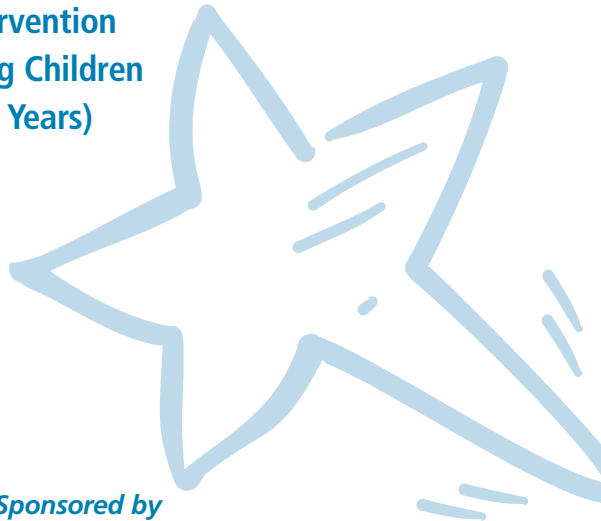


QUICK REFERENCE GUIDE
for Parents
and Professionals



Motor DISORDERS

Assessment
and Intervention
for Young Children
(Age 0-3 Years)



Sponsored by

**New York State Department of Health
Division of Family Health
Bureau of Early Intervention**

CLINICAL PRACTICE GUIDELINE

QUICK REFERENCE GUIDE
FOR PARENTS AND PROFESSIONALS

MOTOR DISORDERS
ASSESSMENT AND INTERVENTION
FOR
YOUNG CHILDREN (AGE 0-3 YEARS)

SPONSORED BY
NEW YORK STATE DEPARTMENT OF HEALTH
DIVISION OF FAMILY HEALTH
BUREAU OF EARLY INTERVENTION

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Table of Contents

Motor Disorders Assessment and Intervention for Young Children (Age 0-3 Years)

Preface	xi
Why the Bureau of Early Intervention Is Developing Guidelines	xii
Chapter I: Introduction	1
Purpose of This Clinical Practice Guideline	2
Scope of This Guideline	3
How This Guideline Was Developed.....	3
Definition of Important Terms	4
Chapter II: Background Information	7
What Is Motor Development?	8
What Is Typical Motor Development?	8
What Are Some of the Important Components of Motor Development?	9
How Do Prematurity and Other Health Conditions Impact Motor Development?	11
What Is a Motor Disorder?.....	12
How Common Are Developmental Motor Disorders and Cerebral Palsy?	13
What Do We Know About the Causes of Motor Disorders?	14
What Is the Impact on the Child and Family?	15
Do Some Children Outgrow Motor Disorders?.....	15
Chapter III: Assessment	17
General Approach.....	18
Identifying Young Children Who Have a Motor Disorder	20
Assessing Young Children Who Have a Motor Disorder	32
Oral-Motor Assessment for Feeding and Swallowing	35
Assessing Other Developmental Domains for Young Children Who Have a Motor Disorder	40
Assessing the General Health Status of Young Children Who Have a Motor Disorder	44
Considerations for Working With the Family	47

TABLE OF CONTENTS

Chapter IV: Intervention	53
Planning and Implementing Interventions	54
Motor Therapy Approaches and Techniques	71
Assistive Technology and Adaptive Devices	79
Oral-Motor Feeding and Swallowing Interventions	85
Approaches for Spasticity Management	88
Orthopedic Management and Surgery Management	93
Interventions for Associated Health Conditions	97
Other Intervention Approaches	98

List of Appendices

Appendix A: Early Intervention Program Information	103
Appendix B: Additional Resources	119
Appendix C: Classification of Cerebral Palsy	123
Appendix D: Summary of Research Findings: Panel Conclusions	129
Reference List	135
Subject Index	145

List of Tables

<i>TABLE 1: DEVELOPMENTAL MOTOR MILESTONES</i>	<i>10</i>
<i>TABLE 2: RISK FACTORS FOR MOTOR DISORDERS</i>	<i>24</i>
<i>TABLE 3: CLINICAL CLUES OF A POSSIBLE MOTOR DISORDER</i>	<i>25</i>
<i>TABLE 4: MILESTONES RELEVANT TO NORMAL FEEDING</i>	<i>37</i>
<i>TABLE 5: QUESTIONS TO BE CONSIDERED IN THE FEEDING HISTORY</i>	<i>38</i>
<i>TABLE 6: CLINICAL CLUES OF A POSSIBLE FEEDING PROBLEM</i>	<i>38</i>
<i>TABLE 7: COMMON ASSOCIATED CONDITIONS IN CHILDREN WITH CEREBRAL PALSY</i>	<i>46</i>
<i>TABLE 8: QUESTIONS TO ASK WHEN SELECTING INTERVENTIONS</i>	<i>56</i>
<i>TABLE 9: IMPORTANT COMPONENTS OF DEVELOPMENTAL SUPPORTIVE CARE</i>	<i>66</i>
<i>TABLE 10: BASIC EXERCISE DEFINITIONS</i>	<i>71</i>

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Foreword

Providing an optimal program of early intervention for young children with developmental disabilities and their families requires knowledge of reliable and current information on research and practice. However, analyzing research studies and determining their relevance to practice can be a perplexing task, even for the professional. Differing methodologies and a variety of conceptual frameworks often make it difficult to judge the quality of the research and to discern outcome patterns that can—and should—influence practice.

Despite the fact that this is a difficult task, practice guidelines based on a sophisticated and rigorous analysis of the extant research literature can convey essential information for the design and implementation of optimal early intervention programs. Young children at risk for, or who have, established motor disorders pose an unusually complex set of problems with regard to both assessment and intervention. Interdisciplinary involvement and the differing perspectives that can result make it even more essential that proper practice guidelines be developed. The *Clinical Practice Guideline for Motor Disorders* has been the result of a sophisticated and methodologically sound approach to accurately gather and summarize information based on the available evidence. This Guideline is of extraordinary value to practitioners from all relevant disciplines, and to parents, administrators, and others interested in the health and well-being of young children with motor disorders.

MICHAEL J. GURALNICK, Ph.D.
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PREFACE

WHY THE BUREAU OF EARLY INTERVENTION IS DEVELOPING GUIDELINES

In 1996, a multiyear effort was initiated by the New York State Department of Health (NYSDOH) to develop clinical practice guidelines to support the efforts of the statewide Early Intervention Program. As lead agency for the Early Intervention Program in New York State, the NYSDOH is committed to ensuring that the Early Intervention Program provides consistent, high-quality, cost-effective, and appropriate services that result in measurable outcomes for eligible children and their families.

This guideline is a tool to help ensure that infants and young children with disabilities receive early intervention services consistent with their individual needs, resources, priorities, and the concerns of their families.

The guideline is intended to help families, service providers, and public officials by offering recommendations based on scientific evidence and expert clinical opinion on effective practices for the following:

- Early identification of children at risk or suspected of having a disability through routine developmental surveillance and screening targeted to identify specific disabilities.
- Provision of multidisciplinary evaluations and assessments that result in reliable information about a child’s developmental strengths and needs and, when possible, a diagnosis.
- The determination of effective intervention strategies and reaching agreement on the frequency, intensity, and duration of early intervention services that will lead to positive outcomes for children and families.
- The measurement of outcomes achieved.

The impact of clinical practice guidelines for the Early Intervention Program will depend on their credibility with families, service providers, and public officials. To ensure a credible product, an evidence-based, multidisciplinary consensus panel approach was used. The methodology for these guidelines was established by the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Healthcare Policy and Research (AHCPR). This methodology was selected because it is a well-tested, effective, and scientific approach to guideline development.

The NYSDOH has worked closely with the State Early Intervention Coordinating Council throughout the guideline development process. A state-level steering committee was also established to advise the department on this initiative. A national advisory group of experts in early intervention has been available to the Department to review and to provide feedback on the methodology and the guideline. Their efforts have been crucial to the successful development of this guideline.

Overview of the Early Intervention Program

The New York State Early Intervention Program is part of the national Early Intervention Program for infants and toddlers with disabilities and their families, first created by Congress in 1986 under the Individuals with Disabilities Education Act (IDEA). IDEA is also the federal law that ensures all children and youth ages 3 to 21 years with disabilities the right to a free appropriate public education. In New York State, the Early Intervention Program is established in Article 25 of the Public Health Law and has been in effect since July 1, 1993.

To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay in one or more of the following areas of development: physical, cognitive, communication, social-emotional, and adaptive development.

The Early Intervention Program offers a variety of therapeutic and support services to infants and toddlers with disabilities and their families that include family education and counseling, home visits, and parent support groups; special instruction; speech pathology and audiology; occupational therapy; physical therapy; psychological services; service coordination; nursing services; nutrition services; social work services; vision services; and assistive technology devices and services.

Major provisions of the New York State Public Health Law that govern the Early Intervention Program require:

- Local administration of the program by an Early Intervention Official (EIO) designated by the chief elected official of each of the 57 counties and New York City. The EIO is responsible for ensuring that eligible children and their families receive the services included in the Individualized Family Service Plan (IFSP) that is developed for the child and family.
- Identification and referral of children at risk or suspected of disability by primary referral sources (including physicians and other health care providers).

PREFACE


- Periodic developmental screening and tracking of at-risk children.
- Provision of service coordination services to eligible children and their families.
- A multidisciplinary evaluation of children referred to the program, at no cost to families, to determine eligibility.
- Individualized Family Service Plans (IFSP) for eligible children and their families.
- Provision of early intervention services as specified in the IFSP at no cost to the family.
- Delivery of services in natural settings in the community where peers are typically found to the maximum extent appropriate.

The mission of the Early Intervention Program is to identify and evaluate, as early as possible, those infants and toddlers whose healthy development is compromised and provide for appropriate intervention to improve child and family development. The program goals are to:

- Support parents in meeting their responsibilities to nurture and to enhance their child(ren)'s development.
- Create opportunities for full participation of children with disabilities and their families in their communities by ensuring services are delivered in natural environments to the maximum extent appropriate.
- Ensure early intervention services are coordinated with the full array of early childhood health and mental health, educational, social, and other community-based services needed by and provided to children and their families.
- Enhance child development and functional outcomes and improve family life through delivery of effective, outcome-based, high quality early intervention services.
- Ensure that early intervention services complement the child's medical home by involving primary and specialty health care providers in supporting family participation in early intervention services.
- Ensure equity of access, quality, consistency, and accountability in the service system by ensuring clear lines of public supervision, responsibility, and authority for the provision of early intervention services to eligible children and their families.

New York State Public Health Law designates the Department of Health as the lead agency for this statewide program. As the lead agency, the NYSDOH is responsible for the overall supervision and administration of the Early Intervention Program. Responsibilities include:

- Implementing statewide policies, procedures, and programmatic and reimbursement regulations.
- Implementing a comprehensive public awareness and child-find system.
- Approving, compiling, and disseminating lists of approved service coordinators, evaluators, and service providers.
- Providing training and technical assistance to municipalities and service providers to enable them to identify, locate, and evaluate eligible children; develop individualized family service plans; ensure the appropriate provision of early intervention services; and promote the development of new services where there is a demonstrated need.
- Safeguarding parent and child rights under the Early Intervention Program.
- Establishing and maintaining an Early Intervention Coordinating Council to advise and assist the department in program implementation.

 **Early Intervention Policy** ❖ Throughout the document, information about relevant Early Intervention Program policy is presented in boxes with this symbol.

CLINICAL PRACTICE GUIDELINE

QUICK REFERENCE GUIDE

MOTOR DISORDERS

ASSESSMENT AND INTERVENTION

FOR

YOUNG CHILDREN (AGE 0-3 YEARS)

This *Quick Reference Guide* is an abbreviated version of the background information and guideline recommendations presented in the full text reports of this clinical practice guideline.

The full text of all the recommendations plus a description of the methodology and evidence used to develop the recommendations can be found in the *Clinical Practice Guideline: The Guideline Technical Report*.

The full text of all the recommendations plus an abbreviated description of the methodology and evidence used to develop the recommendations can be found in the *Clinical Practice Guideline: Report of the Recommendations*.

CHAPTER I: INTRODUCTION

PURPOSE OF THIS CLINICAL PRACTICE GUIDELINE

This *Quick Reference Guide* is based on the *Clinical Practice Guideline Technical Report* that was developed by an independent, multidisciplinary panel of clinicians and parents convened by the New York State Department of Health. The development of this and other guidelines for the statewide Early Intervention Program was sponsored by the New York State Department of Health as part of its mission to make a positive contribution to the quality of care for children with disabilities.

These clinical practice guidelines are intended to provide parents, professionals, and others with recommendations, based on the best scientific evidence available, with “best practices” for assessment and intervention for young children with disabilities.

The primary reasons for developing a clinical practice guideline for young children who have a motor disorder are to:

- Help children and their families learn about appropriate and effective services
- Provide an education and information resource for professionals
- Promote consistency in service delivery
- Facilitate productive communication among professionals
- Facilitate quality improvement in early intervention services
- Indicate where more research is needed

Providers and families are encouraged to use this guide, recognizing that the care provided should always be tailored to the individual. The decision to follow any particular recommendations should be made by the family and the provider based on the circumstances of the individual child(ren) and their families.

SCOPE OF THIS GUIDELINE

The *primary topics* covered in this clinical practice guideline about children who have a motor disorder are:


- Motor disorders in children under three years of age
- Identification and developmental surveillance for young children at risk for motor disorders
- Assessment and intervention for young children who have a motor disorder

“Motor Disorders” as it is Used in This Guideline

For this guideline, the discussion of motor disorders is limited to:

- Developmental motor disorders (motor delays that are part of a global developmental delay or that arise from hypotonia and mild neuromotor dysfunction), and
- Static central nervous system disorders, specifically, cerebral palsy

Because of the need to focus the scope of this guideline, conditions such as spina bifida, juvenile rheumatoid arthritis, as well as neuromuscular disorders such as muscular dystrophy or spinal muscular atrophy are not included as part of either the general background discussion or the recommendations.



Early Intervention Program ❖ In New York State, children with diagnosed conditions that are highly likely to affect development, such as cerebral palsy, are eligible for early intervention services.

HOW THIS GUIDELINE WAS DEVELOPED

A multidisciplinary panel of topic experts, general providers (both clinicians and educators), and parents worked together to develop the guideline. After determining the guideline’s general scope, the guideline panel established the specific assessment and intervention topics and decided which topics were most appropriate for the evidence review process. The group then held a series of meetings to review the available research and develop recommendations. The panel’s final meeting was in 2001.

For some topics, no research evidence meeting the criteria of the guideline was found. Other topics were determined to be inappropriate for a literature search and evidence evaluation. When the panel reviewed these topics, they made recommendations arrived at through consensus.

Using scientific evidence to develop guidelines


Every professional discipline today is being called upon to document the effectiveness of specific approaches in bringing about desired outcomes. Guidelines based on an evaluation of the scientific literature can help professionals, parents, and others learn what scientific evidence exists about the effectiveness of specific clinical methods. When adequate scientific evidence can be found and systematically evaluated, it provides a balanced and objective approach for making informed decisions.

DEFINITION OF IMPORTANT TERMS

Definitions are given below for some important terms as they are used in this guideline:

<i>Assessment</i>	The entire process of identifying and evaluating the child, including the activities and tools used to measure level of functioning, establish eligibility for services, determine a diagnosis, plan interventions, and measure treatment outcomes.
<i>Family</i>	The child's primary caregivers, who might include one or both parents, siblings, grandparents, foster care parents, or others usually in the child's home environment(s).
<i>Parent(s)</i>	The persons who have the primary responsibility for the welfare of the child. Although the primary caregiver may be someone other than the mother or father of the child, the term <i>parent</i> is used to mean the child's primary caregiver(s).
<i>Professional</i>	Any provider of a professional service who is qualified by training, experience, licensure, and/or other state requirements to provide the intended service. The term is not intended to imply any specific professional degree or qualifications other than appropriate training and credentials.

<i>Screening</i>	The early stages of the assessment process. Screening may include parent interviews or questionnaires, observation of the child, or use of specific screening tests. Screening is used to identify children who need more in-depth assessment and evaluation.
<i>Target Population</i>	For this guideline, the target population is children from birth to 3 years of age who have a motor disorder.
<i>Young Children</i>	This term is used broadly to describe the target age group for this guideline (children from birth through 3 years of age). However, age 3 is not an absolute cutoff because many of the recommendations may also be applicable to somewhat older children.



Early Intervention Program ❖ The terms assessment, parents, and screening are defined in regulations that apply to the Early Intervention Program (EIP) in New York State. (See Appendix A, Early Intervention Program Information.)

In New York State, the term used for professionals who are qualified to deliver early intervention services is “qualified personnel.” *Qualified personnel* are those individuals who are approved to deliver services to eligible children, to the extent authorized by their licensure, certification or registration, and who have appropriate licensure, certification, or registration in the area in which they are providing services (see Appendix A).

This version of the guideline provides only a summary of the guideline recommendations. More specific recommendations and detailed information about the research process is described in the more complete versions of the guideline.

**CHAPTER II: BACKGROUND
INFORMATION**

WHAT IS MOTOR DEVELOPMENT?

Motor development is a progression of increasingly complex stages (milestones) through which infants achieve control over use of their muscles for upright posture, balance, and mobility (from holding the head erect, to rolling over, to sitting, to crawling, to standing), and manipulation of objects for interaction with the environment.

In very young children, movement patterns initially appear random and quite variable. As a child advances through the motor developmental milestones, movement becomes more purposeful, and motor skills become incorporated into activities of daily life. This includes holding and manipulating objects, rolling over, independent sitting, crawling, walking, feeding, play, and eventually, self-care.

This progression is dependent on the successful integration of a number of interrelated developmental processes. For example, failure to achieve some of the fine motor skills may be related as much to cognition as to motor control.

In general, motor development includes:

- Gross motor skills (large muscle skills such as head control, sitting, standing, and locomotion)
- Fine motor skills (smaller muscle skills such as grasp, release, and manipulation of objects)
- Oral-motor skills (feeding, swallowing, sound production, and speech)

WHAT IS TYPICAL MOTOR DEVELOPMENT?

Typical motor development generally proceeds in an orderly, predictable sequence, although the rate and age of motor skill attainment varies somewhat from child to child. Even though all children develop at their own rate, the sequence tends to be similar. (For example, children with typical motor development sit independently before they try to stand.)

Motor milestones are motor events by which one can gauge a child's general developmental progress. Delays in a child's attainment of motor milestones are often the parent's or health care provider's first cause for concern. Table 1 (page 10) identifies some general developmental motor milestones and the typical age range in which these milestones are attained.

WHAT ARE SOME OF THE IMPORTANT COMPONENTS OF MOTOR DEVELOPMENT?

There are several basic components that provide the foundation of motor skill development in young children. These include:

- **Muscle tone.** Muscle tone is influenced by all levels of the nervous system, from the brain to the peripheral nerves. It may be affected by the elasticity of the muscle and tendons, the ability of the nervous system to send messages to the muscle, and the ability of the muscle to receive and respond to messages.

Abnormal or atypical muscle tone can be thought of as the inability to adequately and appropriately adjust muscle tension to perform a task or function. Muscle tone can be too low or too high to perform activities efficiently and effectively.

Abnormal muscle tone is usually described as either *hypotonia* (abnormally low or depressed muscle tone) or *hypertonia* (abnormally high or excessive muscle tone). Commonly, children with hypotonia appear to be “floppy” and have decreased resistance to passive stretch. Children with hypertonia usually appear stiff and have increased resistance to passive stretching of the muscle. The two major forms of hypertonia include spasticity (velocity dependent hypertonicity with initial resistance to movement and then apparent relaxation) and rigidity (constant resistance to passive movement regardless of velocity).

- **Primitive reflexes.** Primitive reflexes are involuntary movements that tend to dominate motor movements in the first 3 to 4 months of the baby’s life. Generally, by 6 to 9 months of age, they are no longer visible.
- **Righting and equilibrium reactions.** Righting and equilibrium are balancing reactions that cause us to correct our posture/position in response to the force of gravity. Righting is the ability to keep the head, trunk, and limbs vertical; equilibrium is the ability to maintain and regain balance. Emerging in the first year of life, these reactions are essential in the development of complex motor skills such as sitting, crawling, standing, and walking. Their development gives clues that motor development appears to be proceeding normally.
- **Postural reactions.** Postural control is the ability to establish and maintain a stable position over the base of support. It involves adequate muscle tone as well as righting and equilibrium reactions. Motor development depends on postural control to provide stability for movement activities.

Table 1: Developmental Motor Milestones

Age	Gross Motor	Fine Motor
Birth–6 wks.	<ul style="list-style-type: none">▪ early reflexes present	<ul style="list-style-type: none">▪ grabs adult fingers with tight-fisted hands
6 wk–4 mos.	<ul style="list-style-type: none">▪ holds head erect▪ turns from back to side	<ul style="list-style-type: none">▪ holds a rattle▪ reaches for dangling object with both hands
4–8 mos.	<ul style="list-style-type: none">▪ early reflexes fading▪ can hold head steady▪ rolls from back to stomach▪ sits alone	<ul style="list-style-type: none">▪ picks up cube▪ bangs toys together▪ uses thumb and forefinger grasp
8–12 mos.	<ul style="list-style-type: none">▪ crawls on hands and knees▪ stands alone▪ walks with help	<ul style="list-style-type: none">▪ stacks two cubes▪ releases hold on objects▪ uses pincer grasp▪ can hold a crayon
12–18 mos.	<ul style="list-style-type: none">▪ throws ball▪ crawls or climbs up stairs▪ lowers self from standing▪ walks alone	<ul style="list-style-type: none">▪ turns knobs▪ pushes, pulls, pokes toys▪ turns pages in hardbound books
18–24 mos.	<ul style="list-style-type: none">▪ stands up from stooping▪ climbs onto chairs▪ stands on one foot▪ rides big toy cars▪ kicks ball	<ul style="list-style-type: none">▪ scribbles with crayon▪ completes simple puzzles
24–29 mos.	<ul style="list-style-type: none">▪ walks down steps with alternating feet▪ runs, jumps with two feet	<ul style="list-style-type: none">▪ strings beads▪ scribbles are more controlled
29–36 mos.	<ul style="list-style-type: none">▪ jumps in place▪ rides tricycle	<ul style="list-style-type: none">▪ uses scissors

Adapted from: Geralis 1991

HOW DO PREMATURETY AND OTHER HEALTH CONDITIONS IMPACT MOTOR DEVELOPMENT?

Prematurity

For infants born prematurely, motor development is more closely linked to the gestational age than to the chronological age. For this reason, it is often important to correct for the child's gestational age when assessing motor development. For example, an infant born at 30 weeks gestation would be considered 10 weeks premature. Therefore, when the child is one year old, the corrected age is calculated as 52 weeks minus 10 weeks equals 42 weeks corrected gestational age. Most premature infants who eventually show normal development match the gross motor milestones of full-term infants by their second birthday. Therefore, this correction factor is usually applied only until the child is two years old.

Health-related factors

There are many medical conditions that may affect motor development in young children. Some conditions, such as seizures, hydrocephalus, chronic ear infections, rickets, or metabolic disorders may not directly affect motor development but may result in motor delays. For example:

- *Chronic lung disease or severe congenital heart disease*--These children may show hypotonia as well as muscular weakness. They lack the energy needed for typical gross motor development but often have normal fine motor skills. Generally, as cardiac or pulmonary status improves, so does motor development. However, some children with chronic lung disease or heart disease may remain hypotonic, developing minor neuromotor dysfunction or even cerebral palsy.
- *Technology dependence*--Children with ostomies or children who require technical support to sustain life may exhibit delays. Tracheotomy tubes or feeding gastrostomy tubes often make it difficult to place the child on his or her stomach, which can alter the normal sequence of motor development.
- *Gastrointestinal problems*--A child's discomfort from gastroesophageal reflux and parental worry about exacerbating the reflux may lead to avoidance of the prone (face down) position. Severe reflux leading to respiratory distress may also limit motor exploration. These children may show gross motor delays, but usually fine motor skills develop normally.

