

**CLINICAL PRACTICE GUIDELINE**

**REPORT OF THE  
RECOMMENDATIONS**

**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**

This guideline was developed by an independent panel of professionals and parents sponsored by the New York State Department of Health. The recommendations presented in this document have been developed by the panel and do not necessarily represent the position of the Department of Health.

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# Motor Disorders

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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.

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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.

## PREFACE

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- Identification and referral of children at risk or suspected of disability by primary referral sources (including physicians and other health care providers).
- 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 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.

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**REPORT OF THE  
RECOMMENDATIONS**

**MOTOR DISORDERS**

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

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This *Clinical Practice Guideline: Report of the Recommendations* presents the full text of all the recommendations plus an abbreviated description of the methodology and evidence used to develop the recommendations.

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*.

An abbreviated version of the background information and guideline recommendations can be found in the *Clinical Practice Guideline: Quick Reference Guide*.

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# CHAPTER I: INTRODUCTION

### PURPOSE OF THIS CLINICAL PRACTICE GUIDELINE

This *Report of the Recommendations* guideline 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 about “best practice” based on consensus opinion of the panel and scientific evidence about the efficacy of various assessment and intervention options for young children who have a motor disorder.

The key elements of the guideline development approach include:

- Ensuring multidisciplinary representation
- Developing a guideline that is valid, objective, and credible
- Using a process that includes a combination of systematic review of the available scientific literature and expert clinical opinion

This guideline represents the guideline panel’s concerted attempt to find and interpret the available scientific evidence in a systematic and unbiased fashion. It is hoped that by using an evidence-based approach, the guideline provides a set of recommendations that reflect current best practices and will lead to optimal outcomes for children and their families.

*Providers and families are encouraged to use this guideline, recognizing that **the care provided should always be tailored to the individual**. Not all of the recommendations will be appropriate for use in all circumstances. The decisions to adopt any particular recommendation must be made by the family and the practitioner in light of available resources and circumstances presented by individual child(ren) and their families.*

### REASONS FOR DEVELOPING THIS GUIDELINE

The goals of 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

## **DEFINITION OF MOTOR DISORDERS**

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

- Developmental motor disorders (motor delays that are part of a global developmental delay, motor delays that can 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 the guideline, conditions such as spina bifida, juvenile rheumatoid arthritis, and 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 Policy** ❖ 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. Children with motor delays may be eligible for the Early Intervention Program if these delays are consistent with the State definition of developmental delay.

## **SCOPE OF THE GUIDELINE**


This clinical practice guideline provides recommendations about best practices for assessment and intervention for young children who have a motor disorder. The primary topics of the recommendations in this guideline are:

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

**DEFINITION OF OTHER IMPORTANT TERMS**

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

- Assessment*            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 intervention, and measure treatment outcomes.
  
- Family*                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).
  
- Parent(s)*            The primary caregiver(s) who has (have) significant 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 parent is used to mean the child’s primary caregiver.
  
- Professional*        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. It is beyond the scope of this guideline to address professional practice issues.
  
- Screening*            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.
  
- Target Population*    For this guideline, the target population is children who have a motor disorder from birth to 3 years of age. Throughout this document, the term *young children* is used to describe this target age group.
  
- Young Children*     This term is used broadly to describe the target age group for this guideline (children from birth through 3 years of age).



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



## **THE IMPORTANCE OF USING SCIENTIFIC EVIDENCE TO HELP SHAPE PRACTICE**

Every professional discipline today is being called upon to document effectiveness. Professionals are increasingly asked to document that the approach used is effective in bringing about the desired outcomes. Those providing, receiving, or paying for services often want to know if there are other approaches, or modifications of existing approaches, that might produce better outcomes or similar outcomes at less cost. The difficulty in answering these questions is that many times the effectiveness of the methods used in current professional practice has not been studied extensively or rigorously.

### *Strengths of the evidence-based approach*

Guidelines based on a review and evaluation of the scientific literature can help professionals, parents, and others learn what scientific evidence exists about the effectiveness of specific clinical methods. This approach provides parents and professionals from a variety of disciplines with information to make recommendations based on scientific evidence rather than opinion. When adequate scientific evidence can be found and systematically evaluated, it provides a balanced and objective approach for making informed decisions about intervention and assessment options.

Another strength of the evidence-based approach is that when evidence is sought but not found, it provides strong support for developing research agendas.

### *Limitations of the evidence-based approach*

In general, the most significant limitation to using an evidence-based approach is that there may be a lack of adequate evidence specific to the topic of interest. For this guideline, many articles were found related to the guideline topic, but few articles met the panel's minimum criteria for study quality. Approximately 7,713 abstracts were screened for this guideline, and from these, over 1,121 articles were reviewed to determine if they met the criteria for evidence. For many areas of interest (particularly regarding intervention methods), a limited number of studies were found that met the minimum criteria.

The panel recognized that there are numerous articles in the scientific literature that did not meet criteria for adequate evidence about efficacy, yet still contain valuable information. This would include articles that are case reports and case series (sometimes using pre- and posttest designs), as well as articles that primarily discuss theory or opinion. Although such articles often provide valuable insights that may be useful in clinical practice, these articles cannot provide adequate evidence about the efficacy of specific clinical assessment or intervention methods.

### OVERVIEW OF THE METHODS USED TO EVALUATE THE EVIDENCE

This clinical practice guideline for young children who have a motor disorder is part of a series of clinical practice guidelines being developed by the New York State Department of Health (NYSDOH) for assessment and intervention for young children with developmental disabilities. To develop these guidelines, the NYSDOH has chosen to use a methodology similar to that used by the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Healthcare Policy and Research (AHCPR), a part of the United States Public Health Service.

A multidisciplinary panel of topic experts, generalist providers (both clinicians and educators), and parents of children who have motor disorders developed this guideline. The panel participated in a series of meetings to review the available research and develop guideline recommendations. The panel's final meeting was in 2001.

#### *Scope of the guideline*

The scope of this clinical practice guideline is to provide general background information and specific recommendations related to identification, assessment, and intervention approaches for young children (birth to age three) with motor disorders. While the term motor disorders can be broadly used to include a wide variety of conditions, the guideline panel chose to limit the primary focus of the guideline to developmental motor disorders (motor delays that are part of a global developmental delay, motor delays that can arise from hypotonia, and mild neuromotor dysfunction) and static central nervous system disorders (specifically, cerebral palsy).

A comprehensive review of all conditions that might be considered as motor disorders was not possible for this document. For example, conditions such as spina bifida, juvenile rheumatoid arthritis, and neuromuscular disorders such as muscular dystrophy or spinal muscular atrophy are not addressed in this guideline.

Not all of the topics included in the guideline were appropriate for the review of evidence process. Some topics or methods were determined to be important to address with recommendations, but a specific literature search and evaluation of the evidence was not undertaken. In general, a literature search and review of the evidence was not done when:

- The topic or method was not a primary focus of this guideline (such as specific medical interventions)

- There was a large literature for a topic that is generally not specific to children who have a motor disorder and/or generally not considered controversial (such as oral-motor feeding)
- The topic was generally not the subject of scientific study (such as the importance of multidisciplinary team collaboration)

### *Using the evidence to develop guideline recommendations*

Studies meeting the criteria for adequate evidence received an in-depth review, and relevant information about study design, subject characteristics, and results was systematically abstracted onto evidence tables. The guideline panel critically evaluated each of the articles that met the criteria for review. Based on the information in the article, the panel developed conclusions about the strengths and limitations of the study and the degree of applicability of the evidence to the guideline topic. The panel then used the information from these articles as the basis for developing guideline recommendations.

Standard decision-making rules were used to develop guideline recommendations. When scientific evidence was available, it was given the most weight. When adequate scientific evidence was not found, or when the topic was not a focus of the evidence review, the recommendations were developed based on the expert opinion of the panel. In all instances (evidence-based and expert opinion), the recommendations are the consensus of the panel.

## **STRENGTH OF EVIDENCE RATINGS**

Each guideline recommendation has been given a “strength of evidence” rating, which is designated by the letter [A], [B], [C], [D1], or [D2] in brackets immediately after the recommendation. The strength of evidence rating indicates the amount, general quality, and clinical applicability (to the guideline topic) of scientific evidence the panel used as the basis for that specific guideline recommendation.

- [A] = **Strong evidence** is defined as evidence from two or more studies that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, with the evidence consistently and strongly supporting the recommendation.
- [B] = **Moderate evidence** is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, and where the evidence supports the recommendation.

[C] = **Limited evidence** is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had moderate quality or applicability to the topic, and where the evidence supports the recommendation.

[D] = **Panel consensus opinion** (either [D1] or [D2]):

[D1] = **Panel consensus opinion** based on information not meeting criteria for adequate evidence about efficacy on topics where a systematic review of the literature was done

[D2] = **Panel consensus opinion** on topics where a systematic literature review was not done

The methodology for determining adequate evidence is summarized in Appendix A.

The strength of evidence rating indicates the type of information used as the basis for the recommendation. The strength of evidence rating does not reflect the importance of the recommendation or its direction (whether it is a recommendation for or against use). For example:

- If there was strong evidence that an intervention *is effective*, then a recommendation *for use* of the method would have an [A] evidence rating.
- If there was strong evidence that an intervention is *not effective*, then a recommendation *against use* of the method would also have an [A] evidence rating.

## USING SCIENTIFIC EVIDENCE AS THE BASIS FOR CLINICAL DECISION MAKING

### *Considerations about using scientific evidence*

In developing evidence-based clinical practice guidelines, the process of reviewing the scientific literature to find evidence-based answers to specific clinical questions is challenging. Many of the specific clinical issues of interest have not been studied in well-designed studies to determine if the method is effective. Even when well-designed studies have been done on a particular clinical topic, the study findings themselves seldom present totally straightforward and unambiguous answers to the clinical questions of interest. Careful analysis of the studies and considerable judgment are always needed when using the findings of research studies to help in making informed clinical decisions and developing clinical practice guidelines.

In developing practice guidelines for most clinical topics, it is exceptional to find studies that evaluate exactly the clinical situations and types of subjects that are of interest. Therefore, it is almost always necessary to generalize to some extent in terms of the subject characteristics (such as age) and the clinical setting or the type of assessment or intervention method used. The research reviewed for this guideline was no exception.

In using research evidence to help make clinical decisions, the two primary considerations are the quality of the evidence and its clinical applicability to the question of interest.

- The **quality of the study** is primarily related to the study design and controls for bias: the higher the quality of the study, the more confidence we can have that the findings of the study are valid. Confidence in the study findings become even greater when multiple well-designed studies done by independent researchers find similar results.
- The **clinical applicability of a study** is the extent to which the study's results would also be expected to occur in the particular clinical situation of interest to us. The applicability of a study's findings is considered to be higher when the subject characteristics, clinical methods, and clinical setting are similar between the study and clinical situation of interest.

The overall usefulness of a study's findings to clinical decision making relates both to our confidence in the results (based on the quality and amount of scientific evidence) and the similarity of the study's subjects, clinical methods, and setting to the question of interest (i.e., its applicability).

#### *Criteria for studies used in developing this guideline*

For this guideline, the panel chose to:

- Adhere to relatively rigorous criteria for selecting studies as providing high quality evidence about efficacy.
- Distinguish between high quality/applicability and moderate quality/applicability for intervention studies.

Findings from studies meeting the criteria for evidence were used as the primary basis for developing the evidence-based guideline recommendations. In many cases, the panel also used information from other articles and studies not meeting the criteria for evidence, but information from these sources was not considered evidence and was not given as much weight in making guideline recommendations.

### *Considerations about the applicability of studies*

Of particular concern for this guideline was finding high-quality scientific studies that focused on children under three years of age. For some topics, studies were found that evaluated only children within the guideline's target population (children from birth to three years of age), but for other topics the only studies found evaluated groups that included somewhat older children (over age three).

As noted above, having a study with children over age three does not affect the quality of the study or bias the results, but it may make the study's findings somewhat less applicable to the guideline topic. The panel took this into account when making guideline recommendations, and generally gave more weight to findings from high-quality studies that focused on children under three years of age. However, when there were few good studies found that focused on children in the target age group, the panel thought it important to generalize from evidence found in good studies of somewhat older children.

### *Judging the quality and applicability of the evidence when making guideline recommendations.*

Due to the considerations above, the panel needed to use significant judgment in evaluating the quality and applicability of the scientific evidence when using it as the basis for the evidence-based recommendations. Similar limitations and considerations apply to all evidence-based practice guidelines. The strength of evidence ratings are a reflection of both the amount and quality of the scientific evidence found and its applicability to the guideline topic.

## **PEER REVIEW, GUIDELINE VERSIONS, AND PERIODIC REVISION**

### *The peer review process*

The draft guideline was sent to a variety of topic experts, generalist providers, and parents for peer review. Comments were solicited on the draft document, and the panel reviewed these comments before making final revisions in the guideline. Review comments were received from 68 external reviewers.

### *Guideline versions*

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

The three versions of the Clinical Practice Guideline are:

- *Clinical Practice Guideline: The Guideline Technical Report*  
Includes the full text of the recommendations and related background information plus a full report of the research process and the evidence that was reviewed.
- *Clinical Practice Guideline: Report of the Recommendations*  
Includes the full text of all the recommendations and related background information plus a summary report of the research process and the evidence that was reviewed.
- *Clinical Practice Guideline: The Quick Reference Guide*  
Provides a summary of guideline recommendations and background information.

*Periodic review and revision of the guideline*

It is intended that this NYSDOH Clinical Practice Guideline on motor disorders in children from birth to age 3 be a dynamic document that is updated periodically as new scientific information becomes available. This guideline reflects the state of knowledge at the time of development, but given the inevitable evolution of scientific information and technology, it is the intention of the NYSDOH that periodic review, updating, and revision will be incorporated into an ongoing guideline development process.





**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, playing, 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)

When viewed as part of a broader interrelated developmental process, motor development may be considered to include:

- Neuromotor (tone, postural reflexes, and qualitative aspects of movement)
- Developmental motor (gross motor, fine motor, and oral-motor)
- Sensorimotor (cognitive/perceptual motor functions)

There are a number of theories about the various interrelated processes underlying motor development. For example, according to neuromaturation theory, motor development is related to maturation of the central nervous system. Cognitive theories of development relate motor development to an interaction between the individual and the environment. Dynamic systems theory describes motor development as an interaction among multiple interrelated systems, including maturation of the musculoskeletal and nervous

systems, as well as other dynamic components of development such as sensory perception, arousal, and motivation.

**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 attempt to stand.) Motor milestones are motor events that follow a somewhat predictable sequence by which one can gauge a child’s general developmental progress. Delays in the age of attainment of motor milestones are often the parent’s or the health care provider’s first concern in children with motor or other developmental disorders. Table 1 identifies some general developmental motor milestones and the typical age range when the milestones are attained.

**Table 1: Developmental Motor Milestones**

<b>Age</b>	<b>Gross Motor</b>	<b>Fine Motor</b>
Birth-6 wks.	<ul style="list-style-type: none"> <li>▪ early reflexes present</li> </ul>	<ul style="list-style-type: none"> <li>▪ grabs adult fingers with tight-fisted hands</li> </ul>
6 wks.-4 mos.	<ul style="list-style-type: none"> <li>▪ holds head erect</li> <li>▪ turns from back to side</li> </ul>	<ul style="list-style-type: none"> <li>▪ holds a rattle</li> <li>▪ reaches for dangling object with both hands</li> </ul>
4-8 mos.	<ul style="list-style-type: none"> <li>▪ early reflexes fading</li> <li>▪ can hold head steady</li> <li>▪ rolls from back to stomach</li> <li>▪ sits alone</li> </ul>	<ul style="list-style-type: none"> <li>▪ picks up cube</li> <li>▪ bangs toys together</li> <li>▪ uses thumb and forefinger grasp</li> </ul>
8-12 mos.	<ul style="list-style-type: none"> <li>▪ crawls on hands and knees</li> <li>▪ stands alone</li> <li>▪ walks with help</li> </ul>	<ul style="list-style-type: none"> <li>▪ stacks two cubes</li> <li>▪ releases hold on objects</li> <li>▪ uses pincer grasp</li> <li>▪ can hold a crayon</li> </ul>
12-18 mos.	<ul style="list-style-type: none"> <li>▪ throws ball</li> <li>▪ crawls or climbs up stairs</li> <li>▪ lowers self from standing</li> <li>▪ walks alone</li> </ul>	<ul style="list-style-type: none"> <li>▪ turns knobs</li> <li>▪ pushes, pulls, pokes toys</li> <li>▪ turns pages in hardbound books</li> </ul>

**Table 1: Developmental Motor Milestones**

<b>Age</b>	<b>Gross Motor</b>	<b>Fine Motor</b>
18-24 mos.	<ul style="list-style-type: none"><li>▪ stands up from stooping</li><li>▪ climbs onto chairs</li><li>▪ stands on one foot</li><li>▪ rides big toy cars</li><li>▪ kicks ball</li></ul>	<ul style="list-style-type: none"><li>▪ scribbles with crayon</li><li>▪ completes simple puzzles</li></ul>
24-29 mos.	<ul style="list-style-type: none"><li>▪ walks down steps with alternating feet</li><li>▪ runs, jumps with two feet</li></ul>	<ul style="list-style-type: none"><li>▪ strings beads</li><li>▪ scribbles are more controlled</li></ul>
29-36 mos.	<ul style="list-style-type: none"><li>▪ jumps in place</li><li>▪ rides tricycle</li></ul>	<ul style="list-style-type: none"><li>▪ uses scissors</li></ul>

*Adapted from: Geralis 1991  
(Continued from previous page)*

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**WHAT ARE SOME OF THE IMPORTANT COMPONENTS OF MOTOR DEVELOPMENT?**

As previously mentioned, motor development is a complex process that is dependent on successful integration of a number of interrelated developmental processes. There are many factors that can affect motor development. From a neuromotor perspective, there are several basic components that provide the foundation of motor skill development in young children. These include:

- **Muscle tone.** Muscle tone may be described differently depending on the context or purpose of the description and the manner in which it is assessed. Muscle tone is influenced by all levels of the nervous system, from the brain to the peripheral nerves, and 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 the message. Two common concepts used in defining muscle tone include:
  - **Passive muscle tone.** Passive muscle tone represents the resistance of muscles to passive stretch. Passive movement is when a part of the body is moved, usually by someone else, without active participation or

movement by the child. Passive muscle tone usually spans a range and will vary depending on the activity and the environment, and the child's state of alertness, motivation, and emotions. For example, passive muscle tone will usually decrease when the child is sleeping or is drowsy and increase when the child is active and alert. Common methods to assess passive muscle tone include observing the child's natural range of motion, measuring joint angles, and observing resting posture.

- **Active muscle tone.** This muscle tone represents the active resistance of muscles to forces including the maintenance of posture against gravity (postural tone) or range of motion performed by someone else. This type of resistance represents a form of muscle strength. The central nervous system affects active muscle tone to a much lesser degree than do diseases of the muscle, including myopathies and muscular dystrophies.

Abnormal or atypical muscle tone can be thought of as the inability to adequately and appropriately adjust or vary muscle tension to perform a task or function. Muscle tone can be too low or too high to perform activities efficiently and effectively. Abnormalities in muscle tone are 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 arise from the brain stem. They are complex, stereotyped, and automatic movements that evolve during fetal life and peak in the months after birth. These involuntary movements tend to dominate motor movements in the first 3 to 4 months of the baby's life. As the brain matures, these primitive reflexes become integrated into more mature motor skills and voluntary motor behaviors emerge. By 6 to 9 months of age, the primitive reflexes are generally not visible. Because of this maturation process, it is sometimes difficult to predict the severity of motor disorders from a routine infant neurological examination.
- **Righting and equilibrium reactions.** Righting and equilibrium are balancing responses that cause us to correct our posture/position in response

to the force of gravity. Equilibrium reactions emerge in the first year of life as the neurological, musculoskeletal, and other systems mature. These reactions provide the basis for many motor skills, and they are essential in the development of complex motor skills such as sitting, crawling, standing, and walking. Development of these reactions gives clues that motor development appears to be proceeding normally.

- **Postural reactions.** Motor development is dependent on postural control to provide stability for movement activities. Postural control can be described as the ability to establish and maintain a stable position over the base of support. Postural control involves adequate muscle tone, the ability to right the head, trunk, and limbs (righting reactions), and the ability to maintain and regain balance (equilibrium reactions).

### HOW DO PREMATURETY AND OTHER HEALTH CONDITIONS IMPACT MOTOR DEVELOPMENT?

#### *Prematurity*

Studies of the development of infants born prematurely show that motor development is more closely approximated to the child's chronological age corrected for the degree of prematurity. Subtracting the degree of prematurity from the infant's chronological age derives the corrected age. For example, a 12-month-old (52 weeks old) born at 30 weeks gestation would be considered 10 weeks premature. Therefore, the corrected age would be calculated as  $52 - 10 = 42$  weeks. This correction factor is usually applied until the child is two years old. Most premature infants who eventually show normal development tend to match the gross motor milestones of their full-term peers by their second birthday; therefore, correction is no longer necessary after the second birthday.

#### *Health-related factors*

There are many medical conditions that may affect motor development in young children. Some conditions may not directly affect motor development but may result in motor delays secondary to the health condition. Because of the interplay of the various developmental processes, the list of health conditions and other factors that can influence motor development is extensive. For example, children with seizures, hydrocephalus, chronic ear infections, rickets, or metabolic disorders may all have altered motor development. Examples of health-related factors that may influence motor development include:

- **Chronic lung disease or severe congenital heart disease**--Children with these conditions may show hypotonia as well as muscular weakness and exercise intolerance (often manifesting as feeding difficulties in infants). These children lack the energy needed for typical gross motor development but often have normal fine motor skills. Motor development tends to improve as their cardiac or pulmonary status improves. However, some children may remain hypotonic and develop minor neuromotor dysfunction or even cerebral palsy.
- **Technology dependence**--Children with ostomies or children who require technical support to sustain life may also exhibit delays. Tracheotomy tubes or feeding tubes often make it difficult to place the child in the prone position. Limiting the child's experience in prone position can alter the normal sequence of motor development.
- **Gastrointestinal problems**--Gastroesophageal reflux may lead to discomfort in the child, and parental worry about exacerbating the reflux may lead to avoidance of the prone position. For children with severe reflux leading to respiratory distress with reflux episodes, the child or parent may also limit motor exploration because of worsening of the symptoms. These children may show gross motor delays, but usually fine motor skills proceed normally.
- **Nutrition**--Children with failure to thrive or chronic undernutrition often are hypotonic and weak, lack stamina, and exhibit motor delays. Severe malnutrition may result in hypertonia and increased extensor tone. Motor development tends to improve as nutritional status improves. If malnutrition is severe and long standing, there may be associated retardation of overall brain development and delays in language and cognition.
- **Drugs**--Many medications may influence neurological functions and therefore may affect motor development. Antiseizure medications may lead to lethargy and/or hypotonia. Bronchodilators, such as albuterol, can cause jitteriness, irritability, tremors, and increased reflexes. Babies exposed to certain drugs in utero can demonstrate symptoms of withdrawal and may appear restless or agitated and have evidence of hypertonicity often lasting for months.
- **Vision**--Babies with visual impairment or blindness may have delayed motor development. The maintenance of muscle tone is related to motor exploration, and motor exploration is often affected in children who have limited visual perception. Blind children may be delayed in reaching,

sitting, crawling, and walking. Initial gait is usually wide based because of the lack of visual input used for balance.

### WHAT IS A MOTOR DISORDER?

Motor disorders are manifested by 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). Because of the need to focus the scope of the guideline, many other specific conditions that usually result in some type of motor impairment, such as spina bifida, juvenile rheumatoid arthritis, and neuromuscular disorders, are not included as part of the general background discussion.

#### *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 initial marker for children who are later diagnosed with cognitive impairment. Some young children with global developmental delay will show hypotonia on a neurological exam while others initially have no signs of neurological difference. If other visible features are not present, cognitive and language delays may be overlooked until the child is much older. Although the initial concern may have been a delay or qualitative difference in motor skills, there is frequently an evolution into concern for cognitive disorder as the child gets older. Because some syndromes are genetic, it is important to identify the child as young as possible for family planning and counseling on recurrence risks.
- *Hypotonia.* Muscular hypotonia may lead to a general delay in the acquisition of motor skills. Sometimes hypotonia is isolated, a condition known as benign congenital hypotonia. More commonly, hypotonia is part of a global delay in development or related to some other condition. Muscular hypotonia makes it difficult for the child to maintain posture against gravity, thereby decreasing muscle power and delaying motor skill acquisition. As infants, children with hypotonia appear “floppy” and require more support from the caretaker when held. Instability in sitting and



standing may extend to the acquisition of fine motor skills and present as delayed reaching or instability with reaching, often seen as a tremor. Generally, as the child matures and the 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. It is important for families to understand the child with hypotonia may have little voluntary control of muscle tone; therefore erect posture and some activities may be more challenging.

- *Mild neuromotor dysfunction.* Mild neuromotor dysfunction is an impairment of motor coordination that is not secondary to mental retardation or other neurological disorder 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. The disorder must have had onset in early childhood and cannot be secondary to an underlying neurological condition. The neuromotor impairments of this condition may interfere with educational achievement or adaptive skills. Familial studies have conflicting results for a genetic predisposition to this disorder. Although risk factors have not been conclusively identified, it is speculated that children with developmental coordination disorder have high-risk birth histories, including prematurity. The longitudinal outcome for children with this condition tends to be concerning. The one longitudinal study (Losse 1991) that followed a group of children described as having developmental coordination disorder showed significant differences in physical performance, neuromotor performance, academic achievement, and emotional or behavioral problems. Children with this disorder require more study, and it is crucial that they continue to be monitored over time to provide motor, educational, and behavioral intervention as indicated.

### *Cerebral palsy*

Cerebral palsy refers to 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. There are many types of brain injury that can cause cerebral palsy. Any potential progressive neurological lesions must first be excluded before a diagnosis of cerebral palsy is made.

Although the cerebral lesion is static or fixed, the impact of the lesion on the child's motor development may change over time as the brain matures and as the child grows. Therefore, the functional impairments related to the cerebral palsy may 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, and many of the motor signs of cerebral palsy may appear to improve over time.

There are many types of cerebral palsy, and the severity, symptoms, and associated conditions vary widely depending on the nature and extent of the injury to the brain. 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. These classification systems are described in Appendix E.

### **HOW COMMON ARE MOTOR DISORDERS AND CEREBRAL PALSY?**

#### *Developmental motor disorders*

A prevalence for hypotonia leading to motor delay has not been identified in the general population. Cognitive disorder, which may have associated motor delay, is estimated to be three percent of the population. Poor coordination was studied in school-aged children at 7 years of age, and five percent of the children were felt to be poorly coordinated to such a degree that it interfered with academic or adaptive skills (Kadesjo 1999).

#### *Cerebral palsy*

The prevalence of cerebral palsy is estimated to be 1 to 3 per 1,000 children of early school age. It has been estimated that in the United States, the childhood prevalence of cerebral palsy has risen approximately 20 percent between 1960 and 1986. This trend is most likely due to the increasing survival rates of very premature infants with birth weights less than 1500 grams and the concurrent steady or climbing rates of cerebral palsy in this population (Bhushan 1993, Olney 2000, Mutch 1992, Escobar 1991).

## **WHAT DO WE KNOW ABOUT THE CAUSES OF MOTOR DISORDERS?**

The vast majority of children who have a motor disorder never reveal an etiology or cause, even after extensive investigations. In children without readily identifiable, known risk factors, it is crucial that metabolic or genetic disorders that can mimic motor disorder be excluded. There are some causes with predictable outcomes that are known, and these will be reviewed briefly.

### *Periventricular leukomalacia*

Brain tissue can be damaged when it does not receive enough blood. This is called ischemic brain injury. In the premature infant, the area surrounding the ventricles (the normal fluid-filled areas of the brain) is particularly vulnerable to ischemic injury. This injury is known as periventricular leukomalacia (PVL). PVL is usually visible only with detailed brain imaging (such as MRI). If the injury is so extensive that it is visible on head ultrasound, it is known as cystic or cavitory PVL. 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 affected, but with greater impairment of the legs than of the arms).

### *Periventricular hemorrhagic infarction*

When there is significant bleeding into the brain (periventricular hemorrhage or intraventricular hemorrhage), brain injury and necrosis (death of the brain tissue) can occur, usually in areas of the brain adjacent to the ventricle. This injury is most often seen in premature infants. It is usually unilateral (one side only). The injury and the resulting motor disorder can vary in severity. 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 (such as agenesis of the corpus callosum or holoprosencephaly) often lead to motor disorders. For this reason, brain imaging studies are frequently performed on children presenting with symptoms of motor disorders.

### *Hypoxic ischemia encephalopathy*

Hypoxia (lack of oxygen) of 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. When lack of

oxygen is severe (asphyxia), the result can be brain injury and multiorgan failure. If the child develops cerebral palsy, it is frequently mixed spastic athetoid type cerebral palsy (Appendix E), and often with associated cognitive impairment.

### *Bilirubin encephalopathy*

Bilirubin is something that is normally produced in our blood. Newborns generally have slightly increased levels of bilirubin for a few days after birth. When the level is abnormally high, the baby has a yellowish (jaundice) appearance referred to as kernicterus. Although severe kernicterus is rarely seen today in the United States, it used to be a frequent cause of choreoathetoid type cerebral palsy. High levels of bilirubin in an immature or sick newborn can cross into and be deposited in the basal ganglia in the brain. This area of the brain is located deep in the midbrain area and controls involuntary movements. In addition to the movement disorder, affected individuals may have hearing loss, vertical gaze palsy (inability to look up), and dental enamel dysplasia. Cognitive function (intelligence) is usually not affected.

### *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. The stroke itself can be caused by a variety of factors, such as congenital heart disease, clotting disorders, infections, metabolic conditions, and arteriovenous malformations. Sometimes the cause is unknown.

### *Other*

There are many other possible causes of motor disorders. For example, intrauterine infection, postnatal infection (meningitis, sepsis), traumatic brain injury, child neglect or abuse, spinal cord pathology (such as spina bifida), arthrogryposis, or congenital hip dislocation may all lead to varying degrees of motor impairment and possibly other developmental disorders. Table 2 (page 41) lists some additional risk factors for motor disorders.

## **WHAT IS THE IMPACT ON THE CHILD AND FAMILY OF HAVING A MOTOR DISORDER?**

Children who have a motor disorder can and do live happy and fulfilling lives. The way in which the motor disorder impacts the child and family will depend on many different factors, such as the severity of the condition and the resulting

motor limitations, whether or not there are other associated health and/or developmental problems, the strengths and needs of the family, and the availability of support for the child and family.

In general, infants and young children who have a motor disorder 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 that is received, thus further compromising the exploratory behaviors that are so essential to the development of young children. For some children, this may limit learning and cognitive development. In addition, a young child whose mobility is impaired may be more limited when playing with peers if unable to keep up. Additionally, children who have a motor disorder may not always have the same opportunities as other children to be fully included in play, school, or recreational activities because of accessibility issues or other societal limitations.

Some children may have motor disorders that limit their ability to demonstrate or communicate their knowledge, particularly through traditional testing methods, and thus, some children who have a motor disorder may 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 nonprogressive and static (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 (Nelson 1982). For example, 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 matures. Although the motor disorder may improve, many of these children continue to show delays or deficits in language and learning skills even though they may no longer have the diagnosis of cerebral palsy.

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, or may only be seen when testing upper body strength such as when batting a ball, "wheelbarrow" walking on the hands, or rope climbing. However, it is important to remember that delayed motor development is often associated with, and may be an indicator of, other problems such as language or learning/cognitive

## **CHAPTER II: BACKGROUND INFORMATION**

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disabilities. Therefore, ongoing developmental monitoring is important for all young children who have motor delays and disorders.

## CHAPTER III: ASSESSMENT

### *Topics included in this chapter*

- General Approach for the Identification and Assessment of Young Children Who Have a Motor Disorder
  - Identifying Young Children Who Have a Motor Disorder
  - Assessing Young Children Who Have a Motor Disorder
  - Oral-Motor Assessment for Feeding and Swallowing
  - Assessing Other Developmental Domains for Young Children Who Have a Motor Disorder
  - Assessing the General Health Status of Young Children Who Have a Motor Disorder
  - Considerations for Working With the Family
- 

### *Motor assessment methods*

In this guideline, a motor assessment method is defined as any assessment test, measure, or procedure that can be used to identify or assess a child with a motor disorder. Using this broad definition, assessment methods include both standardized and nonstandardized tests (often based on history, direct observations, and/or physical findings), as well as the use of sophisticated technology (such as imaging tests).

Motor assessment methods can be generally classified according to their intended purpose as follows:

- **Discriminative** methods are used to distinguish between children with and without a particular characteristic or function at a particular point in time.
- **Predictive** methods are used to predict motor delay or cerebral palsy at a later age or to classify types of cerebral palsy based on predicted future status.
- **Evaluative** methods are used to document the magnitude of change in function over time or after intervention. Evaluative assessment methods may serve as baseline measures for treatment planning or as outcome measures for intervention studies.

Some assessment methods are designed for a single purpose, while others might be used in more than one way. In some cases, a particular assessment method may be useful for some purposes and not others. For example, an assessment



method that is helpful for predicting a child’s future motor status may not be useful in measuring change in function over time.

#### *Evaluation of motor assessment methods*

The ability of an assessment method to do what it is intended to do (to discriminate, predict, or evaluate) is referred to as its efficacy. One way to evaluate the efficacy of an assessment method is to determine its sensitivity and specificity compared to an appropriate reference standard (see Appendix A, Table A-3, page 189).

The term “standardized assessment tests,” as used in this guideline, refers to standardized assessment instruments with set protocols for gathering, recording, scoring, and interpreting information about the child. Such standardized tests might make use of direct observations, exam findings, and/or historical information often provided by the parent(s). Many standardized tests have been studied scientifically in order to evaluate their validity, reliability, and other characteristics.

In this guideline, assessment methods are considered as either primarily for the purpose of identifying children with possible current or future motor disorders (discriminative and predictive methods), or primarily for children that have already been diagnosed with a motor disorder (methods used with an evaluative purpose to measure change over time).

### **GENERAL APPROACH FOR THE IDENTIFICATION AND ASSESSMENT OF YOUNG CHILDREN WHO HAVE A MOTOR DISORDER**

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

---

This section provides general recommendations related to identifying and assessing young children who have or are at risk for a motor delay or disorder.

Topics include:

- General Considerations for Identification and Assessment
- General Considerations for Professionals

*Basis for the recommendations in this section*

Recommendations about the general approach for the identification and assessment of young children who have a motor disorder are based primarily on panel consensus opinion. These recommendations address topics for which no scientific literature was found meeting the criteria for this guideline or for which the literature was not specifically reviewed as a focus of this guideline. Some of the recommendations are based on information from review articles that were considered by the panel in the absence of specific studies meeting the criteria for evidence.


**General Considerations for Identification and Assessment**

In assessing young children who have diagnosed or suspected motor disorders, there are some general principles that can be applied. Many of these general principles are not unique to children who have a motor disorder but may be applied within a larger general model for assessment and intervention for all young children.

**Recommendations (General Considerations for Identification and Assessment)**

*Importance of early identification and intervention*

1. 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 help to maximize the child’s general development and may promote better long-term functional outcomes. [D2]



**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.

*Identifying initial concerns about possible motor problems*

2. It is important for professionals and parents to recognize that there are several ways children with motor problems are first identified. These may include:
  - Identification of risk factors (such as prematurity or perinatal problems)
  - A parent’s or professional’s concern about the child’s motor skills or some other aspect of the child’s development
  - A health care provider’s or other professional’s concern about possible motor problems at the time of a periodic health exam, or when the child is being evaluated for some other health or developmental concern [D2]

*The assessment process*

3. It is important that assessment be viewed as an ongoing process that follows the child over time rather than as a single event. [D2]
4. It is recommended that assessment materials and strategies be developmentally appropriate. [D2]
5. It is recommended that the setting in which the assessment is performed be appropriate to the developmental stage of the child and be comfortable for both the parent(s) and the child. The following are important considerations:
  - The child’s schedule
  - Providing an enjoyable, engaging, and positive experience
  - A nondistracting, quiet environment
  - Having a parent or caregiver present
  - Accommodations for the family’s cultural values, including language [D2]
6. It is important for those assessing young children to understand the whole child and to consider any factors that may have an impact on the child’s performance during the assessment process, including the child’s overall health status, hearing status, and vision status. [D2]


**General Considerations for Professionals**

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. This section includes general consideration recommendations for the professionals who work with these children and their families.

