# Cerebral Palsy Road Map:

What to Expect as Your Child Grows



AWARN



To help you understand what having cerebral palsy means for your child, Gillette Children's Specialty Healthcare 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 offers comprehensive, coordinated care that can reduce the effect of cerebral palsy on people's lives. Our medical and rehabilitation specialists provide a broad range of services to meet the needs of children, teens and adults. We work closely with patients and families to develop comprehensive treatment plans.

Because cerebral palsy requires lifelong management and care, we offer assistance when it is time for teens to move to adult care. We provide services for adults at Gillette's adult clinic.



### 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 the abilities 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 pages 4 and 5. 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

- Hypotonia: Arms and legs seem floppy and don't resist movement (low muscle tone).
- Rigidity: Muscles in legs and arms are extremely tight and resist movement, regardless of how quickly or forcefully a person moves.
- 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.

### 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:

- Hemiplegia: The arm and leg on one side are the primary body parts affected. (See below for more about hemiplegia.)
- 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.

### 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.
- Develop impairments in the less involved/uninvolved extremities because they are compensating for the involved extremity.
- 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.

### **Classification Systems**

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

### Manual Ability Classification System (MACS)

Some of our Gillette therapists and other health care providers use the Manual Ability Classification System (MACS) to discuss how people with cerebral palsy use their hands to handle objects in daily activities. For more information about the MACS, see Page 34 in the Glossary.

### Gross Motor Function Classification System (GMFCS)

Gillette'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.

### GMFCS

### 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.

### 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.

### 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.

# 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.

### 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.







# 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	<ul> <li>Moving in and out of sitting, standing positions without help</li> <li>Able to balance while sitting and using both hands to play</li> <li>Crawling on hands and knees</li> <li>Pulling to stand</li> <li>Taking steps while hanging on to furniture, caregivers</li> <li>Walking unassisted by 18 to 24 months old; starting to prefer to move around by walking</li> </ul>	<ul> <li>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)</li> <li>Feeling stiffness in forearm muscles (if hemiplegia is present)</li> <li>Toe-walking or in-toeing</li> </ul>
11	<ul> <li>Able to get in and out of sitting positions on own</li> <li>Having difficulty with balance while sitting and using both hands to play</li> <li>Crawling on stomach or on hands and knees</li> <li>Pulling to stand and cruising by holding on to furniture</li> <li>Delayed in taking steps</li> <li>Preferring to move by walking, but might need a walking aid</li> </ul>	<ul> <li>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)</li> <li>Feeling stiffness in forearm muscles (if hemiplegia is present)</li> <li>Toe-walking or in-toeing</li> </ul>
	<ul> <li>Rolling or belly-crawling to get around</li> <li>Pulling to a stand and cruising short distances by holding on to furniture</li> <li>Needing help to sit; if sitting on own, usually prefers "w-sitting" because it leaves hands free to play with toys</li> <li>Walking with a mobility device, such as walker; needing help to steer and turn</li> </ul>	<ul> <li>Struggling to control movement of legs because of impairment with legs, including hips</li> <li>Struggling to control movement of arms</li> <li>Experiencing increased tightness in legs (which might occur with other movement disorders such as athetosis or dystonia)</li> <li>Toe-walking, in-toeing, scissoring and experiencing stiffness of knees</li> <li>Experiencing poor pelvis positioning and hip instability</li> </ul>
IV	<ul> <li>Rolling or belly-crawling to move around</li> <li>Using supportive equipment to sit and/or stand</li> <li>Using hands for support to sit without equipment</li> </ul>	<ul> <li>Struggling to control movement of legs because of impairment with legs, including hips</li> <li>Struggling to control movement of arms</li> <li>Experiencing leg and arm spasticity, but legs likely more involved</li> <li>Experiencing other movement disorders (athetosis or dystonia)</li> <li>Experiencing muscle contractures that restrict range of motion</li> <li>* Experiencing hip subluxation/dislocation, long bone torsion or foot deformities</li> </ul>
V	<ul> <li>Having difficulty controlling head and trunk stability in most positions</li> <li>Moving around only with assistance or adaptive equipment</li> </ul>	<ul> <li>Unable to control movement of arms and legs</li> <li>Experiencing spasticity and other types of tone/movement disorders in arms and legs, likely more significant in legs</li> <li>Experiencing muscle contractures that restrict the range of motion of the joints, especially in legs</li> <li>Experiencing hip subluxation/dislocation and/or foot deformities</li> </ul>

Level	Communication and Cognition	Feeding and Nutrition
	Your child might be:	Your child might be:
I	<ul> <li>Cooing and starting to speak in words and sentences</li> <li>Turning to sounds</li> <li>Starting to understand, follow directions</li> <li>Reaching, grasping and starting to point to and select objects</li> <li>Using eye contact, eye gazing and facial expressions to communicate</li> </ul>	<ul> <li>Transitioning gradually from breast milk or formula to solid foods</li> <li>Transitioning from bottle to cup and self-feeding</li> <li>Needing supervision when feeding</li> <li>Experiencing a delay in self-feeding</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> </ul>
-	<ul> <li>Cooing and starting to speak in words and sentences</li> <li>Turning to sounds and voices</li> <li>Understanding and following directions</li> <li>Reaching, grasping, pointing and selecting objects</li> <li>Using eye contact, eye gazing and facial expressions to communicate</li> <li>Experiencing slow speech development; requiring support such as pictures, gestures and signing</li> <li>Needing assistance to listen and make choices</li> <li>Experiencing a delay in intellectual development</li> </ul>	<ul> <li>Experiencing a delay in self-feeding</li> <li>Struggling with feeding if experiencing oral muscle weakness, tightness and incoordination</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> <li>Experiencing constipation, especially when mobility and/or diet are limited</li> </ul>
IV- V	<ul> <li>Using eye contact, eye gazing and facial expressions to communicate</li> <li>Experiencing slow speech development</li> <li>Difficult to understand; requiring support such as pictures, gestures and signing</li> <li>Needing assistance to listen and make choices</li> <li>Experiencing a delay in intellectual development</li> </ul>	<ul> <li>Experiencing a delay in self-feeding</li> <li>Struggling with feeding if experiencing oral muscle weakness, tightness, and incoordination</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> <li>Unable to eat foods with particular textures</li> <li>Experiencing constipation, especially when mobility and/or diet are limited</li> <li>Experiencing choking or reflux</li> <li>Having difficulty controlling head and body postures that might affect chewing and swallowing</li> </ul>

