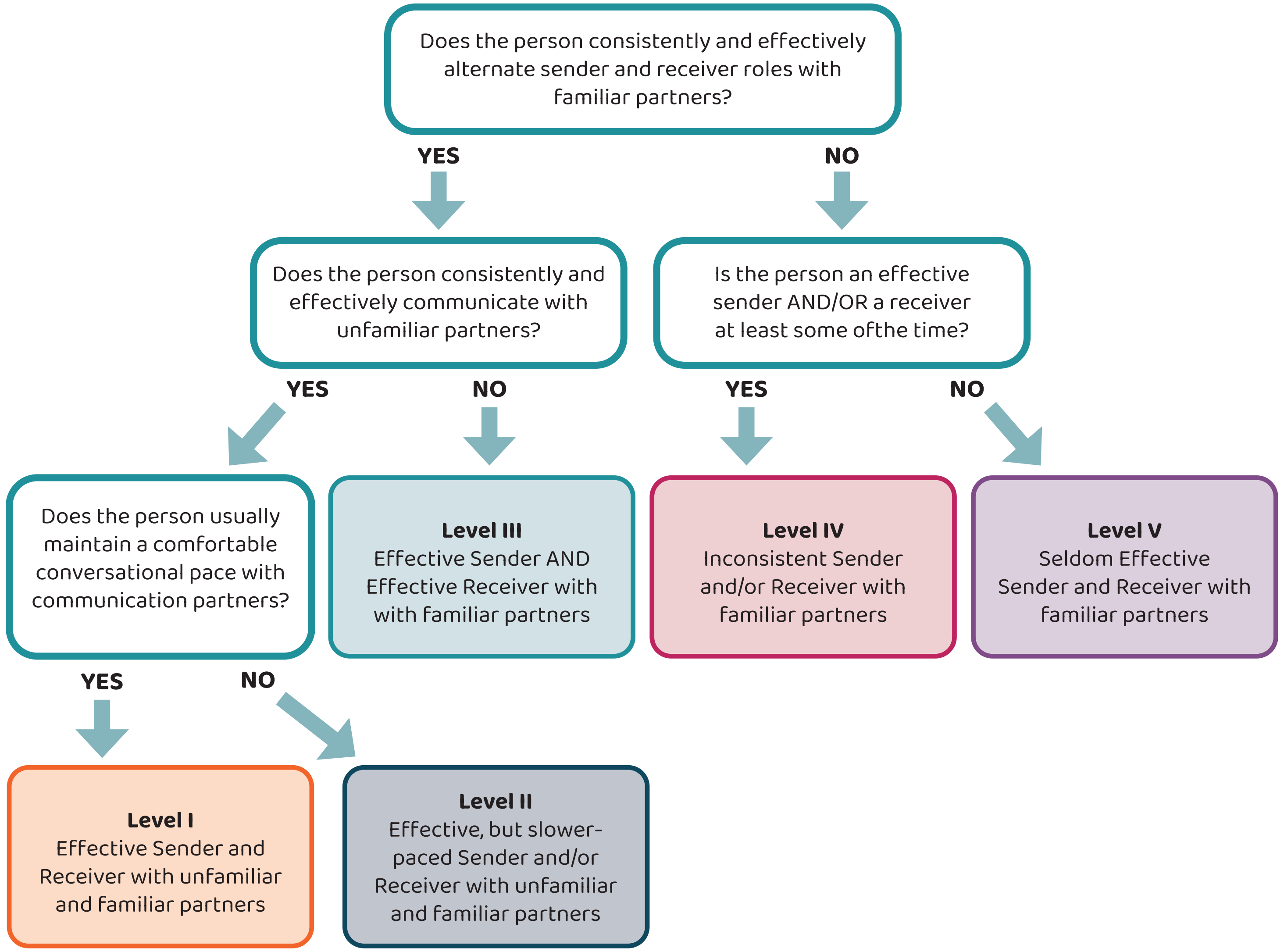
Level IV - Inconsistent Sender and/or Receiver with familiar partners. The person does not consistently alternate sender and receiver roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is sometimes effective with familiar partners.