**Recommendations (General Considerations for Professionals)**

*Importance of understanding about motor disorders*

7. It is important for health care professionals and early childhood professionals to understand typical motor development in young children in order to:
- Make appropriate observations about the child’s development
  - Facilitate recognition of potential motor problems
  - Facilitate the use of appropriate methods for ongoing monitoring (developmental surveillance)
  - Give accurate information to parents and families
  - Facilitate appropriate intervention strategies
  - Assist in making appropriate referrals [D2]



**Early Intervention Policy** ❖ Under the New York State Early Intervention Program (EIP), primary referral sources include a wide range of professionals who provide services to young children and their families (see Appendix D). 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.

*Collaboration, coordination, and integration*

8. It is important that assessment and evaluation plans and approaches be coordinated, integrated, and collaborative across all individuals working with the child and family. [D2]
9. When multiple individuals are involved in assessing or evaluating a child, it is important that all team members communicate with each other and share relevant information (as appropriate and legally consented) about the child’s progress. [D2]
10. It is important that the child’s primary health care provider be included in the communication process with other professionals involved in assessing and evaluating the child. [D2]

*Important professional characteristics*

11. It is important that professionals assessing young children be knowledgeable and experienced. Important characteristics include:
  - Having a solid understanding of typical newborn and early development
  - Having a solid understanding of atypical patterns of development
  - Understanding the importance of observation
  - Having well-developed active listening skills
  - Knowing the importance of gaining information in all developmental domains as well as medical and social history
  - Being able to recognize cues from the child
  - Understanding the importance of being sensitive to parents and knowing how to work within their comfort zone
  - Knowing the assessment tools so the focus is on the infant/child and his or her caregiver(s), not on the assessment tool [D2]

*Considering the cultural and family context*

12. A child's life is embedded within a cultural and family context. A family's way of living is influenced by many factors, including its ethnic and cultural roots. When working with children and families, it is essential to consider:
  - The family's culture
  - Parent priorities
  - Parenting styles
  - Family support systems [D2]
13. In evaluating children with developmental disorders, it is important to recognize that there may be cultural and familial differences in expectations about such things as play and social interaction, pragmatic use of language, and eye contact. Cultural values are also an important consideration as they relate to the development of adaptive or self-help skills and independence. [D2]
14. If English is not the family's primary language, it is important for professionals to look for ways to communicate effectively with the family and the child, including finding professionals and/or translators who speak the primary language of the child and the family. [D2]



**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.

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## **IDENTIFYING YOUNG CHILDREN WHO HAVE A MOTOR DISORDER**

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

---

This section provides recommendations specific to identifying young children who have or are at risk for a motor delay or disorder. Topics include:

- Early Identification of Motor Disorders in Newborns and Infants
- Identifying Delays in Motor Milestone Development
- Using Neuroimaging and Electrophysiologic Tests to Identify Children Who Have a Motor Disorder

### *Basis for the recommendations in this section*

The recommendations for identifying young children who have a motor disorder are derived primarily from the studies that met the criteria for evidence for this topic. This section also includes consensus recommendations for topics for which the literature was not specifically reviewed or for which no scientific evidence was found that met the criteria for this guideline.

### **Early Identification of Motor Disorders in Newborns and Infants**

The early identification of young children who have a motor disorder can occur in a variety of ways. In some cases, concern about the possibility of a motor disorder may be identified at birth if the child is premature or has other known risk factors for developmental problems. However, the majority of infants who have a motor disorder are full-term infants with uncomplicated neonatal periods (Nelson 1996). The concern about a possible motor problem may develop as the result of information from the parent(s) about certain behaviors or lack of progress in the child's development or as the result of direct observation of the child during routine health care visits.

### *Risk factors and clinical clues of a possible motor disorder*

There are a number of risk factors and clinical clues that heighten the concern for a possible motor disorder.

- A *risk factor* is something that increases the possibility that the child will have a motor disorder (Table 2, page 41)
- A *clinical clue* is an early sign or symptom of a possible motor disorder (Table 3, page 42)

The presence or absence of risk factors or clinical clues is not by itself enough to establish that a motor disorder does or does not exist. The recognition of a risk factor or clinical clue is just the first step in the process of identifying children who have a motor disorder, and the presence of these factors merely provides an indication that further assessment may be needed.

### *Newborn and infant physical exam findings*

Motor development is generally an orderly progression that is the result of successful integration of a number of interrelated developmental processes. While there may be some individual variability in the timetable of motor development, the sequence of typical development is generally consistent. The visible progress of motor development is generally easy to observe; therefore, initial identification of infants who have a motor disorder usually occurs through review of the child's developmental history and physical examinations by the child's health care provider. For that reason, much of what is described in this section is related to the history and physical exam findings and observations.

**Note:** Unless otherwise stated, ages are chronologic ages for children delivered at full term, sometimes referred to as number of months "post term." Ages should be adjusted accordingly for premature infants until the child reaches a chronologic age of 24 months.

### *Reflex development*

One of the ways in which the motor development of young children is routinely assessed is to evaluate for the presence and quality of reflex development. There are a number of "primitive reflexes" that are generally present at birth and later are no longer observable as they become integrated into more complex movement patterns as the child matures. In general, primitive reflexes that persist past the age of approximately 6 months are a clinical clue of possible motor and/or other developmental problems.

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

- ***Suckle Reflex:*** The suckle reflex consists of a front-to-back movement of the tongue that results in moving food (such as breast milk or formula) to the back of the mouth. Mature sucking (voluntary rather than reflex suckling) is characterized by a pistonlike, top-to-bottom movement of the tongue. The suckling reflex (and the companion rooting reflex) should be present in the newborn period and should gradually fade by the age of approximately 6 months as the child develops the tongue, lip, and jaw movements for mature sucking.

Problems with early suckling are often an indication of central nervous system abnormalities commonly associated with motor disorders and cerebral palsy. Problems with suckling are often identified by prolonged oral feedings (consistently more 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. Generalized stroking or pressure of the infant's palm will initiate the response. The palmar grasp seems to fade away between 4 to 6 months of age as the child matures and the reflex becomes integrated into normal movement patterns. Absence of the reflex in the newborn period, persistence of the palmar grasp reflex beyond the age of 6 months, or persistent holding of the hands in a fist position at any age are considered abnormal.

Examples of a few of the other commonly described early reflexes include:

- ***Moro Reflex:*** The Moro can be triggered by abrupt extension of the infant's head/neck position in the anterior-posterior plane (sudden movement of the head/neck forward or backward). The standard method for testing the Moro involves a quick momentary release of full support of the infant's head. The Moro response includes a quick outward opening of the arms with extension of the fingers as if surprised or startled. This is followed by a return of the arms towards midline in an "embrace" posture. Moro may also be triggered by a sudden noise or a sudden change of light. This reflex should be present in the newborn period. When the reflex is absent or asymmetrical (not equal



on both sides), it may be an indication of a birth fracture, infection in the bone or joint, a brachial plexus birth palsy, or a significant neurological abnormality. This reflex usually fades by 4 to 6 months of age, and its persistence after 6 months should be a concern.

- Positive Support Reflex:** Holding infants under the arms in an upright vertical position and gently bouncing them on their feet on a firm flat surface will elicit the positive support reflex (Figure 1). During partial weight bearing, the reflex consists of extension (straightening) at the knees and ankles followed by flexion (bending). A positive support reflex consisting of full extension of knees and ankles for greater than 30 seconds is abnormal at any age. This reflex persists to some degree until approximately 2 to 3 months of age and is replaced by voluntary upright standing, usually at approximately 6 to 8 months of age.
- Asymmetric Tonic Neck Reflex (ATNR):** Turning the child’s head to one side with the child lying on its back triggers the asymmetric tonic neck reflex. The reflex consists of extension of the arm and leg in the direction in which the head is turned and flexion (bending) of the arm and leg on the occipital (back) side of the head (Figure 2). This “fencer’s posture” can usually be seen intermittently during the first 4 to 6 months. When this posture lasts for longer than 30 seconds at any age, it is considered abnormal. This reflex, when strong and persistent for longer than 6 months, often results in asymmetric posture and lack of variability of arm and leg movements.

**Figure 1: Positive Support Reflex**



**Figure 2: Asymmetric Tonic Neck Reflex**



- **Tonic Labyrinthine Reflex (TLR):** The tonic labyrinthine reflex can be initiated by either an extension or a flexion of the head/neck. Extension of the neck (the head is lowered slightly below the level of the shoulders) with the infant on its back results in pulling the shoulders back and extending the legs out away from the body (Figure 3a). Flexion of the head/neck (bringing the head forward in front of the trunk) results in pulling forward of the shoulders and flexion at the hips and knees (Figure 3b). In extension, this reflex can contribute to the appearance of arched back (opisthotonic) posturing often seen in infants with severe cerebral palsy.

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**Figure 3a: Extension TLR**



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**Figure 3b: Flexion TLR**



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*Muscle tone in the newborn period*

Evaluation of muscle tone is another way in which motor development of young children is routinely assessed. (See Chapter II for a general description of muscle tone). In the newborn period, passive flexor muscle tone of the arms and legs at the elbows, hips, and knees should be symmetric (the same on both sides) and equal. This can be assessed through observation of the infant’s spontaneous generalized movements and resting extremity posture (equal flexion of arms and legs).

Measuring popliteal angles (the amount of bend at the knee joints) can also be used as an indicator of muscle tone. The popliteal angle is measured with the infant lying on its back by flexing the thigh toward the abdomen until it is vertical. The angle between the back of the thigh and lower leg is estimated, but the accuracy is sensitive to how much force is used by the examiner. In the newborn, the popliteal angle is usually a right angle.

The term *postural tone* is also used to describe muscle tone in young children. Postural tone describes the development of head and trunk control as the infant learns to move against gravity. To achieve adequate postural tone, the muscles need to have enough tone to resist the force of gravity but must not have too much tone to prevent controlled movement.
















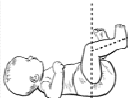
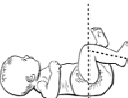
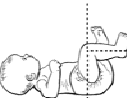
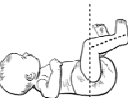

*Development of muscle tone in the first year*

As the child's motor and other systems mature during the first 3 to 4 months post term, there should be a gradual reduction of passive flexor muscle tone of the arms so that the elbows become less flexed when the child is in a resting posture. This reduction of upper extremity flexor tone results in a position with the arms less flexed than the legs are when the child is at rest.

By 6 months of age, there should be a noticeable reduction of passive flexor tone of the leg muscles so that the hips and knees generally become less flexed when the child is at rest. By 6 months of age, there should also be a relaxation of hamstring tone (and increased abdominal strength) resulting in decreased popliteal angles. The reduction in hamstring tone makes possible the "foot-to-mouth" position typically seen in infants beginning at approximately 6 months of age. This gradual reduction of passive flexor tone continues in a head-to-toes (cephalic to caudal) fashion, and by 9 to 12 months of age, passive flexor tone of the extremities is similar to older children and adults. Resistance to passive flexion of the extremities is generally not observed with the neck in neutral position at any age.

Development of increased active tone of the head and trunk also progresses during the first year in a head-to-toes fashion. A balance of flexor and extensor tone in all planes of movement results in head and trunk control, which is followed by sitting balance and finally by standing and walking.

**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 (Prechtl 1997). Observation of the quality of general movements is an important aspect of any physical examination of infants. General movements that lack complexity and variability may be a clinical clue of a possible motor problem. Abnormal movements may be either slow and monotonous or brisk and chaotic. Abnormal general movements usually have a marked reduction in subtle fluctuation of amplitude, force, and speed. A lack of general movements should also be a cause of concern. Children with cerebral palsy usually have abnormalities of general movements.

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**Table 2: Risk Factors for Motor Disorders**

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**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)

**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
- 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
- Intraventricular 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

*Adapted from: Geralis 1991*

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**Table 3: Clinical Clues of a Possible Motor Disorder**

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

**Nonsequential Motor Development**

- Early rolling (infants with extensor posturing of trunk and extremities will often flip over or log roll within the first 2 months of life)
- 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”
- Paucity (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

**Table 3: Clinical Clues of a Possible Motor Disorder**

- “Scissors” legs while standing
- Sits with legs in “w” position (reversed tailor position)

**Observations of Movement and Posture**

- Rolling is accomplished by rotation of arms and legs as a unit (log rolling) after the age of 6 months
- Hyperextension of head and neck in prone position 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 (in a quiet, alert state), comes to a stand instead of a sitting position
- One or more of the following occurs in the sitting position:
  - The pelvis is tilted back (posteriorly) and the child sits on the 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 abducted, 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:
  - Hips are flexed and adducted, knees are flexed, and feet are pronated (crouched gait)
  - Intermittent tiptoe gait and overextension of the knees

*(Continued from previous page)*

### Recommendations (Early Identification of Motor Disorders)

#### *General approach for identifying young children who have a motor disorder*

1. It is important for professionals and parents to recognize that there are several ways children with motor problems are first identified. These may include:
  - Identification of risk factors or clinical clues (Table 2 and Table 3, pages 41 and 42)
  - A parent's or professional's concern about the child's motor skills or some other aspect of the child's development
  - A health care provider's or other professional's concern about possible health or developmental problems either at the time of a periodic health exam or when the child is being evaluated for some other concern

*[A] (Ellenberg 1981, Johnson 1989)*
2. It is recommended that monitoring a child's motor development (developmental surveillance for possible motor problems) be done routinely at specific age points such as during routine health care visits. [D2]
3. It is important for health care providers to recognize that parental concern can be a good indicator of a motor problem. When a parent expresses concern, it is important for the health care provider to follow up the concern with appropriate screening and developmental surveillance.

*[B] (Johnson 1989)*
4. It is important to use multiple measures in identifying children with possible motor disorders, including observation of motor quality and spontaneous movement, motor milestones, and physical exam findings.

*[A] (Cioni 1997, Cioni 1997A, Ellenberg 1981)*

#### *Using risk factors and clinical clues*

5. It is recommended that all newborns be checked for risk factors and clinical clues for possible motor problems (Table 2 and Table 3). [D2]
6. When evaluating newborns for risk factors and clinical clues associated with motor problems, it is important to recognize that:
  - A combination of risk factors and abnormal neonatal exam findings are better predictors for future motor disorders than either one alone



- An isolated abnormal finding on newborn exam by itself is not a good predictor of an adverse neurological outcome and is not useful in making the diagnosis of a motor disorder
- The greater number of neuromotor abnormalities in the newborn period, the greater likelihood of neurological abnormalities at one year
- Problems that persist in the first three months of life are more likely to be predictive of later neurological problems

[A] (Allen 1989, Biermann-VanEendenburg 1981, Dubowitz 1984, Nelson 1982)

7. It is important to recognize that “clinical clues” can be useful in identifying infants and young children who need further observation and assessment for a possible motor disorder. Clinical clues of a possible motor problem include:

- Abnormalities of muscles tone
- Atypical sequence of motor skill development
- Atypical movement patterns
- Qualitative differences in motor development
- Abnormalities in the quality of movement and posture
- Presence of pathological developmental reflexes

[A] (Allen 1989, Capute 1985, Cioni 1997, Cioni 1997A, Ellenberg 1981, Johnson 1990, Lacey 1998, Stewart 1988, Swanson 1992, Wood 2000)

#### *Observation and analysis of motor patterns*

8. It is important to recognize that 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] (Cioni 1997, Cioni 1997A)

9. A videotape approach in combination with direct observation may be useful for monitoring qualitative movement patterns and may be especially beneficial as part of the developmental surveillance and assessment approach for fragile infants. Videotaping in combination with direct observation and interaction with the child may be beneficial because:

- It can provide a record of spontaneous movement patterns for analysis using naturalistic observation
- The video recording can be done in a variety of settings and situations

- It may help the parent(s) learn how to observe and report on the child’s motor development
- It can provide an objective record for monitoring a child’s progress
- It may be useful in helping parents capture and provide information to professionals about suspect/atypical motor behaviors

[A] (Cioni 1997, Cioni 1997A)

### *Preterm infants with risk factors for motor problems*



**Early Intervention Policy** ❖ Infants less than one year of age who were 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.

10. It is important to recognize that preterm infants with risk factors for a possible motor disorder who have normal findings on a newborn neurodevelopmental exam generally have good outcomes. However, continued developmental monitoring is indicated.

[A] (Dubowitz 1984, Molteno 1995, Nelson 1982)

11. When assessing preterm infants, it is important to recognize that:

- Evaluation of general movements during the first 4 to 5 months of life may be more predictive of a future motor problem than a traditional neurological exam done at 1 month
- Normal findings in muscle tone when measured at term may be misleading when related to later motor development. Preterm infants who initially present with hypotonia may experience a shift from hypotonicity to hypertonicity and may look relatively normal at term during this transition

[A] (Cioni 1997, Nelson 1982, Stewart 1988)

12. For preterm infants, it is important to recognize that:

- Preterm infants who have an abnormal neurological or an abnormal cranial ultrasound exam are the most likely to develop neurodevelopmental disorders (e.g., motor, sensory, and cognitive)

- Early motor abnormalities in the newborn period are associated with a high occurrence of general cognitive delays later in childhood

[A] (Dubowitz 1984, Majnemer 1994)

13. For more mature preterm infants, it may be useful to use a standardized neuromotor exam (such as that described by Dubowitz) in the newborn period to help identify infants at greater risk for neuromotor abnormalities.

[A] (Dubowitz 1984, Molteno 1995)


*Ongoing surveillance for infants with risk factors for motor disorders*

14. If heightened concerns of possible motor problems are identified, it is recommended that periodic neurodevelopmental monitoring be done at 1- to-3-month intervals during the first year to detect emerging manifestations of motor dysfunction.

[A] (Ellenberg 1981, Majnemer 1995, Zafeiriou 1995, Zafeiriou 1998)

15. For infants who are at higher risk (have suspect findings, clinical clues, or specific multiple risk factors) for motor disorders, it is important to follow up with enhanced (more frequent) developmental surveillance, screening tests, or further assessment.

[A] (Cioni 1997, Cioni 1997A, Harris 1989, Swanson 1992, Zafeiriou 1995, Zafeiriou 1998)



**Early Intervention Policy** ❖ Under the 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 EIO in the child's county of residence unless the parent objects. Professional judgment and parent concern must be weighed when determining if a child should be referred to the EIO as an at-risk child.

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

- Delays are more noticeable as the newborn matures during the first year

- As more complex skills begin to develop (from 1 to 3 years of age), 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 (cognitive, language, etc.)

[A] (Dubowitz 1984, Majnemer 1994, Majnemer 1995, Molteno 1995)

### *Newborn screening tests*

17. It may be useful to use a standardized screening test for newborns with risk factors for motor problems to help determine the need for ongoing monitoring and further assessment:

- 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 in identifying children who are likely to have neuromotor abnormalities at one year of age
- The Einstein Neonatal Neurobehavioral Assessment Scale (ENNAS) shows good sensitivity in identifying children who are at risk for various developmental deficits including cognition (such as preschool learning problems) and fine motor problems
- The ENNAS is not a good tool for identifying specific problems, but it may be useful for identifying the need for further follow-up in the immediate postnatal period

[A] (Dubowitz 1984, Majnemer 1994, Majnemer 1995, Molteno 1995)

### **Identifying Delays in Motor Milestone 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 attempt to stand.) Motor milestones are motor events that follow a somewhat predictable sequence by which one can gauge a child's general developmental progress (Table 4, page 49).

**Table 4: Developmental Motor Milestones**

(repeated from Table 1, page 15)

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

*Adapted from: Geralis 1991*

Delays in the age of attainment of motor milestones are often the parent’s or the health care provider’s first concern in children with motor or other developmental disorders. Many health care providers use parent recall of motor

milestone attainment as one of the components of routine screening of infants for possible developmental problems.

### **Recommendations (Identifying Delays in Motor Milestones)**

#### *General approach for using developmental motor milestones*

1. It is recommended that developmental milestones be evaluated on all routine health care visits for children from birth (see Table 4, page 49).  
*[A] (Allen 1992, Allen 1994, Allen 1997, Ellenberg 1981)*
2. A child's periodic health care exams (such as routine well-baby checks at 3, 6, 9, and 12 months) may be particularly useful in providing information about possible developmental motor problems because these problems can often be identified in the first year of life. [D2]  
*[A] (Cioni 1997, Cioni 1997A, Zafeiriou 1995, Zafeiriou 1998))*

#### *Evaluating developmental milestones in premature infants*

3. When using motor milestones as one of the components of monitoring motor development in extremely premature infants, it is important to recognize that:
  - A missed motor milestone is an important indicator of the need for enhanced developmental surveillance
  - No single motor milestone is a reliable predictor for identifying young children who are most likely to have cerebral palsy
  - A 50% delay in three motor milestones at the 12-month evaluation may be a good indicator of cerebral palsy at 18 to 24 months. If a delay criteria of 37.5% is used, children may be identified earlier
  - For premature infants, use of corrected age for interpretation of attainment of milestones has a fair to good correlation with cerebral palsy  
*[A] (Allen 1992, Allen 1994, Allen 1997)*
4. It is recommended that information about attainment of the following five motor milestones be obtained as part of the regular follow-up during the first year of life for extremely premature infants to help identify the need for a more in-depth evaluation for motor problems:
  - Rolling stomach to back (prone to supine)
  - Rolling back to stomach (supine to prone)
  - Sitting with and without arm support

- Crawling/creeping
- Cruising

[A] (Allen 1992, Allen 1994, Allen 1997)

5. For high-risk preterm infants, a motor delay any time during the first two years increases the risk for a motor disorder. It is recommended that for high-risk preterm infants, the presence of a motor delay at any point indicates the need for:
  - Continuing developmental surveillance and possibly an enhanced schedule of neuromotor assessments to detect progressive conditions or emerging developmental problems
  - A detailed history of motor development to determine the persistence of the motor delay and the need for an in-depth evaluation for cerebral palsy or other motor disorder

[A] (Allen 1992, Allen 1994, Allen 1997, Cioni 1997, Cioni 1997A, Dubowitz 1984, Harris 1989, Swanson 1992, Zafeiriou 1995, Zafeiriou 1998)

#### *Children with delayed motor milestones*

6. For children not previously identified with a developmental delay or motor problem, late walking may be an important indicator of possible motor delay or other associated disabilities.

[A] (Johnson 1990, Wood 2000)

7. For all children who do not walk by 18 months, it is recommended that:
  - A focused screening be done to attempt to identify motor delays or disorders and assess the need for ongoing surveillance or further assessment
  - Parents be informed that continued observation is important even if the initial screening is not conclusive for a motor problem

[A] (Allen 1992, Allen 1994, Allen 1997, Capute 1985, Johnson 1989, Wood 2000)

#### *Loss of motor milestones*

8. 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. [D2]
9. It is important to recognize that many progressive or degenerative neurological diseases often present with loss of previous motor milestones. Information about the child's development of motor skills is essential in

determining whether an existing motor delay is progressive or static in nature and can be important in arriving at a diagnosis. [D2]

### Using Neuroimaging and Electrophysiologic Tests to Identify Children Who Have a Motor Disorder

#### *Neuroimaging*

Many motor disorders of childhood occur because of either brain injury or malformation of some part of the brain, which can often be visualized with neuroimaging techniques. In the last twenty years, there have been significant advances in neuroimaging. Even relatively small (or what were previously considered inconsequential) lesions can now be correlated with clinical conditions.

There are several ways to image the central nervous system:

- **Conventional x-ray of the skull** visualizes severely small or large heads (microcrania or macrocrania), which can often be clinically detected as well. Calcifications inside the head (intracranial) can be seen but are better visualized on computerized axial tomography (CT) scan. X-rays are generally more useful in the orthopedic management of other body parts (such as hips and lower extremities) of children with cerebral palsy and other motor impairments.
- **Ultrasound** can often (but not always) accurately diagnose certain entities that are often associated with motor disorders, such as hydrocephalus or cystic periventricular leukomalacia. An acoustic window is needed for ultrasound. A fontanel is perfect, but it often closes after a few months of age. Therefore, ultrasound is most useful in the newborn period. It is inexpensive and portable (it can be brought to the bedside), and it gives an instant assessment.
- **Computerized Axial Tomography (CT or CAT)** scanning is done by a narrow, rotating x-ray beam that hits crystal detectors located in a circle around the perimeter of the CT scanner. It lets one see parenchyma, spinal fluid filled cavities, and bone particularly well. However, changes in the posterior fossa (back part of the brain) or changes in consistencies of areas of the brain (such as leukomalacia or softening of the white matter) are often not seen. The technology is so proficient that an entire brain CT scan can be done in a few minutes. The patient needs to lie still for the procedure, but sedation is rarely needed. It is expensive, but far less expensive than Magnetic Resonance Imaging (MRI).



- **Magnetic Resonance Imaging (MRI)** is the most sophisticated method available to visualize the central nervous system. MRI involves a large magnet with a large magnetic field to create the reconstructed images that are seen on the screen. All areas of the brain and all lesions (vascular, spinal fluid, oncologic, etc.) are visualized well. The patient is required to stay still for a prolonged period of time. Therefore, sedation is often required for the young or developmentally delayed child. The expense is considerable but is usually covered by insurance when there are clinical indications for its use.


#### *Electrophysiologic tests*

- **Electroencephalogram (EEG)** records brain electrical activity via the application of electrodes to the scalp to produce a graph of brain rhythms over time. The amplified brain rhythms are strong enough to move an ink-writing pen on the EEG graph paper, which produces a graphic recording of the brain activity. Patients are usually examined in a comfortable chair or bed. The procedure is painless and takes from 1/2 hour to 1 1/2 hours. An EEG is a useful tool for assessing individuals with seizure disorder.
- **Electromyogram (EMG)** and nerve conduction times are used to help diagnose muscle versus nerve disease and to gauge the prognosis of a particular neuromuscular entity. The procedure involves electrodiagnosis of motor function as measured by the relay of electrical activity from the spinal cord to the neuromuscular junction of the muscle via the insertion of needles and the placement of electrodes to record the electrical activity.
- **Evoked potentials** are used to stimulate sensory organs or peripheral nerves to evoke a response in the appropriate receptor area in the brain. Examples of evoked potentials are visual, auditory, and somatosensory. Responses are graphed using computerized averaging methods.

#### *Basis for the recommendations in this section*

While there is an extensive scientific literature specific to neuroimaging and electrophysiologic tests to identify motor disorders, this literature was not directly reviewed by the panel. In the panel's opinion, the effectiveness of using neuroimaging and electrophysiologic testing for infants suspected of having either brain injury or malformation has been adequately documented in scientific studies. Some of the recommendations are based on information from review articles that were considered by the panel in lieu of evaluating specific studies.

**Recommendations (Using 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*

1. In infants suspected of having either brain injury or malformation, it is useful to visualize the lesions using neuroimaging techniques. [D2]
2. It is recommended that all high-risk preterm infants have ultrasound. Ultrasound may help with the early identification and diagnosis of certain findings that are often associated with motor disorders (such as hydrocephalus or cystic periventricular leukomalacia). While not all problems may be identified initially with ultrasound, it is recommended for screening high-risk preterm infants because:
  - It has acceptable sensitivity and specificity to predict cerebral palsy
  - It is easy to administer, portable, and can be brought to the bedside
  - It gives an instant assessment
  - It is inexpensive [D2]
3. It is important to remember that:
  - Ultrasound in the newborn period is a good screening tool but does not always identify children who may later be diagnosed with cerebral palsy or other motor disorders
  - While there is a correlation between neuroimaging findings and outcomes, the neuroimaging findings are not a perfect predictor of the prognosis for a specific child
  - Neuroimaging findings, while not a perfect predictor, can provide information that may help to provide anticipatory guidance and treatment planning
  - Neuroimaging findings do not establish the diagnosis of cerebral palsy (the diagnosis is based on clinical findings) but may be useful for determining the etiology (cause) of cerebral palsy [D2]

4. When choosing a neuroimaging modality, it is important to consider:
  - Side effects
  - Availability
  - Capability of imaging the suspected area
  - Length and difficulty of the procedure
  - Need for sedation or anesthesia
  - Timing of the procedure
  - Expense [D2]
5. 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 if the etiology has not already been established. [D2]
6. Skull x-ray is not recommended to assess structural or anatomical findings related to the brain and central nervous system. [D2]
7. SPECT (single photon emission tomography) scans have not been shown to be clinically useful in assessing children with motor impairments. [D2]

#### *Electrophysiologic studies*

8. It is important to recognize that electrophysiologic studies are not useful in the identification and management of young children with cerebral palsy. [D2]
9. While EEG, EMG, and evoked potentials are not useful in the diagnosis and management of cerebral palsy, they may be useful for other specific purposes. For example:
  - EEG can be useful in the identification and management of seizures in children who have a motor disorder
  - Electrodiagnosis (EMG and nerve conduction studies) may be useful in the identification and management of disorders of the muscles (e.g., myopathies) or the peripheral nervous system
  - Evoked potentials (somatosensory, auditory, and visual) may be useful in the identification and management of sensory deficits in children with motor impairments:
    - Auditory brainstem response (ABR or BAER) – to test hearing
    - Electro Retinogram (ERG) – to test retinal function
    - Visual Evoked Response (VER) – to detect cortical blindness [D2]

### ASSESSING YOUNG CHILDREN WHO HAVE A MOTOR DISORDER

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section provides recommendations specific to assessing young children who have an identified motor disorder. Topics include:

- Assessing Functioning in Young Children Who Have a Motor Disorder
- Identifying and Classifying Cerebral Palsy

*Basis for the recommendations in this section*

The evidence-based recommendations in this section are derived from the studies that met the criteria for evidence for this topic. This section also includes consensus recommendations for topics for which the literature was not specifically reviewed or for which no scientific evidence was found that met the criteria for this guideline.

#### Assessing Functioning in Young Children Who Have a Motor Disorder

There are two general types of functional assessments for children who have a motor disorder.

- Assessment of motor development: This includes both quantitative and qualitative motor function and motor performance.
  - Motor **function** refers to a *quantitative* measure of a child’s gross and fine motor abilities (for example, a numerical measure of the child’s level of activities with regard to rolling, sitting, crawling, or walking).
  - Motor **performance** refers to a *qualitative* description of a child’s motor activity (for example, how well the child performs the motor tasks such as posture of the body when sitting or coordination when walking).
- Assessment of general adaptive or independent functioning: This measures the child’s ability to function in everyday activities such as self-care, mobility, social interaction, and communication.

In many instances, these concepts overlap. For example, a measure of a child’s ability to walk is an assessment of both gross motor skills and of mobility. Functional assessments are further categorized by the purpose they serve.

- **Predictive** methods are used to predict motor delay or cerebral palsy at a later age or to classify types of cerebral palsy based on predicted future status.
- **Discriminative tests** provide information as to whether a child has a delay in a particular area of function. These tests provide an age-equivalent or standard of performance that indicates the degree of delay.
- **Evaluative tests** are used to measure change over time. These measures are an essential component of measuring the effectiveness of ongoing intervention.

#### *Assessment of motor development*

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 (also see Appendix C). For the most part, these are considered observational scales, but most also include interaction with the child to elicit a response using a standardized approach.

*Alberta Infant Motor Scale (AIMS)* The AIMS is used to identify infants with motor delay from birth to 18 months (a discriminative purpose). It measures motor development from both a quantitative and a qualitative perspective.

*The Bayley Scales of Infant Development II:* The BSID-II (Note: BSID-III Published 2005) is a standardized assessment of infant development that is intended to measure a child's level of cognitive, motor, and behavioral development. The test contains items designed to identify young children from 1 to 42 months who are at risk for developmental delay.

*Gross Motor Function Measure (GMFM):* The GMFM is designed to measure changes in gross motor function over time (an evaluative purpose) for children of all ages with cerebral palsy. The test measures only quantitative aspects of motor function. A companion test designed to measure qualitative changes, the *Gross Motor Performance Measure (GMPM)*, is currently being developed.

*Peabody Developmental Motor Scales (PDMS):* The PDMS is designed for use with infants and children from birth to 84 months. It is a quantitative measure that is designed to identify children with a motor delay (a discriminative purpose) as well as evaluate change over time (an evaluative purpose). A revised version, the *PDMS-2*, is now available.

*Toddler and Infant Motor Evaluation (TIME):* The TIME is an observational and interview scale for use with children with suspected motor delay that are 4

to 40 months old. It measures both quantitative and qualitative aspects of motor function and includes two subtests that provide information regarding functional outcomes. It is designed to evaluate change over time (an evaluative purpose).

### *Assessment of general adaptive and independent 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 an interview with the primary caregiver. Assessment instruments that are commonly used include:

*Pediatric Evaluation of Disability Inventory (PEDI)*: The PEDI is designed to assess children with disabilities from 6 months to 7 1/2 years of age. It is a checklist, which is completed by a qualified professional or by interviewing the primary caregiver. It was designed to identify deficits in functional performance (a discriminative purpose) as well as to measure change over time (an evaluative purpose).

*Functional Independence Measure for Children (WeeFIM)*: The WeeFIM is designed to assess children from 6 months to 12 years of age. It is a checklist that is completed by a parent, teacher, or health professional following observation of task items. It was designed to identify deficits (a discriminative purpose) as well as to evaluate change (an evaluative purpose).

*Vineland Adaptive Behavior Scales (VABS)*: The VABS is designed to be used with children from birth to 18 years. It is designed to describe degrees of functional limitations (a discriminative purpose). Scores are obtained through a semistructured interview.

## **Recommendations (Assessing Functioning in Young Children)**

### *General approach*

1. It is recommended that the assessment of children who have a motor disorder focus on the use of functional tests and measures to help ensure that the emphasis of the treatment programs will be meaningful to both the child and the family. These tests can be useful in determining treatment goals and treatment planning. [D1]



**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 D) and be conducted in the child's dominant language whenever feasible.