### Infant and Toddler (0 to 3) continued

Level	Social/Emotional Development and Behavior	Self-Care and Daily Living Skills
	Your child might be:	Your child might be:
I	<ul> <li>Smiling, interacting with family members and peers</li> <li>Crying easily when frustrated</li> <li>Relying on caregivers to maximize physical comfort and provide support during medical procedures; using child life specialists when needed</li> <li>Experiencing a delay in social and emotional development, such as controlling emotional reactions</li> </ul>	<ul> <li>Maintaining a sitting position for feeding</li> <li>Feeding self (holding a bottle) at 6 months old (extra support or positioning might be needed)</li> <li>Needing assistance to unfasten clothing, but able to remove clothing</li> <li>Pushing arms and legs through clothing to get dressed/undressed</li> <li>Beginning to assist with washing hands and body</li> </ul>
- 	<ul> <li>Smiling, interacting with family and peers</li> <li>Crying easily when frustrated</li> <li>Relying on caregivers to maximize physical comfort and provide support during medical procedures; using child life specialists when needed</li> <li>Experiencing a delay in social and emotional development, such as controlling emotional reactions</li> </ul>	<ul> <li>Struggling to coordinate actions of both hands (such as holding a bottle)</li> <li>Using supportive equipment when getting dressed and undressed</li> </ul>
IV- V	<ul> <li>Smiling, interacting with family members and peers</li> <li>Relying on caregivers to maximize physical comfort and provide support during medical procedures; using child life specialists when needed</li> <li>Experiencing a delay in social and emotional development, such as controlling emotional reactions</li> </ul>	<ul> <li>Needing complete positioning assistance from caregivers to complete feeding and dressing</li> <li>Using adaptive seating systems for toileting and bathing in order to stay in a safe sitting position</li> </ul>

Sensory Functions	Recreation and Fitness
Your child might be:	Your child might be:
<ul> <li>Experiencing normal hearing and vision (screening is essential)</li> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Struggling with speech development (hearing assessment is essential)</li> </ul>	<ul> <li>Interacting with cause-and-effect toys (anything that makes a sound or movement based on a child's action)</li> <li>Bouncing, climbing, swinging and sliding</li> </ul>
<ul> <li>Experiencing normal vision (screening is essential)</li> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Struggling to hear nearby sounds (hearing assessment is essential)</li> <li>Experiencing distress from ordinary stimuli, especially sounds or touching things (sensory integration disorder)</li> </ul>	<ul> <li>Interacting with cause-and-effect toys (anything that makes a sound or movement based on a child's action)</li> <li>Initiating bouncing, climbing, swinging and sliding but needing assistance</li> </ul>
<ul> <li>Experiencing normal vision (screening is essential)</li> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Experiencing difficulty with fixing on and following something with the eyes (cortical vision impairment)</li> <li>Struggling to hear nearby sounds (hearing assessment is essential)</li> <li>Experiencing distress from ordinary stimuli, especially sounds or touching things (sensory integration disorder)</li> </ul>	<ul> <li>Interacting with cause-and-effect toys (anything that makes a sound or movement based on a child's action)</li> <li>Enjoying bouncing and swinging; unable to initiate movements</li> </ul>

## Infant and Toddler (0 to 3) continued

Level	Evaluations and Assessments	Interventions	
	Your care team might recommend:	Your care team might recommend:	1
	<ul> <li>Physical examination, medical history and developmental assessments of mobility, communication and fine motor skills (functional status)</li> <li>Imaging studies, such as an MRI or CT scan, to determine the cause of cerebral palsy or area of injury to the brain</li> <li>X-ray of pelvis at 12 months of age and at age 3 to look for subluxation/dislocation</li> <li>Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing and pain</li> <li>Genetic evaluation</li> <li>Appointments with key providers every 3 months or so</li> </ul>	<ul> <li>Treatments to improve mobility, communication and fine motor skills, and to prevent or correct deformity</li> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Collaboration with your school district or early intervention services</li> <li>Child life support during procedures</li> <li>Social work help with resources, grief</li> </ul>	
- 	<ul> <li>Physical examination, medical history and developmental assessments of mobility, communication and fine motor skills (functional status)</li> <li>Imaging studies, such as an MRI or CT scan, to determine the cause of cerebral palsy or area of injury to the brain</li> <li>X-ray of pelvis at 12 months of age and every 6 to 12 months thereafter to look for subluxation/dislocation</li> <li>Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing, and pain</li> <li>Genetic evaluation</li> <li>Appointments with key providers every 3 months or so</li> </ul>	<ul> <li>Treatments to improve mobility, communication and fine motor skills, and to prevent or correct deformity</li> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Collaboration with your school district or early intervention services</li> <li>Orthotics to maintain alignment and provide stability to a joint (usually for feet/ankles and hands/wrists)</li> <li>Adaptive equipment for mobility (such as a walker) and positioning (such as a car seat)</li> <li>Child life support during procedures</li> <li>Social work help with resources, grief</li> </ul>	Care Team Key providers are in bold. Adaptive Equipment Specialist/Vendor of Medical Equipment Audiologist Child Life Specialist Neurodevelopmental Pediatrician Neuropsychologist Nurse Nurse Nurse Practitioner Orthotist
IV- V	<ul> <li>Physical examination, medical history and developmental assessments of mobility, communication and fine motor skills (functional status)</li> <li>Imaging studies, such as an MRI or CT scan, to determine the cause of cerebral palsy or area of injury to the brain</li> <li>X-ray of pelvis at 12 months of age and every 6 to 12 months thereafter to look for subluxation/dislocation</li> <li>Screening of vision, hearing, growth, nutrition, bowel, bladder, sleep, swallowing and pain</li> <li>Genetic evaluation</li> <li>Appointments with key providers every 3 months or so</li> </ul>	<ul> <li>Treatments to improve mobility, communication and fine motor skills, and to prevent or correct deformity</li> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Collaboration with your school district or early intervention services</li> <li>Orthotics to maintain alignment and provide stability to a joint (usually for feet/ankles and hands/wrists)</li> <li>Equipment for bathing</li> <li>Adaptive equipment for mobility (such as a walker or stroller) and positioning (such as a car seat)</li> <li>Child life support during procedures</li> </ul>	Orthotist Pediatric Neurologist Pediatric Neurosurgeon Pediatric Orthopedist Pediatric Rehabilitation Medicine Physician Psychologist Sleep Health Specialist Social Worker Therapeutic Recreation Specialist Therapists – Occupational Therapist Physical Therapist Speech and Language Pathologist