- *Nutrition*--Children suffering from chronic undernutrition or failure to thrive often are hypotonic and weak, lack stamina, and exhibit motor delays. Motor development tends to improve as nutritional status improves.
- *Prescription Drugs*-- Many medications may influence neurological functions, which may in turn affect motor development. Antiseizure medications may lead to lethargy and/or hypotonia. Babies exposed to certain drugs in utero can show hypertonicity that often lasts for months.
- *Vision*--Since maintenance of muscle tone is related to motor exploration, motor exploration is often affected in children who have limited visual perception. Therefore, blind children may show delays in reaching, sitting, crawling, and walking. In addition, initial gait in these children is usually wide based because the visual input normally used for balance is lacking.

WHAT IS A MOTOR DISORDER?

Motor disorders involve mild to severe abnormalities of muscle tone, posture, movement, and motor skill acquisition. For this guideline, the discussion of motor disorders will be limited to developmental motor disorders and static central nervous system disorders (specifically, cerebral palsy).

Developmental motor disorders

Developmental motor disorders include motor delays that are part of a global developmental delay, motor delays that can arise from hypotonia, and mild neuromotor dysfunction.

- *Global developmental delays*: In general, motor milestones may be more easily recognizable than cognitive milestones in the first year of life. Delays in motor skills or qualitative differences in movement may be the first sign of a problem in children who are later diagnosed with cognitive impairment. Because some syndromes are genetic, it is important to identify the child as early as possible for family planning counseling.
- *Hypotonia*: Muscular hypotonia makes it difficult for the child to maintain posture against gravity thereby decreasing muscle power and delaying motor skill acquisition. Instability in sitting and standing may extend to problems with fine motor skills. Generally, as the child matures and muscle strength increases to compensate for the hypotonia, these delays tend to be less noticeable. Some children with hypotonia may have persistent coordination difficulties or later learning difficulties.

- *Mild neuromotor dysfunction:* Mild neuromotor dysfunction is an impairment of motor coordination that is not secondary to mental retardation or other neurological disorders such as cerebral palsy. This condition may also be referred to as developmental coordination disorder, clumsy child syndrome, specific developmental disorder of motor function, and minimal cerebral palsy. Children with this condition show fine or gross motor abilities significantly below the level expected on the basis of cognitive function.

Cerebral palsy

Cerebral palsy is a chronic neurological condition of motor impairment. The term cerebral palsy refers to a combination of symptoms, not a specific disease. The symptoms of cerebral palsy are caused by a static (nonprogressive) cerebral lesion (brain injury) that occurs before the brain is fully developed. Any potentially progressive neurological lesions must first be excluded before a diagnosis of cerebral palsy is made.

Many types of brain injury can cause cerebral palsy, and there are many types of cerebral palsy. The severity, symptoms, and associated conditions vary widely depending on the nature and extent of the brain injury. For descriptive and diagnostic purposes, cerebral palsy is often classified according to the neurological abnormality that is present, the pattern and severity of involvement of the arms and legs, and/or the degree of functional motor impairment.

HOW COMMON ARE DEVELOPMENTAL MOTOR DISORDERS AND CEREBRAL PALSY?

Developmental motor disorders

Hypotonia leading to motor delay has not been identified as prevalent in the general population. Cognitive disorder, which may have associated motor delay, is estimated to affect three percent of the population. When poor coordination was studied in seven year olds, five percent were felt to be poorly coordinated to a degree that it interfered with academic or adaptive skills.

Cerebral palsy

In the United States, the current prevalence of cerebral palsy is estimated to be one to three per 1000 children of early school age, with an estimated rise of approximately 20 percent between 1960 and 1986. This increase is most likely due to the greater survival rates of very premature infants.

WHAT DO WE KNOW ABOUT THE CAUSES OF MOTOR DISORDERS?

Even after extensive investigations, no cause can be found in the vast majority of children who have a motor disorder. In children without readily identifiable risk factors, it is crucial that metabolic or genetic disorders be excluded.

Some known causes have predictable outcomes and these will be reviewed briefly below.

Periventricular leukomalacia (ischemic brain injury)

Brain tissue can be damaged when it does not receive enough blood. This is called ischemic brain injury. Premature infants are particularly vulnerable to a kind of ischemic brain injury called periventricular leukomalacia. This type of injury is usually symmetric (both sides of the body are affected) and generally leads to diplegic types of motor disorder (all limbs are affected, but with greater impairment of the legs than of the arms).

Periventricular hemorrhagic infarction

When there is periventricular hemorrhage or intraventricular hemorrhage (significant bleeding into the brain), brain injury and necrosis (death of the brain tissue) can occur. Most often seen in premature infants, this type of injury usually leads to varying degrees of hemiplegia (affecting only one side, with the leg usually more involved than or as equally involved as the arm).

Brain malformations

Abnormalities in the developing brain often lead to motor disorders. For this reason, brain imaging studies are frequently performed on children who show symptoms of motor disorders.

Hypoxic ischemia encephalopathy

Hypoxia (lack of oxygen) in the newborn was long thought to be the primary cause of cerebral palsy. Although this is now felt to be a minor cause, it may be a factor in some children who later develop a motor disorder.

Bilirubin encephalopathy

Bilirubin is something that is normally produced in our blood. Abnormally high levels of bilirubin in an immature or sick newborn can cross into the area of the brain that controls involuntary movements. This can result in a movement disorder.

Stroke

A stroke is the result of impaired blood flow to the brain. This injury usually leads to a classic pattern of hemiplegia with the arm more involved than the leg.

Other

There are many other possible causes of motor disorders. These may lead to varying degrees of motor impairment and possibly other developmental disorders. Examples include intrauterine infection, postnatal infection (meningitis, sepsis), traumatic brain injury, child neglect or abuse, spinal cord pathology (such as spina bifida), or congenital hip dislocation. Table 2 (page 24) lists some additional risk factors for motor disorders.

WHAT IS THE IMPACT ON THE CHILD AND FAMILY?

Children who have a motor disorder can and do live happy and fulfilling lives. The ways in which the motor disorder will affect the child and family depend on many different factors. These include the severity of the condition, the resulting motor limitations, whether or not there are associated health and/or developmental problems, the strengths and needs of the family, and the availability of support.

In general, infants and young children who have motor disorders usually have a restricted ability to explore their environment, interact socially, and communicate with others. For some children, associated deficits of hearing, sight, and/or touch will decrease the sensory input they receive, further compromising the exploratory behaviors so essential to the development of young children. This may limit learning and cognitive development.

Some children may have motor disorders that restrict their ability to demonstrate their knowledge, particularly through traditional testing methods. These children may therefore be considered less intellectually capable than they actually are.

DO SOME CHILDREN OUTGROW MOTOR DISORDERS?

Although the type of cerebral lesion causing cerebral palsy is static (stays the same), the impact of the lesion on the child's motor development may change as the brain matures. As a result, the impairments related to cerebral palsy may also change over time. For example, hypotonia in infancy may evolve into spasticity as the child ages, or an infant with mild spasticity may gradually improve. While some of the motor signs of cerebral palsy may diminish over time, many of

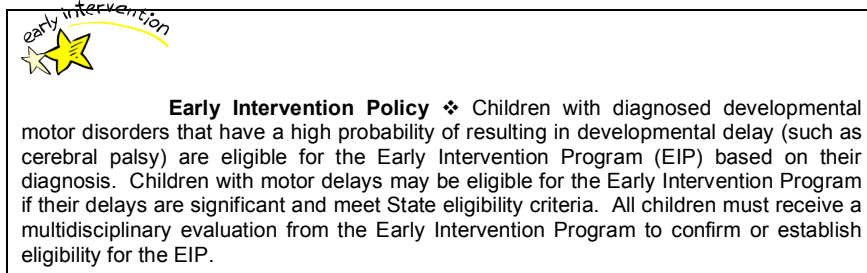
these children will continue to show delays or deficits in language and learning skills.

A child who has a motor delay that does not seem to be associated with other health or developmental problems may eventually achieve an age-appropriate level of function. For example, a child with isolated hypotonia will usually progress to the point where the delays become more of a gross motor coordination problem. The problem may then only be seen when testing upper body strength, such as when batting a ball.

However, it is important to remember that delayed motor development may be an indicator of other problems such as language or learning disabilities. Therefore, ongoing developmental monitoring is important for all young children who have motor delays and disorders.

CHAPTER III: ASSESSMENT

It is important to identify children at risk for motor disorders as early as possible so that appropriate developmental surveillance, identification, and management of motor delays and disorders can be initiated. Early identification and appropriate intervention may promote better long-term functional outcomes and help to maximize the child's general development.

A graphic with a yellow star and the text "early intervention" in a curved font above it. Below the star is a box containing the text:

Early Intervention Policy ❖ Children with diagnosed developmental motor disorders that have a high probability of resulting in developmental delay (such as cerebral palsy) are eligible for the Early Intervention Program (EIP) based on their diagnosis. Children with motor delays may be eligible for the Early Intervention Program if their delays are significant and meet State eligibility criteria. All children must receive a multidisciplinary evaluation from the Early Intervention Program to confirm or establish eligibility for the EIP.

The early identification of motor disorders in newborns and infants can occur in a variety of ways. If the child is premature or has other known risk factors for developmental problems, the possibility of a motor disorder may be identified at birth.

However, the majority of infants who have a motor disorder are full-term infants with uncomplicated newborn periods. Information from parents about certain behaviors or lack of progress in the child's development and/or direct observation of the child during routine health care visits may give rise to concern about a possible motor problem.

GENERAL APPROACH

The assessment process

It is important that assessment be viewed as an ongoing process that follows the child over time rather than as a single event. It is recommended that a child's motor development be monitored regularly at specific age points (developmental surveillance), such as during routine health care visits. It is important to use multiple measures including physical exam findings, history of motor milestones, and observation of motor quality and spontaneous movement.

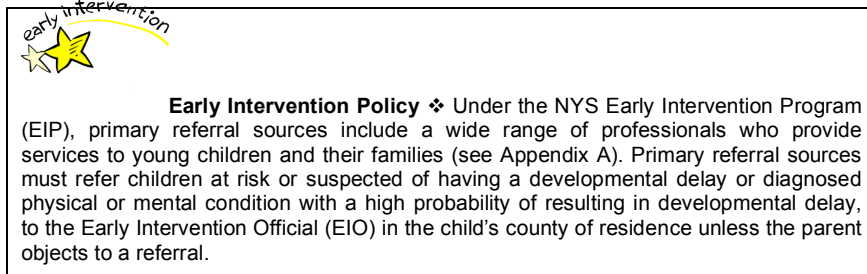
It is recommended that the assessment be appropriate to the developmental stage of the child; take place in a quiet environment; provide a positive experience for both parent and child; and accommodate the family's schedule, culture and

language. In addition, factors that may affect the child's performance, including his or her overall health, hearing, and vision status, need to be considered.

Parental concern can be a good indicator of a motor problem. It is therefore important for the health care provider to follow up on the concern with appropriate screening and developmental surveillance.

It is important for health care and early childhood professionals to understand typical motor development in young children so that they can:

- Recognize potential motor problems
- Use appropriate methods for ongoing monitoring
- Facilitate appropriate intervention strategies
- Assist in making appropriate referrals

A graphic with a black border. In the top left corner, there is a yellow star with a black outline, and the words "early intervention" are written in a curved path above it. The main text of the graphic is as follows:

Early Intervention Policy ❖ Under the NYS Early Intervention Program (EIP), primary referral sources include a wide range of professionals who provide services to young children and their families (see Appendix A). Primary referral sources must refer children at risk or suspected of having a developmental delay or diagnosed physical or mental condition with a high probability of resulting in developmental delay, to the Early Intervention Official (EIO) in the child's county of residence unless the parent objects to a referral.


In addition, professionals need to have a solid knowledge base about typical newborn and early development, atypical patterns of development, and the assessment tools being used. Other key professional characteristics include understanding the significance of observation, recognizing cues from the child, and being sensitive to the needs of parents.

Infants who have a motor disorder often have delays in other developmental domains, and they are at high risk for health problems. Therefore, it is likely that there will be many different professionals involved in an ongoing process of assessment and intervention for these children. It is important that all individuals working with the child and family coordinate evaluation plans and share relevant information about the child's progress.

Considering the cultural and family context

When working with children and families, it is essential to consider parent priorities, parenting styles, and the family's practical and emotional support system. There may be cultural and familial differences in expectations about such things as the development of adaptive or self-help skills and independence, play and social interaction, pragmatic use of language, and eye contact.

If English is not the family's primary language, it is important for professionals to look for ways to communicate effectively. That includes finding professionals and/or translators who speak the family's primary language.



Early Intervention Policy ❖ The multidisciplinary evaluation to determine a child's eligibility for the program must be conducted in the dominant language of the child whenever it is feasible to do so.

IDENTIFYING YOUNG CHILDREN WHO HAVE A MOTOR DISORDER

Reflex development

Evaluating the presence and quality of reflex development is one of the ways that motor development in young children is routinely assessed. In general, the persistence of primitive reflexes past the age of approximately 6 months is a clinical clue of possible motor and/or other developmental problems.

While not always classified as part of the constellation of primitive reflexes, two of the most obvious reflexes present at birth are the *suckle* and *grasp* reflexes. These reflexes also become integrated into normal movement patterns in the child's first 6 months and are equally important indicators of infant development.

- **Suckle Reflex:** The suckle reflex is a front-to-back movement of the tongue. Problems with early suckling are often identified by oral feedings consistently longer than 30 minutes and difficulties with swallowing. Persistence of a prominent suckling reflex beyond the age of 6 months should cause concern.
- **Palmar Grasp Reflex:** The palmar grasp reflex (such as grasping and holding on to someone's finger) can be readily elicited in the newborn period. Absence of this reflex in the newborn period, persistence of the reflex beyond the age of 6 months, or persistent holding of the hands in a fist position at any age are considered abnormal.

A few of the other common early reflexes include:

- *Moro Reflex*--Triggered by a sudden movement of the infant's head/neck forward or backward, the Moro response includes a quick opening of the arms followed by an "embrace" posture. When the reflex is absent or there is asymmetry (movements are not equal on both sides), it may be an indication of an abnormal condition.
- *Positive Support Reflex*--A positive support reflex consists of full extension of knees and ankles followed by bending. A response of holding the legs straight for greater than 30 seconds is abnormal at any age (Figure 1).
- *Asymmetric Tonic Neck Reflex (ATNR)*--Turning the child's head to one side when the child is lying on its back triggers the "fencer's posture". This reflex, when strong and persistent past 6 months, often results in asymmetric posture and lack of variability of arm and leg movements. When this posture lasts for greater than 30 seconds at any age, it is considered abnormal (Figure 2).

Figure 1: Positive Support Reflex

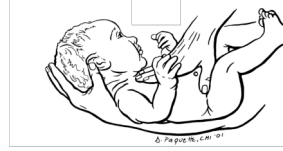
Figure 2: Asymmetric Tonic Neck Reflex

- *Tonic Labyrinthine Reflex (TLR)*--Extension of the neck results in pulling the shoulders back and extending the legs out away from the body (Figure 3a). Flexion of the head/neck results in a fetal position (Figure 3b).

Figure 3a: Extension TLR



Figure 3b: Flexion TLR



Muscle tone in the newborn period

Evaluation of muscle tone is another way in which motor development of young children is routinely assessed. This can be done through observation of the infant's spontaneous movements and the position of the arms and legs at rest.

The popliteal angles (amount of bend at the knee joints) can also be used as an indicator of muscle tone. In the newborn, the popliteal angle is usually a right angle. Measuring the popliteal angle may be useful for identifying infants and young children at risk for cerebral palsy and other motor development problems.

Postural tone is another term used to describe muscle tone in young children. This is the development of head and trunk control as the infant learns to move against gravity. For adequate postural tone, the muscles need to have enough tone to resist the force of gravity but not so much tone as to prevent controlled movement.

Figure 4: Development of Muscle Tone

	34 w GA (Premature)	40 w GA (Full Term)	2 m	6 m	9 m
Posture					
Popliteal Angle	 	 	 	 	

Popliteal angle is measured with patient supine, hip flexed at 90°, and knee extended to point of resistance. This angle can be measured using two different methods: (A) the Dubowitz method and (B) the Bleck method.

Abnormal patterns of general movements

Spontaneous motor activities are generalized movements that occur in young infants in the first 4 to 5 months post term. These movements, as well as those associated with motor activities such as rolling, crawling, and walking, are sensitive indicators of brain function.

General movements that lack complexity and variability may be a clinical clue of a possible motor problem. A lack of general movements should also be a cause of concern.

Children with cerebral palsy usually have abnormalities of general movements. Abnormal movements may be either slow and monotonous or brisk and chaotic.

Using Risk Factors and Clinical Clues to Identify Possible Motor Problems

A *risk factor* is something that increases the possibility that the child will have a motor disorder. A *clinical clue* is an early sign or symptom of a possible motor disorder.

It is recommended that all newborns be checked for risk factors and clinical clues for possible motor problems. However, the presence of risk factors or clinical clues is not by itself enough to establish the existence of a motor disorder. These factors merely provide an indication that further assessment may be needed.

See Tables 2 and 3 for a list of risk factors and clinical clues for motor disorders.

Using observations to identify possible motor problems

The visible progress of motor development is generally easy to observe. Therefore, infants who have a motor disorder are usually first identified through review of the developmental history and during physical medical examinations.

Unless otherwise stated, ages are chronologic ages for children delivered at full term, sometimes referred to as number of months “post term.” (See Background section, page 11, for determining adjusted age of premature infants.)

Direct observation of the quality of the child’s spontaneous general movements, especially in the first 4 to 5 months of life, can provide good information about the child’s developmental status. A videotape approach may also be useful for monitoring qualitative movement patterns.

Table 2: Risk Factors for Motor Disorders

Pregnancy risk factors

- Maternal diabetes or hyperthyroidism
- Maternal high blood pressure
- Vaginal or intrauterine infection
- Poor maternal nutrition
- Maternal seizures
- Incompetent cervix (risk of premature delivery)
- Maternal bleeding from placenta previa or abruptio placentae
- Teratogens (alcohol, drugs, radiation exposure)

Table 2: Risk Factors for Motor Disorders

Delivery risk factors

- Prolonged rupture of the amniotic membranes for more than 24 hours leading to infection
- Severely depressed (slow) fetal heart rate during labor, indicating fetal distress
- Multiple births
- Abnormal presentation, such as breech, face, or transverse lie, which makes for a difficult delivery
- Complications or trauma during delivery

Neonatal risk factors

- Premature birth (less than 37 weeks gestation)
- Low birth weight (less than 1500 grams)
- Hypoxia or asphyxia (insufficient oxygen), cerebral ischemia (poor blood flow to the brain)
- Meningitis
- Interventricular hemorrhage (IVH) (bleeding into the interior spaces of the brain or into the brain tissue)
- Periventricular leukomalacia (PVL) (damage to the brain tissue due to lack of oxygen or problems with blood flow)

Other risk factors

- Genetic syndromes
- Chromosomal abnormalities
- Family history of delays

(Continued from previous page)

Table 3: Clinical Clues of a Possible Motor Disorder

Abnormalities of Muscle Tone

- Asymmetric (not equal on both sides) tone or movement patterns
- Greater passive flexor tone in arms when compared to legs at any age
- Popliteal angles (bend of knee joint) of 90° or more after 6 months post term
- An imbalance of extensor and flexor tone of the neck and trunk
- Extensor posturing of the trunk or excessive shoulder retraction at rest or when pulled to sit

Table 3: Clinical Clues of a Possible Motor Disorder

- Hypotonia (floppiness) of the trunk:
 - The baby slips through the hands when held under the arms in a vertical position
 - There is excessive draping over the hand when held in prone (face down) suspension
- Plantar flexed feet
- Hands held habitually in a fist position

Nonsequential Motor Development

- Early rolling
- Brings head and chest up on forearms in prone position prior to developing good head control
- Preference for early standing prior to sitting
- Walking with support before crawling

Qualitative Differences in Motor Development Commonly Reported by Parents and Caregivers

- Startles easily; jittery
- Does not like to cuddle; seems “stiff”
- Arches back frequently
- Baby seems “floppy”
- Infrequent or limited variety of movement
- Favors one side of body more than the other
- Feeding problems, particularly after 6 months
- Falls backward when in a sitting position
- Crawls in a “bunny hop” fashion
- Walks on tiptoes
- “Scissors” legs while standing
- Sits with legs in “w” position (reversed tailor position)

Observations of Movement and Posture

- Rolling as a unit (log rolling) after the age of 6 months
- Hyperextension of head and neck when prone in conjunction with significant head lag when pulled to sit
- Readily lifts head and neck when prone, but arms are kept extended along trunk
- When pulled to sit from lying down position, comes to standing instead of sitting position


(Continued from previous page)

Table 3: Clinical Clues of a Possible Motor Disorder

- One or more of the following occurs in the sitting position:
 - Child sits on lower lumbar sacral region
 - Hips and knees are flexed and hips are adducted
 - Legs are positioned in a reverse tailor or “w” posture
 - A tendency to thrust trunk backward while sitting
- One or more of the following is observed during crawling:
 - Legs are moved as a unit resulting in “bunny hop” movements
 - Hips are excessively adducted, reciprocal movements of legs are done very slowly, and movements are “jerky” in appearance
- Legs are kept extended and adducted while child creeps (pulls body forward with arms)
- In a supported standing posture, legs are excessively extended and adducted, and child stands on toes
- While walking, one or more of the following are observed:
 - Crouched gait (hips are flexed and adducted, knees are flexed, and feet are pronated)
 - Intermittent tiptoe gait and overextension of the knees

(Continued from previous page)

Preterm infants with risk factors for motor problems



Early Intervention Policy ❖ Infants less than one year of age who are born weighing less than 999 grams are automatically eligible for early intervention services because this is a diagnosed condition with a high probability of resulting in developmental delay. Infants in the 1000 – 1500 grams weight range are considered at risk, and are not considered to have a condition with a high probability of resulting in a developmental delay.

Preterm infants who have an abnormal neurological or an abnormal cranial ultrasound exam are the most likely to develop neurodevelopmental (motor, sensory, and cognitive) disorders. Early motor abnormalities in the newborn period are associated with a high occurrence of general cognitive delays later in childhood.

Preterm infants who have risk factors for possible motor problems, but who have normal findings on a newborn neurodevelopmental exam, generally have good outcomes. However, on-going developmental monitoring is indicated. When measured at term, normal findings in muscle tone may be misleading as to later motor development.


Ongoing surveillance for infants with risk factors

Continued surveillance is important for all infants and young children with risk factors or clinical clues that indicate possible motor problems because:

- Delays are more noticeable during the first year
- As more complex skills begin to develop (from one to three years), a child's limitations become more apparent
- If a child has motor problems in infancy or early childhood, there is a greater risk for associated problems such as cognitive or language difficulties

Newborn screening tests

A standardized neuromotor exam used for infants in the post-term newborn period, such as the Neurological Assessment of Preterm and Full-term Infants (NAPFI), can be useful for identifying young children who are likely to have neuromotor abnormalities. Other tests, such as the Einstein Neonatal Neurobehavioral Assessment Scale (ENNAS), may help to identify children who need follow-up and surveillance for various developmental deficits including cognition (such as preschool learning problems) and fine motor problems.



