

QUICK REFERENCE GUIDE
for Parents
and Professionals



Down SYNDROME

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



Sponsored by

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

CLINICAL PRACTICE GUIDELINE

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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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Health Education Services
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MasterCard and Visa accepted via telephone: (518) 439-7286.

Publication Titles

1. *Clinical Practice Guideline: The Guideline Technical Report.*
Down Syndrome, Assessment and Intervention for Young Children (Age 0-3 Years).
8½" x 11", 404 pages. Publication No. 4959, 2006.

1a. Evidence Tables – Assessment and Intervention. 8½" x 11", 80 pages.
Publication No. 4974, 2006.
2. *Clinical Practice Guideline: Report of the Recommendations.*
Down Syndrome, Assessment and Intervention for Young Children (Age 0-3 Years).
5½" x 8½", 292 pages. Publication No. 4958, 2006.
3. *Clinical Practice Guideline: Quick Reference Guide.*
Down Syndrome, Assessment and Intervention for Young Children (Age 0-3 Years)
5½" x 8½", 176 pages. Publication No. 4957, 2006.
4. *Clinical Practice Guidelines on Compact Disc:* Includes – Guideline Technical
Report, Evidence Tables, Report of the Recommendations, and Quick Reference
Guide. Publication No. 4960, 2006.

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The New York State Department of Health gratefully acknowledges the contributions of individuals who have participated as guideline panel members and peer reviewers for the development of this clinical practice guideline. Their insights and expertise have been essential to the development and credibility of the guideline recommendations.

The New York State Department of Health Bureau of Early Intervention especially appreciates the advice and assistance of the New York State Early Intervention Coordinating Council and Clinical Practice Guidelines Project Steering Committee on all aspects of this important effort to improve the quality of early intervention services for young children with Down syndrome and their families.

The contents of the guideline were developed under a grant from the U.S. Department of Education. However, the contents do not necessarily represent the policy of the Department of Education, and endorsement by the federal government should not be assumed.

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Down Syndrome

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Foreword

Providing an optimal early intervention program for young children with developmental disabilities and their families requires knowledge of the most 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 methodological and 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. The *Clinical Practice Guideline for Down Syndrome* has been the result of just such a sophisticated and methodologically sound approach to accurately gather and summarize information based on the available evidence.

This document is especially innovative in that it thoughtfully integrates developmental profile studies and research from intervention science to yield the best practice recommendations possible.

MICHAEL J. GURALNICK, Ph.D.
University of Washington

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 assure 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 Health Care Policy and Research (AHCPR). This methodology was selected because it is an effective, scientific, and well-tested 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, as defined by the state, 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, including 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 families receive the services included in the Individualized Family Service Plan (IFSP) that is developed for the child and family.
- Identification and referral of children at risk or suspected of disability by primary referral sources (including physicians and other health care providers).

PREFACE

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

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

- Support parents in meeting their responsibilities to nurture and to enhance their children'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.
- Assure 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; developing individualized family service plans; ensuring the appropriate provision of early intervention services; and promoting 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 Program ❖ Throughout the document, information about relevant Early Intervention Program policy is presented in boxes with this symbol.

CLINICAL PRACTICE GUIDELINE

QUICK REFERENCE GUIDE

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

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

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

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

CHAPTER I: INTRODUCTION

PURPOSE OF THIS CLINICAL PRACTICE GUIDELINE

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

This clinical practice guideline on Down syndrome is 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 with Down syndrome.

REASONS FOR DEVELOPING THIS GUIDELINE

The primary reasons for developing a clinical practice guideline for young children with Down syndrome 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

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. The decision to follow any particular recommendations should be made by the family and the provider based on the circumstances of the individual child(ren) and their families.

FOCUS OF THIS GUIDELINE

This clinical practice guideline provides recommendations about best practices for assessment and intervention for young children with Down syndrome. The *primary topics* of this guideline are:

- **Down syndrome in children under three years of age**

The primary focus of the guideline is children with Down syndrome from birth to three years old. However, age three is not an absolute cutoff, since many of the recommendations in this guideline may also be applicable to somewhat older children.