# Early Childhood (4 to 7)

## Early Childhood (4 to 7)

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

Level	Communication and Cognition	Feeding and Nutrition
	Your child might be:	Your child might be:
I	<ul> <li>Communicating effectively</li> <li>Carrying out multistep directions</li> <li>Communicating independently to a variety of people in a variety of settings</li> <li>Using language to recite ABCs, colors, etc.</li> <li>Starting and continuing social interactions</li> <li>Demonstrating generally typical language skills and intellectual development</li> <li>Having attention problems</li> </ul>	<ul> <li>Feeding himself or herself</li> <li>Needing supervision during meals (caregivers encourage healthy food choices and monitor growth)</li> </ul>
- 	<ul> <li>Communicating effectively in some to most situations (independently communicating a small range of topics to familiar people but not able to communicate a wide variety of messages/topics to familiar and unfamiliar people)</li> <li>Using language to recite ABCs, colors, etc.</li> <li>Starting and continuing social interactions</li> <li>Able to express needs and wants through speech/ gesture/facial expression</li> <li>Experiencing a delay in intellectual development</li> <li>Having attention problems</li> <li>Needing support to communicate with unfamiliar listeners</li> </ul>	<ul> <li>Struggling with feeding if he or she has oral muscle weakness, tightness and incoordination</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> <li>Unable to eat foods with particular textures</li> <li>Having constipation, especially when mobility and/or diet are limited</li> </ul>
IV- V	<ul> <li>Needing assistance in many situations, especially with unfamiliar people and environments</li> <li>Communicating routine needs and wants to familiar people</li> <li>Able to attract attention of a person with whom he or she is familiar to interpret communication</li> <li>Accepting, rejecting/refusing and/or protesting choices through body movements or vocalizations</li> <li>Responding to familiar voices and sounds with body movement, facial expression and voice</li> <li>Anticipating activities, routines</li> <li>Needing support to communicate with unfamiliar listeners</li> <li>Needing support to use language to recite ABCs, colors, etc.</li> <li>Needing support to start and continue social interaction</li> <li>Experiencing a delay in intellectual development</li> </ul>	<ul> <li>Experiencing difficulty feeding and swallowing</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> <li>Experiencing choking or reflux</li> <li>Having constipation, especially when mobility and/or diet are limited</li> </ul>

## Early Childhood (4 to 7) continued

Level	Social/Emotional Development and Behavior	Self-Care and Daily Living Skills
	Your child might be:	Your child might be:
I	<ul> <li>Thinking cerebral palsy is reversible or a punishment</li> <li>Having magical, egocentric thoughts</li> <li>Needing to be with caregivers as much as possible</li> <li>Feeling resentment of self or others</li> <li>Having attention problems</li> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Socially immature and preferring the company of younger children</li> <li>Needing help regulating behavior</li> <li>Needing support to initiate and continue social interaction</li> </ul>	<ul> <li>Feeding self in most situations; having challenges when in stressful situations, such as an unfamiliar environment</li> <li>Dressing self if able to use hands during daily activities</li> <li>Learning from repetition of movements necessary for dressing (such as holding with one hand and pulling or pushing with the other hand)</li> <li>Washing hands and face, bathing body, brushing teeth, toileting, and washing hair</li> </ul>
- 	<ul> <li>Thinking cerebral palsy is reversible or a punishment</li> <li>Having magical, egocentric thoughts</li> <li>Needing to be with caregivers as much as possible</li> <li>Feeling resentment of self or others</li> <li>Having attention problems</li> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Socially immature and preferring the company of younger children</li> <li>Needing help regulating behavior</li> <li>Needing support to initiate and continue social interaction</li> </ul>	<ul> <li>Using alternative strategies and adaptations or assistance with self-care skills</li> <li>Using adapted feeding utensils, needing help with cutting or serving food</li> <li>Learning from practicing dressing skills in many different settings</li> <li>Dressing self if able to maintain sitting balance and trunk control</li> <li>Struggling with fasteners such as snaps, zippers and buttons</li> <li>Needing assistance with washing hands and face, bathing body, brushing teeth, toileting, and washing hair</li> </ul>
IV- V	<ul> <li>Demonstrating disruptive and uncooperative behaviors</li> <li>Withdrawing from others</li> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Needing support to initiate and continue social interaction</li> <li>At risk for self-injurious behaviors or aggressive behaviors</li> </ul>	<ul> <li>Using adapted tools to get food on a spoon, move food toward mouth and make similar motions</li> <li>Eating best with highly motivating foods that are easier to manage (such as foods that stick to a spoon, like pudding)</li> <li>Using a communication device or switches to tell caregivers what foods he or she likes or dislikes</li> <li>Needing assistance to use fingers for feeding</li> <li>Doing simple dressing tasks on own (such as removing a hat), but dependent for most dressing tasks</li> <li>Needing assistance with washing hands and face, bathing body, brushing teeth, toileting, and washing hair</li> </ul>