Early Intervention Policy ❖ Under the New York State Early Intervention Program (EIP), primary health care providers are considered 'primary referral sources.' When a child's health care provider suspects a possible motor disorder or developmental delay, the health care provider must inform the parent about the EIP and refer the child to the Early Intervention Official (EIO) in the child's county of residence unless the parent objects to the referral.

When there are heightened concerns about motor development but no confirmed motor disorder, a child may be considered at risk. Primary referral sources must refer children at risk or suspected of having a disability to the Early Intervention Official in the child's county of residence unless the parent objects. Professional judgment and parent concern must be weighed in determining if a child should be referred to the EIO as an at-risk child.

Identifying Delays in Motor Milestones

For extremely premature infants, it is recommended that the following six motor milestones be monitored regularly during the first year of life:

- Rolling stomach to back (prone to supine)
- Rolling back to stomach (supine to prone)
- Sitting with arm support
- Sitting without arm support
- Crawling/creeping
- Cruising

For high-risk preterm infants, a motor delay any time during the first two years increases the risk for a motor disorder.

Children with delayed motor milestones

Late walking may be an important indicator of possible motor delay or associated disabilities. For all children who do not walk by 18 months, it is recommended that:


- A focused screening be done to identify possible motor delays or disorders and assess whether ongoing surveillance or further assessment is needed
- Parents be informed that continued observation is important even if the initial screening is not conclusive

Loss of motor milestones

While it is normal for children to experience brief plateaus in development, it is important to recognize that a period of normal motor milestone acquisition followed by an extended plateau or regression in motor skills warrants a prompt, thorough evaluation.

Many progressive or degenerative neurological diseases also result in loss of previous motor milestones. Determining whether a motor delay is progressive or static in nature can be important in arriving at a diagnosis.

Neuroimaging and Electrophysiologic Tests



Early Intervention Policy ❖ Medical tests, including neuroimaging and electrophysiologic tests, are not reimbursable under the NYS Early Intervention Program unless the test is determined to be necessary to establish a child's eligibility for the program.

Neuroimaging

Many motor disorders of childhood occur because of brain injury or malformation of some part of the brain. In infants suspected of having either brain injury or malformation, it is useful to visualize these conditions using neuroimaging techniques. While there is a correlation between neuroimaging findings and outcomes, neuroimaging findings are not perfect predictors of the prognosis for a specific child.

Methods to image the central nervous system include conventional x-ray of the skull, ultrasound, computerized axial tomography (CT or CAT scan), and magnetic resonance imaging (MRI).

X-rays are generally not useful for neuroimaging. They are more useful in the orthopedic management of the bones and joints such as hips and lower extremities.

Ultrasound may help with the early identification and diagnosis of certain findings that are often associated with motor disorders. It is recommended for high-risk preterm infants because it gives an instant assessment, is easy to administer, and is inexpensive.

CT or *MRI* is recommended if there is an indication of central nervous system (CNS) dysfunction based on clinical assessment (symptoms and physical findings) and the etiology (cause) has not already been established.

MRI is the most sophisticated method available to visualize the central nervous system, allowing all areas of the brain and all lesions (vascular, spinal fluid, oncologic) to be seen.

When choosing a neuroimaging modality, it is important to consider:

- Side effects
- Capability of imaging the suspected area

- Length and difficulty of the procedure
- Need for sedation or anesthesia
- Availability
- Timing of the procedure
- Expense

Electrophysiologic tests


Types of electrophysiologic tests include:

- *Electroencephalogram (EEG)*. Records brain electrical activity, a useful tool for assessing individuals with seizure disorder
- *Electromyogram (EMG)*. Used with nerve conduction studies to help diagnose muscle versus nerve disease
- *Evoked potentials*. Stimulates sensory organs or peripheral nerves to evoke a response in the brain. May be useful in identifying and managing sensory (somatosensory, auditory, and visual) deficits

It is important to recognize that electrophysiologic studies are not useful in the identification and management of young children with motor impairments. However, they may be useful for other specific purposes in children who have a motor disorder.

ASSESSING YOUNG CHILDREN WHO HAVE A MOTOR DISORDER

Assessment of motor development



Early Intervention Policy ❖ The multidisciplinary evaluation team can use a combination of standardized instruments and procedures, and informed clinical opinion to determine a child's eligibility for services.

The multidisciplinary evaluation team must include professionals relevant to the needs of the child and family, and must include at least two qualified personnel of different disciplines. The multidisciplinary evaluation must be performed using nondiscriminatory procedures as defined in program regulations (see Appendix A) and be conducted in the child's dominant language whenever feasible.

The use of multiple sources of information is recommended in assessing children suspected of having motor problems. This would include parental reports, direct observation of the child, and standardized tests.

It is recommended that the assessment of children who have a motor disorder include functional tests and measures. It is also recommended that a comprehensive evaluation of functional abilities include assessment of both motor function and general functioning.

It is important to remember that assessment tests have specific purposes:

- A *discriminative* test is used to identify a delay
- An *evaluative* test is used to measure change over time

When deciding whether to use a particular assessment test, it is important to have information about the purpose of the test, the test's reliability and validity, and the population for which it was designed.

Tests and techniques to identify motor problems

Examples of some of the tests of motor development that are commonly used for infants and young children with motor problems or cerebral palsy are described below. (Additional information about assessment tests can be found in the Motor Disorders Clinical Practice Guideline Report of the Recommendations and the Guideline Technical Report.)

- *Alberta Infant Motor Scale (AIMS)*: Identifies infants with motor delay from birth to 18 months

- The *Bayley Scales of Infant Development II*: The BSID-II (Note: BSID-III Published 2005) identifies young children from 1 to 42 months who are at risk for developmental delay in cognitive, motor, and behavioral areas
- *Gross Motor Function Measure (GMFM)*: Measures changes in gross motor function for children of all ages with cerebral palsy
- *Toddler and Infant Motor Evaluation (TIME)*: For children from 4 to 40 months with suspected motor delay

Selecting tests for assessment of general functioning

Assessments that focus on general functioning provide information about the child's adaptive and independent behaviors in activities of daily living. These assessments generally rely on professional judgment or interviews with the primary caregiver. Assessment instruments for general functioning include:

- *Pediatric Evaluation of Disability Inventory (PEDI)*: Assesses children with disabilities from 6 months to 7 1/2 years of age
- *Functional Independence Measure for Children (WeeFIM)*: Assesses children from 6 months to 12 years of age
- *Vineland Adaptive Behavior Scales (VABS)*: Describes degrees of functional limitations in children from birth to 18 years

Using play-based assessments

Since young children spend most of their time playing and motor functioning is necessary for a child to be able to move and manipulate toys, play-based assessments (such as the *Transdisciplinary Play-Based Assessment*) can be useful for assessing motor development.

Assessing sensory processing

Assessing sensory processing in preterm infants and in young children with indications of motor disorders may provide information about the child's responses to various sensory inputs. Clinical impressions can be supported by the use of a standardized measure of sensory processing and reactivity, such as the *Test of Sensory Functioning in Infants (TSFI)*.

Assessing coping

It is important to recognize that coping mechanisms vary from child to child and from family to family. The internal coping resources of the child, the availability and characteristics of external support resources, and the demands of the

environment can affect the child's ability to interact and learn, to develop feelings of mastery and success, and to function in the environment. It may be useful to use an instrument designed to evaluate coping, such as the *Early Coping Inventory*, when assessing young children who have a motor disorder.

Assessment tests and techniques to identify cerebral palsy

It is important to recognize that assessment techniques to identify cerebral palsy in children younger than 4 to 6 months of age are likely to be different from those used for older children. The tests most effective in identifying cerebral palsy in children younger than 4 to 6 months tend to focus on:

- Spontaneous general movements
- Volition
- Symmetry
- Tone
- Primitive reflexes
- Automatic reactions

Classifying the type of cerebral palsy

It is important that the classification of cerebral palsy be attempted only after physical findings have stabilized and the rate of motor skill acquisition has been accurately estimated. Classification of cerebral palsy can usually be completed between 1 and 2 years of age with reassessment at least yearly thereafter.

It is important that the methods used to classify cerebral palsy and the related implications for the child be clearly and accurately explained to parents as well as to other professionals working with the child and family.

Additional information about classifying cerebral palsy can be found in Appendix C.

Understanding the prognosis

It is important for parents and professionals to recognize that not all children with motor delays or cerebral palsy can be identified based on exam findings in the first year of life.


It is also important to recognize that functional limitations can change over time as the child grows. However, for children who have significant motor delays or cerebral palsy at 1 year of age, the degree of motor impairment at 1 year usually

correlates with later motor outcomes. In addition, these children are at high risk for associated developmental and neurological deficits, including functional limitations in cognition, communication, and sensory function. Children who have significant motor delays or cerebral palsy at 1 year of age who do not have a diagnosis of cerebral palsy at 7 years may still have a high prevalence of other developmental disabilities.

Establishing a diagnosis

It is important to establish an accurate diagnosis when identifying and classifying cerebral palsy. Not always being able to confirm the diagnosis in very young children may require delaying the final diagnosis in order to monitor the child’s development and do additional testing.

ORAL-MOTOR ASSESSMENT FOR FEEDING AND SWALLOWING



Early Intervention Policy ❖ Feeding and swallowing problems often co-occur in children who have motor disorders, and may be an early indicator of a motor or other developmental or health problem. Feeding and swallowing problems are signs and symptoms, and it is important to determine the underlying cause.

An isolated feeding problem in and of itself may not be sufficient to establish a child’s eligibility for the EIP. A child who is a “picky eater” or whose family needs guidance in food selection and introduction, would not be eligible for the EIP. However, a serious feeding dysfunction, impacting on the child’s physical development and functioning and adaptive development, can be sufficient to establish a child’s eligibility for the EIP under the physical and adaptive domains. The nature of the feeding dysfunction (e.g., oral-motor and self-regulatory substrates, etc.) and its impact on the child’s development must be documented in the multidisciplinary evaluation report, including the statement of the child’s eligibility for the EIP.

Problems with feeding and swallowing often occur in children with motor disorders. For some children, problems with feeding and swallowing may be an early indicator of a motor or other developmental or health problem.

A feeding or swallowing problem can lead to inadequate nutrition, dehydration, and decreased energy and stamina. It can affect all areas of the child’s development as well as family functioning. Health problems possibly resulting from abnormal swallowing include pneumonia, reactive airway disease, and recurrent upper airway infections. Children with feeding and swallowing

problems often have prolonged and difficult mealtimes, which may create stress for the child and other family members.

Oral-motor problems are common in both children with pyramidal and extrapyramidal types of cerebral palsy and can lead to significant speech and feeding difficulties. The feeding difficulties increase the risk of aspiration of food into the airway and may result in growth problems.

Early recognition of feeding and swallowing problems

Since feeding and swallowing are essential to a child's health, development, and family functioning, it is recommended that all infant development exams include:

- Asking specific and detailed questions about the child's feeding and swallowing history
- Monitoring feeding milestone attainment (Table 4, page 37)
- Eliciting information from parents about feeding and swallowing concerns

It is important to recognize that feeding problems may reflect the feeding skills of parents as well as the child's. As a result, some parents may feel responsible for the feeding difficulties, and therefore may be reluctant to report feeding problems.

Assessing feeding/swallowing problems

Since feeding and swallowing problems are symptoms and not a diagnosis, it is important to determine their underlying cause(s). It is recommended that an accurate diagnosis be made by an experienced physician in conjunction with feeding specialists.

It is important to consider developmental rather than chronologic age when evaluating feeding skills. The typical milestones for normal feeding are shown in Table 4 (page 37), along with the relevant oral-motor and motor skills required.

Table 4: Milestones Relevant to Normal Feeding

Age / Food	Oral-motor skill	Motor skills
<i>Birth-4 months</i>		
Liquid	<ul style="list-style-type: none"> ▪ Suckle on nipple 	<ul style="list-style-type: none"> ▪ Head control acquired
<i>4-6 months</i>		
Purees	<ul style="list-style-type: none"> ▪ Suckle off spoon ▪ Progress from suckle to suck 	<ul style="list-style-type: none"> ▪ Sitting balance ▪ Hands to midline ▪ Hand-to-mouth play
<i>6-9 months</i>		
Purees	<ul style="list-style-type: none"> ▪ Assisted cup drinking 	<ul style="list-style-type: none"> ▪ Reach, pincer grasp
Soft chewables	<ul style="list-style-type: none"> ▪ Vertical munching ▪ Limited lateral tongue movements 	<ul style="list-style-type: none"> ▪ Assists with spoon ▪ Finger feeding begins
<i>9-12 months</i>		
Ground soft foods	<ul style="list-style-type: none"> ▪ Increased independent cup drinking 	<ul style="list-style-type: none"> ▪ Refines pincer grasp
Lumpy purees		<ul style="list-style-type: none"> ▪ Finger feeding ▪ Grasps spoon with hand
<i>12-18 months</i>		
All textures	<ul style="list-style-type: none"> ▪ Lateral tongue action ▪ Diagonal chew ▪ Straw drinking 	<ul style="list-style-type: none"> ▪ More independent feeding ▪ Scoops food, brings to mouth
<i>18-24 months</i>		
Chewable food	<ul style="list-style-type: none"> ▪ Rotary chewing 	<ul style="list-style-type: none"> ▪ Independence increases
<i>24+ months</i>		
Tougher solids	<ul style="list-style-type: none"> ▪ Increase in mature chewing 	<ul style="list-style-type: none"> ▪ Total self-feeding ▪ Cup drinking, open cup ▪ Increased use of fork

Table 5: Questions to be Considered in the Feeding History

- How dependent is the child on others for feeding?
 - How many minutes does it take to feed the child? Are feedings frequently interrupted? If so, why?
 - Does the child take all feedings orally or is there some tube feeding?
 - Where is the child fed (environment)? Who is present? What else is happening (TV or radio on, people coming and going, other distractions)?
 - What is the child's position during mealtimes? How does it vary?
 - What food textures are consumed? Are the textures developmentally appropriate? Are liquids taken from a bottle or cup? Are solids taken from a spoon or fork? Are the utensils modified?
 - Do feedings produce symptoms such as frequent coughing or progressive "noisy breathing"? Does the child vomit? If yes, when and how much? Is there a history of aspiration pneumonia?
 - Does the child become distressed, refuse feedings, or become sleepy or lethargic during feeds?
 - Does the feeding problem vary with food (texture, taste, temperature, or type); or the beginning, middle, or end of the meal; or the time of day; or different feeders or positions?
 - How do the child and caregiver interact? Is there forced feeding?
 - What happens after meals? Is the child's position/location changed? Is there a routine activity (such as a bath or story) or does it change frequently?
-

Table 6: Clinical Clues of a Possible Feeding Problem

- Prolonged feeding times (>30 minutes)
 - Stress for child and/or parent during or following feeding
 - Poor sucking, difficulty latching on to nipple
 - Losing liquid or food around lips
 - Excessive tongue retraction or protrusion
 - Holding food in mouth or prolonged chewing before swallowing
 - Excessive drooling
 - Indication of respiratory distress during oral feeds (for example, arching back, turning away, eye widening, nasal flaring, difficulty catching breath)
 - Gurgly voice quality
-

Table 6: Clinical Clues of a Possible Feeding Problem

- Difficulty in making transition to a new texture at developmentally appropriate stages
- Coughing or gagging while eating
- Frequent vomiting or excessive spitting up during or after meals
- Poor weight gain
- Reduced interest in or negative response to oral presentation of food

(continued from previous page)

Conducting the initial oral-motor feeding assessment

It is recommended that the initial oral-motor and feeding assessment include an evaluation by a physician and a feeding specialist (usually a speech language pathologist or occupational therapist).

It is important that feeding assessments of older infants and children include observation of:

- The child with a familiar feeder who simulates the typical positioning
- Lip, tongue, and jaw actions during spoon or finger feeding
- Fine motor skills and ability to use feeding utensils
- Differences in efficiency with varied textures and amounts
- Timing of swallows and whether multiple swallows are needed
- Munching or chewing skills
- The coordination of breathing and swallowing during oral feeding

Components of an initial oral motor assessment include physical examination and history, observation of caregiver and child interaction, an oral motor exam, a feeding assessment, and evaluation of diet for adequate nutritional intake.

Oral-motor assessment tests

It is important to recognize that there are no standardized tests or scales for oral-motor assessment. No single test or scale can be recommended for universal use for all infants and children. However, commonly used checklists and scales that may be useful in making systematic observations of infant feeding include Neonatal Oral-Motor Assessment Scale, Schedule for Oral-Motor Assessment, and the Multidisciplinary Feeding Profile.

Physical exam considerations

It is recommended that infants and children with feeding and swallowing disorders have regular follow-up assessments by their primary care physician or a specialty physician. It may be useful to include a speech-language pathologist, occupational therapist, physical therapist, nutritionist, psychologist, and/or dentist, as well as a developmental pediatrician, pediatric otolaryngologist, physiatrist, gastroenterologist, neurologist, or craniofacial surgeon.

Instrumental assessments

It is important to recognize that some children who have a motor disorder may need additional evaluation using instrumental assessments such as a videofluoroscopic swallow study (VFSS) in conjunction with a flexible endoscopic examination of swallowing (FEES). Indications for instrumental assessments include but are not limited to:

- Risk for aspiration (food, liquid, or saliva getting into the windpipe)
- Prior aspiration, pneumonia, or chronic lung disease
- Suspicion of pharyngeal and/or laryngeal problem
- “Gurgly” voice quality
- Stridor (a harsh high-pitched sound while breathing in) at rest or during feeding



Early Intervention Policy ❖ Medical tests such as imaging studies and electrophysiologic assessment techniques are not reimbursable under the NYS Early Intervention Program.

ASSESSING OTHER DEVELOPMENTAL DOMAINS FOR YOUNG CHILDREN WHO HAVE A MOTOR DISORDER


Many young children who are identified as having motor disorders will also have other developmental problems. Consideration of these problems is also an important part of the assessment process.

Importance of the developmental assessment

It is important that all children who have a motor disorder have periodic age-appropriate developmental assessments in cognitive, communication, physical development, social-emotional development, and adaptive/self-help skills. This should include both formal and informal assessments.

Developmental assessments can provide:

- An objective description of the child’s abilities and needs
- A framework for the assignment of appropriate interventions
- A baseline for measuring progress over time



Early Intervention Policy ❖ ❖ The early intervention multidisciplinary assessment must include an assessment of all five areas of development (cognitive, communication, physical, social/emotional, and adaptive) and a parent interview. Families may also participate in an optional family assessment.

The multidisciplinary evaluation team must complete the child’s evaluation in accordance with requirements in NYS Public Health Law and regulations, and standards and procedures for evaluation and eligibility issued by the Department. The multidisciplinary evaluation is provided at no cost to parents.

Conducting the developmental assessment

It is important that the developmental assessment use age-appropriate testing and scoring methods, consider the child’s individual abilities and needs, and make use of parental observations.

It is also important that the assessment recognize *qualitative* differences as well as *quantitative* differences. For example, in addition to determining if the child is able to do a particular task, it is also important to look at *how* the child does the task.


It is recommended that developmental assessment of young children who have a motor disorder include:

- Multiple settings as appropriate, such as the home, day care setting, school, and typical social environments
- Multiple modalities (such as pictures, objects, sounds)
- Multiple examiners (such as teachers, therapists, and health care providers)

It is recommended that the developmental assessment be an ongoing process of periodic structured assessment plus general monitoring of the child. It should take place in more than one session and in more than one setting as appropriate because:

- A child's performance can vary from day to day
- The child's performance may vary depending on familiarity with the environment and the professional
- The child's comfort level with the professional may change over time

It is important that those assessing development in young children make sure to provide any prescribed hearing, vision, and postural aids the child may need to perform optimally.

The graphic features the text "early intervention" in a curved, light blue font at the top left. Below it are two yellow stars of different sizes, with the larger one in the foreground and a smaller one behind it. A thin blue arc connects the two stars.

Early Intervention Policy ❖ Ongoing assessment should be included as part of ongoing early intervention services by all qualified personnel working with the child and family.

Selecting assessment materials

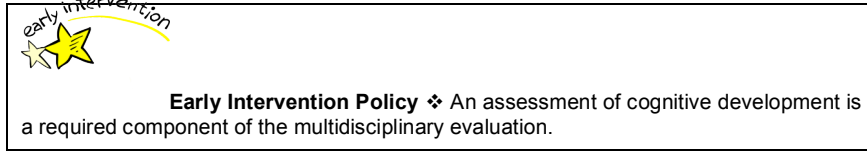
No child is “untestable.” It is important to recognize, however, that some tests may not be appropriate for some children. Input from parents and others who know the child well can be extremely important in determining the most appropriate materials, procedures, and adaptations to be used. Standardized developmental tests may provide information about how a child's performance compares with that of typically developing children, but may not be as useful for understanding how a child's development compares with that of other children who have a motor disorder.

When selecting assessment materials and procedures, it is recommended that the child's sensory capacities and modes of responding be considered to the extent possible. It is also recommended that all assessment tools encompass a wide range of skill levels. The test should not be so easy that the child performs 100 percent of the tasks nor so hard that all the scores are close to zero percent.

Assessing cognition

Assessing cognitive ability in children who have a motor disorder is important because cognitive ability affects functioning in other areas of development and has implications for intervention decisions. However, it is important to

recognize that cognitive development, unlike motor or communication development, is not directly observable but must be inferred through the child's motor movements, facial expressions, use of language, and other observations.

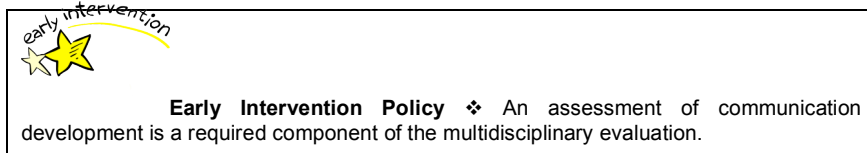
A graphic with a black border. In the top left corner, there is a yellow star with a smaller white star inside it, and the words "early intervention" written in a curved, handwritten-style font above them. To the right of this graphic, the text reads: "Early Intervention Policy ❖ An assessment of cognitive development is a required component of the multidisciplinary evaluation."

Early Intervention Policy ❖ An assessment of cognitive development is a required component of the multidisciplinary evaluation.

It is recommended that components of the cognitive assessment include:

- General information
- Conceptual development
- Memory, attention, and problem-solving skills
- Perceptual motor function and functional motor skills
- Receptive and expressive language
- Adaptive behavior

Assessing communication

A graphic with a black border. In the top left corner, there is a yellow star with a smaller white star inside it, and the words "early intervention" written in a curved, handwritten-style font above them. To the right of this graphic, the text reads: "Early Intervention Policy ❖ An assessment of communication development is a required component of the multidisciplinary evaluation."

Early Intervention Policy ❖ An assessment of communication development is a required component of the multidisciplinary evaluation.

When assessing communication in a young child who has a motor disorder, it is important to consider the child's health status and medical history, including:

- General motor tone and function
- Breath support for vocalization
- History of middle ear infections
- Hearing status and hearing history
- Oral-motor and feeding history
- Vision status

It is important to consider the possibility of hearing loss whenever there are indications of a communication delay or problem. It is recommended that an audiologic evaluation be conducted any time there is concern about hearing loss.

It is also important to consider:

- Developmental status, especially the interrelationship between cognitive development, motor development, and language milestones
- History of speech/language development, including expressive and receptive language performance (syntax, semantics, pragmatics, phonology) and fluency (rate and flow of speech)

When there are indications of a possible communication problem, a more in-depth assessment is recommended. It is important that an in-depth communication assessment for children who have a motor disorder from 6 months to 3 years of age include all of the following:

- Standardized tests of receptive and expressive language
- Use of gestures and other nonverbal communication, including (but not limited to) augmentative systems
- Oral-motor/speech-motor assessment
- Language samples (verbal and nonverbal)
- Parent report

ASSESSING THE GENERAL HEALTH STATUS OF YOUNG CHILDREN WHO HAVE A MOTOR DISORDER


It is recommended that children who have a motor disorder receive routine preventive health care, and that, whenever possible, children who have a motor disorder have a primary health care provider who is knowledgeable about the special health care needs of children who have a motor disorder.