The difference between Levels IV and V is the degree of difficulty that the person has when communicating with familiar partners. In Level IV, the person has some success as an effective sender and/or an effective receiver with familiar partners. In Level V, the person is rarely able to communicate effectively, even with familiar partners.

Level V - Seldom Effective Sender and Receiver even with familiar partners.
The person is limited as both a sender and a receiver. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is seldom effective even with familiar partners.

CFCS Level Identification Chart



Hidecker, M.J.C., Paneth, N., Rosenbaum, P.L., Kent, R.D., Lillie, J., Eulenberg, J.B., Chester, K., Johnson, B., Michalsen, L., Evatt, M., & Taylor, K. (2011). Developing and validating the Communication Function Classification System (CFCS) for individuals with cerebral palsy, Developmental Medicine and Child Neurology. 53(8), 704-710. doi: 10.1111/j.1469-8749.2011.03996.x, PMC3130799.

Appendix 4

Eating and Drinking Ability Classification System (EDACS) Levels

Level I: Eats and drinks safely and efficiently

- Eats a wide range of different texture foods that are age appropriate.
- May be challenged by some very firm bite and chew foods.
- Moves food from one side of the mouth to the other; may close lips whilst chewing.
- Drinks thin or thick fluids from range of cups with consecutive swallows, including through a straw.
- May cough or gag for very challenging textures.
- Eats and drinks at a similar speed to peers.
- Retains most food or fluid in the mouth.
- Clears food from most tooth surfaces and dislodges most foods from the sides of the mouth.

Distinctions between I and II:

Compared with Level I, individuals in Level II will have some limitation with more challenging food textures. Eating and drinking will take longer for individuals at Level II.

Level II: Eats and drinks safely but with some limitations to efficiency

- Eats a range of food textures that are age appropriate.
- Challenged by some firm bite, effortful chew, mixed and sticky textures.
- Moves food slowly from one side of the mouth to the other using the tongue.
- May chew with lips open.
- Drinks thin or thick fluids from most cups with consecutive swallows; may drink through a straw.
- Coughs or gags on new or challenging textures or when tiring.
- May sometimes cough if fluid is fast flowing or large quantity taken in the mouth.
- May tire if textures are challenging and mealtimes will take longer than for peers.
- Loses small amounts of food or fluid especially with challenging textures.
- Some food will collect on tooth surfaces and between cheeks and gums.

Distinctions between II and III:

Individuals in Level II manage most age-appropriate food textures and drink with some slight modifications. Individuals at Level III will need more food textures to be modified to reduce risk of choking.

Level III: Eats and drinks with some limitations to safety; may be limitations to efficiency

- Eats puree and mashed food and may bite and chew some soft chew food textures.
- Challenged by large lumps, firm bite and effortful chew textures which may lead to choking and reduced efficiency.
- It is challenging to move food from one side of the mouth to the other, to keep food in the mouth, and to bite and chew for safe eating.
- Eating and drinking performance is variable and depends upon overall physical ability, positioning or assistance given.
- May drink from an open cup but drinking from cup with a lid or spout may be required to control the flow of fluid.
- May drink thickened fluids more easily than thin and may need time between sips.
- May choose to drink only in certain situations such as with a trusted carer or with no distractions.
- Specific food textures and positioning of food in mouth are required to reduce the risk of choking.
- May cough or aspirate if fluid is fast flowing or a large quantity is taken in mouth.
- May tire whilst eating if food requires chewing and mealtimes will be prolonged.
- Food and fluid loss is likely and food will collect on tooth surfaces, roof of the mouth, and between cheeks and gums.

Distinctions between III and IV:

Individuals at Level III manage to chew soft lumps. Individuals at Level IV will need close attention given to several different factors to swallow food and drink safely because of the significant aspiration and choking risk.