Sensory Functions	Recreation and Fitness
Your child might be:	Your child might be:
<ul> <li>Experiencing normal hearing and vision (screening is still essential)</li> <li>Struggling with speech development (hearing assessment is essential)</li> </ul>	<ul> <li>Participating in imaginative play</li> <li>Starting to share, engage and interact with children of the same age</li> <li>Interacting with hands-on toys, riding toys and action games</li> <li>Hopping, skipping, jumping, throwing and catching</li> <li>Seeking play options that offer a sense of independence</li> <li>Attempting to throw and catch larger, light objects with assistance</li> </ul>
<ul> <li>Experiencing normal hearing and vision (screening is still essential)</li> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Struggling to interpret visual information as it relates to space (visual-spatial learning disability)</li> <li>Struggling with speech development (hearing assessment is essential)</li> <li>Not using involved arm because of sensory issues</li> <li>Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder)</li> </ul>	<ul> <li>Participating in imaginative play</li> <li>Starting to share, engage, interact with children of the same age</li> <li>Interacting with hands-on toys, riding toys and action games</li> <li>Struggling with activities that require fine motor skills, such as crafts or board games</li> <li>Attempting hopping, skipping and jumping, but might not be fully successful</li> <li>Seeking play options that offer a sense of independence</li> <li>Attempting to throw and catch larger, light objects with assistance</li> </ul>
<ul> <li>Experiencing normal hearing and vision (screening is still essential)</li> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Having difficulty fixing on and following something with the eyes (cortical vision impairment)</li> <li>Struggling to interpret visual information as it relates to space (visual-spatial learning disability)</li> <li>Struggling to hear sounds (hearing assessment is essential)</li> <li>Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder)</li> <li>Experiencing significant sensory impairments with sight, hearing, smell, touch, taste or spatial awareness</li> </ul>	<ul> <li>Starting to share, engage, interact with other children</li> <li>Interacting with cause-and-effect toys (anything that makes a sound or movement based on a child's action)</li> </ul>

### Early Childhood (4 to 7) continued

Level	Evaluations and Assessments	Interventions	
	Your care team might recommend:	Your care team might recommend:	
I	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>X-ray of pelvis at age 5</li> <li>Appointments with key providers every 6 months to watch development, reduce deformities</li> <li>Spasticity management with gait analysis and physical therapy to assess muscle tone</li> <li>Referrals to neurodevelopmental pediatrics/ psychology/neuropsychology for learning or behavior problems</li> <li>Meeting with a social worker for mental health support and resources</li> </ul>	<ul> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Selective dorsal rhizotomy surgery or orthopedic surgery</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation</li> </ul>	
11- 111	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>X-ray of pelvis every 6 to 12 months</li> <li>Appointments with key providers every 6 months to watch development, reduce deformities</li> <li>Spasticity management with gait analysis and physical therapy to assess muscle tone</li> <li>Referrals to neurodevelopmental pediatrics/ psychology/neuropsychology for learning or behavior problems</li> <li>Meeting with a social worker for mental health support and resources</li> <li>Assessment of sleep problems</li> </ul>	<ul> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Selective dorsal rhizotomy surgery or orthopedic surgery</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation therapies</li> <li>Adaptive equipment for mobility (walker or a wheelchair) and positioning (car seat)</li> <li>Alternative or augmentative communication devices or methods</li> </ul>	Care Team Key providers are in bold. Adaptive Equipment Specialist/Vendor of Medical Equipment Audiologist Child Life Specialist Neurodevelopmental Pediatrician Neuropsychologist
IV- V	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>X-ray of pelvis every 6 to 12 months</li> <li>Appointments with key providers every 6 months to watch development, reduce deformities</li> <li>Spasticity management to assess muscle tone</li> <li>Referrals to neurodevelopmental pediatrics/ psychology/neuropsychology for learning or behavior problems</li> <li>Meeting with a social worker for mental health support and resources</li> <li>Assessment of sleep problems</li> <li>Evaluation for assistive technology devices, such as power mobility or augmentative and alternative communication devices</li> <li>Evaluation of bowel and bladder function</li> </ul>	<ul> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Intrathecal baclofen pump to reduce spasticity</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Orthopedic surgery to correct a hip dislocation or other deformities</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation therapies</li> <li>Adaptive equipment for mobility (walker, stroller or wheelchair) and positioning (car seat)</li> <li>Adaptive seating, with support as needed</li> <li>Equipment for bathing and/or toileting</li> <li>Van for transportation</li> <li>Alternative or augmentative communication devices or methods</li> </ul>	Nurse Nurse Practitioner Opthalmologist Orthotist Pediatric Neurologist Pediatric Neurosurgeon Pediatric Orthopedist Pediatric Rehabilitation Medicine Physician Psychologist Sleep Health Specialist Social Worker Therapeutic Recreation Specialist Therapists – Occupational Therapist Physical Therapist Speech and Language Pathologist

# Middle Childhood (8 to 12)

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### Middle Childhood (8 to 12)