Medical conditions commonly associated with motor disorders are listed in Table 7 (page 46).

Health assessment for young children with suspected or diagnosed cerebral palsy

It is recommended that professionals assessing health status of children with suspected or diagnosed cerebral palsy actively look for associated health conditions that are seen more commonly in children with cerebral palsy.

It is extremely important to evaluate hearing and vision in a child with suspected or diagnosed cerebral palsy to rule out impairment in these areas as a contributing factor to the child's mobility and communication problems.

The graphic features the text "early intervention" in a curved, yellow font at the top left. Below it is a yellow five-pointed star with a black outline and a smaller white star inside it.

Early Intervention Policy ❖ Audiological and vision evaluations are considered to be early intervention services.

When assessing the health status of young children who have a motor disorder, it is important to pay particular attention to:

- Vision and ocular motor problems
- Growth and nutritional status
- The feeding history
- Musculoskeletal development
- Signs of constipation
- Signs and symptoms of gastroesophageal reflux
- Signs and symptoms that would raise the suspicion for seizures

It is also recommended that a pediatric orthopedic consultation and follow-up be considered depending on the needs of the child.

Assessment of growth and nutritional status

It is recommended that growth assessments for children who have a motor disorder be done routinely as part of the child's ongoing health care visits.

Table 7: Common Associated Conditions in Children With Cerebral Palsy

- Orthopedic Problems of High Tone (hypertonia)
 - Subluxed or dislocated hips
 - Scoliosis (curvature of the spine)
 - Contractures
 - Orthopedic Problems of Low Tone (hypotonia)
 - Dislocated hips
 - Pronation (flat feet affecting weight bearing, stability, balance, and walking)
 - Spine Deformities
 - Lordosis (sway back)
 - Kyphosis (rounded back)
 - Scoliosis (curvature of the spine)
 - Seizures
 - Gastrointestinal Problems
 - Oral-Motor feeding and swallowing
 - Gastroesophageal reflux
 - Constipation
 - Respiratory Problems
 - Urinary Tract Infections
 - Bladder Control Problems
 - Visual and Ocular Motor Problems
 - Refractive errors (farsightedness, nearsightedness, astigmatism)
 - Strabismus (crossed eyes)
 - Amblyopia (lazy eye)
 - Congenital cataracts
 - Retinopathy of Prematurity (ROP)
 - Cortical blindness
 - Hearing Problems
 - Dental Problems
 - Malocclusions (overbite or underbite affecting speech and ability to chew)
 - Enamel problems (leading to early tooth decay)
-


CONSIDERATIONS FOR WORKING WITH THE FAMILY

Informing the parents of an infant's potential for motor disorder

As soon as there are indications that a child may have a motor disorder, it is important that the physician communicate this information to parents.

Specific factors that may affect how the family responds when learning that the child has or is at risk for a motor disorder include:

- What the family knows/believes about the condition
- Certainty of the diagnosis and prognosis
- Preexisting family factors
- The setting in which the family was informed
- The manner in which the health care professionals initially informed them
- The quality of the information provided



Early Intervention Policy ❖ Under the NYS Early Intervention Program, physicians and other health care professionals are considered 'primary referral sources.' When primary referral sources suspect or diagnose a motor disorder, they must inform parents about the Early Intervention Program and the benefits of early intervention services for children and their families, and refer the child to the Early Intervention Official in the child's county of residence, unless the parent objects to the referral.

Delivering the news about a child's diagnosis

It is important to tell the family that the child has or is suspected of having a motor disorder in a sensitive and caring way. It is recommended that the physician do so in person and in private, allowing parents time to process the information and arranging an unhurried follow-up.

When choosing the types of information to tell the parents, it is important to provide understandable information without being patronizing or prejudging the ability of parents to understand. Parents need to receive accurate information about the child's condition in order to develop informed and reasonable expectations about the child's development and to become informed advocates for the child.

Understanding the family's response

It is almost impossible in most circumstances to know with certainty the prognosis of serious medical complications, especially during the newborn period. Some parents may find uncertainty stressful; for others it provides hope. Professionals wanting to prepare parents for the worst may be inadvertently eliminating hope and/or setting up an adversarial relationship between the doctor and parents.

Parents of children with disabilities often hold themselves accountable, or feel others hold them accountable, for their child's disability. It is therefore important to discuss the etiology (cause) of the motor disorder and, to the extent that it is honest, to let parents know that it is not the result of something either parent did or did not do.

It is important to recognize that parents' understanding of what a diagnosis means may be based on stereotypes and misinformation. 'Cerebral palsy,' in particular, may be a frightening term. Therefore, it may be important to discuss with parents not only what a diagnosis means, but also what it does not mean for their child.

When a motor disorder is diagnosed, it is very important to include specialists (for example, neurologists, developmental pediatricians, and pediatric physiatrists) as part of the team available to discuss the health and developmental implications of the child's condition.

The family's cultural background may also affect beliefs and attitudes about:

- The cause of the disability
- How the child will be valued and treated by others
- Allocation of responsibility for daily care of the child and decisions regarding the child
- Attitudes toward health care and other service providers

Professionals need to be aware that even if the news is delivered in the best possible way, a parent may still express anger, disbelief, or dissatisfaction after being informed that the child is at risk for or has a disability. It is important for professionals to provide parents with opportunities for both professional supports, such as counseling, and parent-to-parent support.

Communicating with the family

When communicating with the family about a child’s motor disorder, it is important for health care professionals to:

- Avoid negative labeling of the child or condition
- Refer to the child by name rather than as “the baby”
- Acknowledge the child’s specific personal qualities (such as sense of humor) and other positive attributes
- Minimize the use of medical jargon while helping parents to understand the terms and concepts they will need to know

Cultural attitudes may also influence the parents’ preferred patterns of communication, such as indirect or direct communication, level of detail desired, appropriateness of eye contact, level of formality considered proper, and amount or type of emotion considered acceptable to express.

Assessing the Resources, Priorities, and Concerns of the Family

An assessment of the family’s resources, priorities, and concerns is an important part of the overall assessment process. The strengths and needs of the family are often more predictive of outcome for both child and parents than are the child’s needs alone.

Relevant family interaction patterns include:

- The style of the parent-child interaction (for example, encouraging, affectively warm, appropriately structured, nonintrusive, discourse-based, and developmentally sensitive patterns of caregiver-child interactions)
- The diversity of experiences provided by the family (for example, the frequency and quality of contacts with different adults, the variety of toys and materials available, and the stimulation value of the general environment)
- The ways in which the family ensures the child’s health and safety (for example, providing for routine and specialized health care, a safe home environment, and adequate nutrition)

Family characteristics and processes (family cohesion, level of family support and parent-child interaction) are often more predictive of parent and child-related stress than are specific characteristics of the child. Family processes are also generally more predictive of adaptive development in communication, daily


living, and social skills than are the education of parents or psychomotor measures during infancy.

Just as the availability of strong social support may be an important positive factor in a family's inventory of coping resources, nonsupportive behavior from family, friends, or service providers may become a risk factor. Some of the behaviors reported most often by parents as nonsupportive include:

- Comparisons with other children
- Focusing only on what is “wrong” with the child
- Questions about why a child cannot achieve developmental milestones
- Assuming lower expectations than a child's potential abilities
- Offering unsolicited and inappropriate advice
- Blaming parents for the cause of the condition
- Criticizing parental caregiving
- Pitying remarks about the child or parents

The Family Assessment

A family assessment is designed to help identify the family's resources, priorities, and concerns in order to develop effective and meaningful intervention plans.



Early Intervention Policy ❖ Families must be offered the opportunity to have a family assessment as part of their children's multidisciplinary evaluation. The family assessment is voluntary for families. The evaluation team must use appropriately trained qualified personnel when conducting a family assessment.

Conducting a family assessment requires skill and practice. The task for professionals is to objectively help parents articulate the family's needs and goals. The methods include informal discussions with families, and sensitive and focused interviewing techniques, as well as questionnaires and other assessment tools to help families identify, clarify, and communicate their goals and needs.

While some parents may find a family assessment helpful, others may find it intrusive. It is important for professionals to recognize that some families may

interpret the assessment as a message that something is “wrong” with their family functioning.

It is recommended that family assessments include observation and/or discussion of factors such as the family’s:

- Knowledge and need for information about motor disorders
- Vision of the future for the child, both short-term and long-term
- Composition (including siblings and extended family)
- Caregiving skills and sharing of caregiving responsibilities
- Values and culture
- Stressors and tolerance for stress, as well as the family’s coping mechanisms and styles
- Current support systems and resources (including extended family members and their attitudes)
- Interaction and parenting style

It is important to recognize the role of the family’s cultural and ethnic background. Cultural background may affect:

- Who within the family serves as the primary decision maker regarding the child
- Styles of interaction within the family and between the family and others
- Integration of the nuclear family within larger networks, including extended family and community groups
- Access to and ease in using different types of information
- The family’s comfort with openly expressing needs

It is important to recognize that the family’s priorities, resources, and concerns may change over time. Some families may require more frequent family assessments than do other families. It is recommended that there be ongoing family assessment based on the individual needs of the family.

CHAPTER IV: INTERVENTION


PLANNING AND IMPLEMENTING INTERVENTIONS

It is important to identify children who have a motor disorder and begin appropriate intervention to help speed the child's overall development and facilitate better long-term functional outcomes.

There is no single intervention approach or strategy that is appropriate for all children who have a motor disorder. Children who are identified during the newborn period may enter into intervention at a very young age. Other children may not be identified during the newborn period or they may have early indicators of a potential motor problem that require monitoring and developmental surveillance before determining the need for intervention.

Regardless of when intervention is initiated, it is important for decisions regarding interventions for a particular child to be linked closely to the needs of the child as determined in the assessment process. It is also important for the resources, priorities, and concerns of the family to be considered.

Because young children who have a motor disorder often have problems in different developmental domains, they may be involved with a variety of different professionals. Therefore, teamwork and collaboration among professionals are important components of successful interventions.



Early Intervention Policy ❖ For children referred to the Early Intervention Program in New York State, an Individualized Family Service Plan (IFSP) must be in place for children within 45 days of referral to the Early Intervention Official (EIO). The IFSP must include a statement of the measurable outcomes expected for the child and family, and the services needed by the child and family.

The services in the IFSP are provided at no cost to parents, under the public supervision of the EIO and State Department of Health, and by qualified personnel as defined in State regulation (see Appendix A).

The type, intensity, frequency, and duration of early intervention services are determined through the IFSP process. All services included in the IFSP must be agreed to by the parent and the EIO. When disagreements about what should be included in the IFSP occur, parents can seek due process through mediation and/or an impartial hearing.

Selecting Interventions

There are many different types of intervention approaches and programs that might be considered for a young child who has a motor disorder. Some approaches, such as physical therapy, occupational therapy, and speech-language therapy, might be considered standard or traditional developmental therapies. There are also various therapeutic techniques (such as aquatic therapy or therapeutic horseback riding) that are sometimes referred to as “complementary” or “alternative.” These approaches vary greatly in how commonly they are used, the time commitment required (intensity), cost, availability, and potential benefits and harms.

Parents are likely to find many sources of information about intervention options, including claims that a particular intervention will lead to a dramatic improvement in their child’s condition. Parents need to understand how to evaluate this information, and professionals need to understand how to help them make intervention decisions.

When evaluating information about the effectiveness of interventions, it is important for professionals and parents to understand that:

- Results of uncontrolled studies and individual reports about the effectiveness of intervention methods can be misleading
- The best way to assess the effectiveness of interventions is to rely on the results of controlled research studies
- Results may vary for individual children, regardless of study results

Some interventions for children with motor problems may not have established efficacy for improving motor skills but may still benefit the child if the intervention provides physical activity, social interaction, or opportunities for improving overall development.

Table 8: Questions to Ask When Selecting Interventions

- What do we want to accomplish from this intervention? Is the intervention likely to accomplish this?
- Are there any potentially harmful consequences associated with this intervention?
- What positive effects of the intervention would we hope to see?
- Has the intervention been validated scientifically with carefully designed research studies of young children who have a motor disorder?
- Can this intervention be integrated into the child’s current program?
- What is the time commitment? Is it realistic?
- What are the pros and cons of this intervention? What do other parents and professionals say about it (both pro and con)?
- What claims do proponents make about this intervention? (Note: Claims of dramatic improvement are probably a “red flag.”)
- Does the provider of the intervention have knowledge about the medical and developmental issues associated with motor disorders?
- Does the provider of the intervention have experience working with young children who have a motor disorder?
- What do the child’s pediatrician and other professionals who know the child think about the intervention’s appropriateness?

It is recommended that the use of any intervention, including any home program of therapeutic exercise and activities, for a child with a motor disorder be based on an assessment of the specific strengths and needs of the child and family. In assessing the strengths and needs of the child and family, it is important to recognize that:

- Young children who have a motor disorder differ in terms of their individual strengths and needs, as well as their responses to specific intervention methods or techniques
- Children have different family situations and some families will need more support than others

Considering the child's health status

Before initiating intervention for a young child with a motor impairment, it is important to consult with the child's primary health care physician to obtain all relevant information about the child's health status and any associated health conditions that may affect motor activities and to ensure that there are not contraindications to the intervention.

It is important to monitor the child's health status and tolerance for motor activities throughout the intervention.

Selecting intervention strategies and targets

A comprehensive model of intervention strategies is recommended for most young children who have a motor disorder. This model includes implementing interventions in a variety of settings and providing family support services.

In addition, it is important that interventions, strategies, goals, and objectives be developed in conjunction with the participation of the parents, be appropriate to the family's culture, and assist the child's and family's integration into the community. Interventions that help parents gain a broader understanding of their child's cognitive, sensory, and motor development may enable them to improve parent-child interactions.

When selecting intervention strategies, goals, and objectives, it is important to consider the child's health status and developmental needs and skills, as well as potential risks or harms associated with the intervention. It is also recommended that target behaviors for each individual child be clearly identified and defined, with developmentally appropriate and measurable criteria for mastery.


It is important to work with parents to find ways to include family members and other caregivers in helping the child reach intervention goals.

Determining the intervention setting

In determining the most appropriate settings for interventions, it is important to consider:

- How the child's natural environments support the intervention objectives
- The appropriateness of the setting for supporting the needs of the family and child
- The child's response to current interventions

- The cognitive, social, communication, and motor development of the child (ability to follow directions, sit still, interact with peers, etc.)
- The health status of the child and associated health conditions




Early Intervention Policy ❖ Early intervention services can be delivered in a wide variety of home- and community-based settings. Services can be provided to an individual child, to a child and parent or other family member or caregiver, to parents and children in groups, and to groups of eligible children. (These groups can also include typically developing peers.) Family support groups are also available.

Under the Individuals with Disabilities Education Act and New York State Public Health Law, early intervention services must be provided in natural environments to the maximum extent appropriate to the needs of the child and family. *Natural environments* means settings that are natural or normal for the child's age peers who have no disabilities.

It is important to recognize that children who are developmentally ready for peer interactions may benefit from participation in group motor developmental programs.

Determining the frequency and intensity of the intervention

In deciding on the frequency and intensity for motor interventions, it is important to consider the severity of the child's condition, and the child's ability to engage in and tolerate therapy (which impacts on session length). The child's needs, and the goals for the child, should also be considered, along with the progress made so far. Intervention settings should also be considered. Balancing intervention with the child's and family's routines and schedules is also important.



Early Intervention Policy ❖ The type, intensity, frequency, and duration of early intervention services are determined through the Individualized Family Service Plan process. All services in the IFSP must be agreed to by the parent and the Early Intervention Official.

Ongoing monitoring and modification of the intervention

It is recommended that any intervention be tied to ongoing assessment. In evaluating the child's progress, it is more useful to measure functional and developmental outcomes rather than isolated physical findings such as range of motion or primitive reflexes.

It is recommended that parents be informed that the types or frequency of intervention may need to be adjusted based on ongoing reassessment of the child's progress and needs. Adjusting the intervention might mean changing the frequency, intensity, approach, or setting.

It is recommended that parents and professionals consider modification of an intervention when:

- Target objectives have been achieved
- Progress is not observed after an appropriate trial period
- Target objectives have not been achieved after an appropriate trial period
- There is an unexpected change in a child's behavior or health status
- There is a change in the intervention setting
- There is a change in family priorities

It is also recommended that periodic in-depth reassessment of the child's progress and developmental status be done at least once every six to twelve months. As part of that reassessment, it is important to:

- Include appropriate qualitative information
- Use appropriate standardized testing
- Compare the child's individual progress to age-expected levels of development and functioning

When evaluating the effectiveness of specific interventions, it is also important to consider the following:

- When children are receiving multiple interventions at the same time, it is difficult to assess the effectiveness of any individual therapy
- It is important to evaluate the child's progress in all developmental areas (not just motor development)

- Some children with cerebral palsy or isolated motor delays will improve over time in terms of their motor skills and overall functioning, regardless of what intervention they receive (or even if no interventions are provided)
- For some children, manifestations of cerebral palsy become more severe over time, while for other children these manifestations improve

Assessments suggesting a child's motor skills and overall functioning are not progressing as expected may be the result of:

- The interventions not being effective for that child
- The assessment methods not adequately reflecting progress that is being made by the child
- The frequency or intensity of the interventions not being sufficient
- Some other health or developmental factor interfering

Including the Parents and Family in Planning Interventions

It is likely that the assessment and intervention process for many families will begin at a very early age of the child. Therefore, many of the interventions for infants who have a motor disorder focus on the parents rather than on the infant. These may include the parents' need for information about motor disorders, information about ongoing monitoring/developmental surveillance, or the need for family support. Even in interventions that involve a professional working directly with the child, informal or formal parent training may be an important component. Therefore, many of the recommendations for specific interventions for young children who have a motor disorder include recommendations for parent involvement.

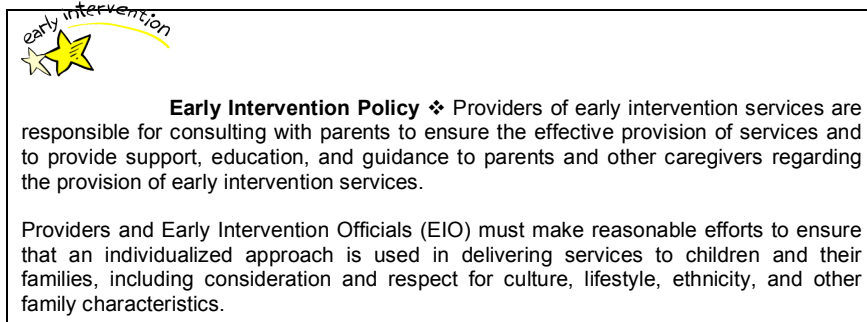
Importance of parent involvement

It is important to involve parents in the assessment of and intervention for their child so that they will understand:

- What to expect regarding their child's development
- Intervention options, goals, and methods
- How to evaluate progress
- How to use naturally occurring opportunities to support and integrate treatment objectives into the child's care at home
- How to advocate for their child

A home intervention program carried out by parents can be an important part of the overall intervention. Because of the importance of parent involvement, it is recommended that parents participate in the intervention planning process. It is recommended that the extent of parental involvement be decided on a case-by-case basis. Factors to consider include the parents' comfort with the intervention, level of interest, availability, and ability to participate, as well as the availability of training and professional support when planning parent involvement in intervention.

Considering the cultural context of the child and family

A graphic titled "Early Intervention Policy" featuring a yellow star with a trail and the text "early intervention" written in a curved path above it. The policy text is enclosed in a rectangular box.

Early Intervention Policy ❖ Providers of early intervention services are responsible for consulting with parents to ensure the effective provision of services and to provide support, education, and guidance to parents and other caregivers regarding the provision of early intervention services.

Providers and Early Intervention Officials (EIO) must make reasonable efforts to ensure that an individualized approach is used in delivering services to children and their families, including consideration and respect for culture, lifestyle, ethnicity, and other family characteristics.

A child's life is always embedded in a cultural context. It is essential to respect the family's culture and primary language when providing interventions for young children with developmental disabilities.

It is also important to remember that a family's cultural context may affect:

- The parent's level of comfort with or approach to professionals
- The parent's confidence in working with a child with special needs
- Patterns of caregiving responsibilities within the family
- Comfort with the child being in public places
- Use of space in the home
- The level of privacy desired within the home (and thus the decision of the home versus other potential settings for the intervention)
- Expectations/desires regarding a child's independence
- Food and feeding style preferences
- Patterns of feeding and holding a young child

- Expectations regarding appropriate language and motor development
- The family's health practices
- The use of traditional or alternative treatments and therapies

It may be helpful for the professional to consult with someone who is familiar with the culture and language of the family. If an interpreter assists in the intervention process, it is important that the interpreter be trained to provide culturally and linguistically accurate interpretations of the child's behaviors.

Including parents in the care of a hospitalized child

It is important for medical and health professionals caring for a child during a hospital stay to understand that parents need to participate in decisions and be an integral part of their child's care.

It is also important for medical and health professionals to help parents develop a level of comfort and confidence when they participate in the care of their hospitalized child. This includes:

- Providing information and support
- Facilitating opportunities for parents to interact with their child
- Helping parents understand basic hospital procedures, such as washing hands and wearing gowns
- Helping parents understand equipment used in their child's care

Working with parents who have a child in the NICU

It is important to recognize that parents have a range of individual responses and emotional reactions to having a child in the neonatal intensive care unit (NICU), who may have serious medical problems and potential for disabilities. When working with parent(s) to plan interventions for a baby in the NICU, it is important to:

- Be accepting of the parent
- Avoid being judgmental
- Pay attention to and value parents' opinions and feelings
- Recognize parents are valuable observers with knowledge to consider in planning their child's care
- Provide opportunities for parents to voice concerns and feelings

- Inform parents about and offer professional support, such as counseling
- Offer opportunities for parent support

Role of the professionals working with parents

It is recommended that professionals collaborate with parents to develop the intervention program. Professionals should ask the parent(s) for their observations about the child's functioning and share regular feedback and progress reports with the parent(s). Professionals should consider the cultural perception of the role of the family in interventions.

It is important that professionals are available to respond to parents' questions and needs on an ongoing basis as the child develops.

Informing parents about interventions

It is important to encourage parent participation in the child's interventions. Parent participation can be an important factor in improving child outcomes.

It is recommended that professionals provide instructions/teaching to parents that will help them foster their child's development. Teaching methods could include verbal instruction, written material, supervision, videotapes, hands-on training, and participation in the child's therapy sessions.

It is important to inform parents about the types and effectiveness of various interventions, the intervention options that are appropriate and available for their child, and the types of professionals who may be providing interventions.

It may be useful for parents to talk to other parents who have had experience with the therapies that are being considered. Parents may also find it helpful to observe, when appropriate, the kinds of therapy being considered before deciding to start a particular intervention.

When talking to parents about intervention options, it is important for the professional to:

- Be knowledgeable about the options, including standard as well as new or alternative intervention methods
- Be open to discussing alternative interventions that the parents may be considering, and make sure that discussions of complementary or alternative interventions provide accurate information while making it clear that the discussion is not an endorsement

- Inform parents about possible efficacy and side effects of the interventions being considered

Parent education and training

It is important to encourage, support, and facilitate parent participation in the child's interventions. It is recommended that structured parent education, including appropriate parent training, be a part of any intervention program. It is important to include specific teaching objectives in all parent training programs.

A home program carried out by parents under the direction of a therapist can be an important part of the overall intervention.