Level IV: Eats and drinks with significant limitations to safety

- Eats smooth purees or well mashed food.
- Challenged by food that requires chewing; choking may occur if lumps are eaten.
- May at times be difficult to co-ordinate swallowing and breathing when eating and drinking as shown by signs of aspiration.
- It is challenging to control the movement of food and fluid in the mouth, to control mouth opening and closure, and to control swallowing, biting and chewing.
- May swallow lumps whole.
- May find it easier to drink thickened fluids than thin fluids; thickened fluids taken slowly and in small quantities from an open cup may increase control whilst drinking.
- May choose not to drink fluids or to drink only in certain situations such as with trusted carer.
- Likely to need time between mouthfuls to swallow repeatedly before continuing.
- Will require specific food textures, fluid consistency, techniques, skilled carers, positioning and modified environment to reduce risks of aspiration and choking and increase efficiency.
- May tire whilst eating and mealtimes are likely to be prolonged.
- Significant food and fluid loss from the mouth.
- Food may become stuck on tooth surfaces, roof of the mouth and between teeth and gums.
- Supplementary tube feeding may be considered.

Distinctions between IV and V:

Individuals at Level IV can swallow safely only if close attention is given to food texture and fluid consistency as well as the way in which food or drink is offered. Individuals at Level V cannot swallow safely. Taking food or drink into their mouths will cause harm.

Level V: Unable to eat or drink safely

- May manage very small tastes or flavors.
- Ability to manage small tastes and flavors will be affected by positioning, personal factors and environmental features.
- Unable to swallow food or drink safely due to limitations to the range and coordination of movement for swallowing and breathing.
- It is likely to be challenging to control mouth opening and tongue movement.
- Aspiration and choking are very likely.
- Harm from aspiration is evident.
- May require suction or medication to keep airway clear of secretions.
- Alternative means of providing nutrition such as tube feeding may be considered.

Sellers D, Mandy A, Pennington L, Hankins M and Morris C (2013). Development and reliability of a system to classify eating and drinking ability of people with cerebral palsy. Developmental Medicine and Child Neurology. 15(3):245-251. DOI: 10.1111/dmcn12352.

Your Care Team

Adaptive Equipment Specialist/ Vendor of Medical Equipment
Evaluates a patient's ability to use assistive technology devices; fits, fabricates or modifies equipment; and assesses equipment needs for home, work or school.

Audiologist
Provides customized hearing assessments and diagnostic testing.

Care Management
Provides a collaborative, family-centered process of care coordination, planning, and advocacy to support patients and their caregivers in managing complex health conditions. Care Management services are provided by a team of nurses, social workers and patient access specialists who work closely with your clinical team.

Complex Care
Focuses on centralizing and coordinating care for children and young adults who have chronic and complex medical conditions. We partner with you, your primary care provider and other specialty providers to help provide a comprehensive care plan. We work in tandem with primary care and other subspecialty providers to proactively meet care needs.

Child Life Specialist
Helps children cope with hospitalization and medical procedures through therapeutic play and child-appropriate hospital tours. Specialists also meet with siblings (to address their questions and concerns) and involve patients and siblings in activities.

Genetics
Genetic counseling helps families understand the risk of passing genetic disorders to your child, which genetic tests to consider, and how to make informed choices about complex conditions.

Developmental and Behavioral Pediatrician
Provides consultations for the evaluation and diagnosis of children with neurological developmental disabilities.

Neuropsychologist
Helps assess and treat developmental, medical, psychiatric, and neurological conditions or problems; might work with developmental pediatricians, pediatric neurologists, child psychiatrists, pediatricians, occupational therapists, and speech and language therapists.

Nurse
Provides care and comfort for patients and works together with other health care providers. Nurses also educate patients and families on diagnoses, medicines, procedures and tests in both the inpatient and outpatient settings.

Nurse Practitioner (NP)
Performs physical exams and diagnostic tests, counsels patients, and develops treatment programs.