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

Level	Communication and Cognition	Feeding and Nutrition
	Your child might be:	Your child might be:
I	<ul> <li>Using language to learn</li> <li>Using stories to describe, contrast and compare</li> <li>Communicating by speaking and writing</li> <li>Using complex language structures</li> <li>Having generally typical language skills and intellectual development</li> <li>Having attention problems</li> <li>Easily overwhelmed</li> <li>Struggling to manage expectations</li> <li>Experiencing learning disabilities</li> </ul>	<ul> <li>Feeding himself or herself</li> <li>Learning how to cook</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> </ul>
- 	<ul> <li>Using language to learn</li> <li>Carrying out multistep directions</li> <li>Using stories to describe, contrast and compare</li> <li>Communicating by speaking and writing</li> <li>Using complex language structures</li> <li>Having attention problems</li> <li>Experiencing learning disabilities or delayed intellectual development</li> <li>Struggling with speech and writing</li> <li>Using technology to communicate more independently</li> <li>Easily overwhelmed</li> <li>Struggling to manage expectations</li> </ul>	<ul> <li>Struggling with feeding if he or she has oral muscle weakness, tightness, and incoordination</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> <li>Unable to eat foods with particular textures</li> <li>Having constipation, especially when mobility and/or diet are limited</li> </ul>
IV- V	<ul> <li>Needing assistance in many situations, especially with unfamiliar people and environments</li> <li>Demonstrating speech and muscle coordination problems that affect communication</li> <li>Using speech, gesture, facial expression or augmented communication</li> <li>Experiencing learning disabilities</li> <li>Experiencing a delay in intellectual development</li> </ul>	<ul> <li>Having difficulty feeding and swallowing</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> <li>Experiencing choking or reflux</li> <li>Having constipation, especially when mobility and/or diet are limited</li> <li>Gaining too much weight due to an inactive lifestyle</li> </ul>

### Middle Childhood (8 to 12) continued

Level	Social/Emotional Development and Behavior	Self-Care and Daily Living Skills
	Your child might be:	Your child might be:
I	<ul> <li>Focusing on facts versus abstract thinking</li> <li>Understanding the condition is not reversible</li> <li>Starting a grieving process</li> <li>Experiencing fears of loneliness and abandonment</li> <li>Having attention problems</li> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Socially immature and preferring the company of younger children</li> <li>Struggling to interpret social cues</li> <li>Needing help managing behavior and emotional reactions</li> </ul>	<ul> <li>Doing many self-care skills, such as dressing and eating on own</li> <li>Needing more time than peers to learn skills (such as zipping coat, managing backpacks, or changing clothes quickly for activities, such as swimming lessons)</li> </ul>
- 	<ul> <li>Focusing on facts versus abstract thinking</li> <li>Understanding the condition is not reversible</li> <li>Starting a grieving process</li> <li>Experiencing fears of loneliness and abandonment</li> <li>Having attention problems</li> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Socially immature and preferring the company of younger children</li> <li>Struggling to interpret social cues</li> <li>Needing help managing behavior and emotional reactions</li> </ul>	<ul> <li>Needing assistance with cutting food</li> <li>Eating food independently if the environment is arranged to meet needs</li> <li>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</li> </ul>
IV- V	<ul> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Demonstrating disruptive and uncooperative behaviors</li> <li>Withdrawing from others</li> <li>At risk for self-injurious behaviors or aggressive behaviors</li> </ul>	<ul> <li>Needing adequate posture support to use hands while eating</li> <li>Requiring total assistance from caregivers to complete feeding and dressing tasks</li> <li>Learning parts of some dressing skills, such as offering a hand or foot when getting clothes or shoes on</li> <li>More likely to have casts and/or braces due to increased stiffness in muscles</li> </ul>

Sensory Functions	Recreation and Fitness
Your child might be:	Your child might be:
<ul> <li>Experiencing normal hearing and vision (screening still essential)</li> <li>Experiencing a change in speech or language abilities (hearing re-evaluation is essential)</li> </ul>	<ul> <li>Participating in supportive play that includes cooperation and compromise</li> <li>Identifying preferences for specific sports, types of music, books and movies</li> <li>Playing team and competitive sports, perhaps with adaptive equipment and modified participation</li> <li>Seeking play options that offer a sense of independence</li> </ul>
<ul> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Experiencing difficulty with fixing on and following some- thing with the eyes (cortical vision impairment)</li> <li>Struggling to interpret visual information as it relates to space (visual-spatial learning disability)</li> <li>Struggling with speech development (hearing assessment is essential)</li> <li>Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder)</li> <li>Not using involved arm because of sensory issues</li> </ul>	<ul> <li>Participating in supportive play that includes cooperation and compromise</li> <li>Identifying preferences for specific sports, types of music, books and movies</li> <li>Struggling with activities that require fine motor skills, such as crafts or board games</li> <li>Playing team and competitive sports using adaptive sports equipment and with modified participation</li> <li>Seeking play options that offer a sense of independence</li> </ul>
<ul> <li>Experiencing normal hearing and vision (screening is still essential)</li> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Experiencing difficulty with fixing on and following something with the eyes (cortical vision impairment)</li> <li>Struggling with speech development (hearing assessment is essential)</li> <li>Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder)</li> <li>Experiencing significant sensory impairments with sight, hearing, smell, touch, taste or spatial awareness</li> </ul>	<ul> <li>Playing with hand-over-hand assistance</li> <li>Socializing and interacting through adapted programs and camps</li> <li>Interacting with cause-and-effect toys (anything that makes a sound or movement based on child's action)</li> <li>Identifying preferences for specific sports, types of music, books and movies</li> <li>Using highly adapted sport options that provide hand-over-hand or full assistance</li> </ul>