2. It is important to remember that assessment tests have specific purposes:
  - A discriminative test is used for the purpose of identifying a delay
  - An evaluative test is used to measure change over time [D2]
3. When deciding whether to use a particular assessment test, it is important to have information about the test's purpose, the population for which it was designed, and the test's reliability and validity. [D2]
4. It is important to use multiple sources of information, including direct observation of the child, standardized tests, and parent report, when assessing children suspected of having motor problems. [D1]
5. It is recommended that a comprehensive assessment of functional abilities include assessment of both motor function and general functioning (functional outcomes). Assessing general functioning (functional outcomes) is important when assessing a child's progress and the effectiveness of any intervention. [D2]

*Tests and techniques to identify motor problems*

6. Information from tests such as the Bayley Scales of Infant Development II (BSID-II) and the Movement Assessment of Infants (MAI) may be useful when considered along with information from other developmental/motor assessments. When considering use of these tests, it is important to remember that:
  - The BSID-II and the MAI are not meant to be diagnostic but can be helpful in identifying children who require additional follow-up
  - The ability of tests such as the MAI and the BSID-II to identify cerebral palsy is increased as the severity of motor limitation increases
  - The Psychomotor Development Index (PDI) on the BSID-II is more sensitive as children get older

- As with any test, use of different scoring criteria and use of corrected versus chronologic age will result in different sensitivities and specificities

[A] (Harris 1984, Harris 1987, Harris 1987A, Harris 1989, Morgan 1996, Nickel 1989, Piper 1992, Swanson 1992)

7. When considering use of the MAI, it is important to recognize that:

- The MAI is designed to be used at specific ages for young children whose motor development is below the 12-months-of-age level
- The MAI has better ability to identify children with quadriplegia than hemiplegia or diplegia
- The MAI has strong sensitivity at 4 months and still stronger at 8 months for identifying children with motor problems, mental retardation, or severe developmental delay
- The MAI, in comparison to the Bayley Motor Scales, is less specific (probably due to its reliance on evaluation of transient neurologic signs) but more sensitive in identifying cerebral palsy

[A] (Harris 1984, Harris 1987, Harris 1987A, Harris 1989, Piper 1992, Swanson 1992)

8. When done by professionals appropriately trained in performing and interpreting the examination, measuring the popliteal angle can be a fast and easy screening technique that may be useful for identifying infants and young children at risk for cerebral palsy and other motor development problems. It is important to remember that:

- Measurement of the popliteal angle alone has low sensitivity for detecting cerebral palsy but may be valuable in combination with other indicators (such as parental concerns or other clinical clues)
- Estimated measurement of the popliteal angle has high specificity but relatively low sensitivity

[B] (Johnson 1989)

### *Tests to assess motor development*

9. For infants and children who have a motor disorder, it is recommended that an assessment of motor function use both quantitative and qualitative measures of functional motor skills performance. [D2]
10. The PDMS is useful for measuring the amount of delay as well as quantitative changes in a child's motor function over time. [D1]



11. The AIMS can be useful for identifying a motor delay in infants, and it measures both quantitative and qualitative aspects of motor function and functional performance. [D1]
12. The GMFM is useful for measuring quantitative changes in a child's motor function over time. [D1]
13. The TIME can be a useful overall assessment because it measures both quantitative and qualitative aspects of motor function and functional performance, and it may be used as a measure of change. [D1]

*Tests for assessment of general functioning*

14. It is important to recognize that there is no one test or measure of general functioning that is valid and useful in all settings, and different measures that complement each other may be used to obtain a more complete picture of the child's strengths and needs. [D1]
15. In choosing a functional assessment measure for clinical application for children with cerebral palsy, it is important to consider the setting and the child's age:
  - The VABS can be useful for children in educational settings and with concurrent cognitive disability
  - The PEDI can be useful for children in acute rehabilitation settings as well as in outpatient and home-based settings
  - The WeeFIM can be useful in inpatient, outpatient, developmental, and community settings, as well as for preschool children [D1]

*Using play-based assessments*

16. Because young children spend most of their time playing and because play is integral to learning and development, play-based assessments (such as the Transdisciplinary Play Based Assessment) can be useful for assessing motor development. It is important to recognize that:
  - Motor functioning is necessary to enable a child to move and manipulate toys
  - Play is important to the acquisition of cognitive, social, and emotional aspects of development
  - Play-based activities can be an important component of the intervention strategy for gross and fine motor skill development [D1]

### *Assessing sensory processing*

17. Assessing sensory processing and reactivity (over-responsivity, under-responsivity, or fluctuating responsiveness) in preterm infants and in children with indications of motor disorders may provide useful information about the nature, degree, and intensity of the child's responses to various sensory inputs. This information may be useful in identifying developmental problems, planning care for the child, and in making intervention decisions. [D2]
18. Sensory processing in infants and young children is most often assessed by clinical observation of or parent interview about the child's response to sensory stimuli in the environment and during daily care activities. Clinical impressions can be supported by use of a standardized measure of sensory processing and reactivity, such as the Test of Sensory Functioning in Infants (TSFI). [D2]
19. It is recommended that tests such as the TSFI be used in conjunction with a more comprehensive developmental assessment. [D2]

### *Assessing coping*

20. It may be useful to use an assessment instrument designed to evaluate coping when assessing young children who have a motor disorder (for example, the Early Coping Inventory). [D2]
21. It is important to recognize that coping mechanisms vary from child to child and 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 impact the child's ability to interact and learn, to develop feelings of mastery and success, and to function in the environment. [D2]

### *Understanding the prognosis*

22. It is important for the parent(s) and professionals to recognize the following:
  - Not all children with motor delays or cerebral palsy can be identified based on exam findings in the first year of life
  - For children who have significant motor delays or cerebral palsy at 1 year of age, functional limitations can change over time, but the degree of motor impairment at 1 year usually correlates with later motor outcomes
  - Children who have significant motor delays or cerebral palsy at 1 year of age 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 of age may still have a high prevalence of other developmental disabilities

[A] (Allen 1989, Dubowitz 1984, Nelson 1982, Wood 2000, Zafeiriou 1995, Zafeiriou 1998)

### **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, nonprogressive 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 and static (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).

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

### *Basis for the recommendations in this section*

The recommendations on identifying and classifying cerebral palsy are based primarily on panel consensus opinion. Review articles and other sources of information were used to help develop this section, but the scientific literature related to these recommendations was not specifically reviewed as a focus of this guideline. In the panel's opinion, these recommendations reflect appropriate practices for identifying and classifying cerebral palsy and are generally consistent with the scientific knowledge in this field.

### **Recommendations (Identifying and Classifying Cerebral Palsy)**

#### *Establishing a diagnosis*

1. For a child with evidence of a motor disorder that is suspected to be cerebral palsy, it is important to establish a diagnosis if possible because:
  - A diagnosis offers information about prognosis and clinical course that can assist in provision of anticipatory guidance and proactive interventions that may improve developmental outcomes
  - A diagnosis can assist the parents in caring for their children, focusing their search for appropriate resources and help, providing educational information, and in future planning that will best meet the needs of their child/family
  - For genetic diseases, it is important to provide genetic counseling
  - For certain conditions, establishing a diagnosis can help focus the search for associated problems/conditions
  - A diagnosis can facilitate understanding of the problem and communication between members of the therapeutic team, as well as between the parent(s) and professionals [D2]
2. It is important to establish an **accurate diagnosis** when identifying and classifying cerebral palsy. For some children, this may require delaying the final diagnosis in order to monitor the child's development and to do additional testing as the child develops. It is not always possible to confirm the diagnosis in very young children. [D2]
3. It is very important that any potential progressive neurological lesions first be excluded before a diagnosis of cerebral palsy is made. [D2]

#### *Assessment tests and techniques to identify cerebral palsy*

4. It is important to recognize that assessment tests and techniques used 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 most effective tests for identifying cerebral palsy in children under 6 months tend to focus on:

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

[A] (Harris 1984, Harris 1987, Harris 1987A, Harris 1989)

#### *Classifying the type of cerebral palsy*

5. It is important that professionals with adequate knowledge of the natural history of motor development and health of children with cerebral palsy be involved in determining the type of cerebral palsy (e.g., spastic, extrapyramidal, mixed) and severity of functional motor limitation (mild to profound cerebral palsy). [D2]
6. It is recommended that professionals, including physical and occupational therapists and physicians, collaborate in determining the type of cerebral palsy. [D2]
7. It is important that the classification of cerebral palsy be attempted only after physical findings, including passive muscle tone and deep tendon reflexes, have stabilized and the rate of motor skill acquisition has been accurately estimated. Classification of cerebral palsy, including description of muscle tone, deep tendon reflexes, and functional motor limitations, can usually be completed between 1 to 2 years of age with reassessment at least yearly thereafter. [D2]
8. When describing and classifying a child's type of cerebral palsy, it is important that:
  - Standardized methods be used to describe passive muscle tone of the four extremities and trunk
  - Spastic tone be differentiated from rigidity
  - A standardized grading system for deep tendon reflexes be utilized
  - Standardized, reliable, and valid measures of functional motor skills be used to estimate the degree of functional motor limitation

- Standardized estimates of both gross and fine motor skills, including developmental quotients, be used for topographic classification [D2]
9. It is important that the methods used to classify cerebral palsy and the related implications for the child are clearly and accurately explained to the parent(s) and other professionals working with the child and family. [D2]

### ORAL-MOTOR ASSESSMENT FOR FEEDING AND SWALLOWING

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section provides recommendations specific to the oral-motor assessment of young children who have a motor disorder.

#### *The importance of assessing oral-motor function*

Children who have a motor disorder frequently have problems with various aspects of feeding and swallowing (Reilly 1996). This is usually related to problems with oral-motor and/or pharyngeal-motor activity. Although there are many acute and chronic health conditions and other factors that can result in feeding and swallowing problems, this section focuses on feeding and swallowing problems specific to motor disorders.

Safe and successful feeding of infants and children is one of the highest priorities for the parent(s) and caregivers. Adequate nutrition, energy, and stamina are essential factors for the health, growth, and development of young children. A feeding or swallowing problem can lead to inadequate nutrition and decreased energy and stamina. It can affect all areas of the child's development as well as family functioning (Arvedson 1993).

Examples of health problems possibly resulting from abnormal swallowing include pneumonia, reactive airway disease, and recurrent upper airway infections (Loughlin 1994). Abnormal swallowing often results in reduced fluid intake that can result in dehydration and/or chronic constipation. Furthermore, children with feeding and swallowing problems often have prolonged and difficult mealtimes, which may create stress both for the child and the other family members.

Successful oral feeding depends on many factors. In addition to the oral-motor and pharyngeal-motor functions necessary for successful oral feeding and swallowing, a child's oral feeding behaviors may be influenced by the child's

health status, cognitive level, and caregiver-child interactions and relationships around feeding, as well as the family’s culture and environment.

The typical feeding progression from birth to 24 months is outlined in Table 5, page 69, along with the relevant oral-motor and motor skills required.

*Basis for the recommendations in this section*

While there is an extensive literature specific to oral-motor feeding and swallowing for young children, this literature was not directly reviewed by the panel because this was beyond the primary scope of this guideline. Some of the recommendations are based on information from review articles and other references that were considered by the panel in lieu of evaluating specific studies on this topic. In the panel’s opinion, these consensus recommendations reflect appropriate practices for oral-motor assessment for children who have a motor disorder and are generally consistent with the scientific knowledge in this field.

**Recommendations (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.

### *Early recognition of feeding and swallowing problems*

1. It is important to recognize that infants who have a motor disorder frequently have feeding and swallowing problems. Similarly, a feeding and swallowing problem may be an early indicator of a motor or other developmental or health problem. [D2]
2. Because a feeding and swallowing problem may be an early indicator of a motor or other developmental or health problem, it is recommended that all infant developmental exams include:
  - Asking specific and detailed questions about the child’s feeding and swallowing history
  - Monitoring of feeding milestone attainment (Table 5, page 69)
  - Eliciting information from the parent(s) about any feeding and swallowing concerns [D2]
3. When risk factors or clinical clues (Table 6, page 70) indicate a possible feeding problem, it is recommended that further assessment for oral-motor feeding problems be done, including observation of feeding and swallowing by a professional with expertise in the assessment of oral-motor feeding problems. [D2]



**Table 5: Milestones Relevant to Normal Feeding**

Age (months)	Progression of liquid and food	Oral-motor skills	Motor skills
<i>Birth to 4</i>	<ul style="list-style-type: none"> <li>▪ Liquid</li> </ul>	<ul style="list-style-type: none"> <li>▪ Suckle on nipple</li> </ul>	<ul style="list-style-type: none"> <li>▪ Head control develops</li> </ul>
<i>4 to 6</i>	<ul style="list-style-type: none"> <li>▪ Purees</li> </ul>	<ul style="list-style-type: none"> <li>▪ Suckle off spoon</li> <li>▪ Progress from suckle to suck</li> </ul>	<ul style="list-style-type: none"> <li>▪ Sitting balance</li> <li>▪ Hands to midline</li> <li>▪ Hand-to-mouth play</li> </ul>
<i>6 to 9</i>	<ul style="list-style-type: none"> <li>▪ Purees</li> <li>▪ Soft chewables</li> </ul>	<ul style="list-style-type: none"> <li>▪ Cup drinking with assistance</li> <li>▪ Vertical munching</li> <li>▪ Limited lateral tongue movements</li> </ul>	<ul style="list-style-type: none"> <li>▪ Reach, pincer grasp</li> <li>▪ Assists with spoon</li> <li>▪ Finger feeding begins</li> </ul>
<i>9 to 12</i>	<ul style="list-style-type: none"> <li>▪ Ground</li> <li>▪ Lumpy purees</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased independent cup drinking</li> </ul>	<ul style="list-style-type: none"> <li>▪ Refines pincer grasp</li> <li>▪ Finger feeding</li> <li>▪ Grasps spoon with whole hand</li> </ul>
<i>12 to 18</i>	<ul style="list-style-type: none"> <li>▪ All textures</li> </ul>	<ul style="list-style-type: none"> <li>▪ Lateral tongue action</li> <li>▪ Diagonal chew</li> <li>▪ Straw drinking</li> </ul>	<ul style="list-style-type: none"> <li>▪ Independent feeding increases</li> <li>▪ Scoops food, brings to mouth</li> </ul>
<i>18 to 24</i>	<ul style="list-style-type: none"> <li>▪ More chewable food</li> </ul>	<ul style="list-style-type: none"> <li>▪ Rotary chewing</li> <li>▪ Decrease in food intake by 24 months</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increased control of utensils</li> </ul>
<i>24+</i>	<ul style="list-style-type: none"> <li>▪ Tougher solids</li> </ul>	<ul style="list-style-type: none"> <li>▪ Increase in mature chewing for tougher solids</li> </ul>	<ul style="list-style-type: none"> <li>▪ Total self-feeding</li> <li>▪ Increased use of fork</li> <li>▪ Cup drinking, open cup and no spilling</li> </ul>

*Adapted from: Arvedson 1996*

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**Table 6: Clinical Clues of a Possible Feeding Problem**

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- 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
- 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

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4. It is important to pay close attention to parental concerns and reports about problems with feeding/swallowing (Table 6). When the parents indicate a concern, it is important to follow up with further assessment. [D2]
  5. It is important to recognize that feeding requires a significant amount of parental involvement and thus may reflect the feeding skills of the parent(s) as well as the child. Some parents may feel responsible for the feeding difficulties and therefore may be reluctant to report feeding problems. [D2]
  6. When there are indicators of a possible feeding or swallowing problem, it is important to obtain the history in a manner that helps the parent(s) feel involved in finding a solution (Table 7, page 71). [D2]

**Table 7: Questions to be Considered in the Feeding History**

- How dependent is the child on others when 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 feedings?
- Does the feeding problem vary with food (texture, taste, temperature, or type); or with the beginning, middle, or end of the meal; or the time of day; or with 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?

*General approach to assessing feeding and swallowing problems*

7. Because of the importance of feeding and swallowing to a child’s health, development, and family functioning, it is recommended that feeding and swallowing problems be identified as early as possible [D2]
8. It is important to recognize and understand that feeding and swallowing problems are signs and symptoms and not a diagnosis, and it is important to determine the underlying cause. [D2]
9. When a feeding/swallowing problem is suspected, it is recommended that an accurate diagnosis be made by an experienced physician in conjunction with feeding specialists before any management decisions are made. [D2]
10. It is important to consider developmental rather than chronologic age when evaluating feeding skills. [D2]

11. It is important to carefully monitor the growth and nutritional status of children who have a motor disorder and feeding problems. [D2]
12. When assessing young children who have a motor disorder and have feeding and swallowing problems, it is important to consider how to ensure the following:
  - Safe feeding with minimal risk for aspiration (saliva, liquid, or food getting into the trachea)
  - Functional feeding with sufficient caloric and nutrient intake within a reasonable period of time
  - Adequate fluid intake
  - Pleasurable and nonstressful feeding [D2]

### *Conducting the initial oral-motor feeding assessment*

13. It is recommended that the initial assessment of a child with feeding problems include a medical evaluation and an evaluation by a feeding specialist (usually a speech language pathologist or occupational therapist). [D2]
14. It is recommended that an initial oral-motor and feeding assessment include the components in Table 8, page 73. [D2]
15. It is important to observe infant nutritive sucking, including the rhythmic pattern of sucking and the coordination of sucking, swallowing, and respiration. Observation of lip closure, tongue action, cheek posture, and laryngeal elevation is also important, as well as the volume of feeding consumed over 15-20 minutes. Signs of feeding difficulties include the following:
  - Increased heart or respiratory rate or “gasping for air”
  - Excessive coughing during or after meal
  - Gagging and spitting
  - Tongue thrusting
  - Squirming, withdrawal, or arching of the back/neck
  - Oral loss of liquid [D2]
16. It is important that feeding assessment of older infants and children include observation of:
  - The child with a familiar feeder who simulates the typical positioning or seating arrangements
  - 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 different amounts per bite or sip
- The time it takes to produce a swallow, and whether multiple swallows are needed to clear food from the oral cavity
- Munching or chewing skills
- The coordination of breathing and swallowing during oral feeding [D2]

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**Table 8: Components of an Initial Oral-Motor Assessment**

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Physical examination and comprehensive history:

- Structure and function of oral, facial, pharyngeal, respiratory, and gastrointestinal systems
- Other conditions that could affect the child's tolerance and stamina (such as cardiac conditions)

Observation of interaction patterns between the child and caregiver

Effects of muscle tone, posture, movement, and positioning

Oral-motor exam, to be performed prior to offering liquid or food, including:

- Presence/absence of oral reflexes
- Structure and coordination of movement of the lips, tongue, soft palate, and jaw
- Oral sensation
- Laryngeal function
- Control of oral secretions (drooling)
- Respiratory rate and effort
- Oral postural control and voice quality

Feeding assessment including:

- Feeding environment
- Level of alertness and attention
- Affect, temperament, and responsiveness
- Ability to self-calm and self-regulate
- Nonnutritive sucking (such as on a pacifier)
- Observation of trial feeding
- Swallowing
- The effect of alternate positioning and modifications of the feeding process

Evaluation of the diet for adequate nutritional intake

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### *Oral-motor assessment tests*

17. It is important to recognize that there are no standardized tests or scales for oral-motor assessment and no single test or scale that can be recommended for universal use for all infants and children. Commonly used checklists and scales that may be useful in making systematic observations of infant feeding include:
- Neonatal Oral-Motor Assessment Scale (Palmer 1993)
  - Pre-Feeding Skills: A Comprehensive resource for feeding development (Morris 1987, Morris 2000)
  - Schedule for Oral-Motor Assessment (Reilly 2000, Skuse 1995)
  - The Multidisciplinary Feeding Profile (Judd 1989, Kenny 1989) [D2]

### *Physical exam considerations*

18. It is recommended that infants and children with feeding and swallowing disorders have regular follow-up assessments by their primary care physician or by consulting a physician specialist. [D2]
19. It is recommended that in addition to the primary care physician, other experienced pediatric specialists be involved in the ongoing assessment and monitoring of children with feeding disorders. Depending on the needs of the child, it may be useful to include:
- Speech-language pathologist
  - Occupational and/or physical therapist
  - Nutritionist (dietitian)
  - Pediatricians with specialty training (such as a developmental pediatrician, pediatric otolaryngologist, psychiatrist, gastroenterologist, neurologist, or craniofacial surgeon)
  - Psychologist
  - Dentist [D2]
20. When conducting a physical examination of a young child with a feeding/swallowing problem, it is important to give special attention to the following findings:
- Cleft of the palate or lip
  - Obstructive lesions of the nose (such as nasal polyps or foreign bodies) that can interfere with the coordination of oral activities and respiration
  - Tonsillar and adenoidal hypertrophy
  - Dental problems

- Inflammatory lesions of the oral cavity
- Mandibular hypoplasia
- Signs of insufficient respiration
- Respiratory rate and chest wall excursion during inspiration
- Auscultation findings of lungs including asymmetrical air movement, rales, wheezes, or prolonged expiration
- Clues to chronic pulmonary disease include a paradoxical pulse, accentuated pulmonary component, and fixed splitting of the second heart sound and clubbing of the fingers
- Stool masses on abdominal examination consistent with constipation
- Special attention should be paid to the cranial nerve examination (cranial nerves V, VII, IX, X, XII) [D2]

#### *Assessment of growth and nutritional status*


21. 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
  - Follow procedures used in a standard pediatric examination such as weight, height (standing or recumbent), and head circumference
  - Compare the child's growth to both standardized growth and body mass index (BMI) charts and the child's own growth curve
  - Consider the child's body fat stores by observing or measuring skinfolds (triceps and/or subscapular), particularly if weight gain is slow and the child is less than fifth percentile for age [D2]
22. Because accurate measurement of height is difficult in children over the age of 3 years who have cerebral palsy and joint contractures or scoliosis, it is recommended that special approaches such as measurement of upper arm and/or lower leg lengths be used rather than height measures for children 3 years of age or older. [D2]
23. It is important to recognize that although recent onset malnutrition manifests initially as a reduced weight-for-height ratio, chronic malnutrition results in symmetric growth stunting. Therefore, weight-for-height ratios may eventually be in the normal range. [D2]

#### *Instrumental assessments*

24. It is important to recognize that following oral-motor and feeding evaluations, 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) (Table 9, page 77). Indications for instrumental assessments include but are not limited to:

- Risk for aspiration (food, liquid, or saliva getting into the windpipe) by history and/or the oral-motor and feeding observation
- Prior aspiration, pneumonia, or chronic lung disease
- Suspicion of pharyngeal and/or laryngeal problem based on cause of the feeding or swallowing problem
- “Gurgly” voice quality
- Stridor (a harsh high-pitched sound during inspiration) at rest or during feeding
- Need to define oral, pharyngeal, and esophageal phases of swallowing for management decisions (Table 9) [D2]



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

25. It is important that the team of professionals, including the radiologist and radiology technician, conducting instrumental assessment:
- Have experience working with young children and be knowledgeable about feeding and swallowing
  - Have specific training in performing swallowing studies in young children
  - Collaborate with feeding specialists (such as the speech language pathologist or the occupational therapist)
  - Understand how to appropriately position the child for the study, including the child’s normal/natural position as well as optimal positions [D2]
26. It is important that the parent(s) be informed that not all hospitals have the appropriate equipment and experienced personnel to perform swallowing studies for young children. It is recommended that professionals help the parent(s) locate appropriate facilities. [D2]



**Table 9: Instrumental Assessments for Abnormal Swallowing**

Abnormal swallowing (dysphagia) may consist of one or more abnormalities of the four phases of swallowing. The four phases are:

- The **oral preparatory phase** is the manipulation of food in the mouth to form a food bolus (a mixture of liquid or food that is ready to be swallowed).
- The **oral phase** begins with moving the food bolus to the back of the mouth by the tongue and ends with swallowing the food.
- The **pharyngeal phase** begins with swallowing the food and the elevation of the soft palate to close off and protect the airway.
- The **esophageal phase** is the movement of the food through the esophagus and into the stomach.

#### **Videofluoroscopic swallow study (VFSS)**

VFSS (also called a modified barium swallow) is a specialized x-ray study to assess how well the swallowing structures work while a child is eating or drinking. This study examines oral, pharyngeal, and upper (cervical) esophageal phases of swallowing. The child is presented with barium sulfate (a bland-tasting liquid or paste mixed with food so the food can be seen during the swallow study). Textures may range from thin liquids to purees to chewable solids (such as a cookie coated with a thick puree mixture). The VFSS is recorded on a videotape to provide a record of swallowing function.

By examining the radiographic findings related to the observed actions during the phase of swallowing, the study can detect aspiration and delineate its characteristics and define the reason for the swallowing problem. This study is also useful in describing pharyngeal motility and in noting differences in pharyngeal motility related to food textures. It is important for a child's position of head, neck, trunk, and hips to be adapted during the swallowing study to ensure the most beneficial environment for swallowing. Some children may require an adapted seat during the swallow study. VFSS exposes the child to radiation (because of the required contrast medium, barium sulfate) and requires patient cooperation.

#### **Ultrasonography**

Ultrasonography uses sound waves to assess the oral phase of swallowing (such as bolus preparation and sucking) and observe movements of the oral structures during speech. Ultrasonography does not require the use of a contrast medium (barium sulfate) or result in radiation exposure. Therefore, swallows can be sampled repeatedly and for a prolonged time period. However, ultrasonography does not directly detect aspiration or define the reason for pharyngeal swallowing problems.

#### **Endoscopy/Flexible Endoscopic Evaluation of Swallowing**

Flexible endoscopic evaluation of swallowing (FEES) involves a tube and an optical system that is used to examine the upper airway. This is done primarily in children with suspected anatomic anomalies of the upper airway and for those at risk for aspiration.

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

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section covers the basic aspects of the developmental assessment for young children who have a motor disorder.

*Importance of the developmental assessment*

Many young children who are identified as having motor disorders will also have other developmental problems. The primary focus of assessment and intervention for many of these children is specific to their motor development needs, but consideration of other possible developmental problems is also an important component of the assessment process.

A developmental assessment for children younger than 3 years of age is an attempt to assess the child’s functioning in a variety of environments.

Understanding how the child functions in the home, as well as in other environments that are commonly part of the lives of the child and family, is an important component of developing a comprehensive intervention strategy for the child and family. Commonly used developmental tests are described in Appendix C.

*Basis for the recommendations in this section*

The recommendations on assessment of other developmental domains for young children who have a motor disorder are based primarily on panel consensus opinion. Scientific studies addressing the general developmental assessment of young children who have a motor disorder were not identified from the literature search for this guideline. In the panel’s opinion, these consensus recommendations reflect appropriate practices for the developmental assessment of children who have a motor disorder and are generally consistent with the current knowledge in this field.

**Recommendations (Assessing Other Developmental Domains)**

*Importance of the developmental assessment*

1. It is important that all children who have a motor disorder have periodic, age-appropriate developmental assessments in all developmental domains.

These include assessment of cognition, communication, physical development, social/emotional development, and adaptive/self-help skills. [D2]



**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.

2. Developmental assessments are important because they can provide:
  - An objective description of the child's abilities and needs
  - A framework for determining appropriate interventions
  - A baseline against which progress and effects of intervention can be measured over time [D2]

*General considerations*

3. When assessing development in young children who have a motor disorder, it is important for those assessing the child to understand the whole child and to consider any factors that may have an impact on the child's performance during the developmental assessment. It is important to ensure that the child has had an adequate evaluation of:
  - Health status
  - Hearing status
  - Vision status [D2]
4. It is important to provide appropriate postural support when assessing young children who have a motor disorder and to make appropriate accommodations for any motor limitations. For example, it is important that professionals ensure:
  - Appropriate seating
  - Head, trunk, and foot support, if needed
  - Appropriate table height, and seat depth and width [D2]

5. When conducting developmental assessments, it is important to use any prescribed hearing and vision aids for the child to perform optimally. [D2]
6. It is important to respect and consider the family’s culture when assessing young children who have a motor disorder. It is important to conduct the assessment in the dominant language of the family whenever possible. [D2]



**Early Intervention Policy** ❖ The multidisciplinary evaluation must be performed using nondiscriminatory procedures as defined in program regulations (see Appendix D) and be conducted in the child’s dominant language whenever feasible.

*Conducting the developmental assessment*

7. Developmental assessments can be performed by a variety of professionals. In order to assure quality and consistency, it is recommended that professionals participating in the developmental assessment:
  - Have experience and expertise in assessing young children who have a motor disorder
  - Use normed and standardized instruments as well as observational information
  - Use procedures that are reproducible by other professionals [D2]
8. When assessing children who have a motor disorder, it is important that the assessment not be limited to measuring only quantitative differences. It is also important to recognize qualitative differences. A good developmental assessment includes qualitative evaluation, quantitative measures, and observation. 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. [D2]
9. It is important that the developmental assessment:
  - Be individualized for each child
  - Use age-appropriate testing and scoring methods
  - Consider the child’s individual abilities and needs, including specific discrepancies in functioning across and within developmental domains
  - Make use of parental observations of the child [D2]
10. It is recommended that developmental assessment of young children who have a motor disorder be a multimodal, multimethod assessment, including:

- 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) [D2]
11. It is recommended that the developmental assessment be an ongoing process (periodic structured assessment plus ongoing general monitoring of the child's development) that occurs in more than one session and in more than one setting as appropriate because:
- 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
  - A child's performance can vary from day to day [D2]



**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.

12. It is important to include observational data obtained in the child's natural environment. [D2]
13. It is important to note in the evaluation report whether any testing modifications were used. [D2]
14. It is recommended that a parent or other primary caregiver be present for the formal assessment whenever possible and that there be an opportunity for other family members to participate in the process. [D2]

*Considerations for assessment strategies, materials, and settings*

15. It is recommended that the setting in which the assessment is performed and the materials and strategies used for the assessment be appropriate to the developmental stage of the child and be comfortable for both the parent(s) and the child. [D2]
16. It is important to recognize that standardized developmental tests are usually not normed for children who have a motor disorder. Standardized developmental tests may provide useful 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. [D2]

17. It is important to recognize that no child is "untestable." Some tests, however, may not be appropriate for some children. It is important to use appropriate testing materials and strategies for each child. [D2]
18. 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. This is important because:
  - If a young child has significant motor limitations, adaptations of materials, setting, or testing/response procedures may be necessary if the assessment results are to reflect accurately the child's development
  - Input from the parent(s) and others who know the child well can be extremely important in determining the most appropriate materials, procedures, and adaptations to be used [D2]
19. It is recommended that all assessment tools encompass a wide range of skill levels so that the score is not influenced by floor or ceiling effects (i.e., the test should not be so easy that the child performs 100 percent of the tasks [ceiling effect], nor so hard that all the scores are close to zero percent [floor effects]). [D2]

### *Components of the developmental assessment*

20. It is recommended that a developmental assessment for a child who has a motor disorder assess the status of the child's functional skills in all developmental domains. Important components of a developmental assessment include both formal and informal assessment of:
  - Family resources, priorities, and concerns
  - Medical history
  - Cognitive ability
  - Communication (receptive and expressive language)
  - Motor skills (fine and gross motor)
  - Sensory processing abilities
  - Adaptive/self-help skills
  - Social/emotional functioning
  - Observation of the child during informal and structured play and of parent-child interactions

- Parental report and interview to elicit concerns, obtain a history of the child’s early development, and gather information about the child’s current level of functioning [D2]




**Early Intervention Policy** ❖ Under the NYS Early Intervention Program, the multidisciplinary evaluation must include a parent interview. The interview may be a formal interview schedule or an informal discussion with the parent about their child’s development.

*Assessing developmental milestones*

21. When assessing children who have a motor disorder, it is important to recognize that they will vary as to when specific developmental milestones are attained. [D2]
22. It is important to follow up on questionable abnormal findings from the developmental assessment of any young child. This might include adding elements to the developmental assessment and/or referring the child to other professionals for more detailed evaluation and specific diagnosis. [D2]

*Assessing cognition*

23. It is important to assess cognitive ability in children who have a motor disorder because the child’s cognitive ability affects the child’s functioning in other areas of development and has implications for intervention decisions. [D2]




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

24. 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. [D2]
25. It is important to recognize that norm-referenced cognitive assessments are generally not considered a valid measure of cognitive function before approximately 6 months of age. [D2]

26. From birth to 12 months of age, it is recommended that a curriculum-linked assessment instrument be used as part of the cognitive assessment. For example:
- Battelle Developmental Inventory
  - Hawaii Early Learning Profile
  - Carolina Curriculum
  - Mullen Scales of Early Learning [D2]
27. From 1 to 3 years of age, it is recommended that standardized/norm-referenced tests be used as part of the cognitive assessment. For example:
- Bayley Scales of Infant Development II (BSID-II)
  - Leiter International Performance Scale - Revised
  - Gesell Developmental Schedules [D2]
28. It is recommended that components of the cognitive assessment include:
- Information-processing functions
  - Conceptual development
  - Memory
  - Attention
  - Problem-solving skills
  - Perceptual motor function
  - Functional motor skills
  - Receptive and expressive language
  - Adaptive behavior [D2]
29. It is important to use standardized scores when reporting the results of a cognitive test. Reporting results in terms of age equivalents is not as useful as the standardized score in describing a child's cognitive functioning as measured by the test.

Assessing communication



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



30. It is recommended that young children who have a motor disorder have a baseline communication assessment and ongoing monitoring of communication development. [D2]
31. It is recommended that the initial communication assessment include observation, parent report, and assessment of:
  - Oral-motor/feeding
  - Visual attention and tracking
  - Responses to sound
  - Vocal quality (cry/pitch/volume)
  - Sound production
  - Attempts to communicate [D2]
32. When there are concerns or indications of a possible communication problem, it is recommended that a more in-depth communication assessment be done. [D2]
33. It is important that an in-depth communication assessment for children who have a motor disorder from age 6 months to 3 years include all of the following:
  - Standardized tests of receptive/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 [D2]
34. When assessing communication in a child who has a motor disorder, it is important to consider the child's:
  - Health status and medical history (such as respiratory function and breath support for vocalization, history of middle ear infections), including
    - General motor tone and function
    - Hearing status and hearing history
    - Oral-motor and feeding history
    - Vision status
  - 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) [D2]
35. When assessing communication in a young child who has a motor disorder, it is important to:
- Provide appropriate postural support for children who have compromised motor control/development
  - Ensure that the testing environment is quiet and free of distractions to help the child maintain attention to the tester and the tasks involved [D2]
36. 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 audiological evaluation be conducted any time there is concern about hearing loss. [D2]

### *Using the findings of the developmental assessment*

37. It is important that the findings of the developmental assessment be used in developing intervention plans for the child. The developmental assessment also provides useful objective reference points for monitoring the progress of the child and assessing the outcomes of interventions. [D2]

### *Communicating the findings*

38. It is recommended that a timely explanation of the results of the assessment be provided to the family with translation into the child's and family's dominant language when possible. It is useful to discuss:
- Important terms and concepts used
  - The results and implications of the assessment
  - Performance in relation to developmental norms [D2]
39. It is important for all professionals involved in the assessment process to communicate with each other regarding their findings and recommendations. [D2]
40. It is recommended that reports from professionals who assess children who have a motor disorder present results in terms understandable to the family and other professionals working with the child and include:
- Strengths and limitations of the tests or processes
  - The child's developmental status and how this may affect the child's functional skills in activities of daily living
  - Strengths as well as the developmental needs of the child [D2]



**Early Intervention Policy** ❖ The multidisciplinary evaluation team is responsible for sharing the results of the evaluation with the child's family and ensuring that the family understands the results and implications of the evaluation. The multidisciplinary evaluation team must also prepare a formal report and evaluation summary, including a statement regarding the child's eligibility, and submit the report to the Early Intervention Official.

41. It is important for professionals to consider how the assessment process and results will impact on the family. [D2]
42. It is important to help families understand their children's strengths and needs, and to identify intervention strategies to maximize the child's potential. [D2]

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

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section provides recommendations specific to general health evaluations for young children who have a motor disorder.

### *Primary reasons for conducting health evaluations*

There are three primary reasons for evaluating the health of children who have a motor disorder. These are:

- To provide a general assessment of the child's health status (as is recommended for all children with possible developmental delays or disorders)
- To identify health problems that occur more commonly in children who have a motor disorder
- To determine the possible relevance of any identified problems to assessment and intervention



**Early Intervention Policy** ❖ An assessment of physical development, including a health assessment, is a required component of the multidisciplinary evaluation. Whenever possible, the health assessment should be completed by the child's primary health care provider.

Medical conditions commonly seen in or associated with motor disorders are listed in Table 10, page 89.

*Aspects of health evaluations reviewed*

It would be an extremely large task to evaluate the efficacy of all possible methods for assessing health status in children who have a motor disorder. Therefore, the scope of this section is limited to the general health evaluation process for children who have a motor disorder, plus the general approach to assessing a few associated health conditions commonly seen in children who have a motor disorder.

*Basis for the recommendations in this section*

The recommendations in this section on health assessments for young children who have a motor disorder are based primarily on panel consensus opinion. While it is acknowledged that there may be studies on this topic that would meet the criteria for evidence for this guideline, a comprehensive literature review to identify scientific studies was not done because assessment for specific health conditions was considered outside the primary scope of the guideline.

**Recommendations (Assessing General Health Status)**


*General health surveillance*

1. It is recommended that children who have a motor disorder receive routine preventive health care, and that whenever possible, children have a primary health care provider who is knowledgeable about the special health care needs of children who have a motor disorder. [D2]

*General health assessment for young children with suspected or diagnosed cerebral palsy*

2. It is recommended that professionals assessing the 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 (Table 10, page 89). [D2]

3. It is extremely important to establish the hearing and vision status in a child with suspected or diagnosed cerebral palsy in order to rule out hearing or vision impairment as a contributing factor for the child’s mobility and communication problems. [D2]



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

4. 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
  - Monitoring growth and nutritional status (measurements of weight, height, and head circumference at each health maintenance visit from infancy through the childhood years)
  - The feeding history (reliable estimates of volume or amount of feeding, fluid and fiber intake, nutritional intake)
  - Musculoskeletal development with particular attention given to joint dislocations or contractures and kyphoscoliosis
  - Signs of constipation, including infrequent bowel movements (less than 1 per day) and hard stools associated with straining
  - Signs and symptoms of gastroesophageal reflux, including vomiting, small volume feedings, discomfort during feedings, poor weight gain, and upper airway congestion
  - Signs and symptoms that would raise the suspicion for seizures [D2]
5. It is recommended that a pediatric orthopedic consultation and follow-up be considered depending on the needs of the child. [D2]

**Table 10: 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)

**Table 10: Common Associated Conditions in Children With Cerebral Palsy**

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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)

*Adapted from: Geralis 1991*

*(Continued from previous page)*

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**CONSIDERATIONS FOR WORKING WITH THE FAMILY**

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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The recommendations in this section focus on working with the families of young children who have or are at risk for a motor delay or disorder. Topics include:

- Communicating the Diagnosis to the Family
- Assessing the Resources, Priorities, and Concerns of the Family

*Basis for the recommendations in this section*

This section's recommendations on considerations for working with the family are based primarily on panel consensus opinion. No scientific literature meeting the criteria for evidence for this guideline was identified for this topic. Some recommendations address topics for which literature was identified, but no studies met the criteria for evidence. Other recommendations address topics that generally do not lend themselves to scientific studies. For some topics, a comprehensive search of the scientific literature was not done as a focus of this guideline. Many of the recommendations are based on findings from review articles that were specific to issues related to family assessment, but a comprehensive literature review was not done for this topic. In the panel's opinion, these recommendations reflect appropriate practices for working with the families of children who have a motor disorder.