Occupational Therapist
Evaluates a patient's fine motor skills, which might be limited due to spasticity or lack of motor control, and teaches patients how to use adaptive equipment for daily activities, such as feeding, dressing, writing, or accessing their environment. Occupational therapists also evaluate a patient's need for power mobility devices and assist patients with cognitive skills related to memory and independence.

Ophthalmologist
Specializes in medical and surgical eye problems and addresses eye diseases, visual development and vision. An ophthalmologist might do eye surgery to correct vision problems caused by conditions such as internal strabismus.

Orthotist
Designs, fabricates and fits a wide variety of orthoses (braces) for upper and lower limbs, the spine and the hips.

Pediatric Neurologist
Evaluates, diagnoses and treats neurological conditions. Pediatric neurologists manage seizures and collaborate with pediatric rehabilitation medicine physicians to recommend interventions for some associated conditions, such as learning, behavior and sensory issues.

Pediatric Neurosurgeon
Provides comprehensive surgical care for patients who have medical conditions that affect the spine, neck, nerves and/or brain. A pediatric neurosurgeon might perform surgeries such as selective dorsal rhizotomy or intrathecal baclofen pump implantation to reduce spasticity; implant shunts to reduce excessive fluid pressure in the brain; or implant vagus nerve stimulators to reduce the occurrence of seizures.

Pediatric Orthopedist
Examines a patient's bones, muscle structure and joint movements in relation to posture, function and gait. An orthopedist might perform surgery to improve the function of a child's legs or arms as he or she grows.

Pediatric Otolaryngologist (ENT)
Specializes in ear, nose and throat care, including surgical management of breathing and hearing disorders.

Pediatric Rehabilitation Medicine Physician
Specializes in rehabilitation services—including therapy, orthotics, and oral or injectable medicines—and recommends specialized equipment.

Physical Therapist
Evaluates patients' function and abilities; recommends treatments that improve gross motor skills and help prevent problems, such as muscle contractures and loss of strength. By monitoring range of motion, strength and functional ability, physical therapists help patients increase their independence and mobility. Physical therapists also help families obtain assistive equipment, such as lifting devices and standing frames.

Psychologist/Psychotherapist
Works with patients to diagnose and treat a wide range of psychological disorders as well as to assist with management of medical conditions. Provide psychotherapy to address a number of difficulties (e.g., anxiety, depression, adherence, adjustment to a medical diagnosis) as well as psychological testing to assess various areas of cognitive, emotional, and behavioral functioning.

Sleep Health Specialist
Evaluates and treats a range of sleep disorders. Testing may uncover coexisting conditions, such as seizures, that may accompany sleep issues.

Social Worker
Helps families determine strengths and needs, then identifies community resources for services that meet family needs; provides educational and emotional support to caregivers and families; helps families order special medical equipment; and assists with practical needs like lodging and transportation. Social workers also provide counseling for patients and families.

Speech and Language Pathologist
Evaluates a patient's ability to communicate, assesses swallowing disorders, and recommends ways to promote safe eating and drinking. Speech and language pathologists also might evaluate a patient's need for augmentative communication devices and help select appropriate equipment.

Therapeutic Recreation Specialist
Assesses the capabilities of patients and recommends programs to help develop healthy leisure lifestyles. Therapeutic recreation specialists provide leisure education, help develop leisure skills, and work with community resources to help patients increase their participation in recreational activities.

VISION

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Mailing Address:

200 University Ave. E.
St. Paul, MN 55101

To see all of our clinic locations, visit gillettechildrens.org/locations

Patient Appointments

651-290-8707 / 800-719-4040

Provider Referrals & Consultations

651-325-2200 / 855-325-2200

Gillette Children's is a global beacon of care for patients with brain, bone and movement conditions that start in childhood. Our research, treatment and supportive technologies enable every child to lead a full life defined by their dreams, not their diagnoses. Founded in 1897, Gillette collaborates with patients, families and our partners in clinical leadership, research and advocacy to set the standard of care and opportunity for children with complex medical challenges. To learn more about Gillette, visit **gillettechildrens.org**.