When providing parent training, it is recommended that the following techniques be considered:

- Helping parents understand the child's approach to motor learning
- Instructing parents in specific therapeutic techniques focused on target behaviors
- Teaching parents play activities that integrate the objectives of the motor intervention into the child's daily life
- Providing support and education through parent-infant interaction groups
- Teaching through modeling, demonstration, manual guidance and verbal feedback

Providing Support to Parents and Families

Family support is a broad concept that includes both informal and formal support, as well as planned and naturally occurring interactions. Family support services are most effective when matched to the individual family. Families with a high need for support tend to view support as positive, while families with a low need for support tend not to respond as positively to family support services. When providing support to families, it may be useful to consider ways of helping the family to mobilize informal support networks rather than relying solely on a formal approach to support. If professional support is given, it is recommended that this support be provided in response to an indicated need for particular kinds of information or resources and in a way that mirrors features found in informal support networks. In evaluating the effects of an intervention program, it is important to include family-related measures as well as child-oriented outcomes.



Early Intervention Policy ❖ Individual family counseling is an early intervention service. Family support groups are a reimbursable early intervention service.

Motor Interventions

Qualifications and experience of professionals providing interventions

It is essential that professionals providing and supervising interventions for young children who have a motor disorder have experience working with young children with motor disorders, are trained in the specific intervention method being used, and understand the developmental and health problems that are commonly associated with motor disorders and the implication of these problems for specific interventions. Professionals working with young children with motor disorders should receive relevant information about the child's health status and associated health conditions (such as cardiac or respiratory problems). Professionals should understand the importance of monitoring the child's health status and tolerance for motor activities.

General approach to providing motor interventions

Motor development is the process of how children learn to sit, stand, move in space or place, and use their hands to work, take care of themselves, and play. Gross motor development refers to the ability to move the large muscle groups of the body (neck, trunk, and limbs). Fine motor development refers to use of the hands and fingers.

Lack of postural tone and atypical muscle tone are the primary problems of most children with motor disorders.

Interventions that target motor development focus on both gross motor and fine motor development, as well as improving postural control and muscle tone.

It is recommended that developmental supportive care (Table 9, page 66), a comprehensive family oriented approach, be provided for premature infants in the NICU and for neonates with abnormal neuromotor findings.

Table 9: Important Components of Developmental Supportive Care

- Appropriate positioning and support to ensure physiological stability (maintaining heart rate, respiratory rate, autonomic responses, etc.) during feeding, positioning, and handling
 - Consistency of caregiving with a primary multidisciplinary team working collaboratively with the family
 - A team approach in which the specialist collaborates with the infant’s nurse and the infant’s parents
 - Teaching parents to hold and position their infant
 - Opportunities for parents to:
 - Care for their hospitalized infant
 - Bond with their infant as early as possible, including physical contact with the baby and opportunities for mothers and fathers to hold their infants skin-to-skin
 - Interact with their infant to learn about the infant’s behavioral and physiologic capabilities and how to respond to the infant’s needs and cues
 - Learn about their child’s condition and have access to information about resources relevant to their child’s condition
 - A quiet, individualized, homelike environment that is comfortable
 - A flexible environment in which:
 - The infant’s 24-hour day can be structured in accordance with his/her sleep-wake cycles, states of alertness, medical needs, and feeding competence
 - Caregiving can be paced to the individual needs of the child with periods of rest and recovery between caregiving actions
 - Increased support can be provided during and between caregiving and around the beginnings and endings of care
 - Individualized feeding support can be provided to assist parents in learning to feed the infant
 - Experienced, specially trained developmental professionals
 - Emotional support for the family dealing with the potential for ongoing serious medical conditions and potential for life threatening complications
 - Realistic expectations about infant development that reflect the range of possible outcomes
 - Staff who are competent at teaching skills and providing the support needed for the family to transition their child home
-

General considerations for planning motor interventions

It is recommended that intervention goals for children with motor disorders reflect the functional skills that parents believe are relevant to the child in the context of the family and physical environment. Activities that promote infant cognitive stimulation are an important component of any intervention program for young children who are a motor disorder.

It is important to remember that the motor disorder may affect the way the child can explore and manipulate the environment and the child's learning style. It is important to plan for generalization of learned motor skills, so the child can apply these skills with different people, in different settings, and in response to different stimuli.

It is important to begin motor intervention for specific motor problems, or when early motor milestones are delayed, to:

- Provide the child with alternate strategies to maintain, improve, and facilitate motor function
- Prevent compensatory movement patterns that may interfere with subsequent motor development
- Prevent the development of deformities that may result from persistent atypical postures
- Provide education and support to parents (e.g., to teach positioning and handling)

Children birth to age 4 months

It is recommended that motor intervention for very young children focus on development of head-erect behavior and postural control (ability to control head and trunk), including:

- Tactile exploration of the infant's body with his own hands
- Orientation to midline
- Coordination of movements, such as hand to face and head, hand to chest, hand to feet, hand to hand, and foot to foot
- Symmetrical rolling
- Graded weight shifting in preparation for moving from horizontal skill development (birth to 6 months) to vertical skill development (7 to 12 months)

- Hand to foot/knee play when lying on back to develop abdominal strength
- Play in prone position to develop neck, hip, and trunk strength

It is recommended that the focus on fine motor interventions begin as early as two to four months old and include:

- Weight bearing to inhibit the grasp reflex
- Activation of the upper extremities in response to a toy
- Scratching and clutching of support surfaces
- Hands to mouth
- Visual inspection of hands
- Grasp of object when placed in the hand

Children age 4 to 12 months

It is important to continue motor interventions related to postural control during this time period, with a focus on development of the following gross and fine motor skills:

- Moving against gravity to bring hands to midline and hands to mouth (fine motor)
- Sufficient trunk and head control for proper alignment in sitting (gross motor)
- Postural control for head and upper trunk righting and upper extremity weight bearing in prone (lying on stomach) position (gross motor)
- Postural control, scapular stability, and upper extremity strength for fine motor control
- Going from prone position to sitting, sitting to hands and knees, and sitting to standing (gross motor)
- Variety of sitting (ring sit, long sit, side sit, etc.) positions (gross motor)
- Sufficient leg strength to support standing (gross motor)
- Transitional movements and mobility (rolling, pivot prone, belly crawling, getting in and out of sitting, etc.) for exploration of the environment (gross motor)
- Appropriate postural control for weight bearing (both gross and fine motor)

If weakness underlies abnormalities of passive muscle tone, strengthening exercises may be appropriate after the age of 4 months. Resistive activities may be used when a background of normal muscle tone is maintained. These may include playing with developmentally appropriate toys of varying weight; picking up small objects; lifting, carrying, and pushing toys; and gentle, graded manual resistance.

It is recommended that more specific gross and fine motor interventions begin when the child has reached the developmental motor level of approximately 6 months. Important components include:

- Sufficient development of leg strength and movement for transitions, weight bearing, and development of walking skills (gross motor)
- Sufficient development of pelvic movement to enable transitions (such as pulling to stand) and locomotion (such as creeping and cruising while holding onto furniture) (gross motor)
- Ability to shift weight easily in different positions (gross motor)
- Shoulder stability when on stomach and when reaching (fine motor)
- Development of hand muscles, especially the arches of the hands (fine motor)
- Digital grasp (fine motor)
- Transfer of objects from hand to hand (fine motor)
- Isolated use of index finger (fine motor)

Children age 12 to 24 months

Important components of intervention for children from 12 to 24 months who have a motor disorder include:

- Development and refinement of unsupported walking (gross motor)
- Climbing on and off of furniture (gross motor)
- Creeping up and down stairs (gross motor)
- Prehension patterns and in-hand manipulation (fine motor)
- Bilateral coordination (fine motor)
- Release of objects such as putting blocks in a container (fine motor)
- Eye-hand coordination, such as putting pegs in a board (fine motor)

- Refinement of grasp patterns, grip strength, and finger control, such as putting blocks in a container; use of spoon, crayon, and cup (fine motor)
- Rotating forearms (fine motor)

Children after age 24 months

Important components of intervention for children who are developmentally at least 24 months include:

- Fast walking/early running (gross motor)
- Beginning to walk up and down stairs with support (gross motor)
- Attempting to stand on one foot (gross motor)
- Attempting to jump (gross motor)
- Propelling a ride toy (gross motor)
- Beginning to use preschool level playground (gross motor)
- Use of writing instruments and scissors (fine motor)
- Use of utensils for activities of daily living (fine motor)
- Manipulation of blocks, beads, and puzzles; turning knobs and lids (fine motor)
- Behavior modification techniques may be beneficial when used with other intervention techniques to target improvement of specific motor skills

Intervention cautions

The use of baby walkers, “exersaucers,” “jolly jumpers,” and other similar equipment is not recommended for children who have a motor disorder. Some of this equipment is associated with injuries in young children. For young children who have a motor disorder, these items may also encourage stereotypic movement patterns that tend to delay the development of typical motor skills.

The use of weighted vests or weights must be used with caution and carefully monitored by a knowledgeable professional (such as a physical or occupational therapist) in order to guard against the development of harmful postures. In addition, children who have a motor disorder may lack the trunk, arm, or leg stability to maintain good alignment with the addition of supplemental pressure (weight).

MOTOR THERAPY APPROACHES AND TECHNIQUES

The term ‘motor therapy,’ as used in this guideline, includes various approaches and techniques typically used within a physical or occupational therapy program. For children who have a motor disorder, physical therapy and/or occupational therapy is usually a significant component of a child’s intervention plan. The recommendations in this section focus on specific approaches or techniques. Physical and occupational therapy interventions usually include an integrated combination of techniques and approaches based on the needs of the child. Interventions covered are: therapeutic exercise; neuromotor and sensorimotor interventions; neuromuscular electrical stimulation and vibratory stimulation; manual therapies; and, specialized exercise interventions.

Therapeutic Exercise

A core component of motor therapy interventions (especially physical therapy and occupational therapy) is often a therapeutic exercise program.

Therapeutic exercise includes approaches designed to improve flexibility (joint/muscle range of motion), strength, cardio-respiratory integrity and endurance, coordination and balance, posture and body alignment, and general functional mobility. Therapeutic exercise programs can be passive or active (see Table 10), designed to address large muscle groups and gross motor function, or very focused on specific movements and fine motor function.

Table 10: Basic Exercise Definitions

Passive Exercise: A part of the individual’s body is moved, usually by someone else, without any active participation or muscle contractions. This is typically used to maintain or increase the flexibility (range of motion) of joints and muscles, and to prevent contractures and/or deformities.

Active-Assistive Exercise: An individual exerts some active, contractile effort of the muscles used to perform the movement but has assistance from an external source.

Active Exercise: An individual performs the entire movement without any external assistance.

Resistive Exercise: An external force (such as weights) is added to active exercise to provide resistance to the movement. This type of exercise is typically used to increase muscle strength, but may also be used to increase endurance, body contour/composition, speed, and/or general cardio-respiratory health.

It is important to understand that not a single, specific approach or technique can be prescribed for all children with a motor disorder.

It is recommended that a continuum of integrated intervention strategies, incorporating appropriate therapeutic exercise techniques, be tailored to the needs of the child as the child's development and independence progresses.

Neuromotor and Sensorimotor Interventions

Neuromotor and sensorimotor therapies are often used as part of physical and occupational therapy interventions for children who have a motor disorder. The most commonly used specific approaches are neurodevelopmental treatment (NDT) and sensory integration therapy (SI).

It is important to understand that the research evidence meeting the criteria for this guideline did not sufficiently demonstrate the effectiveness of interventions based on either NDT or SI for improving motor development or function in young children who have a motor disorder. However, as for any child, the facilitation of varied sensory activities and postural alignment and control may be beneficial to overall development.

It is important that professionals who use the principles and techniques of NDT and SI have appropriate training, licensure, and experience using these approaches with young children.

Neurodevelopmental treatment (NDT)

Neurodevelopmental treatment (NDT) is currently a widely used therapy approach in the United States for children with neuromotor problems. The stated goal of neurodevelopmental treatment (NDT) is to improve the efficiency and quality of functional movement in individuals with neuromotor impairment. A primary focus of NDT is facilitating optimal postural alignment and postural control.

When NDT techniques are used, it is important that they support the attainment of specific intervention goals. Using NDT with an exclusive focus on righting and equilibrium reactions (rather than the full scope of NDT) is not as beneficial as using NDT to support development of a broader range of skills and abilities.

It may be beneficial to combine NDT intervention with behavioral programming. Specifically, combining these approaches may be effective for teaching movement components that are incorporated into functional skills or for teaching appropriate postures. It may also be useful to combine NDT and

structured nonspecific play sessions as a component of the intervention approach for young children who have a motor disorder.

For preterm infants with an abnormal neuromotor exam, NDT may be useful for helping to achieve short-term improvements in antigravity movements during the neonatal period. There is not sufficient evidence to determine if all preterm infants in the neonatal intensive care unit (NICU) can benefit from short-term NDT.

When providing motor intervention such as NDT to hospitalized neonates, it is very important to provide the intervention in the context of a developmental supportive care program with consideration given to the child's special medical needs and health status.

For children with spasticity of the wrist and hand, upper extremity casting in conjunction with NDT treatment may be more effective than NDT alone in improving quality of movement and increasing range of motion and hand functioning.

Sensory integration therapy (SI)

Sensory integration therapy is based on an approach that may help young children who have a motor disorder integrate sensory input with active body movement to produce increasingly complex adaptive responses. The appropriate sensory stimulation may include sight, sound, touch, movement, or balance. As with NDT, it is important that when SI techniques are used, they support the attainment of specific intervention goals.

Rotary movement therapy (vestibular stimulation)

It is important to recognize that use of rotary movement therapy (vestibular stimulation), which is sometimes used as a component of sensory integration approaches, was not found to be effective in improving motor skills in young children who have a motor disorder.

Neuromuscular Electrical Stimulation and Vibratory Stimulation

Neuromotor electrical stimulation

Neuromotor electrical stimulation is stimulation of a muscle with electrical current or impulses for the purpose of strengthening the muscle and preventing atrophy (muscle wasting) of muscles that are not used.

Neuromotor electrical stimulation (NMES) is used to strengthen muscles and prevent muscle atrophy (wasting) from disuse by stimulating the muscle with electric current to produce a muscle contraction.

Threshold electrical stimulation (threshold ES) uses low-intensity, transcutaneous electrical stimulation to elicit a muscle contraction. This is performed during functional activities in order to optimize motor learning, muscle strengthening, and sensory awareness. Threshold ES is also used during sleep, without stimulating muscle contraction, in order to stimulate growth and repair of muscle tissue from increased circulation and metabolic activity.

There was no scientific evidence meeting the criteria for this guideline that demonstrates the effectiveness of NMES for improving motor development or function in young children who have a motor disorder. However, NMES may be prescribed for children who might benefit from:

- Increased sensorimotor awareness of stimulated area
- Change in postural or body part alignment
- Improvement in equilibrium reactions
- Increased balance/stability
- Improvement in weight shifting
- Change in walking pattern
- Increased symmetry

Electrical stimulation must be medically prescribed and can be provided only by trained practitioners with degrees in medicine, physical therapy, or occupational therapy. This modality should be used only to complement other motor therapy approaches.

When electrical stimulation is prescribed for a young child with motor disorders, it is important that it always be kept within the child's tolerance level. The child's tolerance level should be closely monitored. It is important that parameters (ramp time, pulse rate, and amplitude) be administered in accordance with a prescribed protocol and with a period of gradual acclimation to the input of electrical stimulation.

It is recommended that all professionals licensed to administer electrical stimulation who work with young children be specifically trained for this procedure.

It is recommended that professionals demonstrate the effects of electrical stimulation on themselves, and then allow the family to experience the sensation of the electrical stimulation to alleviate concerns about the procedure.

It may be useful to use electrical stimulation in conjunction with other approaches such as dynamic splinting and night splinting.

Therapeutic vibratory stimulation

Therapeutic vibratory stimulation, or muscle vibration, is a technique that is used to facilitate contraction of the muscle being vibrated, and to normalize hypersensitive skin that may be interfering with oral-motor activity. It may be a useful adjunct to other intervention approaches in helping to activate weak muscles.

Vibration therapy is administered using a handheld vibrator designed for this purpose. Specific muscles are targeted to achieve specific results. For example, developing improved head-erect behavior to facilitate visual and auditory orienting movements and visually guided reaching.

It is important that vibratory stimulation be applied only by licensed professionals following specific protocols for young children and only with vibrators that have FDA approval for this method. In addition, children receiving vibratory stimulation must be carefully monitored for possible adverse behavioral, physiological, or neurological reactions.

Manual Therapies

The term “manual therapies” as used in this guideline includes various techniques such as massage or manipulation of soft tissues and joints that generally involve the practitioner working “hands-on” with the child..

Infant massage

Massage is the manipulation of soft tissue for therapeutic purposes. There are several techniques used for infant massage, including swaddling, gliding strokes, gentle friction, simple sustained placement, and skin-to-skin contact (“kangaroo care”).

No evidence was found that indicated massage therapy changes motor function. Currently, researchers are investigating biochemical reactions resulting from massage from which there may be other benefits such as the release of growth hormone, serotonin, norepinephrine, and endorphins; a decrease in cortisol (stress hormone); and electroencephalogram (EEG) changes.

If massage oil is used, a cold pressed nut or fruit oil without preservatives may be suitable, provided the child is not allergic to these. It is important to know if the child has allergies and to check for any possible allergic reaction before using massage oil on an infant or young child. Oils that contain petroleum products (such as mineral oil) are not suitable for young children because of the risk of ingestion.

It is important to recognize that the benefits of infant massage for children who have a motor disorder have not been demonstrated in the scientific literature.

For some infants, massage therapy may be useful for calming the child, facilitating muscle relaxation, or promoting weight gain. It may also help promote parent/child interaction and develop parent confidence in taking care of the child.

It is important to recognize that the response to infant massage will vary from child to child. For many infants, the use of light stroking may be aversive. Even with the same child, the response may vary from one massage to the next.

For children who appear to benefit from infant massage therapy, it is recommended that parents and other caregivers learn appropriate massage techniques from a qualified professional.

Myofascial release treatment

The fascia is a thin, fibrous tissue that surrounds the body beneath the skin, encloses muscles and organs, and separates muscle groups. Myofascial release treatment (MFR) is a manual therapy approach based on the premise that the fascial system is continuous throughout the body and that when injured, this system can become constricted, contributing to restricted mobility. Myofascial release treatment includes stretching, massagelike techniques, and soft tissue manipulation designed to release myofascial constrictions.

It is important to recognize that the benefits of myofascial release treatment for young children who have a motor disorder have not been demonstrated in the scientific literature.

Craniosacral therapy

Craniosacral (cranio/head; sacral/tailbone) therapy is a manual therapy approach based on a theoretical model for evaluating and treating dysfunction within the craniosacral system. This system includes various structures and fluids located between the brain and the base of the spine. Craniosacral therapy techniques are usually indirect in nature (such as massagelike techniques applied to the head).

It is important to recognize that the benefits of craniosacral therapy for young children with or at risk for motor disorders have not been demonstrated in the scientific literature. Absolute contraindications for craniosacral therapy include acute intracranial hemorrhage, intracranial aneurysm, recent skull fracture, and herniation of the brainstem.

If myofascial release treatment or craniosacral therapy are being considered, it is important that this be done within the context of the overall physical or occupational therapy treatment plan for the child. It is important that the therapist is knowledgeable and experienced in the use of these techniques with young children. It is important that the overall health status and any contraindications be assessed.

Joint mobilization therapy (including spinal manipulation)

Joint mobilization is any passive movement technique using repetitive or oscillatory joint movements. The aim of joint mobilization is to restore structures within a joint to their normal or pain free position to allow full range of motion. It is used when there is mechanical joint dysfunction.

Because significant benefits from joint mobilization for young children have not been demonstrated in the scientific literature and because there are significant contraindications and risks (such as possible injury to growth plates and joints, or spinal cord injury), joint mobilization (including spinal manipulation) is not recommended for children under the age of 3 years.

Absolute contraindications for joint mobilization include bacterial infection, neoplasm, recent fracture, malignancy of vertebral column, joint fusion or ankylosis, hypermobility of the joint, and signs or symptoms of spinal cord involvement.

Specialized Exercise Interventions

Therapeutic horseback riding (hippotherapy)

Therapeutic horseback riding (hippotherapy) is sometimes used as an intervention for children who have a motor disorder, although generally not for children under the age of 3 years. The major aims of therapeutic riding include mobilization of the pelvis, lumbar spine, and hip joints; activation of head and trunk musculature; development of head and trunk postural control; and development of balance reactions in the trunk.

The therapist places the child in various positions on the horse (such as prone, side lying, side sitting, or sitting). A soft pad is used rather than a saddle so that the child can experience the warmth and movement of the horse.


Therapeutic horseback riding has not been demonstrated in controlled scientific studies to have efficacy for improving motor development in young children who have a motor disorder. This intervention may offer other benefits such as physical activity, more independent mobility, social interaction, and confidence building.

The age of the child is an important consideration in determining the appropriateness of hippotherapy. Because the benefits of therapeutic horseback riding for improving motor outcomes have not been demonstrated and because of the potential risk for injury, especially for children who are less than three years of age, this intervention generally should not be considered to be appropriate for young children with a motor disorder.

Aquatic therapy

Aquatic therapy is a swimming and aquatic exercise program that uses neuromotor treatment principles in combination with underwater exercise techniques. The water is used to assist the child's movement and control. Proponents believe that aquatic exercise will improve respiratory function.

No evidence meeting the criteria for this guideline was found demonstrating the effectiveness of aquatic therapy in improving specific motor outcomes in young children. As with hippotherapy, however, there may be other nonmotor benefits. Aquatic therapy is used as a component of or in conjunction with a physical therapy program under the direction of an instructor experienced in working with children with disabilities.



Early Intervention Policy ❖ For interventions such as aquatic therapy and hippotherapy, the Early Intervention Program (EIP) may reimburse for the cost of a visit by a qualified person, such as a physical therapist, as provided for in the Individualized Family Service Plan (IFSP), but EIP does not reimburse for other program expenses such as fees for the pool or the horse. Qualified personnel are listed in Appendix A.

ASSISTIVE TECHNOLOGY AND ADAPTIVE DEVICES

The Individuals with Education Disabilities Act (IDEA) defines assistive technology as any item, piece of equipment, or system used to increase, maintain, or improve the performance or functional capabilities of an individual with disabilities. Assistive technology is also known as adaptive equipment or assistive devices. The goal of any assistive device is to allow the individual to complete tasks at a higher level of efficiency than would be possible without the device.

For children who have a motor disorder, assistive technology devices can assist the child in performing many activities of daily life independently. These devices can be either low-technology devices (such as a picture board or wheelchair) or high-technology devices (such as an augmentative communication device). High-technology devices typically have greater complexity and an electronic component.

Assistive devices may be commercially available or custom-made by a therapist, skilled craftsperson, or rehabilitation engineer.


Examples of devices that may be beneficial for children who have a motor disorder include:

- Adapted positioning and specialized seats, such as adapted strollers or prone standers, for a child who lacks postural stability and has atypical muscle tone
- Mobility devices, such as manual or powered wheelchairs, which allow independent exploration of the environment
- Augmentative communication devices, such as picture boards, which help a child communicate when speech is delayed or difficult
- Alternative access methods for learning or achieving a new skill, such as switch toys or joysticks

It is recommended that the need for assistive technology be considered for all children who have a motor disorder. The need for assistive technology should be reassessed on an ongoing basis. Assistive technology devices are recommended when such a device is recognized to have potential benefits for the child such as:

- Increased ability to actively interact with peers
- Improved self-esteem and feeling of self-control over the environment
- Increased independence and decreased potential for “learned helplessness”

- Helping to develop communication, mobility, and self-care abilities
- Reduced energy expenditure when performing tasks
- Greater physical comfort (for example, minimizing pressure ulcers and musculoskeletal deformities)



Early Intervention Policy ❖ Assistive technology devices may be provided to children eligible for the Early Intervention Program when these devices are necessary to increase, maintain, or improve the functional capabilities of an infant or toddler in one or more of the following areas of development: cognitive, physical, communication, social/emotional, or adaptive (10 NYCRR–Section 69-4.1(k)(2)(i)). A guidance document on assistive technology devices is available upon request from the Department of Health.