### Middle Childhood (8 to 12) continued

Level	Evaluations and Assessments	Interventions	
	Your care team might recommend:	Your care team might recommend:	
1	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>Clinical examination of hips, possibly with an X-ray</li> <li>Appointments with key providers every 6 to 12 months to watch development, reduce deformities</li> <li>Referrals to neurodevelopmental pediatrics/ psychology/neuropsychology for learning or behavior problems</li> <li>Meeting with a social worker for mental health support and resources</li> </ul>	<ul> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Selective dorsal rhizotomy surgery or orthopedic surgery to correct skeletal deformities</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation</li> </ul>	
- 	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>X-ray of pelvis at 8 to 10 years of age and every 12 months until skeletal maturity</li> <li>Screening for spinal deformity</li> <li>Appointments with key providers every 6 to 12 months to watch development, reduce deformities</li> <li>Spasticity management to assess muscle tone</li> <li>Referrals to neurodevelopmental pediatrics/psychology/neuropsychology for learning or behavior problems</li> <li>Meeting with a social worker for mental health support and resources</li> <li>Assessment of sleep problems</li> </ul>	<ul> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Selective dorsal rhizotomy surgery or intrathecal baclofen pump</li> <li>Orthopedic surgery to correct skeletal deformities</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation therapies</li> <li>Adaptive equipment for mobility (walker or a wheelchair)</li> <li>Alternative or augmentative communication devices or methods</li> <li>Bracing to control a spinal deformity</li> </ul>	Care Team Key providers are in bold. Adaptive Equipment Specialist/Vendor of Medical Equipment Audiologist Child Life Specialist Neurodevelopmental Pediatrician Neuropsychologist/ Psychologist
IV- V	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>X-ray of pelvis at 8 to 10 years of age and every 6 to 12 months until skeletal maturity</li> <li>X-ray of spine</li> <li>Appointments with key providers every 6 to 12 months to watch development, reduce deformities</li> <li>Spasticity management with gait analysis and physical therapy to assess muscle tone</li> <li>Referrals to neurodevelopmental pediatrics/ psychology/neuropsychology for learning or behavior problems</li> <li>Meeting with a social worker for mental health support and resources</li> <li>Assessment of sleep problems</li> <li>Evaluation of muscle tone</li> <li>Assessment of bone health</li> <li>Evaluation of bowel and bladder function</li> </ul>	<ul> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Intrathecal baclofen pump to reduce spasticity</li> <li>Orthopedic surgery to correct hip dislocation or other deformities</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation</li> <li>Adaptive equipment for mobility (walker or wheelchair)</li> <li>Adaptive seating, with support as needed</li> <li>Equipment for bathing and/or toileting</li> <li>Modifications to your child's home or school environment</li> <li>Alternative or augmentative communication devices or methods</li> <li>Bracing to manage a spinal deformity</li> </ul>	Nurse Nurse Practitioner Opthalmologist Orthotist Pediatric Neurologist Pediatric Neurosurgeon Pediatric Orthopedist Pediatric Rehabilitation Medicine Physician Psychologist Sleep Health Specialist Social Worker Therapeutic Recreation Specialist Therapists – Occupational Therapist Physical Therapist Speech and Language Pathologist

# Adolescence (13 to 18)

### Adolescence (13 to 18)

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

Level	Communication and Cognition	Feeding and Nutrition
	Your child might be:	Your child might be:
I	<ul> <li>Using language to learn</li> <li>Using stories to describe, contrast and compare</li> <li>Communicating by speaking and writing</li> <li>Using complex language structures</li> <li>Having generally typical language skills and intellectual development</li> <li>Having attention problems</li> <li>Easily overwhelmed</li> <li>Struggling to manage expectations</li> <li>Experiencing learning disabilities</li> </ul>	<ul> <li>Feeding himself or herself</li> <li>Learning how to cook</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> </ul>
- 	<ul> <li>Using language to learn</li> <li>Carrying out multistep directions</li> <li>Using stories to describe, contrast and compare</li> <li>Communicating by speaking and writing</li> <li>Using complex language structures</li> <li>Having attention problems</li> <li>Experiencing learning disabilities or delayed intellectual development</li> <li>Struggling with speech and writing</li> <li>Using technology to communicate more independently</li> <li>Easily overwhelmed</li> <li>Struggling to manage expectations</li> </ul>	<ul> <li>Struggling with feeding if he or she has oral muscle weakness, tightness, and incoordination</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> <li>Unable to eat foods with particular textures</li> <li>Having constipation, especially when mobility and/or diet are limited</li> </ul>
IV- V	<ul> <li>Needing assistance in many situations, especially with unfamiliar people and environments</li> <li>Demonstrating speech and muscle coordination problems that need communication</li> <li>Using speech, gestures, facial expressions or augmented or alternative communication devices</li> <li>Experiencing learning disabilities</li> <li>Experiencing a delay in intellectual development</li> </ul>	<ul> <li>Having difficulty feeding and swallowing</li> <li>Having difficulty gaining weight (caregivers encourage healthy food choices and monitor growth)</li> <li>Experiencing choking or reflux</li> <li>Having constipation, especially when mobility and/or diet are limited</li> <li>Gaining too much weight due to an inactive lifestyle</li> </ul>