- **Developmental disabilities related to Down syndrome**

The focus of the recommendations in this document is assessment and intervention for developmental disabilities associated with Down syndrome. While children with Down syndrome commonly have various health or medical conditions that are important to address, it is beyond the scope of this guideline to evaluate specific assessment and treatment for medical conditions (such as heart problems) often found in children with Down syndrome.

“Down Syndrome” as it is Used in This Guideline

The definition of *Down syndrome*, as used in this *Quick Reference Guide*, is any child who is diagnosed with Down syndrome, regardless of the child’s specific karyotype pattern.



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

HOW THIS GUIDELINE WAS DEVELOPED

A multidisciplinary panel of topic experts, general providers (both clinicians and educators), and parents developed this guideline.

After determining the general scope of the guideline, the panel established the specific assessment and intervention topics to be addressed, and which of those topics and methods were most appropriate for the focus of the literature search and evidence review. The guideline panel then participated in a series of meetings to review the available research and develop guideline recommendations. The panel’s final meeting was in 2000.

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

Using Scientific Evidence to Develop Guidelines

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.

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. When adequate scientific evidence can be found and systematically evaluated, it provides a balanced and objective approach for making informed decisions.

More specific information about the research process and the evidence used to develop the guideline recommendations is described in other more complete versions of this guideline.

DEFINITION OF COMMON TERMS

Below are definitions for important terms as they are used in this guideline:

<i>Assessment</i>	The entire process of identifying and evaluating the child, including the activities and tools used to measure level of functioning, establish eligibility for services, determine a diagnosis, plan interventions, and measure treatment outcomes.
<i>Family</i>	The child's primary caregivers, who might include one or both parents, siblings, grandparents, foster care parents or others usually in the child's home environment(s).
<i>Parent(s)</i>	The persons who have the primary responsibility for the welfare of the child. Although the primary caregiver may be someone other than the mother or father of the child, the term <i>parent</i> is used to mean the child's primary caregiver(s).
<i>Professional</i>	Any provider of a professional service who is qualified by training, experience, licensure, and/or other state requirements to provide the intended service. The term is not intended to imply any specific professional degree or qualifications other than appropriate training and credentials.
<i>Screening</i>	The early stages of the assessment process. Screening may include parent interviews or questionnaires, observation of the child, or use of specific screening tests. Screening is used to identify children who need more in-depth assessment and evaluation.
<i>Target Population</i>	The target population is children with Down syndrome from birth to 3 years of age.
<i>Young Children</i>	This term is used broadly to describe the target age group for this guideline (children from birth through 3 years of age). However, age 3 is not an absolute cutoff because many of the recommendations may also be applicable to somewhat older children.



Early Intervention Program ❖ The terms assessment, parents, and screening are defined in regulations that apply to the Early Intervention Program in New York State. See Appendix B, 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 B, “Early Intervention Program Information.”

**CHAPTER II: BACKGROUND
INFORMATION**

WHAT IS DOWN SYNDROME?

Down syndrome is a chromosomal abnormality. A person with Down syndrome has three copies of chromosome 21, instead of the usual two.

WHAT CAUSES DOWN SYNDROME?

The extra copy of chromosome 21 is the direct cause of Down syndrome. Down syndrome is not caused by something the mother does (or does not do) during pregnancy.

Down syndrome can occur in one of three forms:

Meiotic nondysjunction – An error occurs in the separation of chromosome 21 during cell division in the process of forming the embryo (Figure 1).

Translocation– The extra copy of chromosome 21 is attached (translocated) to another chromosome.

Mosaicism – An error occurs during cell division (mitosis) at some point *after* formation of the embryo.

HOW COMMON IS DOWN SYNDROME?

Down syndrome is a relatively common genetic disorder, occurring in about one of every 800 to 1,000 live births. The chance of having a baby with Down syndrome increases significantly with the mother’s increasing age. The risk of having a second child with Down syndrome is higher, especially if one parent is a carrier of a translocated chromosome 21. Families with histories of genetic disorders are more likely to have children with genetic disorders, such as Down syndrome.