It is essential that professionals prescribing assistive technology:

- Be knowledgeable about assistive technology in general and about the particular device being recommended
- Be sensitive to parental readiness for and emotional response to assistive technology
- Help parents make the best decision for their child by educating them about devices being considered for their child
- Help parents understand that these devices may be temporary

It is important to include the physician as part of the team when making decisions about appropriate assistive technology.


Since some assistive devices are very expensive, it may be appropriate to explore options for less expensive devices that would serve the same purpose.

Professionals also need to educate families in order to ensure that the assistive technology selected is practical for the family to use, used as prescribed, not abandoned if there are problems using or adjusting to the device, and properly cared for and maintained. Assistive technology devices provide no benefits if they are not used.

It is important to understand that a recommendation to use an assistive device does not necessarily mean that the child will never achieve a certain developmental skill. The use of assistive technology does not prevent the child from developing skills. In fact, it often provides an opportunity to learn new

skills. However, it is also important to understand that while assistive technology may improve some aspects of the child's functional capabilities, it will not "fix" or "cure" the underlying motor disorder.

Selecting Assistive Devices



Early Intervention Policy ❖ When a device is included in an Individualized Family Service Plan (IFSP), it is the early intervention official's responsibility to ensure that the device is provided as soon as possible after the initial IFSP meeting (or any subsequent amendments to the IFSP) and within a time frame specified in the IFSP. The item should be accessed through rent, lease, or purchase in the most expeditious and cost-effective manner available. All assistive technology devices that are included on the Medicaid Durable Medical Equipment (DME) list require a signed written order by a physician or nurse practitioner for children eligible for the Early Intervention Program regardless of whether or not they are eligible for the Medicaid program.

When selecting assistive devices, it is important to identify options that promote the highest level of independence. In general, acceptable low-tech options that are available often allow the child to develop more independent function.

Factors to consider when selecting assistive devices include:

- The child's cognitive abilities
- The child's vision and hearing status, as well as other sensory and perceptual abilities
- The child's anticipated growth and development
- Health considerations such as airway and gastrointestinal problems
- Impact on the family such as benefit versus cost and time commitment
- Ease of use and need for parent training
- The cultural and environmental context of the family

When possible, the family should be given an opportunity to see and try the device, and have a trial period using the assistive technology. It is important to recognize that some devices may be very expensive, and it may be appropriate to explore options for less expensive/lower technology devices that would serve the same purpose.

It is important to recognize that some assistive devices are more appropriate for older children or children at a higher developmental level (for example, computerized voice output systems).

Adaptive positioning devices

It is recommended that adaptive positioning devices, including adaptive seating and adaptive standing devices, be considered for children who lack postural stability or have atypical muscle tone affecting postural control and alignment. Adaptive positioning should also be considered at any age when a child is no longer able to be safely or properly maintained in commercially available equipment such as bathers, carriers, or strollers.

While there is no evidence that these devices improve physiologic functioning (respiration, gastrointestinal, bone density, etc.) in young children, these devices may help to:

- Improve safety, efficiency, and ease of care
- Promote the child's active participation in daily activities

Mobility devices

It is recommended that mobility devices be considered for children who have a motor disorder when it is clear that age-appropriate independent movement is not possible.

If a mobility device such as a wheelchair is being considered, it is important to assess whether features of the home environment (such as presence of stairs, size of doors and hallways) can accommodate the devices and the available options for transporting the wheelchair.

If the child will be using a wheelchair independently, it is important to ensure that the child has the following skills:

- Adequate cognitive function and behavior to operate safely
- Adequate motor skills to operate the equipment or access the controls
- Adequate awareness of spatial relationships

In general, power wheelchairs are seldom needed or appropriate in children under the age of three.



Early Intervention Policy ❖ Service coordinators should help parents explore environmental adaptations when needed. However, the costs of such adaptations are not reimbursed by the Early Intervention Program.

Augmentative Communication

Augmentative communication devices should be considered for children who have a developmental age of 12 to 18 months but have not yet developed speech. It is important for parents and professionals to recognize that the use of augmentative devices does not prevent the development of oral language. It is important that any communication system being taught have practical/functional and cultural value for the family and child. When a communication system is used, the family/caregiver and professionals working with the child should be familiar with the principles and techniques that will encourage the child to use the system.

When choosing an augmentative communication system, it is important to consider the child's vision, hearing, and cognitive abilities. Augmentative communication interventions should focus on training with a system that:

- Is easy to use
- Enables the child to be understood using a variety of communication partners
- Provides motivation to use the system in response to natural cues in everyday contexts
- Can be modified as the language abilities of the child develop

It is important to focus on the child's communication skills, rather than on the child's skill in using the system. Strategies for supporting the development of natural speech should always be included in augmentative communication strategies for infants and young children.

Orthotics (Including Splints and Casts)

Orthotic devices (including splints and casts) are customized external devices that support joints in order to improve function or to minimize deformities of upper or lower limbs, or of the trunk. These devices may be prescribed short-term to help correct or improve a specific problem, or for long-term support, depending on the needs of the child. Orthotics, splints, and casts may be used to support either upper or lower limbs.

Orthotic must be prescribed by a physician, usually in consultation with a physical therapist, and must be made and fitted to the child by someone who is specially trained to do this (an orthotist). Splints are generally fitted by an occupational or physical therapist. As the child grows and develops, the orthotic device, splint, or cast will need to be adjusted to ensure proper fit and comfort for the child.

For children with motor impairments, orthotic devices may help to:

- Reduce functional limitation
- Prevent secondary impairment
- Facilitate functioning
- Minimize contracture and deformity
- Ensure optimal joint alignment
- Ensure selective motion restriction
- Protect weak muscles
- Control atypical tone and tone-related deviations
- Protect tissues after surgery

There are several types of orthotic devices. It is important to consider the level of function and the specific needs of the child in determining the specific type that is appropriate. Many orthotic devices, especially upper limb orthoses (ULO), are designed to be used intermittently. This allows the child to develop active muscle control when the device is not being used.

When an orthotic device is used, it is important that it fits properly and improves the child's functioning. Parents should understand that repeated visits may be needed to achieve an appropriate fit.

It is also important to educate parents about putting orthotics on, taking them off, and cleaning them; appropriate clothing to wear under/over them; recommended wearing time; and recognizing signs of discomfort or a poor fit.

When an orthotic device is used, it is important that the initial prescription and ongoing monitoring be done by a physician experienced and trained in developmental musculoskeletal issues and orthotic application (such as physicians trained in physical medicine and rehabilitation).

Casting

For children with spasticity of the hand and wrist, upper extremity casting as an adjunct to intervention may help to maximize outcome when wearing a cast for 4 hours a day (an average of 20 hours a week). It is important to recognize that wearing a cast for extremely long periods of time (for example, all day or all night) may be detrimental to the child. Prolonged casting can result in skin breakdown, reduced sensory input to the hand, and reduced function and mobility during wearing time.

ORAL-MOTOR FEEDING AND SWALLOWING INTERVENTIONS

Successful oral feeding depends on many factors, such as the child's anatomical structure, health, and development. Abnormalities of any one of these can lead to feeding and swallowing problems. For an infant or young child with a feeding and swallowing problem related to motor disorders, a therapeutic feeding program may be designed and implemented. This section reviews interventions to promote feeding that are:

- *Safe*, with minimal risk for aspiration (food, liquid, or saliva getting into the windpipe)
- *Functional*, providing sufficient caloric and nutritional intake within a reasonable period of time
- *Pleasurable*, enhancing the nurturing and communicative aspects of meals both for the child and family

Some of the common types of techniques used to promote safe, functional, and pleasurable feeding include:

- Preparatory methods prior to feeding sessions (such as alerting or calming techniques, handling, or positioning)
- Facilitation strategies (such as changing the characteristics of the food, or using prostheses or orthodontic appliances)
- Behavioral methods (such as tolerance for eating situations, alterations of sensory environments, or advancing eating behaviors to a more mature level)

It is important to remember that feeding/eating is a learned behavior. It is important to stimulate the development of feeding/eating patterns and skills through the introduction of and exposure to a variety of foods and appropriately graduated eating experiences.

Due to the high risk for aspiration and other complications in infants and young children who have feeding or swallowing problems related to motor disorders, it is strongly recommended that professionals working with these children have adequate knowledge, training, and experience specific to these conditions.

For a child who has not had ongoing successful feeding, it is important that appropriate medical specialists evaluate the child before attempting oral feedings. It's important to manage gastrointestinal disorders, including gastroesophageal reflux, in order to establish an oral-motor and oral feeding program.

For oral feeding, it is important to establish that infants and young children:

- Have cardiopulmonary stability
- Be in an alert, calm state
- Demonstrate appetite or observable interest in eating
- Are properly positioned for functional and safe swallowing

Abnormal swallowing (dysphagia) may involve one or more of the four phases of swallowing. Different considerations apply, depending on the phase of the feeding or swallowing problem. If indicated, medical or surgical management (such as diagnostic testing, tube feeding, antireflux medications, or repair of anatomic anomalies) may be required.

A feeding management program also needs to provide health, developmental, and psychosocial supports. It is therefore recommended that feeding and oral-motor interventions involve expertise from varied medical and behavioral disciplines.

Since it is uncommon that an infant or a young child's feeding or swallowing problem will be resolved using only one technique or approach, it is recommended that feeding and oral-motor intervention methods be combined.

Tube (non-oral) feedings

It is important to remember that oral feeding is not an attainable goal for all children. It is recommended that non-oral or tube feedings be considered for:

- Infants with severe dysphagia (abnormal swallowing) who are at risk for or have a history of aspiration, acute and chronic lung disease, airway obstruction, and malnutrition
- Children with severe or persistent feeding and swallowing problems

- Children who are chronically unable to meet their nutritional needs via oral feedings alone

It is important that tube feedings not result in the abandonment of oral-motor interventions. It is recommended that a comprehensive oral-motor program, including oral stimulation, be considered for children who are not able to receive oral feedings.

Transition from tube to oral feeding

For some children who have a motor disorder, oral-motor function and swallowing can improve with time, and oral feedings may be resumed. Before starting or resuming oral feeding, children need to be evaluated for the necessary oral-motor and swallowing skills. Children who can eat safely may be able to continue oral feeding while also receiving nourishment from tube feeding.

It is recommended that the following preliminary steps be included in the transition from tube to oral feeding:

- Establishing adequate nutritional intake for growth and development
- Establishing a schedule to promote appetite
- Promoting pleasurable oral-tactile experiences, oral exploration, and vocalizing
- Building up oral-motor skills
- Associating oral-motor stimulation with satisfaction of hunger (for example, nonnutritive sucking while tube feeding is being given)
- Encouraging whatever oral feeding is safe

Mealtime management once children begin spoon feeding

Once children begin spoon feeding, it is recommended that the following management techniques be used:

- Promoting pleasurable feeding with no respiratory, gastrointestinal, or emotional stress, and no forced feeding
- Encouraging self-feeding
- Serving small portions with solids first and fluids last
- Allowing no more than 30 minutes for the meal
- Removing food after 10-15 minutes if the child plays without eating

- Wiping the child's mouth and cleaning up only after the meal is completed
- Avoiding the overuse of food as a reward or present

APPROACHES FOR SPASTICITY MANAGEMENT



Early Intervention Policy ❖ Intramuscular injections, inhibitory casting, rhizotomy, oral medication, and intrathecal infusions are considered medical treatments and are not early intervention services. Therefore, such treatments are not reimbursed by the Early Intervention Program. When a child in the EIP is also receiving spasticity management through a medical care provider, it is important for EIP service providers to be informed about such treatment, and the IFSP should address coordination of medical interventions with early intervention services being delivered to the child.

Cerebral palsy is a static (nonprogressive) condition that affects upper motor neurons.

Usually when movement occurs, there is a balance between excitation of the muscles and the inhibitory influences that control the muscles. In cerebral palsy, the damaged upper motor neurons cannot inhibit the muscles properly. As a result, the muscles do not fully relax and tone is increased. Hypertonia (high tone) refers to when the muscles remain abnormally tight. Spasticity occurs when there is an increase in resistance to passive movement.

Ongoing muscle tightness or spasticity, found in many children with cerebral palsy, can result in reduced muscle function and eventually in contractures (a shortening of the muscles). Problems with the bones and joints can eventually develop and further limit the child's movement.

General approach for spasticity management

It is recommended that children who have significant spasticity that interferes with functioning be evaluated by a comprehensive, multidisciplinary spasticity team.

It is important to have reasonable goals and objectives related not only to spasticity management but also to decreasing spasticity. Examples of such goals and objectives are:

- Prevention of contractures
- Improving functioning
- Pain management
- Improving ease in daily care activities (dressing, bathing, toileting, etc.)


Spasticity management may include a variety of interventions, including intramuscular injections, inhibitory casting, rhizotomy, oral medication, and intrathecal infusions. These interventions may be used in combination or one at a time. With all spasticity management, it is important to monitor children, using systematic methods for measuring spasticity, motor functioning, gait analysis, and qualitative methods of functioning. It is important to ensure that appropriate therapy is provided during treatment.

Overly aggressive spasticity management can sometimes have a negative impact on function. The spasticity may be providing “strength” for function. If the spasticity is decreased, the muscle may not be able to provide sufficient force to resist gravity, making muscle weakness more apparent and function more difficult.

Oral Medications for Spasticity Management

There are many oral medications that can be used to decrease generalized spasticity. Some of the more common ones are diazepam (Valium), baclofen (Lioresal), tizanidine, and gabitril. All of these medications have a calming effect on the central nervous system, with sedation as a possible side effect. However, because of the possible toxicity of these medications and the narrow therapeutic window, most physicians generally do not prescribe these medications for children younger than three years of age.

Due to possible side effects, it is very important that the physician monitor the use of antispasticity medications when prescribed for young children who have a motor disorder. In addition, it is important for parents of a child on antispasticity medications to be aware of potential side effects and know how to recognize them.



Early Intervention Policy ❖ Pharmaceuticals/medications are not paid for by the Early Intervention Program (EIP) in New York State. Oral medications for spasticity management can be provided only under the care and prescription of a treating physician.

Localized Injections for Focal Spasticity

Historically, many chemicals and agents have been used as localized injections to treat spasticity in a particular limb or joint.

Recently, botulinum toxin, although not officially approved for spasticity, has become the favored intramuscular injection for loosening a particular limb or joint.

The medication is administered by intramuscular injections. The procedure may be painful or frightening to a young child, and therefore some sedation or anesthesia is often given before the injections.

The usual duration of effect is generally 3 to 6 months in the upper extremities and 6 to 8 months in the lower extremities. Serial casting may be done in conjunction with the injection to improve results.

Disadvantages of botulinum toxin injections include a relatively short duration of effectiveness and the possibility of antibody formation. In addition, the long-term effect on the muscle and neuromuscular junction is not clear. Possible side effects may include local weakness, flulike illness, dysphasia (speech impairment), and dysphagia (difficulty swallowing).

Advantages of botulinum toxin treatment include its ease of administration, the lack of known cumulative effects, and the opportunity it gives professionals to examine the child's potential function while the child is experiencing reduced spasticity. This medication may also be useful in predicting the effects of more permanent spasticity treatments such as selective dorsal root rhizotomy.

It is important to recognize that botulinum toxins are not FDA approved for spasticity or for children less than 12 years of age. However, like other medications given to children, botulinum toxin injections are frequently used "off-label" with young children at the discretion of the treating physician.

If spasticity is causing significant functional problems with mobility or dynamic contractures, it is appropriate to consider botulinum toxin injections for reducing spasticity in young children with cerebral palsy. Children with specific, localized, and functionally significant muscle spasticity, such as seen in hemiplegia or spastic diplegia, are more appropriate candidates than those with more generalized spasticity.

It is important to combine the use of botulinum toxin injections with a physical and/or occupational therapy plan designed to maximize the effectiveness of the injections.

Intrathecal Baclofen

Baclofen is one of several antispasticity drugs that affect certain spinal cord receptors by inhibiting the release of excitatory neurotransmitters. Baclofen is administered either orally (by mouth) or by a small pump that is surgically implanted to deliver baclofen into the spinal canal (intrathecal baclofen or ITB).

ITB is more effective than oral baclofen. However, ITB has limitations for use in young children because of the size of the implantable pump. ITB can be used after one year of age, but it is usually not used until after the age of 6 years. It is FDA approved for children age 4 years and older.

ITB is used for moderate or severe spasticity and for dystonia. Although ITB may improve various functions, it is very difficult to predict the areas of improvement. Not all patients who are candidates for ITB will respond to or be able to use this treatment. Functional activities may improve. Walking ability usually improves, but this treatment does not cause nonwalking children to start walking. ITB may decrease contractures and reduce the need for surgery.

Common side effects of oral or intrathecal baclofen are drowsiness, drooling, and hypotonia. Complications of intrathecal baclofen may include spinal fluid leak, meningitis, seizures, catheter or pump problems, and catheter infection. Infection usually requires removal of the pump.

Appropriate goals for ITB include improving function, preventing contractures, improving seating, improving ease of general care, and occasionally, relieving pain.

It is recommended that the use of baclofen be considered if spasticity or dystonia is causing sufficient functional difficulty, deformity, or pain to justify the use of a systemic medication. It is further recommended that ITB be considered for children whose response is inadequate or who have excessive systemic side effects with the oral form.

As with most medications, there is potential for side effects. When either oral or intrathecal baclofen is recommended for a young child with spasticity, it is important that:

- The physician recommending these medications be familiar with the treatment of spasticity, as well as with the medication
- The specific indications for using the medication justify the potential risks
- The physician monitor the child for complications and teach parents how to recognize possible side effects

It is important to combine this treatment with physical and/or occupational therapy programs.

Selective Dorsal Root Rhizotomy (SDR)

Selective dorsal root rhizotomy is a neurosurgical procedure in which some of the posterior rootlets coming off the spinal cord are cut. The goals of rhizotomy are to reduce or eliminate spasticity and to improve range of motion and function. Rhizotomy is not appropriate for children with low or fluctuating muscle tone.

The ideal candidate for selective dorsal root rhizotomy is a child over the age of 3 with a history of prematurity and spastic diplegia; reasonable balance, strength, and motor control; absence of dystonia or ataxia; and, the ability to cooperate with the postoperative rehabilitation. The spasticity should be significant enough to be causing difficulties with function.

A multidisciplinary spasticity clinic is the most appropriate setting to evaluate a child for selective dorsal root rhizotomy. Several visits are needed before the surgery. Children typically are seen before 3 years of age, with the surgery being performed at 4 to 6 years of age when walking maturity has been established and the child can respond to a postoperative rehabilitation program.

Possible postoperative complications include spinal fluid leak, bladder infection, epidural abscess, bowel and bladder dysfunction, scoliosis, back pain, hip subluxation and transient or permanent weakness. Approximately two-thirds of all children who receive rhizotomy will require orthopedic surgery, typically one or two years later.

When considering rhizotomy, it is important for parents to realize that while there may be important short-term benefits for many children, the long-term outcomes and complications are not known.

When considering if a child is an appropriate candidate for this procedure, patient selection is most important. The child must have significant spasticity that impairs functioning. Contraindications include dystonia, rigidity, and ataxia. Children who do not meet selection criteria may be candidates for other treatments/interventions. In some children, complete elimination of spasticity may be undesirable since they depend on spasticity for some of their strength and function. For these children, intrathecal baclofen may be a more appropriate choice.



Early Intervention Policy ❖ Surgical interventions are not paid for by the Early Intervention Program in New York State. In addition, this neurosurgical procedure is generally not done for children under age 3. The guideline includes information on this procedure to address the interest and need for information by parents and health care providers.

ORTHOPEDIC MANAGEMENT AND SURGERY MANAGEMENT

Orthopedic management (both nonsurgical and surgical) in infants and young children is well-established for specific conditions that affect the motor system. The focus of this section is specific to young children who have cerebral palsy (See Appendix C for information about classifications of cerebral palsy). All children with cerebral palsy should be evaluated by an orthopedic surgeon.

Many of the recommendations also have application to children with other developmental motor disorders.

Considering surgical intervention

Patient selection and timing of surgery are essential. Orthopedic surgery is rarely an emergency. When making a decision about orthopedic surgery, important considerations include child and family goals, age and maturity of the child, safety of the procedure and risks to the child, the potential to increase functioning, recuperation time, and the need for postoperative physical therapy and assistive devices.

The age of the child and the type of cerebral palsy are important when considering surgery. For children less than 4 years old, particularly children with total involvement cerebral palsy, muscle lengthening about the hip to prevent subluxation or dislocation is most effective. For children over 4 years old with spastic diplegia, surgical treatment may help with specific functional goals (such as improved walking). Children with hemiplegia over 4 years old may benefit from soft tissue procedures to improve walking, hand appearance, or function. It is recommended that surgical treatment for spinal deformities be delayed until the child is at least 10 years old (but before adulthood).

Common orthopedic surgical procedures for children who have a motor disorder include:

- Tendon lengthening and release


- Tendon transfer
- Osteotomy (cutting the bone)
- Arthrodesis (fusing two or more bones)
- Neurectomy (cutting the nerve)

Whenever possible, it is important to group surgical procedures so that they can be performed at the same time.

Although most very young children with cerebral palsy do not require surgery (it is not usually considered until the age of 4 to 6 years), surgery may be helpful for improving function and preventing or treating deformities of the bones and joints in some children when done at the right time.

It is important to remember that although surgical treatment may help with the child's function, the child will still have cerebral palsy. While orthopedic surgery may be appropriate for addressing many of the secondary problems of cerebral palsy (such as contractures, deformity, and joint instability), it does not correct the underlying problems of spasticity, balance, and selective motor control.

It is of the utmost importance to make an accurate and specific diagnosis whenever possible, particularly if the treatment involves surgery.



Early Intervention Policy ❖ Surgical interventions are not paid for by the EIP. Surgical interventions are generally not considered until the age of 4 to 6 years. However, medical examinations to determine the need for surgical interventions are recommended under certain circumstances as early as 18 months. The guideline includes information on surgical procedures to address the interest and need for information by parents and health care providers.

It is important to recognize that although walking is a reasonable goal for many children with cerebral palsy, it may not be for some children and their families. The ability to move about may be a more realistic goal than walking for some children.

The first goal of orthopedic surgery is to prevent deformity. Another important orthopedic goal for the young child is to prevent the development of contractures that could lead to later deformity, dislocations, and arthritis. Once contractures develop, treatment is typically surgical.

Orthopedic management may include the use of braces for some children. Important considerations include:

- Using braces improves the child's function
- Bracing is usually not appropriate for fixed deformities (serial casting, injections, or surgery may be needed before a brace can be applied to the child with a fixed contracture)
- A reasonable goal is to have the patient become brace-free by adulthood

Total involvement cerebral palsy

Total involvement cerebral palsy implies involvement of all extremities (quadriplegia), spine, oral pharynx, and neck. By age 2, these children may still not sit independently. If a child is unable to sit by age 4, walking is unlikely. Only approximately 10 percent of children with total involvement cerebral palsy will eventually walk. The most important orthopedic goal is proper sitting and mobility.

The hips of children with total involvement cerebral palsy are at risk for subluxation, and hip deformity may rapidly progress to dislocation. Therefore, referral for orthopedic care is recommended as early as 18 months of age, or sooner if problems with the hips are suspected.