**Communicating the Diagnosis to the Family**

There are many factors that may influence how parents respond when information about a suspected diagnosis is communicated. The following are factors that are likely to affect parents' response to learning that their child has or is suspected of having a significant disability (Garwick 1995).

Factors that are usually important to parents include:

- Characteristics of the child's condition
- Certainty of the diagnosis and prognosis
- Preexisting family factors (such as previous knowledge and beliefs about the condition, family circumstances, and family stressors)

- 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

Parents' preferences for receiving the news about the diagnosis usually include:

- In person rather than by telephone
- With both parents present
- In a private setting


Informing strategies that parents find helpful generally include:

- Focusing on the child as a whole, rather than focusing only on the limitations of the condition
- Being supportive and sensitive to the feelings of the parent(s)
- Providing opportunities for discussion with knowledgeable professionals and relevant up-to-date written information about the child's condition

**Recommendations (Communicating the Diagnosis)**

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

1. As soon as there are indications that a child may have a motor disorder, it is important that the physician communicate this information to the parent(s). [D2]



**Early Intervention Policy** ❖ Under the NYS Early Intervention Program (EIP), 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 EIP 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.

2. There are specific factors that may affect how the family responds when learning that their child has or is at risk for a motor disorder. For example:
  - What the family knows/believes about the condition
  - Certainty of the diagnosis and prognosis



- Preexisting family factors (such as condition of the mother and infant at the time the news is delivered, family stressors, and previous knowledge and beliefs about the condition)
  - The setting in which the family was informed
  - The manner in which the health care professionals initially informed the family
  - The quality of the information provided [D2]
3. When a motor disorder is suspected, it is important to provide the parent(s) with accurate information about the child’s condition in order to allow the parent(s) to function as active partners with health care providers in monitoring the child’s overall development and health. [D2]

*Delivering the news about a child’s diagnosis*

4. It is recommended that when a young child is suspected of having a motor disorder, the physician share this information in person with the parent(s) and if possible, in private rather than in the presence of strangers. [D2]
5. When information is communicated to the family that the child has or is suspected of having a motor disorder, it is important that this be done in a sensitive and caring way that supports the family. [D2]
6. For the physician “breaking the news” to the parent(s) about the child’s potential for ongoing health and developmental problems or disabilities, it is important to recognize that:
- It is impossible in almost all circumstances to know with certainty the prognosis of serious medical complications during the neonatal period
  - Many parents are able to accept uncertainty and will understand if it is not possible to know or predict the infant’s future outcomes
  - Physicians need to provide an honest assessment of the range of potential outcomes
  - Parents need to be able to hope and believe in a positive future for their child
  - Parents need to receive accurate information about the child’s condition in order to:
    - Develop informed and reasonable expectations about the child’s development
    - Become informed advocates for the child [D2]

7. When providing information about the child to the family, it is important to allow the parent(s) time to understand the information given and to follow up shortly after to discuss any questions the parent(s) may have. [D2]
8. It is important to recognize that parents' understanding of what a diagnosis means for their child's future and for family life may be based on stereotypes and misinformation, and that 'cerebral palsy' in particular may be a frightening term. For example, parents may be concerned because they may believe that diagnosis implies that the child will necessarily be mentally retarded, have to use a wheelchair, and/or will always have to attend a special school. Therefore, it may be important to discuss with the parents not only what a diagnosis means, but also what it does not mean for their child. [D2]
9. When the physician delivers the news that a motor disorder is suspected/diagnosed, it may be helpful to use an approach such as PACE (Garwick 1995):
  - **P**lan the situation and setting in which the family is informed
  - **A**ssess preexisting family factors such as the parents' previous knowledge and experience about motor disorders
  - **C**hoose helpful informing strategies that meet the needs of the family
  - **E**licit feedback from the family [D2]
10. When choosing the types of information and strategies for delivering news to the family that a motor disorder is suspected/diagnosed, it is important to be respectful and to provide understandable information without being patronizing or prejudging the ability of the parent(s) to understand. [D2]
11. When a motor disorder is diagnosed, it is very important to include specialists with expertise in the care and follow-up of young children who have a motor disorder (neurologists, developmental pediatricians, and pediatric physiatrists) as part of the team available to discuss the health and developmental implications of the child's condition. [D2]

### *Communicating with the family*

12. When communicating with the family about a child's motor disorder (or suspected motor disorder), it is important for health care professionals to:
  - Listen to and consider parental observations of the child
  - Focus on and appreciate the child as a valuable person, an individual, and a member of the family; avoid negative labeling of the condition or the child

- Refer to the child by name rather than as “the baby”
  - Consider and make reference to the child’s specific personal qualities (such as the child’s determination, sense of humor, or happy temperament) and positive individual attributes, strengths, and characteristics
  - Minimize the use of jargon and medical vocabulary while helping the parent(s) to understand the terms and concepts they will need to know [D2]
13. Professionals need to be aware that even if the news is delivered in the best possible way, parents may still express anger, disbelief, or dissatisfaction after being informed that their child is at risk for (or has) a disability. This may be a reaction to their feelings about their hopes for the future of the family and the child. [D2]

*Responding to the needs of the family*

14. It is important that professionals listen to family members’ reactions after delivering news about a child’s condition so that appropriate support and information can be provided. It is important to understand that not all families will have the same reaction. [D2]
15. It is important that the parents have opportunities to ask questions and have a discussion with a health care professional that is not hurried or rushed after learning that their child has or is at risk for a motor disorder. [D2]
16. It is important to recognize that:
- Parents may react differently to an uncertain prognosis about the child’s developmental potential: some parents may find uncertainty stressful, but for others it provides hope
  - Professionals wanting to prepare the parent(s) for the worst may be inadvertently eliminating hope and/or setting up an adversarial relationship between the doctor and the parent(s) [D2]
17. It is important to understand that adjusting to the diagnosis may take time, and as the family goes through various phases of understanding and acceptance, the need for information and support may increase. [D2]

*Understanding that parents may feel they are responsible for the motor disorder*

18. When informing the parents that their child has or is suspected of having a motor disorder, it is important to recognize that parents of children with disabilities often hold themselves accountable (or feel others hold them accountable) for their child’s disability. It is important to provide parents


information about the etiology (cause) of the motor disorder and to the extent that it is true, to let them know that it is not the result of something either of the parents did or did not do. [D2]

### *Factors that may affect the family's response*

19. It is important for professionals to recognize that parents have a range of individual responses and emotional reactions to the experience of having a child who may have serious medical problems and potential for disabilities. When interacting with the parent(s), it is important for professionals to:
  - Be accepting and avoid being judgmental of the parent(s)
  - Pay attention to and value parents' opinions and feelings
  - Recognize that parents are valuable observers who have knowledge about the child that needs to be considered in planning their child's care
  - Provide opportunities for the parent(s) to voice concerns and emotions
  - Make sure that the parents know about and are offered opportunities for professional support, such as counseling and emotional support
  - Offer opportunities for parent-to-parent support [D2]
20. It is important to recognize that parental satisfaction with the delivery of news about a child's disability may be greater if the parents feel that the professionals accepted and acted on parental suspicions before the diagnosis was made. [D2]
21. It is important to recognize that the family's cultural background may affect how the family responds to the news that the child has or is at risk for a disability. Variables affected by culture may include beliefs about:
  - The cause of the disability
  - How the child will be valued and treated by others
  - The role of the child within the family and within the larger society
  - Allocation of responsibility for daily care of the child and for decision making regarding the child
  - Informal social support available to and accepted by the family
  - Attitudes toward health care professionals and other service providers
  - Preferred patterns of communication such as:
    - Indirect or direct communication between the parent(s) and the health care and other service providers
    - Level of detail desired

- Appropriateness of eye contact
  - Level of formality considered appropriate
  - Amount or type of emotion considered acceptable to express [D2]
22. It is important to recognize that the parent(s) may consider information based on clinical observation as less reliable than information from laboratory test results or other objective diagnostic tests. As such, it is especially important to:
- Allow enough time to adequately observe the child
  - Take into account the child’s mood and temperament (fatigue, illness, shyness, excitement) at the time of assessment
  - Listen to parents’ observations of the child in other settings (such as home or day care) [D2]

**Assessing the Resources, Priorities, and Concerns of the Family**



**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 to families. The evaluation team must use appropriately trained qualified personnel when conducting a family assessment.

An assessment of the family’s resources, priorities, and concerns is an important component of planning interventions. Intervention services are most effective if they are matched to the strengths and needs of the individual family as well as to the strengths and needs of the child. This is important because the strengths and needs of the family may be more predictive of outcome than are the child’s needs, both for parent-related outcomes and child outcomes.

Essential family interaction patterns relevant to all children and families regardless of a child’s disability or risk status include:

- The style of the parent-child interaction (for example, encouraging, affectively warm, nonintrusive, appropriately structured, discourse-based, and developmentally sensitive patterns of caregiver-child interactions).
- The extent to which the family provides the child with diverse and appropriate experiences within the surrounding cultural, social, and physical environment (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 way in which the family ensures the child's health and safety (for example, obtaining immunizations and routine and specialized health care, providing adequate nutrition and a safe home environment) (Guralnick 1997).

For a child with established disabilities, there are factors that may interfere with a family's ability to establish patterns of interaction that optimally facilitate and support the child's development. Factors may include:

- Lack of information about the child's health and development
- Preconceived notions/beliefs about the condition
- Interpersonal and family stress
- Lack of resources or support
- Language or cultural considerations
- Threats to confidence in parenting skills (Guralnick 1997)

The extent to which stressors actually affect the family patterns depend on the magnitude of the stressors and the characteristics of the family. Not all families are the same. Those with adequate coping resources are less likely to regard potential stressors as stressful (Knussen 1992). Important factors that may impact the family's response to potential stressors include:

- Available supports (e.g., social support networks)
- Financial resources
- Interpersonal and problem-solving styles of the parent(s)
- History of family parenting practices

Research suggests that the most important social support is the existence of a confiding relationship or strong ties, usually within the family (Knussen 1992).

For mothers of children with developmental disabilities, family characteristics and processes (family cohesion, level of family support, and mother-child interactive behaviors) are often more predictive of parenting and child-related stress than are specific child characteristics (Warfield 1999). Family processes such as growth trajectories in communication, daily living, and social skills are also generally more predictive of adaptive development than are other measures such as maternal education or psychomotor measures during infancy (Hauser-Cram 1999).

While the availability of strong social support may be an important factor in a family's inventory of coping resources, nonsupportive behavior from family, friends, or service providers may be "more than the loss of a protective factor and might actually become a risk factor" (Patterson 1997). Some of the behaviors reported most often by parents as nonsupportive include:

- Comparing the child to other children
- Focusing only on what is "wrong" with the child
- Questioning why a child cannot achieve developmental milestones
- Having low expectations of the child's potential abilities
- Offering unsolicited and inappropriate advice
- Blaming parents for the cause of the condition
- Criticizing parental caregiving
- Pitying remarks concerning the child or the parents

#### *The family assessment*

A family assessment is designed to help identify the family's resources, priorities, and concerns in order to be able to develop intervention plans that are meaningful and relevant to the family. Methods for a family assessment include:

- Informal discussions with families, using sensitive and focused interviewing techniques
- Questionnaires and other assessment tools to help families identify, clarify, and communicate their goals and needs to relevant professionals

It is important for professionals to recognize that some families may be uncomfortable about participating in a family assessment and may interpret the assessment as a message that something is "wrong" with their family functioning. While some parents may find it helpful, others may find it intrusive.

Conducting a family assessment requires skill and practice. Many professional assessments of family needs are weakly correlated with the parents' assessment of their needs. In family-oriented assessment, the task for professionals is to objectively and sensitively help the parent(s) to articulate the needs and goals of the family (Krauss 1997).

### **Recommendations (Assessing the Resources, Priorities, and Concerns of the Family)**

#### *Importance of assessing the family*

1. It is recommended that the family of a young child who has a motor disorder be encouraged to participate in a family assessment process. This is important because the information gathered through this process can assist in planning effective intervention strategies and goals/objectives. [D2]
2. It is important that professionals provide an appropriate setting and support individualized to the family's needs to promote the assessment process. [D2]

#### *Components of a family assessment*

3. It is recommended that family assessment include observation and/or discussion of factors such as:
  - The family's knowledge and need for information about motor disorders
  - The family's vision of the future for the child, both short- and long-term
  - Family composition (including siblings and extended family)
  - The family's specific circumstances
  - The family's values and culture
  - The family's stressors and tolerance for stress, as well as the family's coping mechanisms and styles
  - The family's current support systems and resources (including extended family members and their attitudes)
  - Family interaction and patterns of parenting style
  - Caregiving skills and sharing of caregiving responsibilities
  - Interpersonal and problem-solving styles of the parent(s)
  - Issues related to nonsupportive behaviors of family members, friends, and community [D2]
4. 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 [D2]

*Family assessment approaches*

5. Because some families may be uncomfortable with participating in a family assessment, it is important for professionals conducting family assessments to:
  - Foster collaborative, mutually respectful parent-professional relationships
  - Listen effectively and nonjudgmentally to family-identified needs
  - Value and be interested in the parents' input
  - Help the parent(s) understand the importance of and reasons for a family assessment
  - Maintain confidentiality
  - Provide an appropriate setting and sufficient time to allow family members to express needs and concerns
  - Respect differences in family styles and goals
  - Respect cultural differences
  - Avoid tendencies to judge the adequacy of any particular family [D2]
6. It is recommended that information gathered in the family assessment be used to help families establish and articulate needs, develop realistic priorities, and become aware of available services and supports (both formal and informal) for the child and family. [D2]
7. It may be useful to use a specific measurement tool, such as the Parenting Stress Index, the Coping Inventory, or the Family Resource Scale, to measure parental stress that may affect family well-being and child functioning. [D2]
8. 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. [D2]



## CHAPTER IV: INTERVENTION

### *Topics included in this chapter*

- General Approach to Interventions for Young Children Who Have a Motor Disorder
  - Motor Therapy Approaches and Techniques
  - Assistive Technology and Adaptive Devices
  - Oral-Motor Feeding and Swallowing Interventions
  - Approaches for Spasticity Management
  - Orthopedic Management and Surgery
  - Interventions for Associated Health Conditions
  - Other Intervention Approaches for Young Children Who Have a Motor Disorder
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## **GENERAL APPROACH TO INTERVENTIONS FOR YOUNG CHILDREN WHO HAVE A MOTOR DISORDER**

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section provides general recommendations related to providing interventions for young children who have or are at risk for a motor disorder. Topics include:

- General Considerations for Planning and Implementing Interventions
- Including the Parents and Family in Planning Interventions
- Providing Support to Parents and Families
- General Approach for Selecting Interventions
- General Focus for Motor Interventions

### *Basis for the recommendations in this section*

While an extensive literature search and review was conducted to identify scientific studies addressing intervention topics of interest for this guideline, only a limited number of studies were found that met the criteria for evidence. Therefore, as in other parts of this guideline, many of the recommendations

about the general approach for interventions for young children who have a motor disorder are based on panel consensus opinion. These consensus opinion recommendations generally relate to approaches that do not lend themselves to controlled scientific studies.

### **General Considerations for Planning and Implementing Interventions**

The general considerations for planning and implementing interventions for children who have a motor disorder are, for the most part, similar to the considerations involved in intervention planning for children with any condition. Decisions regarding intervention for a particular child are linked closely with that child's assessment results so that the intervention can be individualized to the child's strengths and needs. The family's resources, priorities, and concerns are also taken into account.

There is no single intervention approach or strategy that will be appropriate for all children who have a motor disorder. Some children who have a motor disorder can be identified during the newborn period and therefore may enter into intervention at a very young age. Other children may have early indicators of a potential problem that requires ongoing monitoring and developmental surveillance before determining the need for intervention. The appropriate time to initiate intervention will be determined based on the needs of the child and the family. The types of intervention and the frequency of intervention most appropriate for a particular child and family will need to be modified as the child develops.


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.

**Recommendations (General Considerations for Interventions)**

*Importance of early identification and intervention*

1. 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.

[A] (Cioni 1997, Horn 1995, Majnemer 1995, Mayo 1991, McLaughlin 1998, Steinbok 1998, Wright 1998)



**Early Intervention Policy** ❖ Children’s eligibility under the Early Intervention Program can be established through either the presence of a developmental delay that meets the state definition of developmental delay or the presence of a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. An approved evaluator selected by the parent must establish a child’s eligibility for the program by conducting a multidisciplinary evaluation consistent with State law and regulations, and standards and procedures issued by the Department of Health. Children may be eligible for early intervention evaluation if the child has a suspected developmental delay, a suspected diagnosis of a condition with a high probability of a developmental delay, or a diagnosed condition with a high probability of developmental delay

*Individualizing interventions*

2. It is recommended that the use of any intervention for a child with a motor disorder, including any home program of therapeutic exercise and activities, 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 in their responses to specific intervention methods or techniques
  - Children have different family situations, and some families will need more support than others

[A] (Bragg 1975, Brandt 1980, Chiarello 1998, DeGangi 1983, Gross 1982, Hanzlik 1989, Jenkins 1988, Law 1991, Law 1997, Mayo 1981, Mayo 1991, Palmer 1988, Piper 1986, Reddihough 1998)



**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 included 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 D).

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.

#### *Considering the child's health status*

3. 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 no contraindications to the intervention. [D2]
4. It is important to monitor the child's health status and tolerance for motor activities throughout the intervention. [D2]

#### *Selecting intervention strategies and targets*

5. In young children who have a motor disorder, the nature of the intervention and the child's developmental status at the start of intervention are factors that affect the outcome of the intervention. This is important to understand and consider when selecting the intervention strategies and the expectations for intervention, and when evaluating the effectiveness of intervention approaches. [D1]
6. An individualized comprehensive model of intervention strategies is recommended for most young children who have a motor disorder. A comprehensive model includes the opportunity for intervention in a variety of settings as well as family support services. [D2]




**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.

7. In making a decision either to start or change a specific intervention for a child who has a motor disorder, it is important that parents and professionals consider the:
  - Best available scientific evidence about the effectiveness of the intervention and alternatives
  - Developmental needs and skills of the child
  - Potential risks associated with the intervention [D2]
8. When selecting intervention strategies, goals, and objectives, it is important that they:
  - Be developed in conjunction with the participation of parent(s)
  - Be appropriate to the particular culture of the family
  - Consider the child’s health status and motivation of the child
  - Assist the family and child’s integration into the community [D2]
9. It is recommended that target behaviors for each individual child be clearly identified and defined with developmentally appropriate measurable criteria for mastery.  
*[A] (Bragg 1975, Cannon 1987, Horn 1995)*
10. 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.  
*[A] (Chiarello 1998, Hanzlik 1989, Law 1997, Palmer 1988)*
11. It is important to work with parents to determine appropriate and acceptable ways to include parents/family and other caregivers in facilitating progress towards the intervention goals.  
*[A] (Gross 1982, Chiarello 1998, Hanzlik 1989, Law 1997, Mayo 1981)*
12. When making decisions about interventions for a child who has motor disorders, it is recommended that parents seek guidance from qualified professionals with experience in working with young children who have a motor disorder. [D2]



*Determining the intervention setting*



**Early Intervention Policy** ❖ 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.

13. In determining the most appropriate settings for interventions, it is important to consider the following factors:
  - The range of the child's natural environments (home, child care provider, community settings) and how these settings can support the intervention objectives
  - The appropriateness of the setting for supporting the needs of the family and child
  - The cognitive, social, communication, and motor development of the child (ability to follow directions, sit still, interact with peers, etc.)
  - The child's response to current intervention
  - Health status and associated health conditions [D2]
14. It is important to recognize that children who are developmentally ready for peer interaction may benefit from participation in group motor development programs.  
*[B] (Jenkins 1988)*
15. When a change in the intervention setting is being considered, it is important to address any concerns parents may have about the proposed change (such as from the home to more community-based or group settings). [D2]

*Determining the frequency and intensity of the intervention*

16. In determining the frequency and intensity for motor interventions, it is important to consider the following:
  - Severity of condition
  - Ability of and/or opportunity for parents to follow through on the intervention strategies and techniques that improve motor functioning and developmental outcomes
  - Child's ability to engage and tolerate therapy that impacts the length of the therapy session


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- Needs of the child and the goals for various interventions
- Techniques that are appropriate to address the child's needs
- Child's progress
- Setting(s) where therapy will be provided
- Balance of interventions with child and family routines and schedules [D1]

### *Ongoing monitoring and modification of the intervention*

17. It is recommended that any intervention be tied to ongoing assessment and modification of intervention strategies as needed. [D1]



**Early Intervention Policy** ❖ The Individualized Family Service Plan (IFSP) must be reviewed every six months and evaluated on an annual basis. This may include an evaluation of the child's developmental status, if needed. After the child's initial multidisciplinary evaluation, supplemental evaluations may also be conducted when recommended by the IFSP team, agreed upon by the parent and Early Intervention Official (EIO), and included in the IFSP.

The IFSP may be amended any time the parent(s) and the EIO agree that a change is needed to better meet the needs of the child and family.

Providers of early intervention services are responsible for consulting with parents and other service providers 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.

18. In evaluating the effectiveness of interventions and the child's progress, it is more useful to measure a broader range of functional and developmental outcomes rather than specific, isolated physical findings such as range of motion or primitive reflexes.

[A] (Brandt 1980, Girolami 1994, Mayo 1991, Scherzer 1976, Wright 1973)

19. If ongoing assessment of the child's progress shows that an intervention has not been effective after an adequate trial period, it is recommended that the intervention or specific aspects of its application be changed. [D1]
20. It is recommended that parents and professionals consider modification of an intervention when:
  - The child has progressed and target objectives have been achieved
  - Progress is not observed after an appropriate trial period

- The child has shown some progress, but 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 (such as moving from the home to a preschool setting)
  - There is a change in family priorities [D2]
21. It is recommended that parents be informed that the types of intervention and frequency of intervention may change over time, and that ongoing interventions may need to be adjusted based on ongoing reassessment of the child’s progress and needs. Adjusting the intervention might mean increasing or decreasing the frequency or intensity, or changing some aspect of the approach or the setting. [D2]

*Periodic in-depth reassessment and evaluation*

22. In addition to ongoing monitoring, it is 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 the periodic, in-depth reassessment of the child, it is important to:
- Include appropriate qualitative information about the child’s development and progress
  - Include appropriate standardized testing to assess the child’s progress
  - Assess the child’s individual progress and functional level, and compare these to the child’s age-expected levels of development and functioning [D2]

*Collaboration, coordination, and integration*

23. It is recommended that if multiple intervention components are used, careful consideration be given to integrating the intervention approaches and/or components to make sure they are compatible and complementary. [D2]
24. It is important that techniques and approaches be coordinated, integrated, and collaborative across all individuals working with the child and family. [D2]
25. It is important for all team members, including the parent(s), service providers, and the child’s health care provider, to find ways to communicate consistently and regularly with each other about the child’s progress. [D2]

### **Including the Parents and Family in Planning Interventions**

For all children, including children who have a motor disorder, the family plays an extremely vital role. The child's needs can be understood only within the context of the family and the family's culture. Intervention services are most effective when they are matched to the strengths and needs of the family, as well as to the strengths and needs of the child (Chapter III, page 97).

Inclusion of the parents in decisions about interventions is important to successful outcomes. It is likely that the assessment and intervention process will begin at a very early age for many families because children who have or are at risk for a motor disorder such as cerebral palsy can usually be identified during the first year of life. Therefore, many of the interventions for infants who have a motor disorder focus on the parents rather than on the infant. Interventions may focus on the parents' need for information about motor disorders, information about ongoing monitoring and 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 of the intervention. Throughout this document, many of the recommendations about specific interventions for young children who have a motor disorder are recommendations about parent involvement.

### **Recommendations (Including the Parents and Family in Planning Interventions)**

#### *Importance of parent involvement*

1. It is important that parents be involved in the assessment and intervention for their child in order to understand:
  - What to expect regarding their child's development
  - Intervention options, goals, and methods, and 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 [D2]
2. A home intervention program carried out by parents under the direction of a therapist can be an important part of the overall intervention.

[A] (Gross 1982, Chiarello 1998, Hanzlik 1989, Mayo 1981)

#### *Level of parental involvement*

3. It is important for parents to participate in the intervention planning process and in supporting and implementing interventions. It is recommended that

decisions about the extent of parental involvement in interventions be made on a case-by-case basis and take into account the:

- Parents' level of interest, availability, and ability to participate in the intervention
  - Parents' comfort with the intervention
  - Characteristics of the child's home environment
  - Availability of training and professional support [D2]
4. Because parent involvement can be critical to the success of the intervention, it is important:
- For parents to be involved in determining their own ability and availability to participate in the intervention
  - For professionals to provide opportunities for family members to express their concerns and needs regarding their participation
  - For both parents and professionals to set realistic expectations and to take into account and be respectful of the other demands and priorities of the family

[A] (*Law 1991, Law 1997, Mayo 1981*)

*Considering the cultural context of the child and family*

5. A child's life is always embedded in a cultural context. It is essential to consider and respect the family's culture and primary language when providing interventions for young children with developmental disabilities. [D2]
6. It is important to remember that a family's cultural context may affect many different aspects of its relationship with the child as well as the family's relationships with professionals. For example, a family's cultural context may affect the:
- Parents' level of comfort or approach to interacting with professionals
  - Parents' confidence in working with a child with special needs
  - Patterns of caregiving responsibilities within the family
  - Comfort with having the child present in public places
  - Level of privacy desired within the home (and thus the decision of the home versus other potential settings for the intervention)
  - Use of space in the home
  - Food and feeding style preferences
  - Patterns of feeding and holding a young child
  - Preferred sleeping patterns for the child

- Expectations and desires regarding developing a child’s independence
  - Expectations regarding appropriate language and motor development
  - Use of traditional or alternative treatments and therapies
  - Family’s health practices [D2]
7. It may be helpful for the professional to consult with someone who is familiar with the culture and language of the family. [D2]
  8. 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. [D2]

### *Including parents in the care of a hospitalized child*

9. It is important for medical personnel and other professionals providing care for the child to understand that parents need to participate in decisions and be an integral part of their child’s care during a hospital stay. [D2]
10. It is important for medical personnel and other professionals providing care for the child to help parents develop a level of comfort and confidence when they participate in the care of their hospitalized child. This includes providing information, support, and opportunities for parents to interact with their child, as well as providing information to help parents understand basic hospital procedures (such as washing hands, wearing gowns, visiting hours, and routines) and equipment used in their child’s care. [D2]

### *Working with parents who have a child in the NICU*

11. It is important to recognize that parents have a range of individual responses and emotional reactions to the experience of having an infant in the neonatal intensive care unit (NICU) who may have serious medical problems and potential for disabilities. When working with the parents to plan interventions for an infant in the NICU, it is important to:
  - Be accepting and avoid being judgmental of the parents
  - Pay attention to and value parents’ opinions and feelings
  - Recognize that parents are valuable observers who have knowledge about the child that needs to be considered when planning their child’s care
  - Provide opportunities for parents to voice concerns and emotions
  - Ensure that parents know about and are offered opportunities for professional support, such as counseling and emotional support
  - Offer opportunities for parent-to-parent support [D2]

*Role of the professionals working with parents*

12. It is recommended that the professional:
- Work collaboratively with parents to develop the intervention program
  - Elicit observations from parents regarding the child's functioning
  - Share regular progress reports with parents
  - Give parents regular feedback based on direct observation of the child
  - Consider the cultural perception of the role of the family in intervention [D2]



**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.

13. It is important that professionals are available to respond to parents' questions and needs. It is important that this be ongoing because the questions and needs will change as the child develops. [D2]

*Informing parents about interventions*

14. It is important to encourage, support, and facilitate parent participation in the child's interventions. This is important because parent participation can be an important factor in improving child outcomes.
- [A] (Chiarello 1998, Goodman 1985, Gross 1982, Hanzlik 1989, Mayo 1981, Piper 1986, Rothberg 1991, Saylor 1996, Scherzer 1976)
15. It is recommended that professionals provide instructions/teaching to parents that will allow them to foster their child's development in all domains. Teaching methods could include verbal instruction, written material, supervision, videotapes, hands-on training, and participation in the child's therapy sessions.
- [A] (Chiarello 1998, Goodman 1985, Gross 1982, Hanzlik 1989, Mayo 1981, Piper 1986, Rothberg 1991, Saylor 1996, Scherzer 1976)
16. It is important to provide parents with information about:
- What is known about the types and effectiveness of the various interventions that may be available

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- The intervention options that are appropriate and available for their child
  - The types of professionals who may be providing interventions and what they will be doing [D2]
17. It may be useful for parents to talk to other parents of children who have had experience with the therapies that are being considered. [D2]
18. It may be useful for a parent to observe, when appropriate, the kinds of therapy being considered for the child before making a decision to begin therapy. [D2]

### *Parent education and training*

19. 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] (Chiarello 1998, Goodman 1985, Gross 1982, Hanzlik 1989, Mayo 1981, Piper 1986, Rothberg 1991, Saylor 1996, Scherzer 1976)*
20. When providing parent training, it is recommended that the following techniques be considered:
- Instructing parents in specific therapeutic techniques focused on target behaviors
  - Teaching parents and primary caregivers appropriate play activities that integrate the objectives of the motor intervention into the child's daily life activities
  - Helping parents and primary caregivers understand the child's approach to motor learning
  - Providing support and education through mother-infant interaction groups
  - Teaching through modeling, demonstration, and manual guidance and providing verbal feedback

*[A] (Chiarello 1998, Goodman 1985, Gross 1982, Hanzlik 1989, Mayo 1981, Piper 1986, Rothberg 1991, Saylor 1996, Scherzer 1976)*

### **Providing Support to Parents and Families**

Family support is a broad concept that includes both formal and informal support, as well as both planned and naturally occurring interactions. Family support processes are complex and may affect behavioral outcomes of parents, the child, and the family directly or indirectly.

Family support has the following five components:

*Relational*--the existence and quantity of social relationships



*Structural*--quantitative aspects of personal social networks

*Functional*--the type, quantity, and quality of help provided

*Constitutional*--extent to which the support offered matches the indicated need for help

*Support satisfaction*--extent to which support is perceived as helpful

Intervention services, including family support services, are most effective if they are matched to the needs of the individual family. Families with a high need for support tend to perceive the support as positive, while families with a low need for support tend not to respond as positively to family support services (Affleck 1989).

Experimental studies of family support interventions have found the informal support approach may be more effective than formal support services are in producing positive outcomes of enhancing competencies and satisfaction in parents. Informal support is often characterized by psychological closeness and mutual caring that enhances feelings of well-being. Informal support is usually intended to support parents, but it may also have indirect influences on child outcomes, perhaps mediated through the parent/caregiver sense of well-being and interaction styles with the child.

### **Recommendations (Providing Support to Parents and Families)**

1. It is important to recognize that family support includes:
  - Both informal and formal support
  - Planned and naturally occurring interactions that may be related directly and/or indirectly to child, parent, and family functioning [D2]
2. 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. [D2]
3. It is recommended that family support plans be developed in conjunction with the family to ensure that they match the needs of families. Not all families need the same level of support. [D2]



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

4. 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. [D2]
5. It is important to establish a collaborative parent-professional relationship in which the professionals are able to listen effectively and nonjudgmentally to family-identified needs. [D2]
6. It is important to recognize that family support is not a panacea but is merely one of many intrapersonal, interpersonal, and environmental factors affecting the functioning of children and their families. [D2]
7. In evaluating the effects of an intervention program, it is important to include family-related measures as well as child-oriented outcomes. [D2]

### **General Approach for 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. In addition to these traditional therapies, there is also a diverse collection of therapeutic models and techniques that are sometimes referred to as “complementary” or “alternative” (such as aquatic therapy or therapeutic horseback riding). These approaches vary greatly in how commonly they are used, the time commitment required (intensity), cost, availability, and potential benefits and harms.

Parents and family members are likely to seek information about their child’s disability, and they are likely to find many sources of information about intervention options, including tempting claims that a particular intervention will lead to a dramatic improvement in the child’s condition. Parents need to understand how to evaluate this information and professionals who want to work effectively with parents need to understand how to help them make intervention decisions.

Some interventions for children with motor problems may not have established efficacy for improving motor skills, but may still benefit the child if the interventions provides physical activity, opportunities for social interaction, or otherwise facilitate the child’s overall development. These interventions might be considered to supplement or complement those interventions that focus more specifically on motor development and function.

Regardless of the specific intervention being considered for a particular child, the decision-making process is the same. Therefore, the focus of this section is

the general decision-making process for considering intervention approaches for young children who have a motor disorder. Table 11 (page 120) suggests questions to consider when evaluating various interventions.

### **Recommendations (General Approach for Selecting Interventions)**

*Considering evidence about efficacy when selecting intervention methods*

1. It is important for professionals to recognize that parents often seek out and receive information about a variety of intervention approaches from multiple sources. Because information about some interventions may be limited or incorrect, it is important for both professionals and parents to evaluate the accuracy of such information, rather than taking claims of effectiveness at face value. [D2]
2. It is important for both professionals and parents to understand how to assess the accuracy of information about intervention methods and how to evaluate the effectiveness of an intervention. [D2]

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**Table 11: Questions to Ask When Selecting Interventions**

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

*Adapted from: Nickel 1996*

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3. 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 since they do not adequately control for factors that might bias the study results
  - The best way to assess the effectiveness of interventions is to rely on the results of controlled research trials and other well-designed research studies that attempt to control for placebo and maturation effects, the natural history of the condition, and other potentially confounding factors that might bias the study results
  - The results may vary for individual children regardless of the study results [D2]

*The role of professionals when helping parents make decisions about interventions*

4. It is important for professionals to ensure that families have information about and access to the range of early intervention services (standard services such as physical therapy, occupational therapy, and speech therapy) and are actively involved in intervention decisions. [D2]
5. It is important that professionals and parents work together to make informed decisions about interventions for the child. When talking to parents about intervention options, the role of the professional includes:
  - Being knowledgeable about the proposed benefits, the time commitments, the possible harms, and costs of standard intervention methods as well as new or alternative interventions.
  - Being open to discussing alternative interventions whenever parents ask questions about such methods, and scheduling adequate time for this when intervention options are discussed with parents
  - Making sure that any discussions about complementary or alternative interventions provide accurate information about the intervention while making it clear that the discussion is not an endorsement of the intervention
  - Giving informed opinions to parents about the possible efficacy and potential side effects or harms of the interventions being considered, and providing information about whether there is any adequate scientific evidence regarding these issues
  - Being supportive and helpful in the decision-making process [D2]
6. When considering any intervention, it is recommended that parents and professionals address the questions in Table 11 (page 120) together as an aid to decision making about the use of a particular intervention. [D2]



**Early Intervention Policy** ❖ The Individualized Family Service Plan (IFSP) must be in writing and have the required components as specified in program regulations 10 NYCRR Section 69-4.11 (10). (See Appendix D for Early Intervention Program regulations.) The full regulations are available at [http://www.health.ny.gov/community/infants\\_children/early\\_intervention/index.htm](http://www.health.ny.gov/community/infants_children/early_intervention/index.htm)

### *Developing the overall intervention plan and coordinating activities*

7. It is important that an overall intervention plan be developed for the child by professionals in conjunction with the parents, and that this plan:
- Defines goals for the intervention program and identifies objective outcome measures for these goals
  - Ensures all individual intervention components are compatible and coordinated to avoid any potential conflicts and ensures they are consistent with the overall intervention goals for the child and family
  - Provides for baseline and ongoing assessment of the child's progress, and specifies the methods, schedule, and criteria for such periodic assessments
  - Provides for appropriate modification or discontinuation of the intervention based on periodic assessment the child's progress [D2]



**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. 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 (see Appendix D).