Figure 1: Normal (Non-Down Syndrome) Karyotype

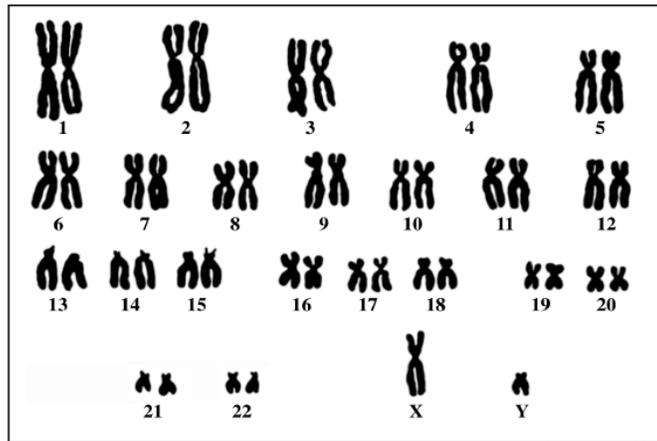


Figure 2: Nondisjunction Down Syndrome (extra free-standing 21)

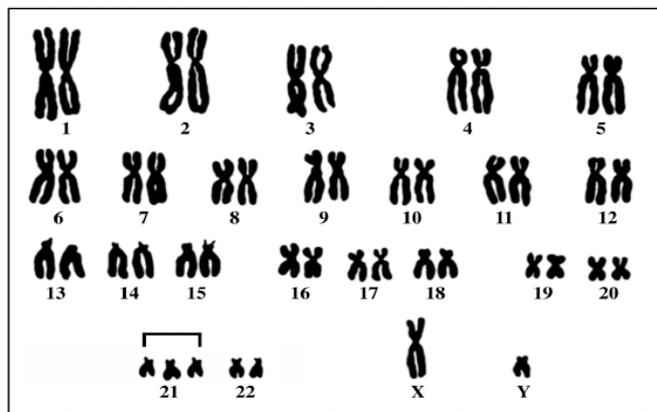


Figure 3: Balanced Translocation (a 21 is attached to a 14: no extra 21 material)

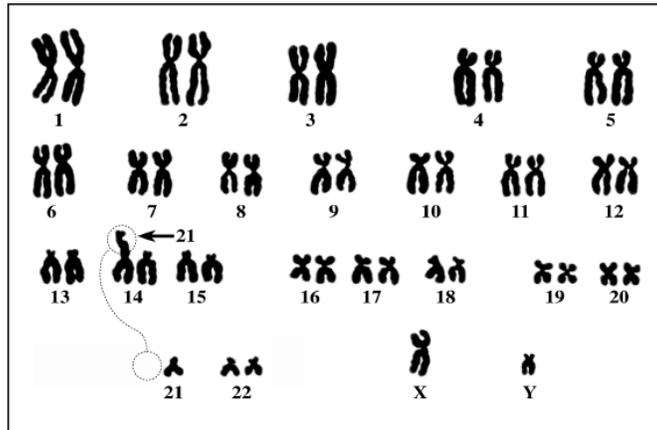
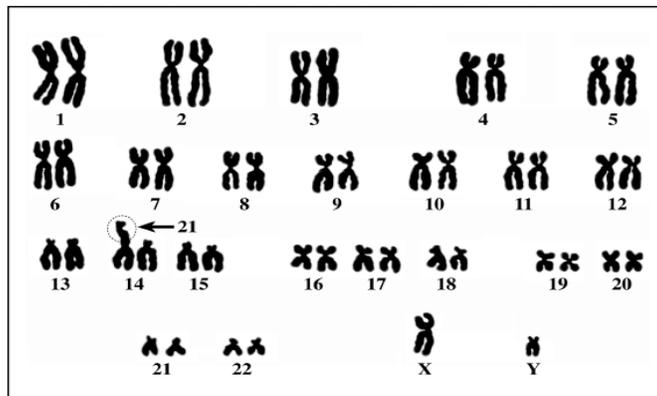


Figure 4: Translocation Down Syndrome (a third 21 is attached to a 14: three copies of 21)



HOW IS DOWN SYNDROME DIAGNOSED?

Diagnosis in the newborn or older individual is confirmed by chromosome analysis of a blood sample. Prenatal diagnosis involves examination of fetal cells floating in the amniotic fluid (obtained by amniocentesis) or of cells taken from the placenta (chorionic villus sampling). Prenatal testing is usually performed when there is an increased risk of the fetus having Down syndrome.