After 18 months to 2 years of age, it is recommended that x-rays be considered to monitor which children may need more extensive treatment.

It is important to recognize that spinal deformities are common in children who do not walk, often beginning by age three. Although they do not prevent spinal deformities, soft or semisoft braces can be used to provide better seating and positioning.

Hemiplegia


It is very common for a young child who has a delay in walking to be found to have unrecognized hemiplegia as the cause of the delay. It is recommended that children who are not walking by the age of 18 months be examined by an orthopedic physician because hemiplegia type cerebral palsy and congenital hip dislocation are common causes of a delay in walking.

Only approximately half of the children with hemiplegia type cerebral palsy will walk by the age of 18 months, depending on the degree of motor involvement. Most children with hemiplegia type cerebral palsy will walk eventually, but they

will all have some difficulty walking because at least one of the lower extremities is involved.

It is important to consider an ankle foot orthotic (AFO) for children with hemiplegia when they start walking, particularly if they walk on their toes or walk with knee hyperextension. As the child becomes more mobile, a hinged brace may be useful.

Children with hemiplegia generally do very well with surgical treatment. Surgery is best done after 4 years of age and most commonly involves lengthening certain muscles in the hips and legs. Some children may also benefit from upper extremity surgery, usually between 6 and 12 years of age.



Early Intervention Policy ❖ Medical tests, such as x-rays, are not considered early intervention evaluations or services under the New York State Early Intervention Program.

Spastic diplegia

Children with spastic diplegia typically have more involvement of the legs than the arms. Those who can sit independently by age two are likely to walk. The ability to cruise holding on to furniture also implies good walking potential. Most children with spastic diplegia walk by age 4.

Surgery may help to improve walking in some children with spastic diplegia. If surgery is being considered, it is important to focus on functional goals, such as walking. The goals of walking generally include greater stability and safety, reasonable step length and speed, and energy conservation.

It is recommended that surgery be delayed until approximately age 4 when walking maturity is more developed and the child is able to cooperate with a postoperative course of rehabilitation. It is common to correct for all deformities and tightness during the same procedure. Tendon surgery before age 4 has a high risk of recurrence.

If the goal of surgery is to improve walking, it is important that the child show an interest in walking before making plans for surgery. It is important to recognize that surgery generally will not make a nonwalking child able to walk.

Surgical aftercare and rehabilitation

Before surgery is performed, it is critical to establish a postoperative plan. Parents may need specific instruction and demonstration of various aspects of postoperative care. The family also needs to be aware of the time commitment and effort that is likely to be involved in postsurgical rehabilitation. For example, if multiple muscles and bones are involved in a surgical procedure, postoperative rehabilitation may take up to 2 years.

It is important to plan for quick return to previous function after surgery. It may be useful to begin gait training and evaluation for postoperative adaptive equipment before the surgery is performed. It is also important to take into consideration that orthotics may fit differently and may need to be remade after the surgery.

INTERVENTIONS FOR ASSOCIATED HEALTH CONDITIONS

The specific health-related interventions for any young child who has a motor disorder will depend on the specific health-related needs for that child. There are some medical conditions that occur more commonly in children who have a motor disorder (children with cerebral palsy in particular) than in typically developing children. Some of these conditions are listed in Table 7 (page 46). It was considered beyond the scope of this guideline to evaluate the efficacy of interventions for these medical conditions.

In general, it is recommended that all children who have a motor disorder receive regular preventive child health care. It is recommended that the child's primary care physician be responsible for the child's general health care and refer the child to other health professionals as needed. Professionals involved in planning and implementing interventions for a child who has a motor disorder need to be aware of:

- The child's overall health, including the child's hearing, vision, and nutritional status
- Any health-related interventions, prescribed regimens, or environmental adaptations that may affect the child's ability to participate in an intervention program

It is important for professionals to be aware that young children who have a motor disorder frequently have visual impairments that may affect their ability to participate in interventions. In addition, the seizure disorders associated with some types of cerebral palsy (such as hemiplegia and quadriplegia) often require

anticonvulsant medication that may affect alertness, mental status, and participation in intervention programs. Parents and professionals working with children who have a motor disorder need to recognize the behaviors suggestive of a seizure and know what to do if the child has one.

OTHER INTERVENTION APPROACHES

This section addresses several other intervention approaches that are sometimes considered for young children who have a motor disorder. These include:

- Conductive Education
- Hyperbaric Oxygen Therapy
- Adeli Suit
- Patterning (Doman-Delacato)
- Feldenkrais Method®
- Tscharnuter Akademie for Movement Organization (TAMO)

These approaches are included because they are interventions that parents and providers may hear about from others. They are generally not considered standard or traditional therapies. However, some may consider them “complementary” or “alternative” approaches.

These interventions often have a group of supporters who strongly believe in the benefits of the approach, although no scientific evidence was found to support their use in improving motor outcomes in young children who have a motor disorder. It is particularly important to use a systematic decision-making process when considering these interventions (see Table 8, page 56).

Conductive Education


Conductive education is an educational approach focused primarily on motor function. The approach was developed in Hungary and is based on the theory that abnormal motor patterns can be transformed into functional motor patterns by intensive “training” that develops alternate neural pathways.

A “conductor” trained in conductive education works with the child throughout the day to facilitate the child’s daily tasks (such as sitting and walking). These tasks are broken down to simpler components. These components are incorporated into a rhyme that the child repeats to self-motivate and anticipate

tasks. In the U.S., many conductive education programs use only selective principles of this method. This potentially compromises the intervention.

No adequate evidence was found to demonstrate the effectiveness of conductive education as an intervention for young children who have a motor disorder. If a child is enrolled in a conductive education program, it is important to closely monitor motor performance and development because there may be some risk for developing persistent pathological motor patterns when using this approach. The conductive education approach may be time-intensive, expensive, and incompatible with other therapies.

Hyperbaric Oxygen Therapy (HBOT)



Early Intervention Policy ❖ Hyperbaric Oxygen Therapy is a medical treatment and is not a reimbursable service under the EIP.

Hyperbaric oxygen therapy uses a pressure chamber to increase the amount of oxygen received by an individual, delivering 15 times as much physically dissolved oxygen to tissues as does breathing room air. Use of HBOT has been reported for treating many conditions, including cerebral palsy.

No evidence was found to support the use of HBOT for young children who have a motor disorder.

Adeli Suit

This method is based on research conducted in the 1970s regarding neurological and morphological changes, and an increased adaptation to gravity forces observed in astronauts after returning from space in a prolonged lack of gravity (weightless) environment. The Adeli suit is a modification of a suit originally designed for use by the Soviet cosmonauts in space. It is patented by a Polish-Russian organization. The suit consists of a jacket and pair of trousers.

The Adeli suit’s jacket and trousers have strategically placed rings so that elastic tension cords can be attached across joints. Selected muscle groups can be exercised while wearing the suit. The suit is used as part of an intensive physical therapy program of 5-7 hours per day, 5-6 days per week. Proponents of the Adeli suit believe that use of the suit can provide controlled exercise of selected muscle groups and increase coordination.

No evidence was found to support the use of Adeli suits for young children who have a motor disorder.

Note: *Adeli suits are not considered assistive technology devices and are not reimbursable under the Early Intervention Program.*

Patterning (Doman-Delacato)

The Doman-Delacato treatment of patterning began as a treatment approach for brain-injured children in 1956. Use of the treatment has been expanded to include children with other developmental disabilities. It is based on the theory that the majority of mental retardation, learning problems, and behavior disorders are caused by brain damage or poor neurological organization, and these problems lie on a single continuum of brain damage. Current knowledge does not support this theory.

No research evidence was found that demonstrates that patterning is an effective approach for young children who have a motor disorder.

Limitations and cautions regarding this approach include unsubstantiated claims that the approach has cured a number of people (this has not been proven), and that use of the Doman-Delacato Development Profile can provide a rapid and conclusive diagnosis.

The regimen is demanding and inflexible, often placing restrictions on activities of which the child is capable (such as walking or listening to music). Therefore, other aspects of the child's development may be negatively affected. The cost for this intervention is high, and it is not covered by insurance or other funding sources.

The American Academy of Pediatrics has evaluated this treatment and found no evidence to support its use. It is important to recognize that the demands on families using this approach are so great that in some cases there may be indirect harms associated with its use.

Feldenkrais Method®

The Feldenkrais Method® is based on an individual's ability to access his own nervous system's innate processes to change and refine functioning. It is described as a melding of motor development, biomechanics, psychology, and the martial arts.

The Feldenkrais Method® emphasizes improvement in posture, flexibility, coordination, and self-image, along with alleviation of muscular tension and pain.

No evidence was found to support the use of the Feldenkrais Method® for young children who have a motor disorder.

Tscharnuter Akademie for Movement Organization (TAMO)

TAMO treatment principles are based on the assumption that motor control is not achieved solely through the influence of the brain, but through the interaction of internal forces (muscular, nervous system, etc.) and external forces (gravity, counter force from support surface, etc.). A therapist assists the child in generating his own response to the forces of gravity in relationship to a support surface and a play activity.

No evidence was found to support the use of the TAMO therapy for young children who have a motor disorder.

**APPENDIX A: EARLY
INTERVENTION
PROGRAM
INFORMATION**

New York State

A-1: EARLY INTERVENTION PROGRAM DESCRIPTION

The Early Intervention Program is a statewide program that provides many different types of early intervention services to infants and toddlers with disabilities and their families. In New York State, the Department of Health is the lead state agency responsible for the Early Intervention Program.

Early Intervention services can help families:

- Learn the best ways to care for their child
- Support and promote their child’s development
- Include their child in family and community life

Early Intervention services can be provided anywhere in the community, including:

- A child’s home
- A child care center or family day care home
- Recreational centers, playgroups, playgrounds, libraries, or any place parents and children go for fun and support
- Early childhood programs and centers

Parents help decide:

- What are appropriate early intervention services for their child and family
- The outcomes of early intervention that are important for their child and family
- When and where their child and family will get early intervention services
- Who will provide services to their child and family

Early Intervention Officials (EIO)

In New York State, all counties and the City of New York are required by public health law to appoint a public official as their Early Intervention Official.

The EIO is the person in the county responsible for:

- Finding eligible children
- Making sure eligible children have a multidisciplinary evaluation

- Appointing an initial service coordinator to help families with their child’s multidisciplinary evaluation and Individualized Family Service Plan (IFSP)
- Making sure children and families get the early intervention services included in their IFSPs
- Safeguarding child and family rights under the Program

The EIO is the “single point of entry” for children into the Program. This means that all children under three years of age who may need early intervention services must be referred to the EIO. In practice, Early Intervention Officials have staff who are assigned to take child referrals.

Parents are usually the first to notice a problem. Parents can refer their own children to the Early Intervention Official. (See Step 1 of Early Intervention Steps, page A-110.) Sometimes, someone else will be the first to raise a concern about a child’s development. New York State public health law requires certain professionals (primary referral sources) to refer infants and toddlers to the Early Intervention Official if a problem with development is suspected. However, no professional can refer a child to the EIO if the child’s parent objects to the referral.

Service Coordinators

There are two types of service coordinators in New York State: an initial service coordinator and an ongoing service coordinator. The initial service coordinator is appointed by the Early Intervention Official. The initial service coordinator helps with all the steps necessary to get services, from the child’s multidisciplinary evaluation to the first Individualized Family Service Plan (IFSP).

Parents are asked to choose an ongoing service coordinator as part of the first IFSP. The main job of the ongoing service coordinator is to make sure the child and family get the services in the IFSP. The ongoing service coordinator will also help change the IFSP when necessary and make sure the IFSP is reviewed on a regular basis. Parents may choose to keep the initial service coordinator, or they can choose a new person to be the ongoing service coordinator.

Eligibility

Children are eligible for the Early Intervention Program if they are under three years old AND have a disability OR developmental delay. A disability means that a child has a diagnosed physical or mental condition that often leads to

problems in development (such as Down syndrome, autism, cerebral palsy, vision impairment, or hearing loss).

A developmental delay means that a child is behind in at least one area of development, including:

- Physical development (growth, gross and fine motor abilities)
- Cognitive development (learning and thinking)
- Communication (understanding and using words)
- Social-emotional development (relating to others)
- Adaptive development (self-help skills, such as feeding)

A child does not need to be a U.S. citizen to be eligible for services. In addition, there is no income “test” for the Program. The child and family do have to be residents of New York State to participate in the Early Intervention Program.

How is Eligibility Decided?

All children referred to the Early Intervention Official have the right to a free multidisciplinary evaluation to determine if they are eligible for services. The multidisciplinary evaluation also helps parents to better understand their child’s strengths and needs and how early intervention can help.

A child who is referred because of a diagnosed condition that often leads to developmental delay, such as cerebral palsy, will always be eligible for early intervention services.

If a child has a diagnosed condition, he or she will still need a multidisciplinary evaluation to help plan for services. If a child has a delay in development and has no diagnosed condition, the multidisciplinary evaluation is needed to find out if the child is eligible for the Program. A child’s development will be measured according to the “definition of developmental delay” set by New York State.

Services

Early intervention services are:

- Aimed at meeting children’s developmental needs and helping parents take care of their children
- Included in an Individualized Family Service Plan (IFSP) agreed to by the parent and the Early Intervention Official

Early intervention services include:

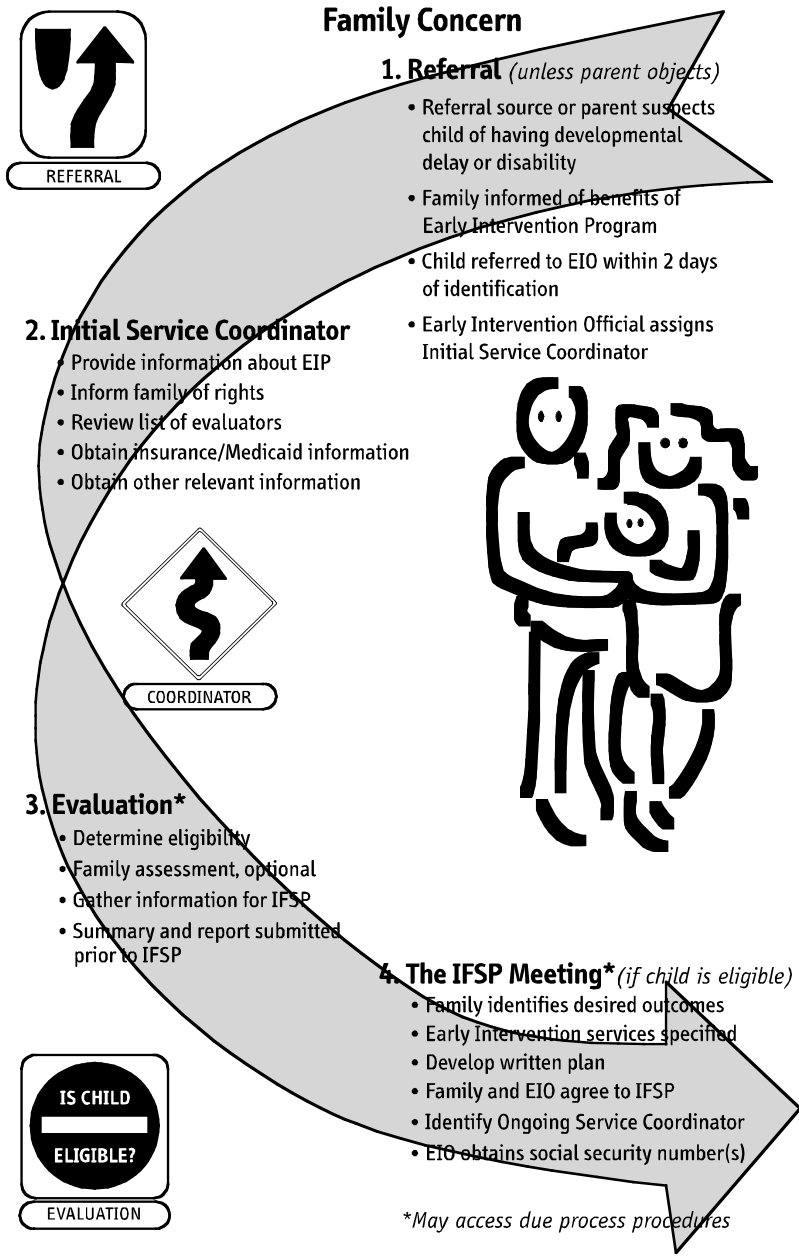
- Assistive technology services and devices
- Audiology
- Family training, counseling, home visits, and parent support groups
- Medical services only for diagnostic or evaluation purposes
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination services
- Social work services
- Special instruction
- Speech-language pathology
- Vision services
- Health services needed for children to benefit from other early intervention services
- Transportation to and from early intervention services

Provision of Services

Only qualified professionals, individuals who are licensed, certified, or registered in their discipline and approved by New York State, can deliver early intervention services. All services can be provided using any of the following service models:

- Home- and community-based visits. In this model, services are given to a child and/or parent or other family member or caregiver at home or in the community (such as a relative's home, child care center, family day care home, playgroup, library story hour, or other places parents go with their children).

- Facility- or center-based visits. In this model, services are given to a child and/or parent or other family member or caregiver where the service provider works (such as an office, a hospital, a clinic, or early intervention center).
- Parent-child groups. In this model, parents and children get services together in a group led by a service provider. A parent-child group can happen anywhere in the community.
- Family support groups. In this model, parents, grandparents, siblings, or other relatives of the child get together in a group led by a service provider for help and support and to share concerns and information.
- Group developmental intervention. In this model, children receive services in a group setting led by a service provider or providers without parents or caregivers present. A group means two or more children who are eligible for early intervention services. The group can include children without disabilities and can take place anywhere in the community.



6. Transition

- Plan for transition included in IFSP
- Transition to:
 - services under Section 4410 of Education Law (3-5 system)
- OR
- other early childhood services, as needed

Areas of Development

- cognitive
- physical (including vision and hearing)
- communication
- social/emotional
- adaptive development

5. IFSP – Review Six Months /Evaluate Annually

- Decision is made to continue, add, modify or delete outcomes, strategies, and/or services
- If parent requests, may review sooner:
 - If parent requests an increase in services, EIO may ask for independent evaluation

Early Intervention Services*

- assistive technology devices and services
- audiology
- family training, counseling, home visits and parent support groups
- medical services only for diagnostic or evaluation purposes
- nursing services
- nutrition services
- occupational therapy
- physical therapy
- psychological services
- service coordination
- social work services
- special instruction
- speech-language pathology
- vision services
- health services
- transportation and related costs

Parent/guardian consent is required for evaluation, IFSP, provision of services in IFSP, and transition.

Revised 12/04

TRANSITION

REVIEW AHEAD

THE IFSP MEETING

REIMBURSEMENT

All services are at no cost to families. The program assesses Medicaid and commercial third party insurance when parents' policies are regulated by the state. County and state funds cover the costs of services not covered by other payers.

For more information about the New York State laws and regulations that apply to early intervention services, contact the Bureau of Early Intervention.

New York State Department of Health
Bureau of Early Intervention
Corning Tower Building, Room 287
Empire State Plaza
Albany, NY 12237-0660

(518) 473-7016

http://www.health.ny.gov/community/infants_children/early_intervention/

bei@health.state.ny.us

A-2: OFFICIAL EARLY INTERVENTION PROGRAM DEFINITIONS

These definitions are excerpted from New York State Code of Rules and Regulations, §69-4.1, §69-4.10 and §69-4.11. For a complete set of the regulations governing the Early Intervention Program, contact the New York State Department of Health, Bureau of Early Intervention at (518) 473-7016 or visit the Bureau's Web page:

http://www.health.ny.gov/community/infants_children/early_intervention/

Sec. 69-4.10 Service Model Options

- (a) The Department of Health, state early intervention service agencies, and early intervention officials shall make reasonable efforts to ensure the full range of early intervention service options are available to eligible children and their families.
 - (1) The following models of early intervention service delivery shall be available:
 - (i) home and community based individual/collateral visits: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at the child's home or any other natural environment in which children under three years of age are typically found (including day care centers and family day care homes);
 - (ii) facility-based individual/collateral visits: the provision by appropriate qualified personnel of early intervention services to the child and/or parent or other designated caregiver at an approved early intervention provider's site;
 - (iii) parent-child groups: a group comprised of parents or caregivers, children, and a minimum of one appropriate qualified provider of early intervention services at an early intervention provider's site or a community-based site (e.g. day care center, family day care, or other community settings);
 - (iv) group developmental intervention: the provision of early intervention services by appropriate qualified personnel to a group of eligible children at an approved early intervention provider's site or in a community-based setting where children under three years of age are typically found (this group may also include children without disabilities); and

- (v) family/caregiver support group: the provision of early intervention services to a group of parents, caregivers (foster parents, day care staff, etc.) and/or siblings of eligible children for the purposes of:
 - (a) enhancing their capacity to care for and/or enhance the development of the eligible child; and
 - (b) providing support, education, and guidance to such individuals relative to the child's unique developmental needs.

Sec. 69-4.1 Definitions

- (b) *Assessment* means ongoing procedures used to identify:
 - (1) the child's unique needs and strengths and the services appropriate to meet those needs; and
 - (2) the resources, priorities, and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability.
- (g) *Developmental delay* means that a child has not attained developmental milestones expected for the child's chronological age adjusted for prematurity in one or more of the following areas of development: cognitive, physical (including vision and hearing), communication, social/emotional, or adaptive development.
 - (1) A developmental delay for purposes of the Early Intervention Program is a developmental delay that has been measured by qualified personnel using informed clinical opinion, appropriate diagnostic procedures, and/or instruments and documented as:
 - (i) a twelve month delay in one functional area; or
 - (ii) a 33% delay in one functional area or a 25% delay in each of two areas; or
 - (iii) if appropriate standardized instruments are individually administered in the evaluation process, a score of at least 2.0 standard deviations below the mean in one functional area or score of at least 1.5 standard deviation below the mean in each of two functional areas.

- (ag) *Parent* means a parent by birth or adoption, or person in parental relation to the child. With respect to a child who is a ward of the state, or a child who is not a ward of the state but whose parents by birth or adoption are unknown or unavailable and the child has no person in parental relation, the term “parent” means a person who has been appointed as a surrogate parent for the child in accordance with Section 69-4.16 of this subpart. This term does not include the state if the child is a ward of the state.
- (aj) *Qualified* personnel are those individuals who are approved as required by this subpart to deliver services to the extent authorized by their licensure, certification, or registration, to eligible children and have appropriate licensure, certification, or registration in the area in which they are providing services including:
- (1) audiologists;
 - (2) certified occupational therapy assistants;
 - (3) licensed practical nurses, registered nurses, and nurse practitioners;
 - (4) certified low vision specialists;
 - (5) occupational therapists;
 - (6) orientation and mobility specialists;
 - (7) physical therapists;
 - (8) physical therapy assistants;
 - (9) pediatricians and other physicians;
 - (10) physician assistants;
 - (11) psychologists;
 - (12) registered dietitians;
 - (13) school psychologists;
 - (14) social workers;
 - (15) special education teachers;
 - (16) speech and language pathologists and audiologists;
 - (17) teachers of the blind and partially sighted;
 - (18) teachers of the deaf and hearing handicapped;
 - (19) teachers of the speech and hearing handicapped;
 - (20) other categories of personnel as designated by the Commissioner.

- (al) *Screening* means a process involving those instruments, procedures, family information and observations, and clinical observations used by an approved evaluator to assess a child's developmental status to indicate what type of evaluation, if any, is warranted.