# Adolescence (13 to 18) continued

Level	Social/Emotional	Self-Care and
Level	Development and Behavior	Daily Living Skills
	Your child might be:	Your child might be:
	<ul> <li>Focusing on facts versus abstract thinking</li> <li>Understanding the condition is not reversible</li> <li>Starting a grieving process</li> <li>Experiencing fears of loneliness and abandonment</li> <li>Having attention problems</li> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Socially immature and preferring the company of younger children</li> <li>Struggling to interpret social cues</li> <li>Needing help managing behavior and emotional reactions</li> </ul>	<ul> <li>Doing many self-care skills, such as dressing and eating on own</li> <li>Needing more time than peers to learn skills (such as zipping coat, managing backpacks, or changing clothes quickly for activities, such as swimming lessons)</li> </ul>
- 	<ul> <li>Focusing on facts versus abstract thinking</li> <li>Understanding the condition is not reversible</li> <li>Starting a grieving process</li> <li>Experiencing fears of loneliness and abandonment</li> <li>Having attention problems</li> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Socially immature and preferring the company of younger children</li> <li>Struggling to interpret social cues</li> <li>Needing help managing behavior and emotional reactions</li> </ul>	<ul> <li>Needing assistance with cutting food</li> <li>Eating food independently if the environment is arranged to meet needs</li> <li>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</li> </ul>
IV- V	<ul> <li>Easily frustrated, emotionally reactive, and demonstrating poor social skills</li> <li>Demonstrating disruptive and uncooperative behaviors</li> <li>Withdrawing from others</li> <li>At risk for self-injurious behaviors or aggressive behaviors</li> </ul>	<ul> <li>Needing adequate posture support to use hands while eating</li> <li>Requiring total assistance from caregivers to complete feeding and dressing tasks</li> <li>Learning parts of some dressing skills, such as offering a hand or foot when getting clothes or shoes on</li> <li>More likely to have casts and/or braces due to increased stiffness in muscles</li> </ul>

Sensory Functions	Recreation and Fitness
Your child might be:	Your child might be:
<ul> <li>Experiencing normal hearing and vision (screening still essential)</li> <li>Experiencing a change in speech or language abilities (hearing re-evaluation is essential)</li> </ul>	<ul> <li>Participating in supportive play that includes cooperation and compromise</li> <li>Identifying preferences for specific sports, types of music, books and movies</li> <li>Playing team and competitive sports, perhaps with adaptive equipment and modified participation</li> <li>Seeking play options that offer a sense of independence</li> </ul>
<ul> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Experiencing difficulty with fixing on and following some- thing with the eyes (cortical vision impairment)</li> <li>Struggling to interpret visual information as it relates to space (visual-spatial learning disability)</li> <li>Struggling with speech development (hearing assessment is essential)</li> <li>Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder)</li> <li>Not using involved arm because of sensory issues</li> </ul>	<ul> <li>Participating in supportive play that includes cooperation and compromise</li> <li>Identifying preferences for specific sports, types of music, books and movies</li> <li>Struggling with activities that require fine motor skills, such as crafts or board games</li> <li>Playing team and competitive sports using adaptive sports equipment and with modified participation</li> <li>Seeking play options that offer a sense of independence</li> </ul>
<ul> <li>Experiencing normal hearing and vision (screening is still essential)</li> <li>Experiencing eye muscle imbalance, such as crossed eyes (strabismus) or lazy eyes</li> <li>Experiencing difficulty with fixing on and following something with his or her eyes (cortical vision impairment)</li> <li>Struggling with speech development (hearing assessment is essential)</li> <li>Experiencing distress from ordinary stimuli, especially sounds or things that he or she touches (sensory integration disorder)</li> <li>Experiencing significant sensory impairments with sight, hearing, smell, touch, taste or spatial awareness</li> </ul>	<ul> <li>Playing with hand-over-hand assistance</li> <li>Socializing and interacting through adapted programs and camps</li> <li>Interacting with cause-and-effect toys (anything that makes a sound or movement based on child's action)</li> <li>Identifying preferences for specific sports, types of music, books and movies</li> <li>Using highly adapted sport options that provide hand- over-hand or full assistance</li> </ul>

### Adolescence (13 to 18) continued

Level	Evaluations and	Interventions	
	Assessments Your care team might recommend:	Your care team might recommend:	
I	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>Clinical examination of hips, possibly with an X-ray</li> <li>Appointments with key providers every 6 to 12 months to watch development, reduce deformities</li> <li>Referrals to neurodevelopmental pediatrics/ psychology/neuropsychology for learning or behavior problems</li> <li>Meeting with a social worker for mental health support and resources</li> <li>Monitoring growth that could lead to recurrent deformities</li> <li>Discussing transition to providers that offer adult care</li> </ul>	<ul> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Selective dorsal rhizotomy surgery or ortho- pedic surgery to correct skeletal deformities</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation</li> </ul>	
- 	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>X-ray of pelvis at 8 to 10 years of age and every 12 months until skeletal maturity</li> <li>Screening for spinal deformity</li> <li>Appointments with key providers every 6 to 12 months to watch development, reduce deformities</li> <li>Meeting with a social worker for mental health support and resources</li> <li>Assessment of bone health</li> <li>Discussing transition to providers that offer adult care</li> </ul>	<ul> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Intrathecal baclofen pump to reduce spasticity</li> <li>Orthopedic surgery to correct skeletal deformities</li> <li>Correction of recurrent deformities due to growth spurts</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation</li> <li>Adaptive equipment for mobility (walker or a wheelchair)</li> <li>Alternative or augmentative communication devices or methods</li> </ul>	Care Team Key providers are in bold. Adaptive Equipment Specialist/Vendor of Medical Equipment Audiologist Child Life Specialist Neurodevelopmental Pediatrician Neuropsychologist/ Psychologist Nurse
IV- V	<ul> <li>Ongoing assessments of mobility, communication and fine motor skills (functional status)</li> <li>X-ray of pelvis at 8 to 10 years of age and every 6 to 12 months until skeletal maturity</li> <li>X-ray of spine</li> <li>Appointments with key providers every 6 to 12 months to watch development, reduce deformities</li> <li>Meeting with a social worker for mental health support and resources</li> <li>Assessment of bone health</li> <li>Discussing transition to providers that offer adult care</li> </ul>	<ul> <li>Surgery to correct a spinal deformity</li> <li>Medicine to reduce tightness/spasticity, such as botulinum toxin or phenol</li> <li>Management of associated conditions, such as seizures</li> <li>Physical, occupational, and speech and language therapy</li> <li>Intrathecal baclofen pump to reduce spasticity</li> <li>Orthopedic surgery to correct hip dislocation or other deformities</li> <li>Correction of recurrent deformities due to growth spurts</li> <li>Orthotics to maintain alignment and provide stability to a joint</li> <li>Collaboration with your school district</li> <li>Child life support during procedures and rehabilitation</li> <li>Adaptive seating and mobility (manual or power wheelchair)</li> <li>Modifications to your child's home or school environment</li> <li>Alternative or augmentative devices or methods</li> <li>Surgery to correct a spinal deformity</li> </ul>	Nurse Practitioner Opthalmologist Orthotist Pediatric Neurologist Pediatric Neurosurgeon Pediatric Orthopedist Pediatric Rehabilitation Medicine Physician Psychologist Sleep Health Specialist Social Worker Therapeutic Recreation Specialist Therapists – Occupational Therapist Physical Therapist Speech and Language Pathologist

### Glossary

Th<mark>is glossary w</mark>ill 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.