WHAT ARE THE PHYSICAL AND DEVELOPMENTAL CHARACTERISTICS ASSOCIATED WITH DOWN SYNDROME?

The most common physical and developmental features of children with Down syndrome are shown in Table 1.

Table 1: Common Characteristics of Children With Down Syndrome

Physical Characteristics	Developmental Characteristics
Short stature	Developmental delay
Low muscle tone	▪ cognitive
Joint laxity	▪ motor
Flat facial profile	▪ communication
Upward slanting eyes	▪ social skills
Abnormal shape of the ears	▪ adaptive/self-help
Little finger with only one joint	
A deep crease across the palm	
Obesity	

Physical characteristics

- Diminished rate of growth. Most people with Down syndrome do not reach average adult height
- Atypical head shape. The head may be smaller than average, with a flat area at the back
- Eyes that slant upward toward the edge of the face and an excess fold of skin over the inner corner of the eyes

- White spots in the colored part of the eyes (called Brushfield spots)
- Small or overfolded ears, a flat nasal bridge, and a small mouth with low oral muscle tone and a protruding tongue
- Short, broad hands with short fingers and a single crease spanning the width of the palm
- Decreased muscle tone

Developmental characteristics

- Delayed cognitive development, usually within the mild to moderate range of mental retardation
- Delayed and atypical speech and language development, with expressive language being more delayed than receptive language
- Delayed motor skills, including delayed rolling over, sitting, and walking
- Delayed development of social and adaptive/self-help skills
- Possible coexistence of other developmental disorders, mental health or behavioral conditions (such as attention deficit hyperactivity disorder, oppositional defiant disorder, or pervasive developmental disorders/autism)

In addition to the general developmental delays that are characteristic of most children with Down syndrome, there may also be other differences in the way children with Down syndrome develop when compared with children who do not have Down syndrome. However, as within any group of children, there will be individual differences in development within any group of children with Down syndrome. It is important to recognize that all children with Down syndrome will have individual strengths and talents, as well as limitations.

WHAT TREATMENTS ARE AVAILABLE FOR DOWN SYNDROME?

There is no cure for Down syndrome. However, many of the specific health and medical conditions associated with Down syndrome can be corrected or improved with appropriate treatment. In the past few decades, advances in medical care have resulted in improved health and life expectancy for individuals with Down syndrome. It is also common that infants with Down syndrome are now referred to early intervention programs shortly after birth. The goal of intervention programs for children with Down syndrome is to maximize each child's developmental potential and improve long-term functional outcomes for children and their families.

WHAT MEDICAL PROBLEMS ARE ASSOCIATED WITH DOWN SYNDROME?

Table 2: Common Associated Conditions in Children With Down Syndrome

	Percent of Children Affected
Congenital heart disease	40
Hypothyroidism	10-20
Joint laxity	15
Psychiatric disorders in adolescence	13
Gastrointestinal tract defect	12
Alopecia (hair loss)	10
Seizures	6
Leukemia	1
Obesity	50
Dental problems:	
▪ hypodontia, malocclusion	60-100
Hearing loss	60-80
Vision problems	
▪ cataracts	3
▪ refractive errors	70
▪ strabismus	50
▪ nystagmus	35

Adapted from: Pueschel 1990

MYTHS AND FACTS *

Myth: Most children with Down syndrome are born to older parents.

Fact: Although the incidence of Down syndrome increases with maternal age, 80 percent of children with Down syndrome are born to women younger than 35 years of age.

Myth: People with Down syndrome are severely retarded.

Fact: Most people with Down syndrome fall within the mild to moderate range of mental retardation.

Myth: Children with Down syndrome should be institutionalized.

Fact: Most children with Down syndrome live at home with their families, participate in community activities, participate in regular education services, do sporting activities, and develop skills for independent living.

Myth: Children with Down syndrome have to be placed in segregated special education settings.

Fact: Children with Down syndrome are generally able to participate in educational and vocational programs, and many are included in regular academic classrooms. Some children with Down syndrome may be integrated into specific activities with typically developing children, while others may be able to be included in all activities in the regular classroom. The appropriate level of integration depends on the ability of the child.

Myth: People with Down syndrome cannot form close, intimate relationships.