### *Using periodic assessments to monitor progress and modify the treatment plan*

8. It is recommended that the initial and periodic assessments of the child's progress include:
- An objective measure of the child's motor development (such as the Gross Motor Function Measure, Toddler and Infant Motor Evaluation, or Peabody Developmental Motor Scales)
  - An objective measure of the child's overall level of adaptive and independent functioning (such as the Pediatric Evaluation of Disability Inventory, Functional Independence Measure for Children, or Battelle Developmental Inventory)
  - Direct observation of the quality of movement by the professional
  - General impressions from parents and other professionals working with the child regarding the child's progress in motor development, and adaptive independent functioning [D2]

**Note:** Additional information about assessment tests can be found in Chapter III, page 57, and in Appendix C.

9. In using standardized tests to assess a child's progress, it is important that:
  - The tests be given at the beginning and at scheduled periodic intervals throughout the intervention program
  - The tests used be developmentally appropriate and consider cultural factors when possible
  - The same tests be used for initial and periodic assessments (unless changes in the child's developmental level require the use of different tests)
  - Test results be analyzed longitudinally to see patterns of change over time
  - Test results be used along with other information to help determine if the intervention program is effective, if interventions may need to be modified or discontinued, and/or if other interventions may be needed [D2]
10. When evaluating the child's progress over time and deciding whether specific interventions are effective or if the intervention plan needs to be modified, it is important to recognize that:
  - When children are receiving multiple interventions at the same time, it may be difficult to assess the effectiveness of any individual therapy
  - Some interventions may also benefit other developmental areas (not just motor development), and this may be a factor in determining the effectiveness of an intervention
  - 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
  - Understanding the clinical features of the condition and results of imaging studies can often provide useful information about the prognosis for an individual child and may provide anticipatory guidance to professionals and parents in designing intervention programs [D1]
11. If periodic assessments suggest a child's motor skills and overall functioning are not progressing as expected, possible explanations might include:

- The type of interventions used are not effective for the child
- The assessment methods used might not be appropriate or might not adequately reflect progress being made by the child
- The frequency or intensity of the interventions are not sufficient to show any effect
- Some other health or developmental factor is interfering with the child's development in this area [D2]

### *Qualifications and experience of professionals providing interventions*

12. It is essential that all professionals providing and supervising interventions for young children who have a motor disorder:

- Have experience working with young children who have a motor disorder
- Have specific training for the intervention method
- Understand the developmental and health problems commonly associated with motor disorders and the implications for specific intervention methods
- Receive relevant information about the child's health status and associated health conditions, such as cardiac or respiratory problems, that may affect the way in which the intervention is implemented
- Understand the importance of monitoring the child's health status and tolerance for motor activities during the intervention
- Have skills in promoting and supporting the participation of parents as team members within the context of the family's strengths and needs
- Have appropriate certification, when applicable [D2]

### **General Focus for 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), while fine motor development refers to the use of the hands and fingers. Interventions that target motor development focus on both gross motor development and fine motor development.

The primary problems of most young children who have a motor disorder are lack of postural control and atypical muscle tone. Therefore, this is an important focus of early intervention for children who have a motor disorder.



**Recommendations (General Focus for Motor Interventions)**

*General considerations for planning interventions for children who have a motor disorder*

1. It is recommended that when developing intervention goals for children who have a motor disorder, the goals reflect the functional skills that parents believe are relevant to the child within the context of the family and physical environment. [D2]
2. Activities that promote infant cognitive stimulation are recommended as an important component of any intervention program for young children who have a motor disorder.  
*[B] (Reddihough 1998)*
3. When planning interventions for a child with 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. Therefore, it may be important to include interventions directed toward the child's cognitive development. [D1]
4. It is important to plan for generalization of learned motor skills so that these skills can be applied with different people, in different settings, and in response to different stimuli.  
*[B] (Horn 1995)*
5. It is important to begin motor intervention either for specific motor problems or when attainment of early motor milestones is delayed in order 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 secondary to persistent atypical postures
  - Provide education and support to parents (e.g., to teach positioning and handling) [D2]

*General considerations for the hospitalized child*

6. It is recommended that developmental supportive care (Table 12, page 126), a comprehensive, family-oriented approach, be provided for premature infants in the neonatal intensive care unit (NICU) and for neonates with abnormal neuromotor findings. [D2]

**Table 12: Important Components of Developmental Supportive Care**

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- 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 children birth to age 4 months*

7. It is recommended that motor intervention for young children who have a motor disorder (birth to age 4 months) focus on development of postural control (ability to control head and trunk). Development of appropriate postural control as well as specific motor skills will help to facilitate future development. Poor postural control as an infant may lead to the use of compensatory patterns that result in future problems with motor development. Therefore, some important areas to focus on are:
  - Tactile exploration of the infant's body with his own hands, such as hand to face/head, chest, and feet
  - Orientation to midline, such as hand to hand, hands to feet, and foot to foot
  - Symmetrical rolling
  - Graded weight shifting in prone and supine in preparation for transitional abilities and moving from horizontal skill development (birth to 6 months) to vertical skill development (7 to 12 months)
  - Hand to foot/knee play in supine to develop abdominal strength
  - Prone play to develop neck, hip, and trunk strength

*[B] (Girolami 1994, Cannon 1987)*
8. It is recommended that the focus on fine motor interventions begin as early as 2 to 4 months of age. This provides the foundation for later refinement of skill. Important components of intervention at this age should include:
  - Weight bearing to inhibit the grasp reflex
  - Activation of 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 [D1]

*General considerations for children age 4 to 12 months*

9. It is important to continue motor interventions related to postural control as the child develops during the first year. It is important that these interventions focus on the following gross and fine motor skills:
  - Development of the ability to move against gravity to bring hands to midline and to mouth (fine motor)

- Development of postural control for head and upper trunk righting and upper extremity weight bearing in prone (lying on stomach) position (gross motor)
  - Development of sufficient trunk and head control for proper alignment in sitting position (gross motor)
  - Development of postural control, scapular stability, and upper extremity strength to support fine motor control (fine motor)
  - Ability to transition from prone to sit, sit to hands and knees, and sit to stand (gross motor)
  - Development of a variety of sitting (ring sit, long sit, side sit, etc.) positions (gross motor)
  - Development of sufficient strength in the legs to support the development of standing (gross motor)
  - Development of transitional movements and mobility (rolling pivot prone, belly crawling, getting in and out of sitting, etc.) for exploration of the environment ((gross motor)
  - Development of appropriate postural control for weight bearing (both gross and fine motor) [D1]
10. If weakness underlies abnormalities of passive muscle tone, strengthening exercises may be appropriate after the age of 4 months. This may be important in some young children who have a motor disorder to strengthen muscles needed for joint stability and for postural reactions. Resistive activities may be used when a background of normal muscle tone is maintained. These may include:
- Gentle, graded manual resistance
  - Playing with developmentally appropriate toys of varying weights
  - Picking up small objects
  - Lifting, carrying, and pushing toys [D1]
11. 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 movement and strength of legs for transitions, weight bearing, and development of walking skills (gross motor)
  - Sufficient development of pelvis movement in relation to the legs and spine to enable transitions such locomotion (such as creeping and cruising) and pull to stand (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) [D1]

*General considerations for children age 12 to 24 months*

12. It is recommended that intervention for development of gross and fine motor skills be continued in children who have a motor disorder. Important components of intervention for children from 12 to 24 months include:
- Development and refinement of unsupported walking (gross motor)
  - Climb on and off furniture (gross motor)
  - Creep 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) [D1]

*General considerations for children after age 24 months*

13. It is recommended that intervention for development of gross and fine motor skills be continued in children who have a motor disorder. Important components of intervention for children who are developmentally at least 24 months include:
- Fast walking/early running (gross motor)
  - Begin to walk up and down stairs with support (gross motor)
  - Attempt to stand on one foot (gross motor)
  - Attempt to jump (gross motor)
  - Propel a ride toy (gross motor)
  - Begin 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, puzzles, turning knobs, and lids (fine motor) [D1]

14. Behavioral modification may be beneficial when used in conjunction with other intervention techniques to target improvement of specific motor skills. While children generally benefit from positive reinforcement, more specific behavior modification techniques may be more effective in children who are at least 2½ years old.

[A] (Bragg 1975, Horn 1995)

### *Intervention cautions*

15. The use of baby walkers, “exersaucers,” “jolly jumpers,” and other similar equipment is not recommended for children who have a motor disorder. These are not recommended because:
- Some of this equipment is associated with injuries in young children (American Academy of Pediatrics)
  - Items may encourage stereotypic movement patterns that tend to delay the development of typical motor skills
  - Children who have a motor disorder tend to stiffen their legs and stand on their toes, and therefore are not able to maintain good alignment while using this kind of equipment [D2]
16. 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, to prevent the development of harmful postures. 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). [D2]

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**MOTOR THERAPY APPROACHES AND TECHNIQUES**

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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Motor therapy, as used in this guideline, is intended to be a broad term that includes various approaches and techniques that are used primarily within the context of a physical or occupational therapy program. For children who have or are at risk for a motor disorder, physical therapy and/or occupational therapy are usually significant components of a child's intervention plan. The recommendations in this section focus on specific approaches and techniques. But more often than not, physical and occupational therapy interventions incorporate an integrated combination of techniques and approaches based on the needs of the child.

Topics in this section include:

- Therapeutic Exercise
- Neuromotor and Sensorimotor Interventions
  - Neurodevelopmental Treatment (NDT)
  - Sensory Integration Therapy (SI)
- Neuromuscular Electrical Stimulation and Vibratory Stimulation
  - Neuromuscular Electrical Stimulation
  - Therapeutic Vibratory Stimulation
- Manual Therapies
  - Infant Massage
  - Myofascial Release Treatment (MFR)
  - Craniosacral Therapy
  - Joint Mobilization (including spinal manipulation)
- Specialized Exercise Interventions
  - Therapeutic Horseback Riding (hippotherapy)
  - Aquatic Therapy

### *Basis for the recommendations in this section*

The recommendations for motor therapy approaches and techniques include a combination of both evidence-based and panel consensus recommendations. The evidence-based recommendations are derived from the scientific literature that met the criteria for evidence. Some of the consensus recommendations in this section relate to topics for which a literature search and review to identify evidence was done, but no evidence meeting the criteria for this guideline was found. Other consensus recommendations relate to approaches for which the literature was not specifically reviewed. In the panel's opinion, these consensus recommendations reflect appropriate practices for providing interventions to young children who have a motor disorder and are generally consistent with the scientific knowledge in this field.

### **Therapeutic Exercise**

Motor therapy interventions generally occur within the context of a physical and/or occupational therapy plan and are often a major part of the intervention strategy for a child with a motor disorder. A core component of motor therapy interventions is often a therapeutic exercise program in combination with other therapeutic techniques to meet the needs and achieve the goals for the child. The principles guiding such interventions are generally the same as those described in exercise physiology and sports and physical education programs, but with variations and precautions to address the needs of young children with suspected or identified motor disorders. Numerous government and professional organizations have developed and issued guidelines for physical fitness and exercise that apply to therapeutic exercise as well (American Academy of Pediatrics 2000, National Association for Sport and Physical Education 1998, United States Department of Health and Human Services 1996).

Therapeutic exercise may include 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 13, page 133) and can be designed to address large muscle groups and gross motor function or can be very focused on specific movements and fine motor function.

### **Recommendations (Therapeutic Exercise)**

1. It is important to understand that:
  - Therapeutic exercise is an important component of intervention programs for young children who have a motor disorder



- There is not a single specific approach or technique that can be prescribed for all children who have a motor disorder
  - Therapeutic exercise and other motor therapy programs will vary widely depending on the strengths and needs of the child [D1]
2. It is recommended that a continuum of integrated intervention strategies that incorporate appropriate therapeutic exercise be tailored to the needs of the child as the child's development and independence progresses. [D1]
  3. It is recommended that monitoring of the child's progress be an ongoing aspect of all therapeutic exercise and other motor therapy interventions, and that the intervention strategies and approaches be adjusted as needed in order to ensure that the child is making progress toward intervention goals. [D1]

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**Table 13: Basic Exercise Definitions**

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**Passive Exercise**

Exercise during which a part of the body is moved, usually by someone else, without active participation or contraction of the muscles used to move that part. This is typically used to maintain or increase the flexibility (range of motion) of joints and muscles that perform functional movements and to prevent contractures and/or deformities.

**Active-Assistive Exercise**

Exercise during which there is some active, contractile effort on the part of the muscles used to perform the movement but with assistance from an external source. The assistance may be provided because of muscle weakness or because of precautions against using full active force by the individual.

**Active Exercise**

Exercise during which the muscles required to execute the movement are performing the entire movement with no external assistance.

**Resistive Exercise**

Exercise during which an external force (such as weights, manual resistance, etc.) 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.

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### Neuromotor and Sensorimotor Interventions

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

#### *Neurodevelopmental treatment (NDT)*

Neurodevelopmental treatment (NDT) is currently a widely used therapy approach in the United States for children with neuromotor problems. NDT is a treatment approach based on a theoretical framework developed in the 1940s by Dr. Karel Bobath and his wife, Berta Bobath. The approach is sometimes referred to as the *Bobath technique*. One of the basic tenets of the NDT approach is the belief that “control of movement is based on a complex interaction of many body systems that are plastic and adaptable, as well as on the tasks presented and the environments in which the tasks are performed. Therefore, function can be altered by changing any one or all of the elements” (Bobath 1972).

The stated goal of NDT is to improve the efficiency and quality of functional movement in individuals with neuromotor impairment. To achieve this goal, a primary focus of NDT is to facilitate optimal postural alignment and postural control. The treatment method advocated is the use of graded sensory input by careful handling and positioning of the child as well as active participation of the child through practice and repetition of skills to be learned. Family involvement (such as teaching parents appropriate methods for positioning, carrying, and handling their child) is crucial for the effective provision of NDT.

#### *Sensory integration therapy (SI)*

Sensory integration therapy (SI) is based on a theoretical framework that was initially proposed in the 1960s by Dr. A. Jean Ayres. Dr. Ayres, an occupational therapist, was instrumental in developing the theory of sensory integrative dysfunction in children. This theory proposes a neurobiological process that receives and organizes sensory input (such as touch, taste, smell, visual and auditory stimuli, etc.). Sensory integrative dysfunction is defined as a “disorder in brain function that makes it difficult to integrate sensory input and may result in varying degrees of problems in development, learning, and behavior” (Sensory Integration International 1991).

Sensory integration therapy is based on an approach that evaluates children for sensory processing disturbances and provides them with the appropriate sensory stimulation to elicit an adaptive response from the child. The stated goal of SI

therapy is to assist in the organization of varied sensory input for functional interaction in the environment. It is purported that this may facilitate the development of the nervous system's ability to process sensory input and may help young children who have movement problems integrate sensory input experiences with active body movement to produce increasingly complex adaptive responses (Sensory Integration International 1991). Sensory experiences may include sight, sound, touch, movement, or balance. The sensory experiences used generally include goal-oriented play that provides opportunities for enhanced sensory intake.

### **Recommendations (Neuromotor and Sensorimotor Interventions)**

#### *General approach – neurodevelopmental treatment and sensory integration therapy*

1. It is important to understand that the scientific research evidence meeting the criteria for this guideline did not sufficiently demonstrate the effectiveness of interventions based on either neurodevelopmental treatment (NDT) or sensory integration therapy (SI) approaches for improving motor development or function in young children who have a motor disorder.

*[A] (DeGangi 1983, Girolami 1994, Goodman 1985, Jenkins 1988, Piper 1986, Rothberg 1991, Sellick 1980, Weindling 1996)*

2. As for any child, facilitating postural alignment and postural control, in addition to incorporating varied sensory activities such as movement into therapeutic intervention approaches, may be beneficial to overall development. [D1]
3. It is important that when NDT and SI techniques are used, they support the attainment of specific intervention goals. [D1]
4. It is important to recognize that 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.

*[B] (Palmer 1988)*

5. NDT intervention, when combined with behavioral programming, may be useful for children who have a motor disorder. Specifically, this approach may be effective for teaching movement components that are incorporated into functional skills or for teaching appropriate postures.

*[A] (Bragg 1975, Horn 1995)*

6. A combination of NDT and structured, nonspecific play sessions may be beneficial as a component of the intervention approach for young children who have a motor disorder. [D1]

7. It is important that professionals who use the principles and techniques of NDT and SI have appropriate licensure, training, and experience in their application with young children. [D1]

### *Neurodevelopmental treatment for preterm infants*

8. It may be useful to provide NDT to preterm infants with an abnormal neuromotor exam 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.  
*[B] (Girolami 1994, Goodman 1985, Rothberg 1991)*
9. When providing motor intervention (such as NDT) to hospitalized neonates, it is very important to provide the intervention in the context of developmental supportive care (Table 12, page 126) and with consideration given to the child's special medical needs and health status. [D2]

### *Using NDT and upper extremity casting*

10. 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, increased range of motion, and hand functioning.  
*[B] (Law 1991)*

### *Rotary movement therapy (vestibular stimulation)*

11. 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.  
*[B] (Sellick 1980)*

## **Neuromuscular Electrical Stimulation and Vibratory Stimulation**

### *Neuromotor electrical stimulation*

Neuromotor electrical stimulation (NMES) is stimulation of a muscle with electrical current/impulses for the purpose of strengthening the muscle and preventing atrophy (muscle wasting) of the muscle from disuse. Disuse atrophy is often part of the disability/impairment of neurologically involved individuals.

Neuromotor electrical stimulation (NMES) is used to produce a muscle contraction when applied. Threshold electrical stimulation (threshold ES) uses low-intensity, transcutaneous electrical stimulation to elicit a muscle contraction

during functional activities for motor learning, strengthening, and increasing sensory awareness. Threshold ES can also be used during sleep without stimulating muscle contraction. Threshold ES used during sleep is aimed at stimulating growth and repair of muscle tissue from increased circulation and metabolic activity rather than from muscle contraction. NMES may be prescribed for children who might benefit from:

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

Electrical stimulation must be medically prescribed, and only trained practitioners with degrees in medicine, physical therapy, or occupational therapy may provide the treatment.

#### *Therapeutic vibratory stimulation*

Therapeutic vibratory stimulation, or muscle vibration, is a technique that is sometimes used as a component of a physical, occupational, or speech/language therapy approach. Two general purposes for using this technique are described:

- To facilitate contraction of the muscle being vibrated
- To normalize hypersensitive skin interfering with oral-motor activity (Heiniger 1981)

The 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).

**Recommendations (NMES and Vibratory Stimulation)**

*Neuromotor electrical stimulation*

1. It is important to understand that there was no scientific research evidence meeting the criteria for this guideline that demonstrated the effectiveness of NMES for improving motor development or function in young children who have or are at risk for a motor disorder. [D1]
2. It is important that if used, electrical stimulation be medically prescribed and that it be used as a complement to other motor therapy approaches. [D1]
3. It is recommended that when electrical stimulation is prescribed, it is used as a component of the total intervention plan and that the goals and objectives for the electrical stimulation are closely coordinated with goals and objectives of other therapies the child may be receiving. [D1]
4. When electrical stimulation is prescribed for a young child who has motor disorders, it is important that it is always kept within the child’s tolerance and that:
  - The child’s tolerance be monitored closely
  - Parameters (ramp time, pulse rate, amplitude) be administered according to a prescribed protocol with a period of gradual acclimation to the input of electrical stimulation, including:
    - Stimulation begins at low level input to stimulate sensory awareness and no muscle contraction
    - Gradually progress to increasing levels of stimulation with regard to ramp time (time for contraction to be generated), amplitude (strength of contraction), and pulse rate (length of contraction)[D1]
5. It is recommended that all professionals licensed to administer electrical stimulation who work with young children be specifically trained for this procedure. [D1]
6. It is important to consider the child’s functional activity and use informed clinical judgment combined with parent feedback on results/carryover of previous placement when determining electrode placement. [D1]
7. It is recommended that the professional 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. [D1]

8. It may be helpful to simulate the sensation of electrical stimulation using a handheld vibrator and to allow the child to become accustomed to this sensation before beginning electrical stimulation treatment. [D1]
9. It may be useful to use electrical stimulation in conjunction with other approaches such as dynamic splinting and night splinting. [D1]

#### *Therapeutic vibratory stimulation*

10. Therapeutic vibratory stimulation may be a useful adjunct to other intervention approaches to help stimulate activation of weak muscles.  
*[B] (Cannon 1987)*
11. It is important to carefully monitor children receiving vibratory stimulation for possible adverse behavioral, physiological, or neurological reactions. [D1]
12. When used, it is important that vibratory stimulation be applied only by licensed professionals following specific protocols for young children and with vibrators that have FDA approval for this method. [D1]

### **Manual Therapies**

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

#### *Infant massage*

Massage is a sensory intervention defined as the manipulation of soft tissue for therapeutic purposes (Watson 1998/1999). Massage can be adapted for children who are medically fragile or have special needs (Drehobl 1991). While no evidence was found that massage therapy changes motor function, current research is investigating possible 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.

There are several techniques used for infant massage, including swaddling, gliding strokes, gentle friction, simple sustained placement, and skin-to-skin contact (“kangaroo care”). If massage oil is used, a cold pressed nut or fruit oil without preservatives may be suitable as massage oil, provided the child is not allergic to them. Oils that contain petroleum products (such as mineral oil) are not suitable for young children because of the risk of ingestion.

### *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 stiff and restricted, thus restricting other tissues underlying the injured area of fascia as well as more distant structures. In this conceptual model, the myofascial (muscle-fascia) restrictions then contribute to asymmetries, malalignment, and restricted mobility (Barnes 1990). Myofascial release treatment includes stretching and massagelike techniques and soft tissue manipulation designed to release myofascial constrictions.

### *Craniosacral therapy*

Craniosacral therapy is a manual therapy approach based on a theoretical model for evaluating and treating dysfunction within the craniosacral system. Cranio refers to the head and sacral refers to the tailbone or base of the spine. The anatomic parts of this system include the meningeal membranes (the lining around the brain) and all the bony structures and connective tissue structures related to the meningeal membranes, and the cerebrospinal fluid and all structures related to production, reabsorption, and containment of the cerebrospinal fluid. Evaluating and treating dysfunction in the craniosacral system is based on the premise that the craniosacral system is characterized by rhythmic mobile activity that can be palpated on the head. Craniosacral therapy techniques are usually indirect in nature (such as massagelike techniques applied to the head). Craniosacral therapists say they rely on the client's own self-corrective process to assist the body in its own rehabilitation and to remove the various restrictions found within the system (Upledger 1987).

The four major contraindications for craniosacral treatment are acute intracranial hemorrhage, intracranial aneurysm, recent skull fracture, and herniation of the brainstem through the foramen magnum of the skull.

### *Joint mobilization therapy (including spinal manipulation)*

Joint mobilization is any passive movement technique utilizing 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 painless movement. It is used when there is mechanical joint dysfunction.

Joint mobilization is used when there is restriction in joint motion (range of motion) due to pain, capsular tightness, ligamentous adhesions, joint effusion, subluxation, or intraarticular derangement. Young children usually do not have



capsular restrictions. Therefore, full joint range of motion is usually facilitated through neuromotor treatment approaches without the need for joint mobilization. Skilled application of joint mobilization techniques in combination with neuromotor treatment to increase active and passive movement may be more appropriate for some older children with long standing hypomobility of joints, capsular tightness, and adhesions that restrict joint movement.

### **Recommendations (Manual Therapies)**

#### *Infant massage*

1. 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. [D1]
2. For some infants, infant massage therapy may be useful to calm the child, facilitate muscle relaxation, or promote weight gain. Infant massage may also help to promote parent/child interaction and develop parent confidence in taking care of the child. [D1]
3. Before initiating massage therapy for any child, it is important to ensure that there are no health-related or other contraindications. Examples of possible contraindications include:
  - Respiratory or cardiac problems
  - Acute infections (especially upper respiratory infections)
  - Pitting edema, hemophilia, high blood pressure, skin disorders (especially infectious disorders such as impetigo or ringworm)
  - Burns, fractures, osteogenesis imperfecta, or hernias. [D1]
4. 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 a young child. [D1]
5. It is important to understand that the response to infant massage will vary from child to child and that an individual child's response may vary from one massage to the next. [D1]
6. It is important to understand that the use of light stroking may be aversive to many infants. [D1]
7. It is recommended that for children who appear to benefit from infant massage therapy, parents, family members, and/or caregivers learn appropriate techniques for massaging their child. It is important to ensure that a qualified professional instructs the family/caregiver in appropriate infant massage techniques. [D1]

### *Myofascial release treatment and craniosacral therapy*

8. It is important to recognize that the benefits of myofascial release treatment and craniosacral therapy for young children who have a motor disorder have not been demonstrated in the scientific literature. [D1]
9. If myofascial release treatment or craniosacral therapy is being considered, it is important that this be done within the context of the overall physical or occupational therapy treatment plan for the child. [D1]
10. If myofascial release treatment or craniosacral therapy is used as a component of the therapy plan, it is important that the therapist:
  - Be knowledgeable and experienced in the use of these techniques with young children
  - Have knowledge of the child's overall health status and any possible contraindications
  - Monitor the child's response to treatment techniques with modification as needed to continue progress toward the intervention goals [D1]
11. Absolute contraindications for craniosacral therapy include:
  - Acute intracranial hemorrhage
  - Intracranial aneurysm
  - Recent skull fracture
  - Herniation of the brainstem through the foramen magnum of the skull [D1]

### *Joint mobilization (including spinal manipulation)*

12. Joint mobilization (including spinal manipulation) is not recommended for children under the age of 3 years 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). [D1]
13. Absolute contraindications for joint mobilization include:
  - Bacterial infection
  - Neoplasm
  - Recent fracture
  - Malignancy of vertebral column
  - Joint fusion or ankylosis
  - Hypermobility of the joint

- Signs or symptoms of spinal cord involvement, including Cauda equina lesion producing disturbance of bowel and bladder function [D1]

### **Specialized Exercise Interventions: Therapeutic Horseback Riding (Hippotherapy) and Aquatic Therapy**

#### *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 1) mobilization of the pelvis, lumbar spine, and hip joints; 2) activation of head and trunk musculature; 3) development of head and trunk postural control; and 4) 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 walking horse. Sometimes the therapist and child will ride together so the therapist can facilitate the movement. The horse is usually led at a walking pace by a skilled equestrian to ensure safety.

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. For young children who have a motor disorder, as with all children in this age group, the potential for injury that may result from horseback riding needs to be considered when deciding whether to use this intervention approach.


#### *Aquatic therapy*

Aquatic therapy is a swimming and aquatic exercise program that employs neuromotor treatment principles in combination with underwater exercise techniques. The water is used to assist the child's production of movement and control. Aquatic therapy is sometimes used as part of a comprehensive physical activity program for children with motor and other developmental disabilities. According to proponents of aquatic therapy, one indication for its use is reduced lung capacity. Proponents believe that aquatic exercise will improve respiratory function, including the modification of learned postural responses that prevent efficient breathing. Aquatic therapy is usually 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.

**Recommendations (Hippotherapy, Aquatic Therapy)**

*Therapeutic horseback riding (hippotherapy) and aquatic therapy*

1. It is important to recognize that no evidence meeting the criteria for this guideline was found demonstrating the effectiveness of therapeutic horseback riding or aquatic therapy in improving specific motor outcomes in young children. [D1]



**Early Intervention Policy** ❖ For interventions such as aquatic therapy and hippotherapy, the Early Intervention Program 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. However, EIP does not reimburse for other program expenses such as fees for the pool or the horse. Qualified personnel are listed in Appendix D.

2. There may be benefits such as physical activity, more independent mobility, social interaction, confidence building, and other nonmotor outcomes from interventions such as aquatic therapy when used within the context of the child’s overall occupational or physical therapy intervention plan. [D1]
3. It is recommended that therapeutic horseback riding generally not be considered as an appropriate intervention for young children who have a motor disorder because the benefits of it for improving motor outcomes have not been demonstrated and because of the potential risk for injury, especially for children who are under 3 years of age. For some older children, there may be benefits such as physical activity and other nonmotor outcomes associated with this intervention. [D1]
4. Before beginning any new therapy for a young child with motor impairment, it is important that the child’s health status be considered to ensure that no contraindications to the therapy exist. [D2]
5. It is recommended that any intervention be tied to ongoing assessment of the child’s response to the intervention (using both motor function and functional measures) with modification of the intervention plan as appropriate. [D2]
6. It is important that interventions such as therapeutic horseback riding and aquatic therapy be implemented by knowledgeable and experienced providers who:
  - Have specific training for the intervention method

- Understand the developmental and health problems commonly associated with motor disorders and the safety and other implications for the specific intervention provided [D1]

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**ASSISTIVE TECHNOLOGY AND ADAPTIVE DEVICES**

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section addresses the use of various assistive technology devices for young children who have a motor disorder. The recommendations address assistive technology devices such as adaptive positioning equipment, mobility devices, and augmentative communication. The use of orthotics, splints, and casting is also included in this section. Topics include:

- Assistive Technology
- Orthotics (including splints and casts)

*Basis for the recommendations in this section*

The recommendations for assistive technology and adaptive devices for young children who have a motor disorder include both evidence-based and panel consensus recommendations. The evidence-based recommendations are derived from the scientific literature that met the criteria for evidence for this section. Some of the consensus recommendations relate to topics for which a literature search and review to identify evidence was done, but no evidence meeting the criteria for this guideline was found. Other consensus recommendations relate to approaches for which the literature was not specifically reviewed.

**Assistive Technology**

The Individuals with Disabilities Education 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 that it should allow the child to complete tasks at a higher level of efficiency with the device than without it.

Assistive technology devices can change the physical characteristics of the child's environment to assist the child in performing many activities of daily life independently. Devices that fall into this category can be either low-technology

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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 craftsman, or rehabilitation engineer. Those devices that are commercially available can be accessed through an equipment vendor, specialty catalogs or health care stores.



**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.

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

- Adapted positioning and specialized seats (such as adapted strollers, seat inserts, or prone standers) for a child who lacks postural stability and has atypical muscle tone affecting the acquisition of developmentally appropriate motor skills
- Mobility devices to allow independent exploration of the environment when motor skills are limited. This may include manual wheelchairs, powered mobility, or other ambulation devices such as walkers
- Augmentative communication devices (such as picture boards) including use of assistive technology devices, when appropriate, to promote communication when speech is delayed/difficult
- Alternative access methods for learning or achieving a new skill such as adapted switches (e.g., switch toys, a joystick, head switch, or light-scanning system)

### *Augmentative communication*

Some children may require augmentative communication, especially when speech is not an effective mode of communication. In some children, the need for augmentative communication may be transitional or temporary.

Augmentative communication involves using various methods and/or equipment to assist in communication. An augmentative communication system may be a composite of communication components, which may include communication strategies, manual signs, and a variety of communication devices such as a manual communication board, a computer, or a dedicated electronic device.

### **Recommendations (Assistive Technology)**

#### *General approach for assistive technology*


1. It is recommended that the need for assistive technology be considered for all children who have a motor disorder and that this need be reassessed on an ongoing basis. [D2]
2. Assistive technology devices are recommended for children with motor impairments when the use of such a device is recognized as having a potential benefit for the child and family. Potential benefits may include:
  - Increased ability to actively participate in interactions with peers
  - Improved self-esteem and self-identity, and feeling control over the environment
  - Increased independence and decreased potential for learned helplessness
  - Facilitating development of communication, mobility, and self-care abilities
  - Reduced energy expenditure when performing tasks
  - Providing greater physical comfort (including minimizing pressure ulcers and musculoskeletal deformities) [D1]
3. It is important that any assistive technology selected must have purpose and meaning for both the child and the parent. It must be practical and feasible for the family to use. Assistive technology provides no benefits if it is not used. [D2]
4. It is essential that the professionals recommending the assistive technology or providing intervention services to the child:
  - Be knowledgeable about assistive technology in general as well as the particular device being recommended
  - Be sensitive to parental readiness and to the emotional response of family members when assistive technology is prescribed

## CHAPTER IV: INTERVENTION

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- Understand (and make sure parents understand) that these devices may be temporary and that their immediate benefit is to assist in the child’s interaction with the environment and the accomplishment of new skills
- Educate families about assistive technology to:
  - Help them make the best decision for their child
  - Ensure that it is used appropriately and as prescribed (and not abandoned if family has problems using or adjusting to the device)
  - Ensure the family understands how to properly maintain and care for the device
  - Monitor the use of the assistive technology to ensure that:
    - It is meeting the needs of the child and family
    - It is not overused based on nominal success [D1]
- 5. It is important for parents 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 and often provides an opportunity to learn new skills. [D1]
- 6. It is important to understand that while assistive technology may improve some aspects of the child’s functional capabilities, it will not “fix” or “cure” the motor disorder. [D1]
- 7. It is important to include the physician as part of the team in making decisions about appropriate assistive technology. [D2]

### *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 they are eligible for the Medicaid program.

- 8. 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. [D1]

9. Factors that need to be considered when selecting assistive devices include:
  - The specific needs of the child and family
  - The potential for improving the child's function
  - The child's cognitive abilities
  - The child's sensory function, including vision and hearing status and other sensory and perceptual abilities
  - The child's anticipated growth and developmental trajectory
  - Health considerations such as airway, respiration, and gastrointestinal problems
  - The impact on the family (benefit versus cost and time commitment, etc.)
  - The specific cultural and environmental context of the family
  - Ease of use and need for training [D1]
10. It is recommended that when possible, the family be given an opportunity to see and try the device, and have a trial period using the assistive technology. [D1]
11. It is important to recognize that some assistive devices are more appropriate for older children or children at a higher developmental level (such as high-technology computerized voice output systems). [D1]
12. It is important to recognize that some assistive 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. [D2]
13. When an assistive device has been selected, it is important that appropriate training in the use of the device be provided for persons who are involved with the child and that this training be done by professionals with appropriate expertise in the use of the assistive device. [D2]

#### *Adaptive positioning devices*

14. 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. While there is no evidence that these devices improve physiologic functioning (respiration, GI, bone density, etc.) in young children, these devices may help to:
  - Improve safety, efficiency, and ease of care

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- Promote active participation of the child in daily activities such as eating, bathing, play, preacademic activities, and functional communication
  - Some adaptive seating devices may facilitate pulmonary function while the child is in the device [D1]
15. It is recommended that adapted positioning should be considered when a child is no longer able to be safely or properly maintained in commercially available daily care equipment such as bathers, carriers, or strollers. Additional attention should be given to positioning devices that may improve the young child's ability to play and interact with the environment (such as side lying or adapted seating systems). [D1]
16. When selecting adaptive seating, it is important to consider health issues such as respiratory problems. [D1]

### *Mobility devices*

17. It is recommended that mobility devices be considered for children who have a motor disorder when it is clear that independent movement will not be possible at the age when typically developing children first develop this skill, and for children who are not expected to develop independent mobility without such devices. [D1]
18. It is important to consider the following child characteristics and abilities when considering the use of a wheelchair:
- Adequate cognitive functioning and behavioral skills to operate safely (for children who are expected to self-propel)
  - Adequate motor skills to operate the equipment or access the controls
  - Adequate awareness of spatial relationships [D1]
19. If a mobility device such as a wheelchair is being considered, it is important to assess the home environment (stairs, size of doors and hallways, and options for transporting the wheelchair). [D2]



**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.

20. It is important to recognize that in general, power wheelchairs are seldom needed or appropriate in children under the age of 3 years. [D1]

*Considerations for use of augmentative communication*

21. It is recommended that basic augmentative communication devices be considered for children who have a developmental age of 12 to 18 months but have not yet developed speech. [D2]
22. It is important for parents and professionals to recognize that the use of augmentative communication does not prevent oral language development. [D2]
23. When assessing the need for an augmentative communication system, it is important to consider the needs of both the child and the family as well as to consider the environments and contexts in which communications need to occur. [D2]
24. It is important that any communication system being taught have practical/functional and cultural value to the family and child. [D2]
25. When an augmentative communication system is used, it is important for families/caregivers and those working with children to be familiar with the principles and techniques that will encourage its use. [D2]

*Selecting an augmentative communication system*

26. When choosing an augmentative communication system, it is important to consider the following factors:
  - The child’s vision, hearing, and cognitive abilities
  - The intended audience
  - Access, portability, adaptability, possibilities for expansion, and maintenance requirements [D2]
27. It is recommended that augmentative communication interventions 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 [D2]
28. It is important to focus on the child’s communication skills rather than on the child’s skill in using the system. [D2]
29. When developing the vocabulary for an augmentative communication system, it is important to:

- Provide the child with vocabulary items that are meaningful to the child and appropriate for both the child’s developmental and chronological age
  - Include words from a variety of semantic/syntactic classes so the child will have opportunities to learn and use language [D2]
30. It is recommended that strategies for supporting the development of natural speech always be included in augmentative communication intervention strategies for infants and young children. [D2]

### **Orthotic Devices (Including Splints and Casts)**

Orthotic devices (including splints or casts) are customized external devices that support joints to improve function or minimize deformities of upper or lower limbs or trunk. These devices may be prescribed to supplement a child’s therapeutic exercise program, either 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.