**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.

**Depakene** – Valproic acid; an antiepileptic seizure medicine.

**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.

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.

### Level

<ul> <li>The person:         <ul> <li>Handles most objects, but with a reduced quality and/or speed in achieving tasks and activities.</li> <li>Struggles with some activities; might need alternative ways of doing tasks. (These limitations usually don't interfere with independence in daily activities.)</li> </ul> </li> <li>The person:         <ul> <li>Handles objects with difficulty.</li> <li>Needs help to prepare or adapt activities.</li> <li>Does tasks slowly.</li> <li>Experiences limited success regarding quality and quantity of tasks and activities.</li> <li>Performs activities independently only if they have been set up or adapted.</li> </ul> </li> <li>The person:         <ul> <li>Handles a limited selection of easily managed objects in adapted situations.</li> <li>Performs only parts of activities with effort and limited success.</li> <li>Requires continuous assistance and/or adapted equipment to attempt an activity.</li> </ul> </li> <li>The person:         <ul> <li>Cannot handle objects.</li> <li>Experiences severely limited ability to perform even simple actions.</li> <li>Requires total assistance.</li> </ul> </li> </ul>	L	<ul> <li>The person:</li> <li>Handles objects easily and successfully.</li> <li>Experiences limitations in performing manual tasks requiring speed and accuracy. (These limitations don't interfere with independence in daily activities.)</li> </ul>
<ul> <li>Handles objects with difficulty.</li> <li>Needs help to prepare or adapt activities.</li> <li>Does tasks slowly.</li> <li>Experiences limited success regarding quality and quantity of tasks and activities.</li> <li>Performs activities independently only if they have been set up or adapted.</li> <li>The person:</li> <li>Handles a limited selection of easily managed objects in adapted situations.</li> <li>Performs only parts of activities with effort and limited success.</li> <li>Requires continuous assistance and/or adapted equipment to attempt an activity.</li> <li>Cannot handle objects.</li> <li>Experiences severely limited ability to perform even simple actions.</li> </ul>	II	<ul> <li>Handles most objects, but with a reduced quality and/or speed in achieving tasks and activities.</li> <li>Struggles with some activities; might need alternative ways of doing tasks. (These</li> </ul>
<ul> <li>Handles a limited selection of easily managed objects in adapted situations.</li> <li>Performs only parts of activities with effort and limited success.</li> <li>Requires continuous assistance and/or adapted equipment to attempt an activity.</li> <li>The person:</li> <li>Cannot handle objects.</li> <li>Experiences severely limited ability to perform even simple actions.</li> </ul>	111	<ul> <li>Handles objects with difficulty.</li> <li>Needs help to prepare or adapt activities.</li> <li>Does tasks slowly.</li> <li>Experiences limited success regarding quality and quantity of tasks and activities.</li> </ul>
<ul> <li>Cannot handle objects.</li> <li>Experiences severely limited ability to perform even simple actions.</li> </ul>	IV	Handles a limited selection of easily managed objects in adapted situations.
	V	<ul> <li>Cannot handle objects.</li> <li>Experiences severely limited ability to perform even simple actions.</li> </ul>

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.

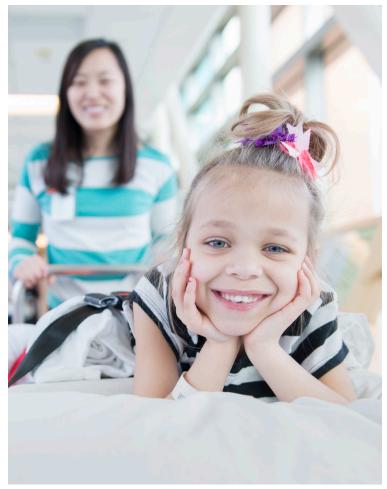
**Triplegia** – Involvement of both legs and one arm.

Upper extremities – Arms.

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).



## 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.

### **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.

### Neurodevelopmental 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.

### Opthalmologist

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 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

Evaluates patients' cognitive, academic and psychosocial abilities. Psychologists talk with patients and families about the effects of a disability and help children cope with pain and stress. Our specialists also contact patients' schools to discuss special academic services or behavior-management strategies.

### 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.

#### **Our Mission**

Gillette Children's Specialty Healthcare provides specialized health care for people who have short-term or long-term disabilities that began during childhood. We help children, adults and their families improve their health, achieve greater well-being and enjoy life.



gillettechildrens.org

St. Paul (Main) Campus 200 University Ave. E. St. Paul, MN 55101 651-291-2848 800-719-4040

Patient Appointments 651-290-8707 / 800-719-4040

Provider Referrals & Consultations 651-325-2200 / 855-325-2200

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

Gillette Children's Specialty Healthcare is named in honor of orthopedic surgeon Arthur Gillette, MD, who helped found the nation's first hospital for children who have disabilities. We are an independent, not-for-profit children's hospital, and our organization has no affiliation with the Gillette Company or the Gillette brand of personal care products.

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