Fact: People with Down syndrome can date and form on-going relationships. Some may decide to marry. A woman with Down syndrome can have children, but there is a 50 percent chance that the children will have Down syndrome. There has been only one documented case of a male with Down syndrome being fertile.

** Myths and Facts adapted from information provided by The National Down Syndrome Society.*

WHERE CAN I GET MORE INFORMATION?

NDSS: The National Down Syndrome Society, founded in 1979, is a not-for-profit organization. It is the largest nongovernmental supporter of Down syndrome research in the United States.

National Down Syndrome Society (800) 221-4602 (toll-free)
666 Broadway, 8th Floor (212) 460-9330 (tel)
New York, NY 10012-2317 (212) 979-2873 (fax)
Website: www.ndss.org

NDSC: The National Down Syndrome Congress is a not-for-profit membership organization that serves as a national resource for families who have children with Down syndrome, professionals, and interested others.

National Down Syndrome Congress (800) 232-6372 (toll-free)
1370 Center Drive (770) 604-9500 (tel)
Suite 102 (770) 604-9898 (fax)
Atlanta, GA 30338 Website: www.NDSCcenter.org

DSPN: The Down Syndrome Parent Network is an organization whose goal is to provide accurate, up-to-date information on Down syndrome to parents, families, professionals, and the general public.

Down Syndrome Parent Network (800) HELP-309 (toll-free)
3626 Church Road Website: www.dspn.org
Easton, PA 18045

Additional resources are listed in Appendix C.

***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.*

CHAPTER III: ASSESSMENT

Children with Down syndrome can usually be identified at birth, or shortly thereafter. Identification usually occurs because the child has certain characteristics that are signs of Down syndrome (Table 1, page 11). The diagnosis is then confirmed by doing a blood test for a chromosome analysis.

After the diagnosis is confirmed, it is important to begin the assessment and intervention process as soon as possible. It is not necessary to wait for signs of a developmental delay.



Early Intervention Policy ❖ Children with Down syndrome are eligible for the Early Intervention Program because they have a diagnosed condition with a high probability of developmental delay. Services may begin before a quantified developmental delay is evident.

Importance of understanding Down syndrome

It is important that professionals assessing young infants with Down syndrome have a solid knowledge of typical early childhood development as well as an understanding of usual patterns of development for young children with Down syndrome. This is important so that the professional can:

- Make appropriate observations about the child's development
- Give accurate information to parents
- Make appropriate referrals
- Develop appropriate intervention strategies

IDENTIFICATION AND DIAGNOSIS OF DOWN SYNDROME

Physical Findings at Birth

Signs that an infant might have Down syndrome are usually apparent at birth. The most common of these signs are listed in Table 1 (page 11). If a newborn shows more than six of these signs, it is very probable that the child has Down syndrome. Even when a child has some of the signs of Down syndrome, a chromosome analysis is still necessary to confirm the diagnosis.

Table 3: Hall's Ten Signs of Down Syndrome in Newborns

Neonatal sign	% Frequency (percent of newborns affected)
Poor Moro reflex	85
Hypotonia	80
Flat facial profile	90
Upward-slanting palpebral fissures (eyelid openings)	80
Morphologically simple, small round ears	60
Redundant loose neck skin	80
Single palmar crease	45
Hyperextensible large joints	80
Pelvis radiograph morphologically abnormal	70
Hypoplasia of fifth finger middle phalanx	60

Adapted from: Tolmie 1998

General Description of Neonatal Signs

<i>Poor Moro reflex</i>	Often referred to as the “startle reflex”; babies with Down syndrome have a poor Moro reflex when body support is suddenly withdrawn
<i>Hypotonia</i>	Low muscle tone, floppiness
<i>Flat facial profile</i>	The bridge of the nose tends to be low and the cheekbones high, which makes the face look flat and the nose look small
<i>Upward-slanting palpebral fissures</i>	The eyes have an upward and outward slant
<i>Morphologically simple, small round ears</i>	Ears tend to be small, low-set, and have very small or absent earlobes
<i>Redundant loose neck skin</i>	The neck often appears slightly short with loose skin folds at the sides and back
<i>Single palmar crease</i>	A single crease across the palm, either on one hand or both hands
<i>Hyperextensible large joints</i>	A tendency for loose joints
<i>Pelvis radiograph morphologically abnormal</i>	X-ray of the pelvis shows that the pelvis is rather small and the bones less developed than in infants who do not have Down syndrome
<i>Hypoplasia of fifth finger middle phalanx</i>	The middle section of the little finger is short

Communicating the Diagnosis to the Family

When a child is diagnosed as having Down syndrome, the news is likely to be unexpected. It is important to deliver the news in a sensitive and caring way that supports the family.