Common orthotics used to help support the foot and/or leg in proper alignment for standing or walking include:

- Shoe inserts to help position the foot
- Supramalleolar orthoses (SMOs) to help support the ankle joint and hold the foot in neutral while still allowing for some ankle movement
- Ankle foot orthoses (AFOs) to help hold the ankle and foot in a neutral position (either hinged or solid at the ankle)
- Knee ankle foot orthoses (KAFOs) to help hold the knee, ankle, and foot in a neutral and functional position

Orthotics 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.

### **Recommendations (Orthotics)**

*Considerations for using orthotic devices (including splints and casts)*

1. Orthotic devices can be useful for children with motor impairments to:
  - Reduce functional limitation
  - Prevent secondary impairment

- Facilitate function
  - Minimize contracture and deformity
  - Ensure optimal joint alignment
  - Ensure selective motion restriction
  - Protect weak muscles
  - Control atypical tone and tone-related deviations
  - Protection of tissues postoperatively [D1]
2. 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. For example:
    - Lower limb orthotics may help improve the function for children who are developing walking skills and have dynamic equinus (toe walking) and/or tight heel cords
    - Children without tight heel cords who have foot deformities may benefit from other less restrictive orthotics such as supramalleolar orthoses (SMO), foot plates, heel cups, or shoe inserts [D1]
  3. It is important to recognize that many orthotic devices, especially upper limb orthoses (ULO), are designed to be used intermittently to allow the child to develop active muscle control while the device is removed. [D1]
  4. When an orthotic device is used, it is important that:
    - The orthotic fit appropriately and that it improves the child's functioning
    - Parents understand that repeated visits may be necessary to achieve an appropriate fit
    - There is ongoing monitoring and refitting to accommodate growth and developmental change
    - Parents and other caregivers be educated about
      - Recognizing signs of discomfort or a poor fit
      - Putting them on, taking them off, and cleaning them
      - Appropriate clothing to wear under/over them
      - Wearing time [D1]
  5. When an orthotic device is being considered, 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

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rehabilitation, orthopedic surgeons, and others) and that the physician be knowledgeable about the child's needs. [D1]

### *Casting*

6. When using upper extremity casting (UE) as an adjunct to intervention for children with spasticity of the hand and wrist, wearing a cast for 4 consecutive hours a day for an average of 20 hours per week may help to maximize the outcome.

[A] (Law 1991, Law 1997)

7. It is important to recognize that casts, when worn for extremely long periods of time (such as all day or all night), may be detrimental to the child because:
  - Prolonged casting can result in skin breakdown, reduced sensory input to the hand, and reduced function/active mobility during the wear time
  - The casting may become aversive to the child, therefore, compliance will be reduced [D1]



**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.

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## ORAL-MOTOR FEEDING AND SWALLOWING INTERVENTIONS

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section addresses interventions for oral-motor feeding and swallowing problems in young children who have a motor disorder.

### *Interventions for oral-motor feeding and swallowing*

For an infant or young child who has a feeding and swallowing problem related to motor disorders, a therapeutic feeding program may be designed and implemented. The purpose of this section is to review interventions to promote feeding that is:

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

Successful oral feeding depends on many factors, including the child's anatomical structure, health, and development. Abnormalities of any one of these factors can lead to feeding and swallowing problems. Feeding and oral-motor interventions for a child may include several methods, dependent upon the results of a thorough oral-motor assessment as described in Chapter III (page 66). Some of the common types of methods or techniques to promote safe, functional, and pleasurable feeding include:

- Preparatory methods that are implemented prior to feeding sessions (such as alerting or calming techniques, handling, positioning, oral-facial desensitization, or specific intraoral or perioral sensory input)
- Facilitation strategies (such as changing the characteristics of the food, or using prostheses or orthodontic appliances)
- Behavioral methods (such as tolerance for eating situation, alterations of sensory environments, or advancing eating behaviors to more mature skills)

If indicated, medical or surgical management (such as diagnostic testing, tube feeding, antireflux medications, or repair of anatomic anomalies) may be required.

Abnormal swallowing (dysphagia) may involve one or more of the four phases of swallowing. The oral preparatory phase is the manipulation of food in the mouth to form a food bolus (a mixture of liquid or food that is ready to be swallowed). The oral phase begins with moving the food bolus to the back of the mouth by the tongue and ends with swallowing the food. The pharyngeal phase begins with swallowing the food and simultaneously blocking the airway to prevent aspiration. The esophageal phase is the movement of the food through the esophagus and into the stomach. There are different management considerations and techniques depending on the phase of the feeding or swallowing problem.

There are also different management considerations for children who are receiving non-oral or tube feedings and children who are making the transition from tube to oral feeding. Oral feeding is not always an attainable goal for some children with severe feeding and swallowing problems. In some children, oral-motor function and swallowing can improve with time, and oral feedings may be started or resumed.

### *Basis for recommendations in this section*

The recommendations on oral-motor feeding interventions for young children who have a motor disorder are based primarily on panel consensus opinion. These recommendations address topics for which scientific literature was not specifically reviewed as a focus of this guideline.

### **Recommendations (Oral-Motor Feeding and Swallowing)**

#### *General principles for oral- motor management of infants and young children who have a motor disorder*

1. It is recommended that the approach to oral-motor therapy be considered in light of the whole child (e.g., safety, comfort, enjoyment). [D2]
2. It is recommended that management decisions be made with the understanding that nutrition and respiratory status are critical. [D2]
3. It is recommended that professionals and parents keep close monitoring of nutrition status in children with motor impairments who may require combined oral-motor therapy and oral caloric supplementation. [D2]



4. It is important to manage gastrointestinal disorders including gastroesophageal reflux optimally in order to establish a meaningful oral-motor and oral feeding program. [D2]
5. It is recommended that all persons working with children who have a motor disorder keep in mind that changes in management will be needed as children make gains or when regression is noted. [D2]
6. 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 (utensils and food textures, etc.). [D2]

#### *Qualifications of professionals*

7. Because of 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. [D2]
8. It is recommended that feeding and oral-motor interventions involve expertise from varied medical and behavioral disciplines because it is important that a feeding management program also provide health, developmental, and psychosocial supports. [D2]

#### *Prerequisites for oral feedings*

9. For a child who has not had ongoing successful feeding, it is important that appropriate medical specialists evaluate the child and that there is medical approval for oral feedings. [D2]
10. It is important to establish that infants and young children have the following prerequisites for oral feeding:
  - Cardiopulmonary stability
  - An alert, calm state
  - Demonstration of appetite or observable interest in eating before starting feeding programs
  - Proper position to allow for functional and safe swallowing [D2]

#### *Selecting oral-motor and feeding intervention techniques*

11. 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. Feeding and oral-motor intervention methods may include:

- Preparatory methods that are implemented prior to feeding sessions (such as alerting or calming techniques, handling, or positioning changes)
  - Compensation or facilitation (such as strategies that impose alteration in behavior, bolus characteristics, prostheses, and orthodontic appliances)
  - Medical or surgical management (such as diagnostic testing, tube feeding, antireflux medications, or repair of anatomic anomalies)
  - Behavioral methods (such as oral-facial desensitization, tolerance for eating situation, alterations of sensory environments, or advancing eating behaviors to more mature skills) [D2]
12. It is important to revise techniques and strategies as appropriate to meet the child's changing needs. [D2]

### *Management of feeding and swallowing problems by phase*

13. It is recommended that oral-motor intervention be directed primarily toward the oral preparatory and oral phases (the movement of food or liquid through the mouth to prepare to swallow and swallowing). [D2]
14. It is recommended that during the oral preparatory or bolus formation phase of swallowing (such as chewing), the following strategies may be useful:
- Changing food textures, temperatures, and bolus sizes to facilitate improved timing of swallowing
  - Selecting appropriate utensils for safe, therapeutic feeding and eventual independence
  - Establishing a midline neutral position of the head and neck in the absence of structural deformity (different structure may necessitate modified alignment of head and neck to ensure safe feeding)
  - Waiting until the child has swallowed and cleared the mouth of any food or liquid remnant before presenting more food so that the child does not take too much food into the mouth, thereby making it more difficult to prepare to swallow effectively
  - Targeting specific anatomic structures (such as the jaw, lips, cheeks, tongue, or palate) for treatment [D2]
15. It is recommended that management of oral phase problems takes into consideration:
- Positioning to facilitate safe coordination of breathing and swallowing (appropriate positioning and support of the trunk, neck, and head for the specific needs of the child)

- Sensory aspects (hyposensitivity versus hypersensitivity: may consider changes in temperature, texture, or taste)
  - Presentation (timing, size of bolus, utensils, environment)
  - Texture (common problem textures are thin liquids, dry or lumpy foods, multitextured foods, and foods that do not dissolve such as raw fruits or vegetables) [D2]
16. It is recommended that indirect management of pharyngeal phase problems includes:
- Oral-motor treatment that may help to improve tongue propulsion of the bolus
  - Positioning and texture changes to enhance safety of pharyngeal swallow
  - Texture changes that allow for a swallow to be produced without delay, coughing, gagging, or any other signs of stress [D2]
17. It is recommended that esophageal phase problem management includes direct medical or surgical intervention as recommended by appropriate physicians. [D2]



**Early Intervention Policy** ❖ Medical tests, surgical interventions, and medications are not considered early intervention evaluations or services under the New York State Early Intervention Program. The service coordinator should help families in accessing services, if needed and appropriate, through the child's primary health care provider.

### *Tube (non-oral) feedings*

18. It is important for professionals and parents to remember that oral feeding is not always an attainable goal for all children. It is recommended that non-oral or tube feedings be considered for:
- Infants with severe dysphagia 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 [D2]
19. 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. [D2]

### *Transition from tube to oral feeding*

20. It is important to recognize that for some children who have a motor disorder, oral-motor function and swallowing can improve with time and oral feedings may be resumed. Children who can eat safely may be able to continue oral feeding while also receiving nourishment from tube feeding. [D2]
21. It is recommended that the following be considered when evaluating the readiness of children who have a motor disorder to start or resume oral feeding:
  - Medical condition (history and current status)
  - Prerequisite oral-motor skill levels
  - Swallowing abilities – a videofluoroscopic swallow study (VFSS) may be needed if there is any indication of potential swallowing problem or difficulty (see Table 9, page 77) [D2]
22. It is recommended that the following preliminary steps be included in the transition from tube to oral feeding:
  - Establishing an adequate caloric and nutritional intake for growth and development
  - Developing oral-motor skills by promoting oral-tactile experiences, oral exploration, and vocalizing
  - Associating oral-motor stimulation with satisfaction of hunger (for example, nonnutritive sucking while tube feeding is being given)
  - Encouraging whatever oral feeding is safe
  - Scheduling oral and nonoral feedings for optimum success and to promote appetite (regular, consistent practice several times per day for short periods is better than occasional practice for longer durations)
  - Minimizing negative experiences [D2]

### *Mealtime management once children begin spoon feeding*

23. Once children begin spoon feeding, the following management techniques are recommended:
  - Promoting pleasurable feeding (no gastrointestinal, respiratory, or emotional stress and no forced feeding)
  - Encouraging self-feeding

- Balancing mealtimes with between-meals snacks to achieve adequate and good nutrition because frequent snacks may decrease the child’s appetite at mealtime
- 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 (although periodic oral-motor stimulation may be necessary to facilitate continued oral-motor control during the course of the mealtime)
- Avoiding the overuse of food as a reward [D2]

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**APPROACHES FOR SPASTICITY MANAGEMENT**

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section addresses the options commonly used for spasticity management in young children who have a motor disorder. Topics include:

- General Approach to Spasticity Management
- Use of Oral Medications for Spasticity Management
- Localized Injections for Focal Spasticity
- Intrathecal Baclofen
- Selective Dorsal Root Rhizotomy (SDR)



**Early Intervention Policy** ❖ Intramuscular injections, inhibitory casting, rhizotomy, oral medication, and intrathecal infusions are considered medical treatment 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.

### *Basis for the recommendations in this section*

The recommendations for spasticity management for young children who have a motor disorder include both evidence-based and panel consensus recommendations. The evidence-based recommendations are derived from the scientific literature that met the criteria for evidence for this section. Many of the consensus recommendations in this section relate to topics for which a literature search and review to identify evidence was done, but no evidence meeting the criteria for this guideline was found. Other consensus recommendations relate to approaches for which the literature was not specifically reviewed.

### **General Approach to Spasticity Management**

Cerebral palsy is a static condition (nonprogressive) that affects the 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. The result of this is that 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.

### **Recommendations (General Approach to Spasticity Management)**

#### *General approach—spasticity management*

1. It is recommended that children who have significant spasticity that interferes with functioning be evaluated by a comprehensive, multidisciplinary spasticity team. [D2]
2. It is important to have reasonable goals and objectives related not only to spasticity management but also to decreasing spasticity. Examples of reasonable goals and objectives for spasticity management are:
  - Prevention of contractures
  - Improvement in functioning
  - Management of pain
  - Providing ease in daily care activities (dressing, bathing, toileting, etc.) [D2]

3. It is important to recognize that addressing spasticity can sometimes have a deleterious impact on a child’s functional skills. Overly aggressive spasticity management can be detrimental by unmasking underlying motor weakness, because the spasticity may be providing “strength” for function. (If the spasticity is decreased, the muscle may not be able to provide sufficient force production to resist gravity, thereby making the underlying muscle weakness more apparent and function more difficult.) [D1]
4. 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 sequentially.

*[A] (Corry 1998, Flett 1999, Koman 2000, Law 1991, Law 1997, McLaughlin 1998, Steinbok 1997, Steinbok 1998, Wright 1998)*

5. For all methods of spasticity management, it is important to monitor children using systematic methods for measuring spasticity (such as the Ashworth Scale) and motor functioning (such as the Gross Motor Function Measure [GMFM]), gait analysis, and qualitative methods of functioning), and to ensure that appropriate therapy is provided following the treatment.

*[A] (Corry 1998, Flett 1999, Koman 2000, Wright 1998)*

### **Use of Oral Medications for Spasticity Management**

There are many oral medications that can be used to decrease generalized spasticity. Some of the more commonly used medications are diazepam (Valium), baclofen (Lioresal), tizanidine, and gabitril. All of these medications have a calming effect on the central nervous system and have sedation as a 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.

### **Recommendations (Use of Oral Medications)**

1. Because of the risk of 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. [D2]
2. It is important that parents and other caregivers be aware that the child is on antispasticity medications and of the potential side effects and how to recognize them. [D2]

### Localized Injections for Focal Spasticity

Historically, many chemicals and physical agents have been used as a localized injection to treat spasticity in a particular limb or joint. Many of these treatments are destructive to muscle tissue. In particular, alcohol and phenol injections have been promoted as treatments for spasticity. Recently, botulinum toxin, although not officially approved for spasticity, has become the favored intramuscular injection for loosening a particular limb or joint.

Botulinum is an exotoxin derived from *Clostridium botulinum* bacteria. It blocks acetylcholine release at the neuromuscular junction. There are eight types known, and two of these are commercially available. Botulinum type A (Botox) and botulinum type B (Myobloc) are the forms most commonly used in North America.

Currently botulinum toxin injections are not FDA-approved for children younger than 12 years of age or for spasticity. However, like other medications used in children, botulinum toxin injections are frequently used “off-label” for young children at the discretion of the treating physician. Botulinum toxin injections are generally contraindicated if significant contractures are present.

The medication is administered by intramuscular injections. The procedure may be painful or frightening to a young child, so some sedation or anesthesia is often given before the injections. The botulinum toxin injections are injected directly into the muscle. 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 the results.

Treatment with botulinum toxin injections is comparable to serial cast stretching for dynamic calf tightness in children with cerebral palsy. It directly addresses the spasticity and has been found to be more acceptable to parents than casting (Flett 1999). The effect of the toxin is longer acting and has fewer side effects than using only serial casts (Corry 1998).

Disadvantages of botulinum toxin injections include the possibility of antibody formation, the short duration, and the uncertainty of the long-term effect on the muscle and neuromuscular junction. Side effects may occur in some children and may include local weakness, flulike illness, dysphasia (speech impairment), and dysphagia (difficulty swallowing).

Advantages of botulinum toxin include its ease of administration, no known cumulative effects, and the ability to examine the child’s potential function with reduced spasticity. This medication may be useful in predicting the expected effects of more permanent spasticity treatment such as selective dorsal root rhizotomy.




**Recommendations (Localized Injections for Focal Spasticity)**

1. It is important to recognize that the use of botulinum toxin injections has not been approved for use in children younger than 12 years of age. [D2]
2. It is recommended that:
  - If spasticity is causing significant functional problems with mobility or dynamic contractures, it is appropriate to consider botulinum toxin injections. Children with specific, localized, and functionally significant muscle spasticity such as in hemiplegia or spastic diplegia are more appropriate candidates than are those with more generalized spasticity
  - If a child has responded well to repeated botulinum toxin injections and additional injections cannot be continued, it may be appropriate to consider more permanent spasticity reduction such as intrathecal baclofen or selective dorsal root rhizotomy
  - If a child did not respond well to a previous botulinum toxin injection, repeated doses are not indicated (however, other types of botulinum toxin may be considered)

*[A] (Corry 1998, Flett 1999, Koman 2000, McLaughlin 1998, Steinbok 1997, Steinbok 1998, Wright 1998)*

3. 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 botulinum toxin injections. [D1]
4. It is important to consider the need to modify the existing physical and occupational therapy program following a botulinum toxin injection treatment to facilitate improvement in function and carry-over, and to maximize the effectiveness of the botulinum toxin injections. [D1]



**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.

**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).

Oral baclofen is less effective than ITB because it does not cross the blood brain barrier as well as intrathecal baclofen and because it often has undesirable side effects at therapeutic levels. ITB can achieve much higher levels in the spinal fluid than oral baclofen.

ITB is used for spasticity of moderate or severe degree (Ashworth scores of 3-5) and for dystonia. ITB can be used after one year of age but is usually not used until after 6 years of age. It is FDA-approved for children 4 years of age and older. ITB has limitations for use in younger children because of the size of the implantable pump.

Although ITB may improve various functions, it is very difficult to predict the areas of improvement. Furthermore, not all patients who are potential candidates for ITB will show a clinical response and be able to use this form of treatment. Spasticity in the upper extremities is generally reduced in most patients, and range of motion is usually improved. There may also be some collateral (environmental) reduction of spasticity in the upper extremities. Functional activities, oral-motor function, transfers, and walking also improve in many patients. Although walking ability usually improves, ITB does not cause nonwalking children to start walking. ITB may decrease contractures and reduce the need for orthopedic surgery. For dystonia, ITB decreases movement in most patients. However, function is improved much less than is seen with spasticity (Albright 1991, 1993, 1995).

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

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.

### **Recommendations (Intrathecal Baclofen)**

1. 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. [D1]
2. It is recommended that the use of intrathecal baclofen be considered for children who have inadequate response or excessive systemic side effects before the desired clinical effects are seen with oral baclofen. [D1]
3. As with most medications, there are potential side effects. When oral or intrathecal baclofen is recommended for a child with spasticity, it is important that:

- The physician recommending these medications be familiar with the effects, treatment, and outcomes of spasticity as well as with the medication
  - The specific indications for using the medication justify the potential risks of the medication
  - The physician monitor the child for side effects and complications and inform the parent(s) of how to recognize possible side effects [D1]
4. It is important to combine baclofen treatment with a physical and/or occupational therapy plan following treatment and to consider the need to modify any existing physical and occupational therapy programs following baclofen treatment. [D1]

### **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 improve range of motion and function. Rhizotomy is not appropriate for children with hypotonicity (low muscle tone) or children with extrapyramidal type (fluctuating tone) cerebral palsy.

The ideal age is thought to be between 4 and 6 years of age when walking maturity has been established and the patient can respond to a postoperative rehabilitation program. Although rhizotomy is not typically done for children younger than three years of age, the process of considering and evaluating children for the procedure often begins before three years of age.

Rhizotomy may not be very useful for patients with mild spasticity who do not have a significant functional deficit that could be improved (McLaughlin 1998). Occasionally, some totally involved patients with significant spasticity are evaluated for rhizotomy. However, intrathecal baclofen or other interventions may be a better first choice for these patients.

In performing the surgical procedure, general anesthesia is required. The surgery is done through an incision in the lower back. The ideal candidate for selective dorsal root rhizotomy is a patient with a history of prematurity, spastic diplegia, no dystonia or unusual movement disorder, and has pure spasticity, good selective motor control, balance, strength, and minimal deformities.

Postoperative complications that have been reported 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 still need orthopedic

surgery later, typically being done approximately 1 or 2 years after the rhizotomy.



**Early Intervention Policy** ❖ Surgical interventions are not paid for by the Early Intervention Program in New York State. The service coordinator should help families in accessing services, if needed and appropriate, through the child's primary health care provider.

### Recommendations (Selective Dorsal Root Rhizotomy)

1. The ideal candidate for selective dorsal root rhizotomy is a child over three years of age 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. [D1]
2. A multidisciplinary spasticity clinic is the most appropriate setting to evaluate children for selective dorsal root rhizotomy. Several visits with the spasticity team are needed before the surgery is performed. Children typically are seen before 3 years of age, with surgery being performed at 4 to 6 years of age. [D1]
3. It is important for parents considering rhizotomy to realize that while there may be important short-term benefits for many children, the long-term outcomes and complications are unknown.  
*[A] (McLaughlin 1998, Steinbok 1997, Steinbok 1998, Wright 1998)*
4. When considering whether a child is appropriate for selective dorsal root rhizotomy, it is important to recognize that patient selection is most important.
  - The child must have significant spasticity that is affecting function. Dystonia, rigidity, and ataxia are relative contraindications. The child must not have significant contractures, weakness, and loss of trunk or head control, nor have imbalance or loss of selective motor control.
  - Children who do not meet the selection criteria for rhizotomy may be candidates for other spasticity reduction techniques and/or for other modalities/types of treatment.
  - 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 (rather than rhizotomy) may be a more appropriate choice. [D1]

5. It is important to combine rhizotomy treatment with a physical and/or occupational postsurgical therapy plan and to consider the need to modify any existing physical and occupational therapy programs following surgery.  
*[A] (McLaughlin 1998, Steinbok 1997, Steinbok 1998, Wright 1998)*

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## ORTHOPEDIC MANAGEMENT AND SURGERY

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section addresses orthopedic management and surgery as an intervention for young children who have a motor disorder, with particular attention paid to cerebral palsy. All children with cerebral palsy should be evaluated by an orthopedic surgeon.

*General use of orthopedic management and surgery*



**Early Intervention Policy** ❖ Surgical interventions are not paid for by the Early Intervention Program in New York State. 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.

Orthopedic management (both nonoperative and surgical) in infants and young children is well established for specific conditions that affect the motor system. Such disorders include developmental hip dysplasia, clubfoot, spina bifida, congenital limb deficiencies, spine deformities, trauma and posttraumatic deformities, musculoskeletal infections, brachial plexus palsy, torticollis, arthrogyposis, spinal muscle atrophy, and idiopathic toe walking.



**Early Intervention Policy** ❖ Not all conditions that affect the motor system will result in eligibility for the Early Intervention Program. To be eligible for the EIP, children must have a diagnosed physical or mental condition with a high probability of resulting in developmental delay. Physical conditions that respond to medical treatment (such as torticollis) are not considered conditions with a high probability of resulting in developmental delay for purposes of EIP eligibility. A child with such a physical condition may be eligible for the EIP if the condition impacts one or more areas of the child's development to the extent that the child has a delay consistent with the State definition of developmental delay.

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)

Although the focus of the recommendations in this section is specific to young children with cerebral palsy, many of the recommendations also have application to children with other developmental motor disorders.

### *Orthopedic management and surgery for children with cerebral palsy*

When planning orthopedic management and surgery for children with cerebral palsy, most orthopedic surgeons use a simple topographical classification approach (see Appendix E). Cerebral palsy can be generally differentiated as:

- Total involvement (quadriplegia)
- Hemiplegia
- Spastic diplegia

### *Total involvement cerebral palsy*

Total involvement cerebral palsy implies involvement of all extremities (quadriplegia), spine, oral pharynx, and neck. By age 2, the child may still not sit independently. If the child is not able to sit by age 4, he or she is very unlikely to walk (Rang 1990). Only approximately 10 percent of children with

total involvement cerebral palsy will 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 (Moreau 1979). The hips may dislocate as early as 18 months of age. By 3 to 4 years of age, children with total involvement cerebral palsy who have at-risk hips (those that are tight or that show radiological evidence of subluxation) generally need surgical intervention to help prevent later hip dislocations (Bagg 1993). When hip surgery is done early enough, soft tissue release may be sufficient. For many children, early surgery often prevents the need for more involved surgery later.

There is some controversy as to whether or not it is prudent to perform surgery on both hips if there is subluxation on only one side. In older children, there are some arguments for performing surgery only on the involved side, with the realization that the other hip may need surgery at a later date.

### *Hemiplegia*

Most children with hemiplegia type cerebral palsy will walk, but they will all have some difficulty walking because of the involvement of at least one of the lower extremities. Only approximately half will walk by the age of 18 months, depending on the degree of motor involvement. It is very common for a young child who has a delay in walking to be found to have an unrecognized hemiplegia as the cause of the delay.

Children with hemiplegia generally do very well with surgical treatment. Surgery is best done after 4 years of age and most commonly involves lengthening of certain muscles in the hips and legs. When surgery is performed too early in children with hemiplegia (before 4 years of age), recurrence of the deformity may occur. The recurrence rate of Achilles tightness after surgery in hemiplegia is 25 percent if performed under 4 years of age, but only approximately 12 percent if done after 4 years of age (Rang 1990). Some children may also benefit from upper extremity surgery, usually between 6 and 12 years of age.

### *Spastic diplegia*

Children with spastic diplegia typically have more involvement of the legs than the arms. Children with spastic diplegia who can sit independently by 2 years of age will likely be able to walk. The ability to cruise holding on to furniture implies that the child has good walking potential. Most children with diplegia walk by 4 years of age.

Surgery may be helpful to improve walking in some children with spastic diplegia, but surgery is usually delayed until approximately 4 years of age when walking maturity is more developed. Tendon surgery before 4 years of age has a high risk of recurrence. Generally all deformities and tightness are corrected during the same operative procedure.

### *Basis for the recommendations in this section*

The recommendations for orthopedic management and surgery for young children who have a motor disorder are primarily panel consensus recommendations. Many of the recommendations are based on current literature, but an extensive review of the scientific literature was not done because this topic was considered outside the primary scope of the guideline. In the panel's opinion, these consensus recommendations are generally consistent with the scientific knowledge in this field.

### **Recommendations (Orthopedic Management and Surgery)**

#### *Basic nonoperative principles of orthopedic management*

1. It is always important to remember the basic principle of all medical and surgical care: first, do no harm. [D2]
2. It is important to recognize that in a general cerebral palsy clinic, not all children necessarily have cerebral palsy. Another more specific yet undiagnosed condition may be present. It is of utmost importance to make an accurate and specific diagnosis whenever possible because this is important in making treatment decisions, particularly if the treatment involves surgery. [D2]
3. Whatever treatment is recommended, it is important to have a functional goal in mind. [D2]
4. It is important to establish long-term goals in consideration of the goals of the child, parent(s), the health care team, and the community. Overall, the goals are to help the child reach full functional potential and be happy, and for the family to develop in a healthy, intact manner. [D2]
5. Because hemiplegia type cerebral palsy and congenital dislocation of the hip are two possible common causes of a delay in walking, it is recommended that an orthopedic physician examine children who are not walking by the age of 18 months, particularly if there are risk factors or other indicators of a possible motor disorder. [D2]
6. 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. [D2]

7. 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. [D2]
8. Orthopedic management may include the use of braces for some children. Important considerations include:
  - When braces are used, it is important that they have a functional purpose, that they improve the child's functioning, and that they be discontinued if not fulfilling a goal,
  - 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)
  - In general, children with cerebral palsy do not require bracing above the knees
  - A reasonable goal is to have the patient become brace-free by adulthood [D2]
9. As the child reaches approximately 3 to 4 years of age, consultation by a multidisciplinary spasticity team may be helpful if spasticity seems to be causing significant functional problems. This is particularly important in the walking child with significant spasticity who is being considered for orthopedic surgery. Although orthopedic surgery may still be required after spasticity management is begun, it is important to evaluate and to possibly treat the underlying spasticity before the secondary orthopedic problems are addressed with surgery. [D2]
10. When presenting information about and options for orthopedic management, it is important for the family to have time to process the information provided. A follow-up appointment is appropriate before surgery is undertaken. [D2]

#### *General principles when considering surgical intervention*

11. It is important to remember that cerebral palsy is a static condition. The child's function may improve with surgical treatment, but the child will still have cerebral palsy. [D2]
12. It is important to recognize that while orthopedic surgery may be appropriate for addressing many of the secondary problems of cerebral palsy (such as contractures, deformity, inefficient mechanical function of

the muscles, and joint instability), it does not correct the primary underlying problems of spasticity, balance, and selective motor control. [D2]

13. Surgery is rarely an emergency. It is important that the surgeon spend time to establish a relationship with the patient and family, and to determine what the important treatment goals are. [D2]
14. When considering surgery, it is important to determine if the child is likely to benefit from the procedure. It is important that there be a functional goal, and there must be a reasonable expectation that surgical treatment can achieve that goal with acceptable risk. [D2]
15. Important considerations when making a decision about orthopedic surgery include:
  - Child and family goals
  - Age and maturity of the patient
  - Safety of the procedure and risks to the patient
  - Functional potential
  - Recuperation time
  - Need for postoperative physical therapy and assistive devices [D2]
16. Patient selection and timing of surgery are essential. Most very young children with cerebral palsy do not require surgery. (It is not usually considered for most children until 4 to 6 years of age.) However, when performed at the right time, surgery may be helpful for improving function and preventing or treating deformities of the bones and joints for some children. [D2]
17. Whenever possible, it is important to group surgical procedures that can be performed at the same time. [D2]

### *Specific surgical principles*

18. The age of the child and the type of cerebral palsy are important when considering surgical interventions.
  - For children under 4 years of age, particularly for patients with total involvement (quadriplegia) cerebral palsy, the most effective orthopedic procedure is muscle lengthening about the hip to prevent subluxation or dislocation
  - For the older child with spastic diplegia, typically over 4 years of age, surgical treatment may help with specific functional goals such as improved walking

- Children with hemiplegia who are over 4 years of age may benefit from soft tissue procedures to improve walking, hand appearance, or function
  - It is recommended that surgical treatment for spinal deformities (such as segmental spine instrumentation and fusion to the pelvis) be delayed if possible until the child is older, typically 10 years of age or older (but before adulthood)
  - Children with athetosis or significant movement disorders should generally avoid tendon releases or transfers [D2]
19. It is generally better to release fixed contractures early because delaying it may result in the need for more extensive reconstructive surgery, and the outcome may not be as good. [D2]

*Orthopedic management of total involvement cerebral palsy*

20. The hips of children with total involvement cerebral palsy are at increased risk for subluxation and dislocation. It is recommended that the child be referred for orthopedic care as early as 18 months of age, or sooner if problems with the hips are suspected. [D2]
21. It is important to recognize that an early hip dislocation may not be painful. If there is limited hip motion (there should be at least 30 degrees of abduction in each hip), it is important to refer the child to an orthopedic surgeon with special interest and training in the orthopedic care of this problem. [D2]
22. After 18 months to 2 years of age, it is recommended that radiographs (x-rays) be considered for children with total involvement cerebral palsy to monitor which children may need more extensive treatment. [D2]
23. It is important to recognize that spinal deformities are common in children who do not achieve walking. Spinal deformity often begins by 3 years of age. Although they do not prevent spinal deformities, soft or semisoft braces can be used to provide better seating and positioning. [D2]

*Orthopedic management of hemiplegia cerebral palsy*

24. 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. [D2]
25. 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. [D2]

26. Because children with hemiplegia generally do well with surgical treatment to improve walking, it is recommended that surgical intervention be considered and discussed with the family if there are obvious problems with walking or if the child has become dependent on a brace for walking. [D2]

### *Orthopedic management of spastic diplegia cerebral palsy*

27. If surgery is being considered for a child with spastic diplegia, it is important to focus on functional goals such as walking. The goals of walking generally include:

- Energy conservation
- Stability and safety
- Reasonable step length and speed
- Safe limb clearance [D2]

28. It is recommended that surgery be delayed until approximately 4 years of age when walking maturity is more developed and the child is able to cooperate with a postoperative rehabilitation course. [D2]
29. 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. [D2]
30. It is important to recognize that surgery generally will not make a nonwalking child able to walk. [D2]

### *Surgical aftercare and rehabilitation*

31. Before surgery is performed, it is critical that a postoperative plan be established and that the child and the family be aware of and agree to cooperate with the postsurgical plan. [D2]
32. The family 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, particularly for the older child, postoperative rehabilitation may take up to 2 years. [D2]
33. It is important to recognize that parents may need specific instruction and demonstration of various aspects of postoperative care. [D2]
34. It is important to plan for quick return to previous function after surgery. [D2]
35. It may be useful to begin gait training and evaluation for postoperative adaptive equipment before the surgery is performed. [D2]
36. It is important to recognize that orthotic devices may fit differently and may need to be remade after the surgery. [D2]

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**INTERVENTIONS FOR ASSOCIATED HEALTH CONDITIONS**

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Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section addresses the interventions for associated health conditions for young children who have a motor disorder.

*Determining the need for health-related interventions*

The specific health-related interventions for any young child who has a motor disorder will depend on the results of the health evaluations that identify 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 10 (page 89). It was considered beyond the scope of this guideline to evaluate the efficacy of interventions for these medical conditions.

*Basis for the recommendations in this section*

The recommendations for interventions for associated health conditions for young children who have a motor disorder are primarily panel consensus recommendations. Many of the recommendations are based on current literature, but an extensive review of the scientific literature was not done because this topic was considered outside the primary scope of the guideline. In the panel's opinion, these consensus recommendations are generally consistent with the scientific knowledge in this field.

**Recommendations (Associated Health Conditions)**

*General approach to health interventions*

1. It is recommended that children who have a motor disorder receive preventive child health care. [D2]
2. It is recommended that the primary care physician be responsible for the child's general health care, and that the primary care physician refer the child to specialists and other health professionals as needed. [D2]
3. It is recommended that professionals involved in planning and implementing interventions for a child who has motor disorders be aware of:
  - The child's health status, including the child's hearing, vision, and nutritional status

## CHAPTER IV: INTERVENTION

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- Any health-related interventions, prescribed regimens, or environmental adaptations that may affect the child’s ability to participate in an intervention program [D2]

### *Vision problems*

4. It is important to remember that young children who have a motor disorder frequently have visual impairments that may impact their ability to move and to participate in interventions and other activities. It is important that professionals working with young children who have a motor disorder be aware of this and be able to grossly assess functional vision. [D2]

### *Seizure disorders*

5. It is important to remember that seizure disorders are associated with some types of cerebral palsy (such as hemiplegia and quadriplegia), and they often require anticonvulsant medication. [D2]
6. It is important to remember that anticonvulsant medication may affect alertness, mental status, and participation in intervention programs. [D2]
7. It is important for parents and professionals working with children who have a motor disorder to be aware of the behaviors suggestive of seizures and know what to do if the child has a seizure. [D2]

## **OTHER INTERVENTION APPROACHES FOR YOUNG CHILDREN WHO HAVE A MOTOR DISORDER**

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### Evidence Ratings:

[A] = Strong [B] = Moderate [C] = Limited

[D1] = No evidence meeting criteria [D2] = Literature not reviewed

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This section addresses several other intervention approaches that are sometimes considered for young children who have or are at risk for a motor disorder.