Sec. 69-4.11 (a)(10)

- (10) The IFSP shall be in writing and include the following:
- (i) a statement, based on objective criteria, of the child's present levels of functioning in each of the following domains: physical development, including vision and hearing; cognitive development; communication development; social or emotional development; and adaptive development;
 - (ii) a physician's or nurse practitioner's order pertaining to early intervention services which require such an order and which includes a diagnostic statement and purpose of treatment;
 - (iii) with parental consent, a statement of the family's strengths, priorities and concerns that relate to enhancing the development of the child;
 - (iv) a state of
 - (a) the major outcomes expected to be achieved fro the child and the family, including timelines, and
 - (b) the criteria and procedures that will be used to determine whether progress toward achieving the outcomes is being made and whether modifications or revisions of the outcomes or services is necessary.

A-3: TELEPHONE NUMBERS OF MUNICIPAL EARLY INTERVENTION PROGRAMS

Please visit our Web page for at
www.health.ny.gov/community/infants_children/early_intervention/

**APPENDIX B: ADDITIONAL
RESOURCES**

APPENDIX B

American Academy for Cerebral Palsy and Developmental Medicine 1910 Byrd Avenue, Suite 118 P.O. Box 11086 Richmond, VA 23230-1086	(804) 282-0036
American Association of University Affiliated Programs for Persons With Developmental Disabilities 8605 Cameron Street, Suite 406 Silver Springs, MD 20910	(301) 588-8252
American Council for the Blind Suite 1100 1010 Vermont Avenue, NW Washington, DC 20005	(202) 393-3666
American Physical Therapy Association 1111 North Fairfax Street Alexandria, VA 22314	(703) 684-2782
American Occupational Therapy Association P.O. Box 1725 1383 Piccard Drive Rockville, MD 20850	(301) 943-9626
American Society for Deaf Children 914 Thayer Avenue Silver Springs, MD 20910	(301) 585-5400
American Speech-Language-Hearing Association 10801 Rockville Pike Rockville, MD 20852	(301) 897-5700
The Arc of the United States (Association for Retarded Citizens) 1010 Wayne Avenue, Suite 650 Silver Spring, MD 20910	(800) 433-5255 (301) 565-3842 (301) 565-3843 (fax) www.thearc.org
Clearinghouse on Disability Information Office of Special Education and Rehabilitative Services U.S. Department of Education 400 Maryland Avenue, SW Room 312 Switzer Building Washington, DC 20202-2524	(202) 732-1241 (202) 732-1245 (202) 732-1723

Easter Seals National Headquarters

230 West Monroe, Suite 1800
Chicago, IL 60606

(312) 726-6200
www.easter-seals.org

March of Dimes Foundation

1275 Mamaroneck Avenue
White Plains, NY 10605

(914) 428-7100

**National Dissemination Center for Children and Youth
With Disabilities**

P.O. Box 1492
Washington, DC 20013-1492

(800) 695-0285
(202) 884-8200
(202) 884-8441 (fax)
www.NICHCY.org

United Cerebral Palsy Association

Seven Penn Plaza
Suite 804
New York, NY 10001

(212) 268-6655
(800) USA-1UCP

Note: *Inclusion of these organizations is not intended to imply an endorsement by the guideline panel or the NYSDOH. The guideline panel has not specifically reviewed the information provided by these organizations.*

**APPENDIX C: CLASSIFICATION
OF CEREBRAL
PALSY**

Identifying and Classifying Cerebral Palsy

Cerebral palsy is not a specific disease. The term cerebral palsy refers to a group of nonprogressive disorders affecting motor function, movement, and posture (Bax 1964). Cerebral palsy is a chronic neuromotor condition caused by a developmental abnormality or an injury to the immature brain. The symptoms of cerebral palsy are the result of a cerebral (brain) lesion occurring before the brain is fully developed.

Although the type of cerebral lesion causing cerebral palsy is nonprogressive (stays the same), the impact of the lesion on the child's motor development may change over time as the brain matures. Therefore, as the child grows, the symptoms and degree of functional impairment may change. For example, hypotonia (low muscle tone) in infancy may evolve into spasticity as the child ages. Likewise, an infant with mild spasticity may gradually improve over time as the neuromotor system matures, and some of the motor signs of cerebral palsy may diminish as the child grows (Nelson 1982).

Classification of cerebral palsy

There have been numerous attempts at grouping or classifying common attributes of different types of cerebral palsy. The three systems most commonly used to describe or classify cerebral palsy are the physiological system, the topographical system, and the level of function/level of disability classification system (Blair 1997, Palisano 1997).

Reliable and valid methods of classification are essential in improving our understanding of the natural history of cerebral palsy and the effects of various intervention strategies. Worldwide, however, there is still a great deal of variability in the classification of cerebral palsy (Blair 1997).

Physiological classification

The physiological system is a model based on the physical manifestations resulting from the brain lesion. Cerebral palsy is usually classified as either *pyramidal* or *extrapyramidal*. Almost all children generally fall into one category more than the other, but they usually have some degree of both types.

- *Pyramidal* refers to a type of cerebral palsy in which there is significant spasticity. This is commonly referred to as *spastic cerebral palsy*. Spasticity is an abnormal increase in muscle tone that is proportionate to the velocity (speed) of externally imposed muscle stretch. The resistance to stretch is greatest at the initiation of movement, similar to the opening of a pocket knife (sometimes referred to as “clasp knife”). This increased muscular tension

cannot be released voluntarily. Spasticity often results in abnormal postural control and poor quality of movement affecting the development and use of gross motor, fine motor, and oral-motor skills. The development of contractures (permanent muscle shortening) associated with spasticity is common. Seizures are also common in certain types of pyramidal cerebral palsy.

- *Extrapyramidal* refers to a type of cerebral palsy in which there is variability of muscle tone. Sometimes the tone will fluctuate considerably, and it is often influenced by the child's state of relaxation or activity. Involuntary movements are often present in extrapyramidal cerebral palsy. Because of this variability, contractures tend to form later and are often positional in nature, such as from prolonged sitting in a wheelchair. Clonus or increased deep tendon reflexes are often observed. Seizures are less common with extrapyramidal cerebral palsy. Extrapyramidal cerebral palsy may be further subdivided by the type of abnormal involuntary movements that are present. For example:
 - *Choreoathetoid*. Choreoform movements are irregular, quick, isolated movements of a single muscle group, such as a rapid raising of the arms due to contraction of the shoulder muscles. Athetosis is a continuous slow, sinuous, writhing, purposeless movement. This appears as "snakelike" movements of an extremity. The wrists are frequently held in flexion, while the fingers, shoulders, and much of the legs are in extension. Athetosis is often exaggerated during activity or stress but not seen during sleep. Frequently both chorea and athetosis are combined to produce jumpy movements that interfere with both hand skills and balance. Individuals with choreoathetoid type cerebral palsy often require a wheelchair for mobility. Oral feeding impairments are common, and auditory impairments also occur at a higher rate. Children with choreoathetoid cerebral palsy are often quite thin due to constant movement and caloric expenditure.
 - *Ataxic*. This type of cerebral palsy is characterized by difficulty in coordinating muscles to produce voluntary movement. Incoordination of muscle activity may create the appearance of lurching or staggering when walking. In the extremities dysmetria may occur, which is a reaching beyond a target. Nystagmus, a back-and-forth horizontal movement of the eyes, may or may not be present.

- *Rigid or Dystonic.* In this form of cerebral palsy, the child assumes a very rigid or stiff posture when awake or stimulated, but usually relaxes during sleep.

Oral-motor problems are common in both pyramidal and extrapyramidal types of cerebral palsy and can lead to significant speech and feeding difficulties. The feeding difficulties increase the risk of aspiration of food into the airway and may result in growth problems.

Topographical system

The topographical system can be used to further describe various attributes of pyramidal (spastic) cerebral palsy. In essence, this is a classification system based on the specific motor function of each limb. The pattern of involvement can give clues to the etiology (cause) of the cerebral palsy and can help in determining screening and monitoring strategies because particular classifications tend to have similar complications. The major topographical classifications include:

- *Hemiplegia*--Hemiplegia is the most common type of cerebral palsy. Abnormalities of motor control are localized to one side of the body. In classic hemiplegia, there is more motor impairment of the arm than the leg. A delay in walking or an early hand preference may be the first noticeable sign of mild hemiplegia.

Sensory deficits on the affected side are quite common, sometimes including a difference in the visual field (homonymous hemianopsia). Growth may be different on the affected side, leading to limb length discrepancies and sometimes even a visible difference in right and left side of the face. Seizures are common with hemiplegia type cerebral palsy. Intelligence may be normal, but there are often learning disorders. Most individuals with hemiplegia are quite functional and are usually able to ambulate independently.

A reverse pattern of hemiplegia may be seen in premature infants who suffered significant intraventricular hemorrhage (bleeding in the brain). In this type, the leg is either more involved than or as equally involved as the arm. Associated deficits tend to be less severe, depending on the severity of the hemorrhage.

- *Diplegia*--All four extremities are involved in diplegia, but the arms are somewhat less involved than are the legs, and hand function is generally not significantly affected. Motor involvement in diplegia is often about the same on both sides of the body, with one side being slightly more affected than the other. Strabismus (crossed eyes) is common with diplegia, and there are often

associated sensory, perceptual, and learning problems. One side being significantly more involved (asymmetrical involvement) may be a diplegia with a hemiplegia (sometimes referred to as triplegia).

- *Quadriplegia*--In this type, all four extremities are significantly involved with the legs more so than with the arms, but with considerable limitation of hand use. This type might also be referred to as *tetraplegia* (because the head and trunk are also usually involved) or *total involvement* (because the face, swallowing, and speech may be affected). Seizures and significant cognitive impairment are common with this type of cerebral palsy. There are frequently major musculoskeletal problems with the hips and spine. As in diplegia, strabismus is common. Oral-motor and feeding problems are usually a significant component of quadriplegia type cerebral palsy.

Level of function/level of disability classification

A third method of classification is based on the concept of level of functional motor impairment or disability. The most common model for classifying function and disability is the *International Classification of Functioning, Disability and Health*, known as ICFIDH-2. The ICFIDH-2 is part of the classification system developed by the World Health Organization (WHO) to promote standardization of the classification of information about various aspects of health, such as diagnosis, functioning and disability, and reasons for contact with health services (WHO 1980).

The framework of the ICFIDH-2 classification system includes factors specific to the individual's condition as well as contextual factors (environmental and personal). This approach acknowledges the dynamic interactions and complex relationships (medical/developmental and societal) that shape how an individual functions (WHO 1980).

The core components (constructs) of the ICFIDH-2 classification framework include:

- Body functions (physiologic systems) and structures (body parts)
- Activities (execution of a task or action) and participation (involvement in life situations)
- Contextual factors--environmental (the physical, social, and attitudinal environment) and personal (features of the individual that are not part of the health condition or personal state)

There are other approaches specific to motor function that can be used to assess and describe the degree of functional motor impairment. For example, motor

function can be defined through use of various standardized motor assessment tests such as the Bayley Scales of Infant Development (Bayley 1993), the Motor Quotient (Capute 1985), and more recently the Gross Motor Function Classification System (GMFCS) (Palisano 1997, Wood 2000). Additional assessment tests are described in the assessment chapter (page 32).

**APPENDIX D: SUMMARY OF
RESEARCH
FINDINGS:
PANEL
CONCLUSIONS**

Predicting Motor Disorders in High-Risk Infants Using Physical Exam Findings

1. In infants who are at high risk for motor disorders, a neurodevelopmental exam during the newborn period can provide useful information for predicting later cerebral palsy or other motor or developmental problems (Allen 1989, Nelson 1982, Zafeiriou 1998).
2. Normal findings on a newborn exam are generally associated with good neurological outcomes (Allen 1992, Biermann-van Eendenburg 1981, Dubowitz 1984, Molteno 1995, Stewart 1988).
3. An abnormal finding on a newborn exam by itself does not predict an adverse neurological outcome (Allen 1992, Biermann-van Eendenburg 1981, Dubowitz 1984, Molteno 1995, Stewart 1988).
4. The greater number of neuromotor abnormalities in the newborn period, the greater likelihood of later neurological abnormalities (Dubowitz 1984, Ellenberg 1981).
5. Problems that persist in the first three months of life are more likely to be predictive of later neurological abnormalities (Nelson 1982).

Predicting Motor Disorders in High-Risk Infants Using Standardized Tests

1. The Bayley Scales of Infant Development (BSID) and the Movement Assessment of Infants (MAI) are not meant to be diagnostic but can be helpful in identifying children who require additional follow-up for possible neuromotor or other developmental problems (Harris 1987A, Swanson 1992).
2. As with any screening test, use of different cutoff scores will result in either higher or lower sensitivities and specificities (Harris 1984, Harris 1989, Morgan 1986, Nickel 1989, Piper 1992, Swanson 1992).
3. The ability of tests such as the Movement Assessment of Infants (MAI) and the Bayley Scales of Infant Development (BSID) to identify cerebral palsy is increased as the severity of motor limitation increases (Harris 1989).
4. The Motor Scale on the Bayley Scales of Infant Development (BSID) is more sensitive as children get older (Harris 1989, Swanson 1992).
5. The Movement Assessment of Infants (MAI) is designed to be used at specific ages for young children whose motor development is below the 12-month age level (Harris 1984, Harris 1987, Harris 1989, Piper 1992, Swanson 1992).

6. The Movement Assessment of Infants (MAI) is better able to identify children with quadriplegia than hemiplegia or diplegia (Harris 1989).
7. The Movement Assessment of Infants (MAI) has strong sensitivity at 4 months adjusted age and still stronger at 8 months adjusted age for identifying children with neuromotor problems, mental retardation, or severe developmental delay (Swanson 1992).
8. The Movement Assessment of Infants (MAI), when compared with the Bayley Motor Scales, is less specific (possibly due to its reliance on evaluation of transient neurologic signs) but more sensitive in identifying cerebral palsy (Harris 1987A, Harris 1989).

Monitoring Motor Milestone Development

1. Sequential measurement of motor milestone attainment during the first year by health care professionals is useful in identifying children who require further screening or in-depth assessment because delayed milestone attainment is an indicator of increased risk for a motor disorder. However, milestone attainment does not provide information about the quality of movement, and no single milestone has extremely high sensitivity and specificity for identifying motor disorders (Allen 1992, Allen 1994, Allen 1997, Ellenberg 1981, Johnson 1990, Wood 2000).
2. Focusing on a series of milestones rather than a single milestone, adjusting age for prematurity, and using a greater delay criterion increases the specificity of milestone attainment for predicting cerebral palsy (Allen 1992, Allen 1994, Allen 1997).
3. The Gross Motor Function Classification System (GMFCS) can be useful for measuring gross motor function information that is routinely observed and documented and can be a good predictor of later walking status for young children with cerebral palsy (Wood 2000).
4. In both the general population and infants at high risk for a motor disorder, parents may be reassured that cerebral palsy is extremely unlikely when a child attains all the motor milestones without delay (Ellenberg 1981).
5. For low birth weight and other high-risk infants, the walking milestone at the age of 18 months can be a useful indicator of future motor status. However, the prevalence of late walking increases with decreased gestational age (Johnson 1990).

Motor Therapies for Low Birth Weight Premature Infants at Risk for Cerebral Palsy

1. In premature infants with abnormal neuromotor exam findings, neurodevelopmental treatment (NDT) provided during the hospital stay may improve some motor outcomes for a short period of time, but the long-term effect of the intervention was not evaluated (Girolami 1994).
2. Overall, there is no clear evidence that the motor therapy interventions evaluated improved the long-term functional motor outcome for infants who are at risk for motor disorders. Almost all children show improvement in their motor skills over time, particularly during the first year, regardless of whether they receive intervention or not. Delaying motor therapy interventions until a definite motor delay or disability has been diagnosed does not appear to affect the developmental outcome (Goodman 1985/Rothberg 1991, Piper 1986, Weindling 1996).
3. Based on the studies evaluated, the Vojta approach does not appear to be effective in improving motor outcomes for infants who are at risk for motor disorders and may be uncomfortable for some children (Brandt 1980).

Motor Therapies for Infants and Children Who Have Motor Disorders

1. The research evidence found did not adequately demonstrate the effectiveness of interventions based on either neurodevelopmental treatment (NDT) or the sensory integration (SI) approach for improving long-term functional motor outcomes in young children with suspected or confirmed motor disorders (DeGangi 1983, Jenkins 1988, Mayo 1991, Palmer 1988).
2. Motor therapy approaches such as neurodevelopmental treatment (NDT) and sensory integration (SI) can be readily combined with parent training, behavioral approaches, and casting. The involvement of parents who are effectively trained in helping with the intervention program can increase the opportunity for a child to practice, improve, and acquire skills (Hanzlik 1989, Law 1991, Law 1997, Palmer 1988).
3. The neurobehavioral approach, a combination of neurodevelopmental and behavioral techniques, can be used for teaching specific movement components that are incorporated into functional skills. Teaching movement components as a part of a functional skill can lead to maintenance of the movement component after the intervention and improvement in the activity (Horn 1995, Reddihough 1998).
4. The efficacy of using conductive education for treating young children who have motor disorders was not adequately demonstrated (Horn 1995, Reddihough 1998).

Approaches for Spasticity Management

There are a number of intervention approaches currently used for managing significant spasticity in young children with cerebral palsy. There appear to be advantages and disadvantages to each of these approaches; none is clearly superior in efficacy.

Botulinum toxin A (BtA) and serial casting

1. Children receiving BtA (compared with children receiving placebo injections) may experience a significant gain in gait pattern lasting after intervention for up to 8 weeks, as well as significant increases in active ankle range of motion and ankle position at strike (Koman 2000).
2. There is mixed evidence about whether BtA is superior to serial casting for improving motor function in children with significant spasticity. Of the two randomized controlled trials (RCT) comparing these two interventions, one study found no significant differences between groups. The other study found that both groups initially improved but that by 12 weeks after treatment, the improvements persisted in the BtA injection group but not in the serial casting group (Corry 1998, Flett 1999).
3. Compared with serial casting, parents appear to prefer BtA injections as an intervention since it works fast, offers freedom and convenience, and allows a child to walk with less stiffness than a child wearing a cast (Corry 1998, Flett 1999).
4. The studies found fewer side effects for BtA injections than for serial casting. Adverse effects of BtA injections reported in other studies include calf pain and possible systemic side effects. The long-term effects of BtA injection therapy are not known (Corry 1998, Flett 1999).
5. Potential adverse effects of serial casting have been reported to include pain in the foot, leg or calf, skin inflammation, and increased weakness in the legs and falling. Parents also consider serial castings to be inconvenient, and it may make it more difficult for the family to care for the child (Corry 1998, Flett 1999).

Selective posterior rhizotomy (SPR) and physical/occupational therapy approaches

6. For children with cerebral palsy who have significant spasticity, selective posterior (dorsal) rhizotomy (SPR) in combination with physical/occupational therapy (PT/OT) results in significantly greater improvement in gross motor function than does PT/OT alone. This finding was consistently seen in the three randomized controlled trials (RCT)

reviewed on this topic (McLaughlin 1987, Steinbok 1997/Steinbok 1998, Wright 1998).

7. The long-term outcomes and complications of selective posterior rhizotomy (SPR) are not known. Studies report some intraoperative complications (such as aspiration pneumonia) and postoperative complications including back pain, sensory problems, neurogenic bladder or bowel problems, urinary tract infection, epidural abscess, and transient urinary retention (McLaughlin 1987, Steinbok 1997/Steinbok 1998, Wright 1998).

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REFERENCE LIST

This reference list is limited for the purpose of this *Quick Reference Guide*. The complete Bibliography can be found in the *Report of the Recommendations* or the *Technical Report* versions of this guideline. First author in **bold** indicates that the article met the criteria for evidence for this guideline.

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SUBJECT INDEX

SUBJECT INDEX

Adeli suit 99

Assessment

- clinical clues 24, 38
- developmental assessment 41
- electrophysiologic tests 31
- family assessment 50
- feeding/swallowing/oral-motor 35
- health evaluations 45
- muscle tone 9, 22, 25
- neuroimaging tests (CAT scan/MRI) 30
- postural tone 9, 22
- reflex development 9, 20
- risk factors 24
- tests 32

Assistive technology devices 78

Augmentative communication 83

Botulinum toxin A (BtA) 90, 133

Cerebral palsy

- associated medical conditions 11, 46, 97
- classifying 34
- defined 123
- prevalence 13

Clinical clues 24, 38

Communicating the diagnosis 47

Communicating with the family 49

Conductive education 98

Definition of guideline terms 4

Developmental assessment 41

- cognition 42
- communication 43
- motor milestones 10, 29

Electrophysiologic tests 31

Exercise, therapeutic 71

Family assessment	50
Feeding/swallowing	35, 85
Horseback riding,(hippotherapy, therapeutic)	77
Hyperbaric Oxygen Therapy (HBOT)	99
Intervention	
adeli suit	99
aquatic therapy	78
assistive technology devices	78
associated health conditions	97
augmentative communication	83
botulinum toxin A (BtA)	90, 133
casting	83, 85
conductive education	98
craniosacral therapy	76
exercise, therapy	71
feeding	85
Feldenkrais Method®	100
hippotherapy	77
HBOT	99
infant massage	75
Intrathecal Baclofen (ITB)	90
joint mobilization therapy	77
jumpers and walkers	70
manual/physical/occupational therapies	71, 75
medications (spasticity management)	89
mobility devices	79, 82
motor therapy	65, 71, 74
myofascial release treatment	76
Neurodevelopmental Treatment (NDT)	72
Neuromotor Electrical Stimulation (NMES)	73
oral-motor, feeding	39, 85
orthotics	83
parent education	64
patterning (Doman-Delacato)	100
rotary movement therapy (vestibular stimulation)	73

SUBJECT INDEX

seizure disorders	97
selecting, questions to ask	56
Sensory Integration therapy (SI).....	73
spasticity management	89
surgery	93
Tscharnuter Akademie for Movement Organization (TAMO).....	101
vibratory stimulation, therapeutic	71, 73, 75
vision problems.....	97
weighted vests.....	70
Joint mobilization therapy	77
Manual/physical/occupational therapies.....	71, 75
Medications (spasticity management).....	89
Mobility devices	79, 82
Motor development	
defined	8
milestones.....	10, 29
muscle tone.....	9, 22, 25
postural tone.....	9, 26
prematurity	11, 27
reflex development	9, 20
Motor disorders	
causes.....	14
clinical clues.....	25, 38
defined	3, 12
development delays	11, 20, 29
diagnosis.....	20, 32
identification	20
prevalence.....	13
risk factors.....	24
Motor therapy	65
Neurodevelopmental Treatment (NDT).....	72
Neuroimaging tests (CAT scan/MRI).....	30
Oral-motor feeding/swallowing.....	39, 85
Orthopedic management	83
Parent education	64

Periventricular leukomalacia	14
Physical/occupational therapy	71, 77, 133
Positioning devices.....	82
Reflex development.....	9, 20
Rhizotomy.....	92
Risk factors	24
Rotary movement therapy (vestibular stimulation).....	73
Seizure disorders	97
Spasticity management	88
Spinal manipulation.....	92
Surgery	93
Tschamuter Akademie for Movement Organization (TAMO)	101
Vestibular stimulation	70
Vibratory stimulation	73, 75

GUIDELINE VERSIONS

There are three versions of each clinical practice guideline published by the Department of Health. All versions of the guideline contain the same basic recommendations specific to the assessment and intervention methods evaluated by the guideline panel, but with different levels of detail describing the methods and the evidence that supports the recommendations.

The three versions are

THE CLINICAL PRACTICE GUIDELINE:

Quick Reference Guide

- summary of major recommendations
- summary of background information

Report of the Recommendations

- full text of all the recommendations
- background information
- summary of the supporting evidence

The Guideline Technical Report

- full text of all the recommendations
- background information
- full report of the research process and the evidence reviewed

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