It is important to understand that not all families will have the same reaction to learning that their child has Down syndrome. Some parents may hold themselves accountable, or feel they are held accountable by others, for their child's disability, so it is important to let them know that it is not the result of anything that either of the parents did or did not do before the child was born.

It is also important to recognize that parents may react differently to an uncertain prognosis about the child's developmental potential. Some parents may find it stressful; others find that uncertainty provides hope.

- When communicating the diagnosis, it is important for health care professionals to focus on the child as an individual and member of the family; the positive individual attributes, strengths, and characteristics of the child; the ways in which the child will be similar to typically developing children; and the fact that the child will learn, grow, and develop.
- It is recommended that parents be given current facts about Down syndrome and referrals to appropriate resources, such as the Early Intervention Program and appropriate health care specialists, so they can participate as active partners with health care providers in monitoring the development and health of their child.



Early Intervention Policy ❖ Primary referral sources, including doctors, must inform families of children with Down syndrome about the Early Intervention Program (EIP). Primary referral sources must refer children eligible for the EIP to the Early Intervention Official in the child's county of residence unless the parents object to the referral.

THE DEVELOPMENTAL ASSESSMENT

General Approach to Developmental Assessment

Children with Down syndrome have *quantitative* delays in many aspects of development when compared with typically developing children. Current research suggests that children with Down syndrome also have *qualitative* delays in development when compared with typically developing children. In other words, children with Down syndrome generally develop at a slower rate than do typically developing children and also have different patterns of development.

Conducting the developmental assessment

It is important that all children with Down syndrome have periodic, ongoing developmental assessments in all developmental domains. Since Down syndrome is usually identified early, it is important that this process of ongoing developmental assessments of all developmental domains begin in the first three months of life.

When assessing children who live in multilingual homes, it is important to use the primary language of the family.



Early Intervention Policy ❖ All children referred to the EIP, including children with Down syndrome, must receive a multidisciplinary evaluation to establish eligibility for the EIP and to help develop an Individualized Family Service Plan. The multidisciplinary evaluation must assess all five areas of development (cognitive, communication, physical, social-emotional, and adaptive development). Ongoing assessment of a child's progress is part of early intervention service delivery. The multidisciplinary evaluation team should provide the family with information about the development of children with Down syndrome (e.g., discussing information in these clinical practice guidelines and other sources of information).

The multidisciplinary evaluation to establish eligibility is provided at no cost to parents and must be performed using nondiscriminatory procedures as defined in program regulations (see Appendix B). The evaluation must be performed in the child's dominant language whenever feasible.

Considerations for planning and conducting assessments

It is important to consider general and specific factors that relate to the child and family when planning for and conducting developmental assessments (Table 4).

Table 4: Considerations for Planning and Conducting Assessments for Young Children

Planning the Assessment

- Ensure that professionals are experienced with this age group
- Make sure that the parents are available to be present for the assessment
- Ask the parents what their needs and expectations are for the assessment process
- Be aware of and informed about medical conditions that might influence the infant’s tolerance for the assessment process
- Be considerate of the child’s sleep/wake/alert routines
- Allow for extra time in the evaluation process for baby care or child care, such as feeding and diapering

Conducting the Assessment

- Explain each step of the assessment process before it is performed, and provide an explanation for why each aspect of the assessment is needed
 - Be sensitive to parent and child needs and reactions during the assessment process
 - Take cues from the parent in setting the pace of the assessment process (e.g., allowing time for breaks)
 - Be sensitive to the family’s current life/work issues, (e.g., adjusting to having a new baby)
 - Encourage parent observations of their child’s developmental status and temperament
 - Provide opportunities for the parent to discuss concerns and information needs
 - Be aware of the need for—and provide—postural control and support
 - Be alert to signs of other medical problems that may not have been identified
 - Begin the assessment with the child in positions that are comfortable for the child. Save tests that the child may not like, such as range of motion or protective responses, for the end of the assessment
 - Attend to biologic cues/behavior/evidence of overstimulation or responses to stress (crying, yawning, hiccups, irritability)
 - Be aware that very young infants may have difficulty regulating body temperature
 - Provide feedback to the family about the assessment
-