Topics in this section include:

- Conductive Education
- Hyperbaric Oxygen Therapy
- Adeli Suit
- Patterning (Doman-Delacato)
- Feldenkrais Method<sup>®</sup>
- 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. Some may consider them as “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.

*Basis for the recommendations in this section*

The recommendations for other intervention approaches for young children who have a motor disorder are primarily panel consensus recommendations. A literature search to identify evidence specific to these approaches for young children who have a motor disorder was done, but no literature was found that met the criteria for evidence for this guideline except for one article about conductive education (Reddihough 1998). The guideline panel did not make specific recommendations about most of these approaches other than to indicate that there is a lack of evidence to support their use.

**Conductive Education**

Conductive education is an educational approach focused primarily on motor function. This approach, developed in Budapest, Hungary, in the 1940s, is based on the theory that abnormal motor patterns (“dysfunction”) can be transformed into functional motor patterns (“orthofunction”) by intensive “training” to develop alternate neural pathways.

Each child works with a “conductor” who is specifically trained in the technique of conductive education. It is the responsibility of the conductor to work with the child throughout the day to produce favorable conditions that facilitate the child’s daily tasks. Additional assistants employ a “hands-on” technique with more impaired children. Daily tasks (such as sitting and walking) are broken down to their simpler components. These components are then incorporated into a rhyme or song that the child repeats to self-motivate and anticipate the task before him. In the United States, many conductive education programs use only selective principles of this method, thereby potentially compromising the method.

No controlled scientific studies were found that demonstrate the effectiveness of conductive education for improving motor development in young children who have a motor disorder.

### Recommendations (Conductive Education)

1. Adequate evidence was not found to demonstrate the effectiveness of conductive education as an intervention for young children who have a motor disorder.  
*[B] (Reddihough 1998)*
2. If a conductive education program is considered for a young child who has a motor disorder, it is important to recognize that:
  - Conductive education may vary--not all conductive education programs strictly follow the original conductive education model
  - The conductive education approach may be time-intensive and expensive, and may not be compatible with some other therapies
  - Parents may need to make a significant time commitment
  - Children must be cognitively able to participate [D1]
3. If a child is enrolled in a conductive education program (or a program based on conductive education), it is important to continue to monitor motor performance and development because there may be some risk for developing persistent pathological motor patterns when using this approach. [D1]
4. As with any intervention approach, if conductive education (or a program based on conductive education) is considered, it is important that this be part of an overall intervention plan for the child (developed by professionals in conjunction with parents), and that this plan:
  - Define goals for the intervention program and identify objective outcome measures for these goals
  - Insure all individual intervention components are compatible and consistent with the overall intervention goals for the child and family
  - Be coordinated with other interventions the child is receiving to avoid any potential conflicts in establishing and achieving goals for the interventions
  - Provide for baseline and ongoing assessment of the child's progress, and specify the methods, schedule, and criteria for such periodic assessments
  - Provide for appropriate modification or discontinuation of the intervention based on periodic assessment of the child's progress [D1]
5. When parents are interested in an intervention for their child, especially when considering nonstandard intervention options such as conductive education, it is




important for professionals to provide unbiased information and to facilitate the parents' access to information (Table 11, page 120). [D1]

### **Hyperbaric Oxygen Therapy**

Hyperbaric oxygen therapy (HBOT) physically dissolves extra oxygen into the blood plasma. The breathing of pure oxygen at three times normal atmospheric pressure (3 A.T.A.) delivers 15 times as much physically dissolved oxygen to tissues as does breathing room air. Use of HBOT has been reported for treating many conditions. It is probably most well known for treating decompression sickness in SCUBA divers. This therapy has been used by proponents for the care of preterm babies in order to reverse hypoxia and control periventricular hemorrhages, and its use has been reported for young children with cerebral palsy.

Hyperbaric oxygen therapy uses a pressure chamber to increase the amount of oxygen received by an individual. Chambers vary in size to accommodate only a small infant or an adult patient and surgical team.

Limited information was found about HBOT because it is used for young children who have a motor disorder, and no studies were found evaluating the effectiveness of this approach for children who have a motor disorder.



**Early Intervention Policy** ❖ Hyperbaric oxygen therapy is a medical treatment and is not a reimbursable cost under the Early Intervention Program.

### **Recommendations (Hyperbaric Oxygen Therapy)**

No evidence was found to support the use of HBOT for young children who have a motor disorder. [D1]

### **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 Soviet cosmonauts in space. It is patented by a Polish–Russian organization and is available primarily from a rehabilitation facility located in Poland. Proponents of the Adeli suit believe that use of the suit can provide controlled exercise of selected muscle groups and increase “coordination.”

## CHAPTER IV: INTERVENTION

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The Adeli suit consists of a jacket and pair of trousers. The suit has strategically placed rings so that elastic tension cords can be attached across joints. Selected muscle groups can be exercised as the child moves while wearing the suit. Proponents believe that movement in the Adeli suit is a form of controlled exercise against resistance. The Adeli suit is used as part of a comprehensive program of intensive physical therapy of 5-7 hours a day, 5-6 days a week for 4 weeks.

Limited information was found about the use of Adeli suits for young children who have a motor disorder, and no studies were found evaluating the effectiveness of this approach for children who have a motor disorder.



**Early Intervention Policy** ❖ Hyperbaric oxygen therapy is a medical treatment and is not a reimbursable cost under the Early Intervention Program.

### **Recommendations (Adeli Suit)**

No evidence was found to support the use of Adeli suits for young children who have a motor disorder. [D1]

### **Patterning (Doman-Delacato)**

The Doman-Delacato treatment of patterning originated as an approach for treating brain-injured children in 1956. Its use has expanded to include children with other developmental disabilities. The treatment is based on the concept of how “ontogeny recapitulates phylogeny,” which dates back to the 1920s and 1930s (Holm 1983), and the importance of cerebral dominance (dominance of either the right or left side of the brain). According to the theory, the majority of mental retardation, learning problems, and behavior disorders are caused by brain damage or poor neurological organization, and all these problems lie somewhere on a single continuum of brain damage (American Academy of Pediatrics 1982). Current knowledge does not support this theory (American Academy of Pediatrics 1982, Chapanis 1981, Holm 1983).

No research evidence was found that demonstrates that patterning is an effective approach for young children who have a motor disorder. In a policy statement issued by the American Academy of Pediatrics (1982), it was concluded that “the tenets (of patterning) are either unsupported or overwhelmingly contradicted.”

Limitations and cautions regarding this approach include:

- Unsubstantiated claims (which may lead to unrealistic expectations) including:
  - A substantial number of cures have occurred (this has not been proven)
  - A rapid and conclusive diagnosis can be made based on the “Doman-Delacato Developmental Profile” (there is no evidence of any attempts to validate this assessment tool by comparison with any other method)
- The treatment and regimens prescribed are demanding and inflexible
- The treatment often places restrictions on age-appropriate activities which the child is capable of (such as walking or listening to music), and therefore the 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
- It is asserted that the child’s potential will be reduced if therapy is not carried out as rigidly prescribed, and if there is less than 100 percent effort, the treatment approach may fail (i.e., the responsibility for success is on the parent and child)

### **Recommendations (Patterning)**

1. No evidence was found to support the use of patterning for young children who have a motor disorder. [D1]
2. It is important to recognize that in a policy statement evaluating the Doman-Delacato Treatment, the American Academy of Pediatrics did not find evidence to support the use of patterning treatment (American Academy of Pediatrics 1982, Reaffirmed 1993).
3. 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. [D1]

### **Feldenkrais Method®**

The Feldenkrais Method®, developed by D. Moshe Feldenkrais, DSc, is said to be 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 martial arts. The method emphasizes improvement in posture, flexibility, coordination, self-image, and alleviation of muscular tension and pain (Feldenkrais 1991, Shafaman 1997).

Awareness Through Movement® and Functional Integration® are two other approaches promoted as part of the Feldenkrais Method®.

### **Recommendations (Feldenkrais Method®)**

No evidence was found to support the use of the Feldenkrais Method® for young children who have a motor disorder. [D1]

### **Tscharnuter Akademie for Movement Organization (TAMO)**

TAMO was developed by Ingrid Tscharnuter, an Austrian physical therapist. 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.). The interaction between the internal and external forces is an important focus in TAMO therapy. TAMO therapeutic handling consists of a therapist providing directional input (vectors) to assist the child in generating his own response to the forces of gravity in relationship to a support surface and a functional (play) activity (Tscharnuter 1996).

### **Recommendations (TAMO)**

No evidence was found to support the use of the TAMO therapy for young children who have a motor disorder. [D1]

**APPENDIX A: METHODOLOGY  
TABLES**

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**Table A-1: General Criteria for Selecting Evidence Studies**

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To be selected as a study meeting the criteria for evidence review, a scientific article had to meet all of the general criteria given below as well as the additional criteria applicable to studies of identification and assessment methods (Table A-2) or intervention methods (Table A-4).

To meet the general criteria for evidence review, studies had to:

- Be published in English in a peer-reviewed scientific/academic publication
  - Use original quantitative data for outcomes of interest and appropriate statistical analysis of results (or be a systematic synthesis of such data from other studies)
  - Include data on the child (not just parent reaction or behavior)
  - Evaluate children of the appropriate age, meeting at least one of the following criteria:
    - The majority of subjects are  $\leq 48$  months of age, or
    - The study group is described as “infant,” “toddler,” or “early intervention” (EI)
-

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**Table A-2: Criteria for Adequate Evidence: Assessment Studies**

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Articles meeting the following quality and applicability criteria were considered to meet the minimum evidence criteria for evidence of efficacy of identification and assessment methods for young children who have a motor disorder. Identification and assessment studies had to:

- A. Meet all the general criteria for evidence in Table A-1, and
- B. Meet the following additional criteria for studies of identification and assessment methods:
  - Evaluate a method currently available to providers in the U.S. (obsolete or clearly experimental methods were generally excluded)
  - Provide an adequate description of the method evaluated
  - Give the sensitivity and specificity of the test or method compared to an adequate reference standard or provide enough data so that these could be calculated
  - Include at least 10 subjects with the condition and at least 10 without the condition (according to the reference standard)

Studies were considered to have *high quality/applicability* if the study design, study population, and results were adequately described and no significant issues were noted regarding factors which might bias results.

Studies were considered to have *intermediate quality/applicability* if the study design, study population, and results were not adequately described or issues were noted regarding factors which might bias results.

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**Table A-3: Interpreting Sensitivity and Specificity**

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The established method for evaluating the efficacy (or accuracy) of an identification or assessment test (or method) is to determine its sensitivity and specificity compared to an adequate reference standard. These concepts are defined as follows:

- The **sensitivity** of a test is the percentage of all persons with the condition (according to the reference standard) who are correctly identified by the test as having the condition. Sensitivity is also known as the true positive rate.
- The **specificity** of a test is the percentage of all persons who do not have the condition (according to the reference standard) who are correctly identified by the test as being free of the condition. Specificity is also known as the true negative rate.
- A **reference standard** is an independent measure to determine if a subject actually has the condition that the test is attempting to identify. It is presumed that the reference standard is a more accurate way to identify the condition than is the test being evaluated. To be useful in calculating sensitivity and specificity, a reference standard must have specified criteria to determine if a person does or does not have the condition.
- Cutoff criteria are the rules to determine if the test or reference standard is positive (indicating the individual has the condition) or negative (indicating that the person does not have the condition).

**Table A-3: Interpreting Sensitivity and Specificity**

Term	Definition	Formula
<b>Sensitivity</b>	The percentage of those who have the condition who have positive tests	$[a/(a+c)] [x100]$
<b>Specificity</b>	The percentage of those who do not have the condition who have negative tests	$[d/(b+d)] [x100]$

		<b>Reference Standard</b>		
		Have condition	Do not have condition	
<b>Test</b>	Positive	a true positive	b false positive	a + b
	Negative	c false negative	d true negative	c + d
		a + c	b + d	a + b + c + d

**Considerations for interpreting sensitivity and specificity**

1. The higher the sensitivity and specificity, the greater the accuracy of the test.

Sensitivity and specificity are expressed as percentages. The perfect test would have both sensitivity and specificity of 100 percent.

- A test with 100 percent sensitivity would correctly identify all those with the condition (100% sensitivity = no false negatives).
- A test with 100 percent specificity would not incorrectly identify a person as having the condition if they did not have it (100% specificity = no false positives).

As sensitivity or specificity decreases, the rate of false negatives or false positives increases. For example,

- A test with 70 percent sensitivity would correctly identify 7 out of 10 with the condition, and there would be 3 individuals with the condition who are not identified by the test (false negatives).

*(Continued from previous page)*

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**Table A-3: Interpreting Sensitivity and Specificity**

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- A test with 70 percent specificity would correctly identify 7 out of 10 who do not have the condition, and there would be 3 individuals incorrectly identified as having the condition (false positives).

2. What is “acceptable” for sensitivity or specificity depends on the situation.

In the real world, assessment methods for screening and early identification of a disorder rarely have 100 percent sensitivity and specificity. There is no general agreement about what the acceptable levels of sensitivity and specificity for an assessment test are. Acceptable levels may vary depending upon a variety of factors such as:

- The intent of the test
- The potential impact of false positives or false negatives
- The setting of testing (general population or a specific subgroup at risk for the condition)
- The prevalence of the condition in the group being tested
- Alternate methods of assessment

3. Changing cutoff criteria affects sensitivity/specificity.

In calculating sensitivity and specificity, the reference standard must use specific criteria to determine if a person does, or does not, have a condition and the test must use specific criteria to determine if the test result is positive or negative. Using different cutoff criteria for either the test or the reference standard will yield different sensitivity and specificity. In general, as one goes up, the other goes down.

*(Continued from previous page)*

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**Table A-4: Criteria for Adequate Evidence: Intervention Methods**

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Articles meeting the following quality and applicability criteria are considered to meet the minimum evidence criteria for evidence of efficacy of intervention methods for young children who have a motor disorder.

**For all studies of intervention methods, studies had to:**

- A. Meet all the general criteria for evidence in Table A-1, and
- B. Meet the following additional criteria for studies of intervention methods:
  - Evaluate an intervention method currently available to providers in the U.S. (obsolete or clearly experimental methods were generally excluded)
  - Provide an adequate description of the intervention method evaluated
  - Evaluate the efficacy of the intervention using functional outcomes important for the child

**For group studies:**

- Provide adequate quantitative description of study findings and appropriate statistical analysis of results
- Include a comparison group (receiving an alternate intervention) or a control group (receiving no intervention)
- Report baseline developmental characteristics of subjects

**Group studies were considered to have high quality/applicability if:**

- All subjects have a motor disorder
- Subjects are reported to be allocated to groups randomly or using some other method not likely to introduce bias into the study
- Outcomes are reported for at least 10 subjects per group

**Group studies were considered to have moderate quality/applicability if:**

- Assembly of study groups is retrospective or the method of group assignment is not specified (but baseline characteristics are generally comparable between groups)
- Outcomes are reported for at least 8 subjects per group

**For single-subject design studies:**

(Considered *intermediate quality/applicability*)

- Include at least 3 subjects with a motor disorder younger than 48 months of age
- Use an acceptable single-subject design methodology (either multiple baseline or ABAB design)

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**Table A-5: Strength of Evidence Ratings for Guideline Recommendations**

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Each of the guideline recommendations in Chapters III and IV is followed by one of the four “strength of evidence” ratings described below. These strength of evidence ratings indicate the amount, general quality, and clinical applicability (to the guideline topic) of scientific evidence used as the basis for each guideline recommendation.

- [A] = **Strong evidence** is defined as evidence from two or more studies that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, with the evidence consistently and strongly supporting the recommendation.
- [B] = **Moderate evidence** is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had high quality and applicability to the topic, and where the evidence supports the recommendation.
- [C] = **Limited evidence** is defined as evidence from at least one study that met criteria for adequate evidence about efficacy and had moderate quality or applicability to the topic, and where the evidence supports the recommendation.
- [D] = **Panel consensus opinion** (either [D1] or [D2] below):
- [D1] = **Panel consensus opinion** based on information not meeting criteria for adequate evidence about efficacy on topics where a systematic review of the literature was done
  - [D2] = **Panel consensus opinion** on topics where a systematic literature review was not done
-



**APPENDIX B: SUMMARY OF  
EVIDENCE**

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## ASSESSMENT

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

The identification of young children who have motor disorders, as with other developmental disorders, can occur in a variety of ways. Initial identification of infants who are at higher risk for motor problems and other developmental disorders often begins at birth for children who are born prematurely, especially if the child is premature and low birth weight. The definition of a low birth weight infant is generally considered to be a child who weighs less than 1500 grams at birth.

Early identification of motor disorders is usually accomplished through a combination of observation, neurodevelopmental examinations, and monitoring of the child's attainment of developmental milestones. Therefore, much of the literature reviewed in this section is related to the physical exam findings and observations that are useful in identifying infants who are at higher risk for motor disorders.

#### Studies Meeting Criteria for Evidence

##### A. *Infant Neuromotor/Neurodevelopmental Exam*

1. **Allen, M.C.**, and Capute, A.J. Neonatal neurodevelopmental examination as a predictor of neuromotor outcome in premature infants. *Pediatrics* 1989; 83[4]: 498-506.
2. **Bierman-van Eendenburg, M.E.**, Jurgens-van der Zee, A.D., Olinga, A.A., Huisjes, H.H., and Touwen, B.C. Predictive value of neonatal neurologic exam: A follow-up study at 18 months. *Developmental Medicine and Child Neurology* 1981; 23[3]: 296-305.
3. **Lacey, J.L.**, and Henderson-Smart, D.J. Assessment of preterm infants in the intensive-care unit to predict cerebral palsy and motor outcome at 6 years. *Developmental Medicine and Child Neurology* 1998; 40[5]: 310-318.
4. **Stewart, A.**, Hope, P.L., Hamilton, P., Costello, A.M., Baudin, J., Bradford, B., Amiel-Tison, C., and Reynolds, E.O. Prediction in very preterm infants of satisfactory neurodevelopmental progress at 12 months. *Developmental Medicine and Child Neurology* 1988; 30: 53-63.

5. **Zafeiriou, D.I., Tsikoulas, I.G., and Kremenopoulos, G.M.** Prospective follow-up of primitive reflex profiles in high-risk infants: Clues to an early diagnosis of cerebral palsy. *Pediatric Neurology* 1995; 13[2]: 148-152.
6. **Zafeiriou, D.I., Tsikoulas, I.G., Kremenopoulos, G.M., and Kontopoulos, E.E.** Using postural reactions as a screening test to identify high-risk infants for cerebral palsy: A prospective study. *Brain and Development* 1998; 20[5]: 307-311.

**B. Infant Neuromotor Screening Tests and Techniques**

7. **Dubowitz, L.M., Dubowitz, V., Palmer, P., Miller, G., Fawer, C.L., and Levene, M.I.** Correlation of neurologic assessment in the preterm newborn infant with outcome at 1 year. *Journal of Pediatrics* 1984; 105[3]: 452-456.
8. **Johnson, A., and Ashurst, H.** Is popliteal angle measurement useful in early identification of cerebral palsy? *Developmental Medicine and Child Neurology* 1989; 31[4]: 457-465.
9. **Majnemer, A., Rosenblatt, B., and Riley, P.** Predicting outcome in high-risk newborns with a neonatal neurobehavioral assessment. *American Journal of Occupational Therapy* 1994; 48[8]: 723-732.
10. **Majnemer, A., and Rosenblatt, B.** Prediction of outcome at school entry in neonatal intensive care unit survivors, with use of clinical and electrophysiologic techniques. *Journal of Pediatrics* 1995; 127[5]: 823-830.
11. **Moltano, C., Grosz, P., Wallace, P., and Jones, M.** Neurologic exam of the preterm and full-term infant at risk for developmental disabilities using the Dubowitz Neurological Assessment. *Early Human Development* 1995; 41: 167-176.
12. **Pinto-Martin, J.A., Torre, C., and Zhao, H.** Nurse screening of low-birth-weight infants for cerebral palsy using goniometry. *Nursing Research* 1997; 46[5]: 284-287.

**C. Qualitative Assessment of General Movements and Neuromotor Status**

13. **Cioni, G., Ferrari, F., Einspieler, C., Paolicelli, P.B., Barbani, T., and Prechtl, H.F.** Comparison between observation of spontaneous movements and neurologic examination in preterm infants. *Journal of Pediatrics* 1997; 130[5]: 704-711.
14. **Cioni, G., Prechtl, H.F., Ferrari, F., Paolicelli, P.B., Einspieler, C., and Roversi, M.F.** Which better predicts later outcome in full-term infants: Quality of general movements or neurologic exam? *Early Human Development* 1997; 50[1]: 71-85.

15. **Ellenberg, J.H.** and Nelson, K.B. Early recognition of infants at high-risk for cerebral palsy: Examination at age four months. *Developmental Medicine and Child Neurology* 1981; 23[6]: 705-716.

#### **D. Other Findings**

16. **Nelson, K.B.**, and Ellenberg, J.H. Children who “outgrew” cerebral palsy. *Pediatrics* 1982; 69[5]: 529-536.

#### **Panel Conclusions (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, Moltano 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, Moltano 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**

Many tests have been developed to assess infants considered at increased risk for motor disorders to identify those who would benefit from further assessment or intervention. The studies of these tests that met the criteria for evidence were those that presented information about (or data to calculate) sensitivity and specificity (described in Chapter I) against an acceptable reference standard.

#### **Studies Meeting Criteria for Evidence**

1. **Harris, S.R.**, Swanson, M.W., Andrews, M.S., Sells, C.J., Robinson, N.M., Bennett, F.C., and Chandler, L.S. Predictive validity of the “Movement Assessment of Infants.” *Journal of Developmental and Behavioral Pediatrics* 1984; 5[6]: 336-342.

2. **Harris, S.R.** Early neuromotor predictors of cerebral palsy low-birth weight infants. *Developmental Medicine and Child Neurology* 1987; 29: 508-519.
3. **Harris, S.R.** Early detection of cerebral palsy: Sensitivity and specificity of two motor assessment tools. *Journal of Perinatology* 1987; 7[1]: 11-15.
4. **Harris, S.R.** Early diagnosis of spastic diplegia, spastic hemiplegia, and quadriplegia. *American Journal of Diseases of Children* 1989; 143[11]: 1356-1360.
5. **Morgan, A.M.,** and Aldag, J.C. Early identification of cerebral palsy using a profile of abnormal motor patterns. *Pediatrics* 1996; 98[4 Pt 1]: 692-697.
6. **Nickel, R.E.,** Renken, C.A., and Gallenstein, J.S. The infant motor screen. *Developmental Medicine and Child Neurology* 1989; 31[1]: 35-42.
7. **Piper, M.C.,** Pinnell, L.E., Darrah, J., Byrne, P.J., and Watt, M.J. Early developmental screening: Sensitivity and specificity of chronological and adjusted scores. *Journal of Developmental and Behavioral Pediatrics* 1992; 13[2]: 95-101.
8. **Swanson, M.W.,** Bennett, F.C., Shy, K.K., and Whitfield, M.F. Identification of neurodevelopmental abnormality at four and eight months by the movement assessment of infants. *Developmental Medicine and Child Neurology* 1992; 34[4]: 321-337.

**Panel Conclusions (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 MAI and the BSID to identify cerebral palsy is increased as the severity of motor limitation increases (Harris 1989).
4. The Motor Scale on the BSID is more sensitive as children get older (Harris 1989, Swanson 1992).
5. The MAI is designed to be used at specific ages for young children whose motor development is below the 12 months of age level (Harris 1984, Harris 1987, Harris 1989, Piper 1992, Swanson 1992).

6. The MAI is better able to identify children with quadriplegia than hemiplegia or diplegia (Harris 1989).
7. The 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 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

Delays in the age of attainment of motor milestones are often the parent's or the health care provider's first concern in children with motor or other developmental disorders. Many health care providers use parent recall of motor milestone attainment as one of the components of routine screening of infants for possible developmental problems. Age at attainment of motor milestones has been studied in both full-term and preterm infants as a predictor of later motor outcomes.

### Studies Meeting Criteria for Evidence

1. **Allen, M.C.,** and Alexander, G.R. Using gross motor milestones to identify very preterm infants at risk for cerebral palsy. *Developmental Medicine and Child Neurology* 1992; 34[3]: 226-232.
2. **Allen, M.C.,** and Alexander, G.R. Screening for cerebral palsy in preterm infants: Delay criteria for motor milestone attainment. *Journal of Perinatology* 1994; 14[3]: 190-193.
3. **Allen, M.C.,** and Alexander, G.R. Using motor milestones as a multistep process to screen preterm infants for cerebral palsy. *Developmental Medicine and Child Neurology* 1997; 39[1]: 12-16.
4. **Capute, A.J.,** and Shapiro, B.K. The Motor Quotient: A method for the early detection of motor delay. *American Journal of Diseases of Children* 1985; 139: 940-942.
5. **Ellenberg, J.H.** and Nelson, K.B. Early recognition of infants at high-risk for cerebral palsy: Examination at age four months. *Developmental Medicine and Child Neurology* 1981; 23[6]: 705-716.
6. **Johnson, A.,** Goddard, O., and Ashurst, H. Is late walking a marker of morbidity? *Archives of Disease in Childhood* 1990; 65[5]: 486-488.

7. **Wood, E., and Rosenbaum, P.** The Gross Motor Function Classification System for cerebral palsy: A study of reliability and stability over time. *Developmental Medicine and Child Neurology* 2000; 42: 292-296.

### **Panel Conclusions (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. Using the Gross Motor Function Classification System (GMFCS) can be useful for measuring gross motor function 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).

## **INTERVENTIONS**

### **Motor Therapy Approaches and Techniques**

Motor therapy, as used in this guideline, is intended to be a broad term that includes a variety of approaches and techniques generally used within the context of a physical or occupational therapy program. The evidence reviewed in this section includes:

- Motor Therapy Interventions for Infants With Risk Factors for Motor Disorders

- Motor Therapy Interventions for Young Children Who Have a Motor Disorder

#### A. *Motor Therapy Interventions for Infants With Risk Factors for Motor Disorders*

This section evaluates the evidence about the efficacy of motor therapy interventions for infants with risk factors for motor disorders, specifically cerebral palsy. The majority of studies evaluated low birth weight premature infants. There were six studies on this topic that met the panel's criteria for adequate evidence about efficacy of interventions for this population.

#### Studies Meeting Criteria for Evidence

1. **Brandt, S.**, Lonstrup, H.V., Marnier, T., Rump, K.J., Selmar, P., and Schack, L.K. Prevention of cerebral palsy in motor risk infants by treatment ad modum vojta: A controlled study. *Acta Paediatrica Scandinavica (Stockholm)* 1980; 69: 283-286.
2. **Girolami, G.L.**, and Campbell, S.K. Efficacy of neuro-developmental treatment program to improve motor control in infants born prematurely. *Pediatric Physical Therapy* 1994; 6: 175-184.
3. **Goodman, M.**, Rothberg, A.D., Houston-McMillan, J.E., Cooper, P.A., Cartwright, J.D., and Van Der Velde, M. Effect of early neurodevelopmental therapy in normal and at-risk survivors of neonatal intensive care. *Lancet* 1985; 2[8468]: 1327-1330.
4. **Piper, M.C.**, Kuno, V.I., Willis, D.M., Mazer, B.L., Ramsay, M., and Silver, K.M. Early physical therapy effects on the high-risk infant: A randomized controlled trial. *Pediatrics* 1986; 78[2]: 216-224.
5. **Rothberg, A.D.**, Goodman, M., Jacklin, L.A., and Cooper, P.A. Six-year follow-up of early physiotherapy intervention in very low birth weight infants. *Pediatrics* 1991; 88[3]: 547-552.
6. **Saylor, C.F.**, Casto, G., and Huntington, L. Predictors of developmental outcomes for medically fragile early intervention participants. *Journal of Pediatric Psychology* 1996; 21[6]: 869-887.
7. **Weindling, A.M.**, Hallam, P., Gregg, J., Klenka, H., Rosenbloom, L., and Hutton, J.L. A randomized controlled trial of early physiotherapy for high-risk infants. *Acta Paediatrica Scandinavica (Stockholm)* 1996; 85: 1107-1111.

**Panel Conclusions (Motor Therapy Interventions for Infants With Risk Factors for Motor Disorders)**

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).

***B. Motor Therapy for Young Children Who Have a Motor Disorder***

This section evaluates the evidence about the efficacy of motor therapy interventions for infants and children with diagnosed motor delay or cerebral palsy. There were seventeen studies on this topic that met the panel’s criteria for adequate evidence about efficacy of motor therapy interventions for infants and children who have motor disorders.

**Studies Meeting Criteria for Evidence**

1. **Bragg**, J.H., Houser, C., and Schumaker, J. Behaviour modification: Effects on and reverse tailor sitting in children with cerebral palsy. *Physical Therapy* 1975; 55: 860-868.
2. **Cannon**, S.E., Rues, J.P., Melnick, M.E., and Guess, D. Head-erect behavior among three preschool-aged children with cerebral palsy. *Physical Therapy* 1987; 67[8]: 1198-1204.
3. **Chiarello**, L.A., and Palisano, R. J. Investigation of the effects of a model of physical therapy on mother-child interactions and the motor behaviors of children with motor delay. *Physical Therapy* 1998; 78[2]: 180-194.
4. **DeGangi**, G.A., Hurley, L., and Linscheid, T. R. Toward a methodology of the short-term effects of neurodevelopmental treatment. *American Journal of Occupational Therapy* 1983; 37[7]: 479-484.



5. **Gross**, A.M., Eudy, C., and Drabman, R.S. Training parents to be physical therapists with their physically handicapped child. *Journal of Behavioral Medicine* 1982; 5[3]: 321-327.
6. **Hanzlik**, J.R. The effect of intervention on the free-play experience for mothers and their infants with developmental delay and cerebral palsy. *Physical and Occupational Therapy in Pediatrics* 1989; 9[2]: 33-51.
7. **Horn**, E.M., Warren, S.F., and Jones, H.A. An experimental analysis of a neurobehavioral motor intervention. *Developmental Medicine and Child Neurology* 1995; 37[8]: 697-714.
8. **Jenkins**, J.R., Fewell, R., and Harris, S.R. Comparison of sensory integrative therapy and motor programming. *American Journal of Mental Deficiency* 1988; 88[2]: 221-224.
9. **Law**, M., Cadman, D., Rosenbaum, P., Walter, S., Russell, D., and DeMatteo, C. Neurodevelopmental therapy and upper-extremity inhibitive casting for children with cerebral palsy. *Developmental Medicine and Child Neurology* 1991; 33[5]: 379-387.
10. **Law**, M., Russell, D., Pollock, N., Rosenbaum, P., Walter, S., and King, G. A comparison of intensive neurodevelopmental therapy plus casting and a regular occupational therapy program for children with cerebral palsy. *Developmental Medicine and Child Neurology* 1997; 39: 664-670.
11. **Mayo**, N.E. The effect of a home visit on parental compliance with a home program. *Physical Therapy* 1981; 61: 27-32.
12. **Mayo**, N.E. The effect of physical therapy for children with motor delay and cerebral palsy: A randomized clinical trial. *American Journal of Physical Medicine and Rehabilitation* 1991; 70[5]: 258-267.
13. **Palmer**, F.B., Shapiro, B.K., Wachtel, R.C., Allen, M.C., Hiller, J.E., Harryman, S.E., Mosher, B.S., Meinert, C.L., and Capute, A.J. The effects of physical therapy on cerebral palsy: A controlled trial in infants with spastic diplegia. *New England Journal of Medicine* 1988; 318[13]: 803-808.
14. **Reddihough**, D.S., King, J., Coleman, G., and Catanese, T. Efficacy of programmes based on Conductive Education for young children with cerebral palsy. *Developmental Medicine and Child Neurology* 1998; 40[11]: 763-770.
15. **Scherzer**, A.L., Mike, V., and Ilson, J. Physical therapy as a determinant of change in the cerebral palsied infant. *Pediatrics* 1976; 58[1]: 47-52.

16. **Sellick**, K.J., and Over, R. Effects of vestibular stimulation on motor development of cerebral-palsied children. *Developmental Medicine and Child Neurology* 1980; 22[4]: 476-483.
17. **Wright**, T., and Nicholson, J. Physiotherapy for the spastic child: An evaluation. *Developmental Medicine and Child Neurology* 1973; 15: 146-163.

### **Panel Conclusions (Motor Therapy)**

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 NDT and 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**

This section evaluates the evidence about the efficacy of specific methods for managing spasticity in young children with cerebral palsy. Spasticity occurs when there is an increase in resistance to passive movement. Cerebral palsy (CP) affects the upper motor neurons so they cannot inhibit muscles properly and the muscles do not fully relax. When spasticity is ongoing, as in many children with cerebral palsy, reduced muscle function and contractures (a shortening of the muscles) can result.

Various approaches that are currently used for spasticity management in children with cerebral palsy include motor therapies; casting, splints, and

orthoses; oral medications (mainly muscle relaxants), medication infused into the spinal canal (intrathecal Baclofen infusion), and injections in the muscles with Botulinum toxin A (BtA); and surgery to selectively cut spinal nerve roots (selective posterior rhizotomy). To find evidence on efficacy of spasticity management methods, the panel did extensive literature searches on each of these topics.

There were six studies that met the panel's criteria for adequate evidence about efficacy of the interventions for spasticity management in children under 3 years old. These studies evaluated the efficacy of Botulinum toxin A (BtA) injections, serial casting, selective posterior rhizotomy, and use of physical/occupational therapy.

There were no studies that met criteria for adequate evidence that evaluated the use of oral or intrathecal medications for spasticity management.

### Studies Meeting Criteria for Evidence

1. **Corry, I.S.**, Cosgrove, A.P., Duffy, C.M., McNeill, S., Taylor, T.C., and Graham, H.K. Botulinum toxin A compared with stretching casts in the treatment of spastic equinus: A randomized prospective trial. *Journal of Pediatric Orthopedics* 1998; 18[3]: 304-311.
2. **Flett, P.J.**, Stern, L.M., Waddy, H., Connell, T.M., Seeger, J.D., and Gibson, S.K. Botulinum toxin A versus fixed cast stretching for dynamic calf tightness in cerebral palsy. *Journal of Paediatrics and Child Health* 1999; 35[1]: 71-77.
3. **Koman, L.A.**, Mooney, J.F., Smith, B.P., Walker, F., and Leon, J.M. Botulinum toxin type A neuromuscular blockade in the treatment of lower extremity spasticity in cerebral palsy: A randomized, double-blind, placebo-controlled trial. *Journal of Pediatric Orthopedics* 2000; 20[1]: 108-115.
4. **McLaughlin, J.F.**, Bjornson, K.F., Astley, S.J., Graubert, C., Hays, R.M., Roberts, T.S., Price, R., and Temkin, N. Selective dorsal rhizotomy: Efficacy and safety in an investigator-masked randomized clinical trial. *Developmental Medicine and Child Neurology* 1998; 40[4]: 220-232.
5. **Steinbok, P.**, Reiner, A.M., Beauchamp, R., Armstrong, R.W., Cochrane, D.D., and Kestle, J. A randomized clinical trial to compare selective posterior rhizotomy plus physiotherapy with physiotherapy alone in children with spastic diplegic cerebral palsy. *Developmental Medicine and Child Neurology* 1997; 39[3]: 178-184.

6. **Steinbok**, P., and Schrag, C. Complications after selective posterior rhizotomy for spasticity in children with cerebral palsy. *Pediatric Neurosurgery* 1998; 28[6]: 300-313.
7. **Wright**, F.V., Sheil, E.M., Drake, J.M., Wedge, J.H., and Naumann, S. Evaluation of selective dorsal rhizotomy for the reduction of spasticity in cerebral palsy: A randomized controlled trial. *Developmental Medicine and Child Neurology* 1998; 40[4]: 239-247.

### **Panel Conclusions (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; however, 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 post-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 post 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; increased weakness in the legs; and falling. Parents also consider serial castings to be inconvenient. 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) result in significantly greater improvement in gross motor function than 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 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).



**APPENDIX C: DEVELOPMENTAL  
ASSESSMENT  
TESTS**

*Tests for identification  
and assessment of young  
children who have a  
motor disorder*

## APPENDIX C

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## APPENDIX C

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### Agnes and Stages Questionnaires

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<i>Purpose:</i>	To identify children as needing further testing and possible referral to early intervention services.
<i>Age Range:</i>	4 to 48 months
<i>Components:</i>	Areas screened include gross motor, fine motor, communication, personal-social, and problem solving. There are 3 versions.
<i>Scoring:</i>	The ASQ was designed to be used by parents having a variety of income and educational levels.
<i>Time:</i>	Not specified
<i>Standardization:</i>	The test was standardized on a sample of 2,008 children (53% were male, and the occupational and ethnic statuses of families were diverse). Children with disabilities and those at environmental or medical risk were included in this sample. Reliability and validity is included in the manual.
<i>Training:</i>	Not specified
<i>Other Versions:</i>	Spanish

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### Alberta Infant Motor Scale (AIMS)

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<i>Purpose:</i>	Measures gross motor maturation in infants. Identifies infants whose motor performance is delayed or aberrant.
<i>Age Range:</i>	Birth to 18 months (independent walking)
<i>Components:</i>	Assesses 58 items for infants at increased risk for motor problems. The focus of the assessment is on postural control relative to four postural positions: supine, prone, sitting, and standing.
<i>Scoring:</i>	Scored through observation with little or no handling.
<i>Time:</i>	15 minutes
<i>Standardization:</i>	Based on a sample of 2,400 infants
<i>Training:</i>	Physical therapists observe the infants

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**Assessment of Preterm Infants' Behavior (APIB)**

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<i>Purpose:</i>	Educates parents about premature infants.
<i>Age Range:</i>	Appropriate for use with preterm, at-risk, and full-term neonates, provided the infant is medically stable in an open isolette or crib at room temperature and in room air.
<i>Components:</i>	Individually administered battery of ordinal scales. Items are in part derived from BNBAS. Additional items created based on developmental principles and parameters for assessment believed to be important for identifying precursors for later development and on authors' extensive experience in observing behavior of preterm and at-risk infants.
<i>Scoring:</i>	System scores can be used to classify infants by behavioral organization and competence independent of maternal variables and gender, and not synonymous with (although influenced by) gestational age at birth. Scoring takes 45 to 60 minutes.
<i>Time:</i>	Takes 30 to 45 minutes to administer
<i>Standardization:</i>	No specific content validation or standardization procedures described in the manual.
<i>Training:</i>	Extensive (4 stages) training required for reliability

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**Battelle Developmental Inventory, 1984**

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<i>Purpose:</i>	Identifies children with disabilities, strengths and areas of need of children without disabilities; assists with designing appropriate instructional plans for individual children; and monitors children’s progress.
<i>Age Range:</i>	Birth to 8 years
<i>Components:</i>	Test has one form with five domains: personal-social, adaptive, motor, communication, and cognitive. Some testing materials are supplied with manual.
<i>Scoring:</i>	Items are scored from 0-2 based on interviews of caregivers or teachers, observation, and/or task performance. Emerging skills are included. Scores include percentile ranks for the overall test, domains, and some sub-domains. Standard scores can be obtained for conversion of percentile scores.
<i>Time:</i>	1 to 2 hours for entire test; 0 to 30 minutes for screening test; 30 minutes for cognitive domain.
<i>Standardization:</i>	A total of 800 children were selected based on region, gender, race, and urban/rural residency according to 1981 census statistics.
<i>Training:</i>	Not specified

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**Bayley Scales of Infant Development II (BSID-II) Second Edition 1993  
(Note: Third Edition Published 2005)**

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<i>Purpose:</i>	To measure a child's level of development in three domains: cognitive, motor, and behavioral.
<i>Age Range:</i>	1 to 42 months
<i>Components:</i>	The BSID-II consists of three scales: mental, motor, and behavior rating scales. The test contains items designed to identify young children who are at risk for developmental delay.
<i>Scoring:</i>	The examiner presents test materials to the child and observes the child's responses and behaviors. Performance results can be expressed as a developmental age or developmental quotient.
<i>Time:</i>	30 to 60 minutes
<i>Standardization:</i>	BSID normative data reflects the U.S. population in terms of race/ethnicity, infant's gender, education level of parents, and demographic location of the infant. The Bayley was standardized on 1,700 infants, toddlers, and preschoolers between 1 and 42 months of age. Norms were established using samples that did not include disabled, premature, and other at-risk children. Corrected scores may be used for these higher risk groups, but their use is controversial.
<i>Training:</i>	It is recommended that the test be administered and scored by appropriately trained clinical or school psychologists.

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**Carolina Curriculum for Infants and Toddlers with Special Needs (CCITSN)**

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<i>Purpose</i>	A curriculum-based assessment used to determine curricular interventions for infants and toddlers with mild to severe special needs.
<i>Age Range</i>	Birth to 24-month level of development
<i>Components</i>	Curriculum is divided into 26 teaching sequences that cover the 5 developmental domains. Specific activities and adaptations appropriate for diverse functional levels and disabilities, including perceptual impairment and motor delay, are included.  Instructional activities are process oriented, providing suggestions for incorporating activities into daily care and modifications for infants with motor, visual, or hearing impairments.
<i>Scoring</i>	Items scored pass-fail. Based on examiner’s judgment, infant’s performance may also be scored as partially successful. Child must successfully perform an item for 3 of 5 trials to reach teaching criterion.
<i>Time</i>	Not specified
<i>Standardization</i>	Criterion referenced. Scores not norm-referenced. Fieldtested curriculum and assessment with details provided. Interrater reliability of 96.9% agreement reported for first edition.
<i>Training</i>	Formal training not required. Designed to be administered by professionals from numerous disciplines.

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**Denver Developmental Screening Test; Denver II (DDST)**

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<i>Purpose:</i>	Primarily designed to identify children with delays in multiple domains who are at risk for mental retardation. Can also be administered to monitor the development of infants who attend a high-risk infant follow-up clinic.
<i>Age Range:</i>	Birth to 6 years
<i>Components:</i>	Denver II retains structure of DDST in which items are divided into four domains: personal-social, fine motor adaptive, language, and gross motor. Items were expanded from 105 to 125, and 5 “test behavior” items were added.
<i>Scoring:</i>	Directions for administration are clear. Test is easy to administer, requires no special equipment, and is acceptable to both children and parents. Items arranged by domain and age level on a single-page screening form. Items are scored “pass,” “fail,” “no opportunity,” or “refusal.” Results are interpreted as normal, abnormal, questionable, or untestable.
<i>Time:</i>	Can be administered in less than 20 minutes
<i>Standardization:</i>	Technical manual includes details of revision and standardization.
<i>Training:</i>	Users of test are physicians conducting developmental surveillance as part of primary health care and high-risk infant follow-up programs.

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## APPENDIX C

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### Early Coping Inventory

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<i>Purpose:</i>	Designed to measure coping-related behaviors used by infants and toddlers in daily life. Can be used for intervention planning for children and to enhance collaboration between parents and staff through a shared understanding of child's coping behavior.
<i>Age Range:</i>	4 to 36 months, chronological or developmental age
<i>Components:</i>	Test assesses three categories of coping-related behaviors including sensorimotor organization, reactive behavior, and self-initiated behavior. Provides information on level of coping effectiveness, coping style, and specific coping strengths and vulnerabilities.
<i>Scoring:</i>	The child is observed in a variety of situations over a period of time. Behaviors are rated using the rating form. A coping profile is constructed from the three categories of coping related behaviors in order to determine a coping style.
<i>Time:</i>	Time will vary based on familiarity with child and context.
<i>Standardization:</i>	A criterion-related test to be used as a diagnostic tool. Poor test/retest reliability, and only item content validity was investigated.
<i>Training:</i>	Manual provided for administration and scoring

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### Early Motor Pattern Profile (EMPP)

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<i>Purpose:</i>	Used to assess children with possible cerebral palsy.
<i>Age Range:</i>	6 to 12 months
<i>Components:</i>	Test consists of 15 items reflecting variations in muscle tone, reflexes, and movement.
<i>Scoring:</i>	A three-point scoring system (normal-abnormal) is applied to each item. Prediction of cerebral palsy is made from the outcome.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Not specified
<i>Training:</i>	Physicians test the infants using various manipulations. Many of the manipulations are used as routine testing of infants by physicians.

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**Einstein Neonatal Neurobehavioral Assessment Scale (ENNAS)**


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<i>Purpose:</i>	To evaluate clinically observable features of neurologic and behavioral organization of newborn infant/term infants and high-risk newborn infants
<i>Age Range:</i>	Newborn infants/term infants
<i>Components:</i>	20 test items and 4 summary items including passive and active movement, tone, reflexes, and response to auditory and visual stimuli.
<i>Scoring:</i>	Scored on 3- to 7-point scale, cutoff scores for deviant performance (normal/suspect/abnormal)
<i>Time:</i>	30 to 45 minutes
<i>Standardization:</i>	Selected items related to organization of nervous system at term, discarded items thought to have no clinical interpretive value, as well as redundant and unreliable items.
<i>Training:</i>	Specialized training not required

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**Functional Independence Measure for Children (WeeFIM)**


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<i>Purpose:</i>	Functional assessment for children to determine the severity of a disability and the amount of assistance required.
<i>Age Range:</i>	6 months to 7 years
<i>Components:</i>	Measures a range of 18 functional abilities based on self-care, sphincter control, transfers, locomotion, communication, and social cognition.
<i>Scoring:</i>	Seven level ordinal scale rated from complete dependence to complete independence, based on caregiver interview, direct observation, or a combination of both.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Not specified
<i>Training:</i>	Training program for examiners is required, which includes lectures, rating videotape and completing three written case studies.

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## APPENDIX C

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### **Gesell and Amatruda Developmental and Neurological Examination – Revised**

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<i>Purpose:</i>	A standardized test of a child’s general development. Constructed for use by pediatricians in the developmental diagnosis of young children.
<i>Age Range:</i>	4 weeks to 36 months
<i>Components:</i>	Items included in motor section are familiar to physical therapists.
<i>Scoring:</i>	Revised test consists of 489 items divided into five domains of behavior: adaptive, gross motor, fine motor, language, and personal-social. Items are representative of developmental milestones and fairly easy to administer.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Standardized and normed between 1975 and 1977 on 927 infants in Albany, NY. Children tested 4 weeks apart between 4 and 56 weeks, and 3 months apart between 15 and 36 months. 489 out of 1,000 items were placed at the age passed by 50% of normative sample.
<i>Training:</i>	No formal training required

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**Gross Motor Function Measure (GMFM)**

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<i>Purpose:</i>	Measure used to evaluate change in gross motor function in children who have cerebral palsy.
<i>Age Range:</i>	All ages
<i>Components:</i>	88 items based on normal gross motor developmental milestones are arranged in developmental sequence and grouped into the following five testing dimensions: 1) lying and rolling, 2) sitting, 3) crawling and kneeling, 4) standing, 5) walking, running, and jumping.
<i>Scoring:</i>	Each item is scored using a 4-point Likert scale. Scores are individually summed within each of the 5 dimensions and converted into percentages (child's score/maximum score x100). The aggregate score can be calculated by adding the percentage scores and dividing by the number of dimensions.
<i>Time:</i>	The GMFM may be completed in 1 to 2 evaluation sessions of 45 minutes each.
<i>Standardization:</i>	Tested on 111 children with cerebral palsy younger than 20 years of age and 34 typically developing children.
<i>Training:</i>	Training is recommended. GMFM guidelines are available and include tester instructions, item definitions, and scoring key and equipment. Often administered by physical therapists.

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## APPENDIX C

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### Gross Motor Performance Measure, Quality of Movement (GMPM)

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<i>Purpose:</i>	An observational instrument that measures changes in quality of movement in children with cerebral palsy
<i>Age Range:</i>	All ages
<i>Components:</i>	Various gross motor activities measuring alignment, stability, coordination, weight shift, and disassociated movement.
<i>Scoring:</i>	Parent and therapist ratings on a 15-point Likert scale.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Not specified
<i>Training:</i>	One-day administration training and scoring sessions

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### Infant Neurological International Battery (INFANIB)

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<i>Purpose:</i>	Designed to assess neurologic integrity of infants being monitored following treatment in neonatal intensive care units.
<i>Age Range:</i>	Neonates and infants up to 9 months
<i>Components:</i>	Battery of 20 items, 14 of which can be assessed in neonatal period; 6 others are added between 3 and 9 months of age. Items consist of resistance to passive movement (e.g., scarf sign, popliteal angle), reflexive responses (e.g., foot grasp, ANTR), equilibrium reactions (e.g., parachute responses), and quality of certain milestones (e.g., sitting position, weight bearing in standing).
<i>Scoring:</i>	Measures muscle range
<i>Time:</i>	Not specified
<i>Standardization:</i>	Not specified
<i>Training:</i>	Not specified

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**Leiter International Performance Scale (LIPS)**


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<i>Purpose:</i>	Measures intelligence through testing of nonverbal items. Serves as supplementary measure of intelligence.
<i>Age Range:</i>	2 years to 21 years
<i>Components:</i>	Based on 2 nationally standardized test batteries. The visualization and reasoning domain battery was revised and the attention and memory domain battery was added in 1997.
<i>Scoring:</i>	Uses age-scale format. Composite IQ scores are given using a mean value of 100 and a standard deviation of 15. Scores may be obtained by domain and subtest.
<i>Time:</i>	30 to 35 minutes to administer
<i>Standardization:</i>	Norms outdated and validity data is limited
<i>Training:</i>	Psychologist or trained professional

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**Milani-Comporetti Motor Development Screening Test (M-C)**


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<i>Purpose:</i>	Screens children who have developmental delays.
<i>Age Range:</i>	6 to 16 months
<i>Components:</i>	Calculations in the categories of normality, transient abnormality, and abnormality.
<i>Scoring:</i>	5-point scale. Pearson Product-Moment Correlation Coefficients calculated between item scores and 3 categories.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Tested 999 high-risk infants at ages 6 and 16 months.
<i>Training:</i>	Not specified

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## APPENDIX C

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### Miller Assessment of Preschoolers (MAP)

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<i>Purpose:</i>	Screening test to discriminate delays in sensory, motor, and cognitive abilities. Identifies children who may have future problems in school performance.
<i>Age Range:</i>	3 to 6 years
<i>Components:</i>	Quality of Movement Supplemental Measure includes wide range of items to assess motor dysfunction typical of children with cerebral palsy. Supplemental appendices compiled to assess qualitative aspects of language, vision, touch, movement, and drawing abilities.
<i>Scoring:</i>	Scoring limited to present/absent scale that may limit value in evaluating gradual change in motor behavior.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Main test standardized on 616 children in US
<i>Training:</i>	Not specified

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### Movement Assessment of Infants (MAI)

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<i>Purpose:</i>	Discriminates among children who have a motor disorder in high-risk population. Describes functional and qualitative components of gross motor behavior.
<i>Age Range:</i>	Birth to 12 months
<i>Components:</i>	65 items are grouped into the following 4 major categories: 1) muscle tone, 2) primitive reflexes, 3) automatic reactions, and 4) volitional movement.
<i>Scoring:</i>	A 6-point scale is used to score items in the muscle tone category. The scores represent gradations between hypotonia and hypertonia. The remaining 3 categories are graded on a 4-point scale based on the strength and maturity of each response.
<i>Time:</i>	30 to 40 minutes to administer
<i>Standardization:</i>	Not specified
<i>Training:</i>	Degrees of training vary. Physicians, therapists, and nurses.

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**Neonatal Behavioral Assessment Scale, Brazelton (NBAS or BNBAS)**


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<i>Purpose:</i>	To profile full range of neonatal behavior to describe status of infants' autonomic, motor, state, and socioattentional systems as they interact and become integrated.
<i>Age Range:</i>	Newborn to 2 months and preterm infants (at term)
<i>Components:</i>	28 behavioral items and 18 reflex items arranged into 8 subscales: habituation, social-interactive, motor system, state organization, state regulation, autonomic system, supplementary items and reflexes.
<i>Scoring:</i>	Behavior items scored on 9-point scale, reflexes scored on 4-point scale.
<i>Time:</i>	20-30 minutes
<i>Standardization:</i>	Not specified
<i>Training:</i>	Training required, certification provided

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**Neonatal Neurobehavioral Examination, Morgan (NNE)**


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<i>Purpose:</i>	To characterize changes in neurobehavioral function that occur with increasing maturation.
<i>Age Range:</i>	Term and high-risk infants.
<i>Components:</i>	Measures 27 tone and motor patterns, and primitive reflexes that reflect changes with maturation.
<i>Scoring:</i>	3-point scale according to response expected for age, behavioral scores derived.
<i>Time:</i>	15 minutes
<i>Standardization:</i>	Tested 54 normal term infants and 29,888 high-risk infants.
<i>Training:</i>	Specialized training not required

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## APPENDIX C

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### Neonatal Neurological Examination (NEONEURO)

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<i>Purpose:</i>	To assess neurologic and neurobehavioral performance of neonate/term newborn infants.
<i>Age Range:</i>	Neonate/term newborn infants
<i>Components:</i>	Tests 32 items, 7 factors: hypertonus, primitive reflexes, limb tone, neck support, reflexes and tremor, alertness, fussiness.
<i>Scoring:</i>	5-, 3-, and 2-point scales, factor scores summed for a total score, classified normal to abnormal.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Administered 44 items to newborn infants under uniform conditions, qualified responses, grouped items using factor analysis and refined test.
<i>Training:</i>	Administered by health professionals, specialized training not required.

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### Neonatal Oral-Motor Assessment Scale (NOMAS)

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<i>Purpose:</i>	Devised to identify oral-motor problems in the neonate.
<i>Age Range:</i>	Neonate
<i>Components:</i>	Observation of tongue and jaw motion in nutritive and nonnutritive sucking.
<i>Scoring:</i>	Scoring scale originally divided into normal and abnormal categories of feeding patterns. Twelve points assigned in each characteristic category. An optimal score is given; anything less indicates oral-motor difficulty.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Not specified
<i>Training:</i>	Not specified

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**Neurobehavioral Assessment of the Preterm Infant (NAPI)**


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<i>Purpose:</i>	To measure developmental progression of neurobehavioral function in preterm infants.
<i>Age Range:</i>	Preterm infants >31 weeks to term
<i>Components:</i>	Measures the following neurobehavioral dimensions: motor development and vigor, scarf sign, popliteal angle, alertness and orientation, irritability, cry quantity and percent asleep, behavioral state.
<i>Scoring</i>	3-0-point scales, table converts to scores from 0-100, cluster scores are summed and average score calculated.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Norms developed based on 973 assessments of 521 infants.
<i>Training:</i>	Training includes a 30-minute training videotape. Examiner must achieve reliability in administration and scoring as determined by a qualified teacher.

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**Neurological Assessment of the Preterm and Full-Term Newborn Infant, Dubowitz (NAPFI)**


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<i>Purpose:</i>	To examine infants sequentially, using a simple and objective scoring system.
<i>Age Range:</i>	Term infants (within first 3 days), preterm infants (birth to term)
<i>Components:</i>	33 items divided into 4 subsections: habituation, movement and tone, reflexes, neurobehavioral responses.
<i>Scoring:</i>	5-point scale, no total score provided
<i>Time:</i>	15 minutes
<i>Standardization:</i>	Tested neurologic items on 50 infants, selected and modified items using set criteria, used diagrams and scoring system of Parmelee.
<i>Training:</i>	Specialized training not required

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## APPENDIX C

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### Neurological Evaluation of the Newborn and Infant (Amiel-Tison)

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<i>Purpose:</i>	Assesses infants' neuromotor abilities
<i>Age Range:</i>	Birth to 1 year
<i>Components:</i>	Test includes parent interview and physical examination of the infant including examination of the head, infant's posture and spontaneous motor behavior, passive and active muscle tone, primary reflexes, as well as the lateral adduction maneuver.
<i>Scoring:</i>	Record form contains infant's responses for the entire first year. Scores are marked on a grid shaded to show typical profiles according to age. The infant's outcome is categorized at the end of a year based on data gathered.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Not specified
<i>Training:</i>	Not specified

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### Neurological Examination of the Full-Term Infant (Prechtl)

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<i>Purpose:</i>	To document condition of nervous system and to detect neurologic disorders of neonate/term infants and preterm infants (at term).
<i>Age Range:</i>	Neonate/term infants and preterm infants
<i>Components:</i>	42 items are measured: state, posture, spontaneous movement, tremor, eyes, reflexes, and responses.
<i>Scoring:</i>	Each item scored as optimal/not optimal, maximum score of 42
<i>Time:</i>	30 minutes
<i>Standardization:</i>	1,378 term infants tested and each item rated as optimal or not optimal, selection of items not discussed.
<i>Training:</i>	Specialized training not required

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**Oral-Motor Feeding Rating Scale**


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<i>Purpose:</i>	Assessment of oral-motor feeding in children. Has potential value in clinical application for evaluation of patients and documentation of progress pending further work to establish reliability.
<i>Age Range:</i>	1 to 3 years
<i>Components:</i>	Tests oral-motor/feeding patterns: eight behaviors are evaluated and analyzed for lip and cheek movement, tongue movement, and jaw movement
<i>Scoring:</i>	The test is simple to administer, and scoring is easily read and interpreted.  The scale contains five sections: identifying information, oral-motor feeding patterns, related areas of function, respiration-phonation (optional), and rating scale synopsis.  The grading in the scale is from 0 to 5. Additional scales grade as “normal,” “inconsistent problem area,” or “consistent” problem area.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Not specified
<i>Training:</i>	Not specified

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**Peabody Developmental Motor Scales (PDMS)**


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<i>Purpose:</i>	Test able to discriminate between motor-delayed and typically developing children. Evaluates changes over time, and aids in treatment and planning.
<i>Age Range:</i>	Newborn to 7 years
<i>Components:</i>	Functional items well defined. Lack of items related to quality of movement is main drawback to test for its use in assessing motor performance in cerebral palsy.
<i>Scoring:</i>	Raw score (or scaled score for children with handicaps) can be calculated.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Assessed 617 newborn to 7-year-old children in U.S.
<i>Training:</i>	Not specified

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**Pediatric Evaluation of Disability Inventory (PEDI)**

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<i>Purpose:</i>	A judgment-based functional assessment that samples content in domains of self-care, mobility, and social function. Functional assessment of infant and toddler through interview with parents.
<i>Age Range:</i>	Test is designed for children between ages of 6 months and 7.5 years, but can be used for older children if functional abilities fall below those expected of typically developing 7-year-old children.
<i>Components:</i>	Measures both capability (197 functional skill items) and performance
<i>Scoring:</i>	Not specified
<i>Time:</i>	Not specified
<i>Standardization:</i>	Not specified
<i>Training:</i>	Not specified

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**Pre-Speech Assessment Scale (PSAS)**

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<i>Purpose:</i>	Rating scale of pre-speech behaviors. Most specific and in-depth assessment available.
<i>Age Range:</i>	Birth through 2 years
<i>Components:</i>	Twenty-seven pre-speech performance areas are divided into 6 categories for evaluation: feeding behavior, sucking, swallowing, biting and chewing, respiration-phonation, and sound play. In addition, some general postural motor patterns and behaviors relating to feeding and pre-speech are evaluated.
<i>Scoring:</i>	Double scaling system. One scale ranging from -1 to -9 is used to score abnormal behaviors. Another scale ranging from +1 to +24 months is used to score normal developmental patterns from primitive to higher level mature patterns. From pre-speech assessment form, a pre-speech assessment scale score is assigned. A summary of scores for repeated evaluation and a graph may be filled out.
<i>Time:</i>	Many testers choose to use only parts of test. Entire test is lengthy.
<i>Standardization:</i>	Not specified
<i>Training:</i>	Not specified

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**Primitive Reflex Profile (PRP)**


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<i>Purpose:</i>	Standardized assessment of 7 primitive reflexes.
<i>Age Range:</i>	Newborn to 24 months; 18 months to 21 years
<i>Components:</i>	Constructed to provide method of quantifying primitive reflexes. Reflexes selected based on clinical observations of persistence of primitive reflexes in children with cerebral palsy (CP).
<i>Scoring:</i>	A five-point ordinal scale is used to score reflex responses with 0 indicating that the reflex response is absent and 4+ indicating that the reflex response is obligatory. Composite bar graphs and graphs of mean scores published. Consistency on 3 of 5 trials is required for particular score. Guidelines are not provided for interpretation of total score.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Ability of test to discriminate functional levels of ambulation in children with CP was investigated in 53 subjects, ages ranged from 18 months to 21 years.
<i>Training:</i>	No equipment needed to administer test. The manual includes instructions for administering and scoring each item. Qualification for administration not in manual.

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**Schedule for Oral-Motor Assessment (SOMA)**


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<i>Purpose:</i>	To evaluate oral-motor function as an indicator of a possible neurodevelopmental disorder.
<i>Age Range:</i>	Up to 38 weeks
<i>Components:</i>	A variety of tastes and textures are presented to the infant
<i>Scoring:</i>	Information obtained from interviews about early and current feeding difficulties, along with a videotaped feeding session and a feeding administered by the tester. Behavior of the infant scored as “normal” or “abnormal.” Scores are then parsed into “mild,” “moderate,” or “severe.”
<i>Time:</i>	20 to 30 minutes
<i>Standardization:</i>	Not Specified
<i>Training:</i>	Information regarding qualifications of the examiner is not specified. Parents may require some training.

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**Test of Infant Motor Performance (TIMP)**

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<i>Purpose:</i>	To assess components of postural and selective control of movement important for function.
<i>Age Range:</i>	Early infancy/preterm and term infants from 32 weeks gestational age through 4 months of age.
<i>Components:</i>	27 spontaneously observed behaviors and 25 elicited items, including orientation of head in space, response to auditory and visual stimuli, body alignment, and distal and antigravity control of arm and leg movements.
<i>Scoring:</i>	Observed items: present or absent; elicited items: 5- or 6-point scale.
<i>Time:</i>	25 to 40 minutes
<i>Standardization:</i>	Item development based on a Rasch psychometric model using 100 infants of varying medical risk (32 weeks gestational age to 3.5 months post-term) administered to 76 infants, and additional item changes were made.
<i>Training:</i>	Not Specified

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**Test of Motor Impairment (TOMI) and Test of Motor Impairment-Henderson Revision (TOMI-H)**

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<i>Purpose:</i>	Test to discriminate typically developing children’s clumsiness from children with motor disorders.
<i>Age Range:</i>	5 to 12 years
<i>Components:</i>	Many items involve high-level, coordinated movements such as jumping rope, which may be suitable for use with clumsy children but not appropriate for majority of children with cerebral palsy.
<i>Scoring:</i>	Pass/Fail basis, which is unlikely to detect small changes in performance accurately.
<i>Time:</i>	Not specified
<i>Standardization:</i>	Based on test of 949 typically developing children in Great Britain and North America.
<i>Training:</i>	Not specified

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**Test of Sensory Function in Infants (TSFI)**

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<i>Purpose:</i>	Diagnostic tool designed to assess sensory processing and reactivity in infants with regulatory disorder, developmental delays, or at risk for later learning and sensory processing disorder (i.e., high-risk premature infants)
<i>Age Range:</i>	4 to 18 months
<i>Components:</i>	Includes 5 subdomains including reactivity to deep pressure, adaptive motor functions, visual tactile integration, oculo-motor control and reactivity to vestibular stimulation. Observations elicited through structured facilitation of response to select sensory stimuli. Can be administered while infant is positioned on parent's lap.
<i>Scoring:</i>	Scoring sheet is provided for individual items to reflect the infant's profile relative to each subtest. Each test is scored as either normal, at risk, or deficient. Examiner must follow verbal directions and administer exactly as described in test manual. Items must be given in the specified order. Parent can be coached to assist in the event of stranger anxiety.
<i>Time:</i>	Approximately 20 minutes
<i>Standardization:</i>	Criterion-referenced test. Based on a sample of 288 normal infants, 27 delayed infants, and 27 infants with regulatory disorders.
<i>Training:</i>	Examiners should become familiar with administration and scoring prior to use. Two hours of practice is the recommended minimum amount.

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**Toddler and Infant Motor Evaluation (TIME)**

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<i>Purpose:</i>	Measures quality of movements in children with suspected motor dysfunction. It provides information to be used in treatment planning and to measure change over time.
<i>Age Range:</i>	Birth to 42 months
<i>Components:</i>	Content domains measured include mobility, stability, organization, and dysfunctional positions. Incorporates flexible administrative format in which examiner observes child's spontaneous movements and parent does necessary manipulation.
<i>Scoring:</i>	Spontaneous movements are recorded for first 10 seconds that child spends in each starting position: supine, prone, sit, quadruped, and stand. The sequence of positions assumed is recorded, as are any abnormalities. Some evoked movements are also scored. Positioning and handling of child done by parent, with only verbal cues given by therapist.
<i>Time:</i>	15 to 30 minutes
<i>Standardization:</i>	Pilot tested on sample of over 600 children, including 133 infants and toddlers with motor delays stratified by major demographic variables. Standard scores will be available.
<i>Training:</i>	Appears easy to administer, instructions are clear. Unclear how much training needed for final form; however, tester will probably need to have significant experience in developmental testing.

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**Transdisciplinary Play Based Assessment (TPBS)**

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<i>Purpose:</i>	For infants with regulatory disorder, developmental delay, or at risk for later learning and sensory processing disorders (i.e., high-risk premature infants). Designed to obtain information in the following areas: social-emotional, cognitive, language/communication, and sensorimotor. Results can be used in planning intervention strategies.
<i>Age Range:</i>	6 months to 6 years
<i>Components:</i>	Four domains are assessed: cognitive, social-emotional, communication and language, and sensorimotor.
<i>Scoring:</i>	Sessions can be videotaped for later viewing and scoring by team members.
<i>Time:</i>	Not specified
<i>Standardization:</i>	No evidence of reliability or validity studies.
<i>Training:</i>	Not specified

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**Vineland Adaptive Behavior Scales (VABS)**

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<i>Purpose:</i>	To assess communication, daily living skills, socialization and motor skills domains.
<i>Age Range:</i>	Newborn to adult
<i>Components:</i>	Three forms are available: the Interview Edition Survey, the Expanded Form, and the Classroom Edition.
<i>Scoring:</i>	A respondent who knows the individual well (either a parent, a teacher, or another professional) answers behavior-oriented questions about the individual's adaptive behavior. Results can be expressed as a standard score, percentiles, or age equivalents in each domain, as well as in the form of an Adaptive Behavior Composite.
<i>Time:</i>	Approximately 90 minutes
<i>Standardization:</i>	The Interview Edition Survey and Expanded Form were standardized on 3,000 individuals from birth through 18 years old. Separate norms are available for children with mental retardation, emotional disorders, and physical handicaps. An additional 3,000 children ranging in age from 3 to 12 years served as the normative group for the Classroom Edition.
<i>Training:</i>	The examiner needs some level of supervised training, as the Vineland involves asking open-ended questions.

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**Wolanski Gross Motor Evaluation**

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<i>Purpose:</i>	Screening/discriminative test for gross motor delay.
<i>Age Range:</i>	3 to 13 months
<i>Components:</i>	Not specified
<i>Scoring:</i>	Not specified
<i>Time:</i>	Not specified
<i>Standardization:</i>	212 apparently typically developing children from 3 to 13 months of age in Poland composed test sample.
<i>Training:</i>	Not specified

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**APPENDIX D: EARLY  
INTERVENTION  
PROGRAM  
INFORMATION**

*New York State*

**D-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 248.) 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.



## Family Concern



REFERRAL

### 1. Referral *(unless parent objects)*

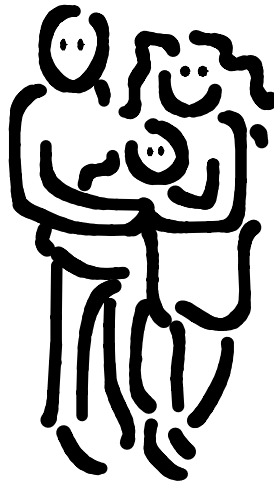
- Referral source or parent suspects child of having developmental delay or disability
- Family informed of benefits of Early Intervention Program
- Child referred to EIO within 2 days of identification
- Early Intervention Official assigns Initial Service Coordinator

### 2. Initial Service Coordinator

- Provide information about EIP
- Inform family of rights
- Review list of evaluators
- Obtain insurance/Medicaid information
- Obtain other relevant information



COORDINATOR



### 3. Evaluation\*

- Determine eligibility
- Family assessment, optional
- Gather information for IFSP
- Summary and report submitted prior to IFSP



EVALUATION

### 4. The IFSP Meeting\* *(if child is eligible)*

- Family identifies desired outcomes
- Early Intervention services specified
- Develop written plan
- Family and EIO agree to IFSP
- Identify Ongoing Service Coordinator
- EIO obtains social security number(s)

\*May access due process procedures

## 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



TRANSITION

## 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



REVIEW AHEAD

### 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

## APPENDIX D

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All services are at no cost to families. The program accesses 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.nyhealth.gov/community/infants\\_children/early\\_intervention/index.htm](http://www.nyhealth.gov/community/infants_children/early_intervention/index.htm)

[bei@health.state.ny.us](mailto:bei@health.state.ny.us)

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## D-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 at:

[http://www.nyhealth.gov/community/infants\\_children/early\\_intervention/index.htm](http://www.nyhealth.gov/community/infants_children/early_intervention/index.htm)

### 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.



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- (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 for 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;

### D-3: TELEPHONE NUMBERS OF MUNICIPAL EARLY INTERVENTION PROGRAMS

The following phone numbers were up to date at the time this document was published. Please visit our Web page for updates at:  
[www.nyhealth.gov/community/infants\\_children/early\\_intervention/index.htm](http://www.nyhealth.gov/community/infants_children/early_intervention/index.htm)

Albany	518-447-4820
Allegany	585-268-7545
Broome	607-778-2851
Cattaraugus	716-373-8050
Cayuga	315-253-1459
Chautauqua	716-753-4491
Chemung	607-737-5568
Chenango	607-337-1729
Clinton	518-565-4798
Columbia	518-828-4278 Ext. 1303/1305
Cortland	607-756-3439
Delaware	607-746-3166
Dutchess	845-486-3403
Erie	716-858-6161
Essex	518-873-3500
Franklin	518-481-1709
Fulton	518-736-5720
Genesee	585-344-8506 Ext. 3
Greene	518-719-3600
Hamilton	518-648-6141
Herkimer	315-867-1176
Jefferson	315-785-3283
Lewis	315-376-5401
Livingston	585-243-7290
Madison	315-363-1014
Monroe	585-530-4274
Montgomery	518-853-3531
Nassau	516-227-8661
New York City	212-219-5213

## APPENDIX D

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Niagara	716-278-1991
Oneida	315-798-5249
Onondaga	315-435-3230
Ontario	585-396-4439
Orange	845-291-2333
Orleans	585-589-2777
Oswego	315-349-3510
Otsego	607-547-6474
Putnam	845-278-6014 Ext. 2170
Rensselaer	518-270-2665 Ext. 2655
Rockland	845-364-2626
Saratoga	518-584-7460 Ext. 390
Schenectady	518-386-2815
Schoharie	518-295-8705
Schuyler	607-535-8140
Seneca	315-539-1920
St. Lawrence	315-386-2325
Steuben	607-664-2146
Suffolk	631-853-3100
Sullivan	845-292-0100 Ext. 2700
Tioga	607-687-8600
Tompkins	607-274-6644
Ulster	845-334-5251
Warren	518-761-6580
Washington	518-746-2400
Wayne	315-946-7262
Westchester	914-813-5094; Spanish 914-813-5085
Wyoming	585-786-8850
Yates	315-536-5160

*(Continued from previous page)*

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**APPENDIX E: 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 (increased deep tendon reflexes) is 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*--This 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 of 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 either *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 ICDH-2. The ICDH-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 ICDH-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 ICDH-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 57) and in Appendix C.

**APPENDIX F: ADDITIONAL  
RESOURCES**

## APPENDIX F

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**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  
Silversprings, MD 20910

(800) 433-5255

(301) 565-3842

(301) 565-3843 (fax)  
[www.thearc.org](http://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)

**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.*



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REVIEWERS**

**PEER REVIEWERS**

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Pomona Pediatrics PC  
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Churchville, NY

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Just Kids Learning Center  
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## APPENDIX G

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Buffalo Children's Hospital  
Buffalo, NY

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