Components of the developmental assessment

When assessing young children with Down syndrome, it is important to consider the child's home and family environment. Aspects to consider include:

- The cultural values and customs of the family
- The opportunities for nurturing, stimulation, and learning in the child's home and other environments
- Any significant family history factors
- The emotional responses of the family to the birth of a child with Down syndrome, and how these family responses may have an impact on the child's development

It is recommended that the developmental assessment for a young child with Down syndrome include parent reports and interviews, medical records, child care and other relevant records, standardized tests (Appendix A) where appropriate, direct observation of the child, and information about the family concerns, priorities, and resources.



Early Intervention Policy ❖ 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.

Assessing developmental milestones

When assessing a child with Down syndrome, it is important to consider the child's developmental milestone progress relative to both children with Down syndrome and typically developing children (Table 5, page 33; Table 8, page 39; and Table 9, page 40). It is important to use the milestone charts to identify general reference points recognizing that children will vary as to when they attain specific developmental milestones.

Children with hearing, vision, or motor delays

If a young child has significant limitations in hearing, vision, or motor abilities, it may be necessary to adapt the materials, setting, or testing/response procedures.

Using the findings of the developmental assessment

Information from the developmental assessment is important for developing intervention plans for the child and family. The developmental assessment also provides useful objective reference points monitoring the child's progress and measuring outcomes of interventions. It is important to follow up on any questionable findings from the developmental assessment.

Communicating findings to parents and other professionals

It is recommended that the family be provided with a timely explanation of the results of the assessment (with translation into the child's and family's dominant language when needed). It is useful to discuss important terms and concepts, the results and implications of the assessment, and the child's performance level compared to developmental norms and to other children with Down syndrome.



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

Assessing Cognition

Cognition allows us to experience the environment, and to remember, think, act, and feel emotions. The components of cognition that are particularly important for children with Down syndrome are attention and exploration, learning and memory, and reasoning and problem solving.

There is a wide range of cognitive skills and abilities in children with Down syndrome, just as there is in the general population. While they are likely to be developmentally behind typically developing children of the same age, most children with Down syndrome learn and grow intellectually, especially when provided with learning opportunities that promote cognitive and social competence. It is important to assess cognitive ability in children with Down syndrome because it affects all other areas of development, helps in planning appropriate interventions, and provides a baseline for measuring progress.



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

Young children with Down syndrome appear to acquire specific cognitive skills in a sequence that is similar to typically developing children, but they tend to have:

- A slower rate of cognitive development (cognitive development is delayed and new skills are learned more slowly)
- More difficulty generalizing skills (more difficulty applying what is learned in one setting to a new setting)
- Some qualitative differences in how cognitive skills are performed or integrated with other behaviors
- More difficulty with complex reasoning and judgment
- A lower final level of cognitive skills and abilities

Conducting the cognitive assessment

When evaluating the cognitive function of young children with Down syndrome, it is important to:

- Conduct evaluations at “eyelevel” with the child
- Provide appropriate postural supports for children who have not yet developed postural control
- Take into account fine and gross motor skills when methods are selected to assess cognitive status
- Adjust testing procedures (if appropriate) to accommodate the longer response time needed by children with Down syndrome

It is recommended that the choice of tests used to assess the cognitive level of a child with Down syndrome be based on both the child’s mental age (MA) and chronologic age (CA).

Use and interpretation of cognitive assessment tests

When assessing a child with Down syndrome, it is important to include both standardized and nonstandardized tests. However, it is important to remember that when a child is young, performance on cognitive tests may fluctuate so the

test scores are often not stable. Therefore cognition may not be adequately measured in a single session or a single setting.

When interpreting results of standardized tests of cognition for young children with Down syndrome, it is important to recognize that developmental quotients (DQs) for children with Down syndrome typically appear to decline during the first two years of life. The apparent decline in DQ during the first two years in children with Down syndrome usually does not represent a true decline in cognitive functioning but rather is usually an artifact of the tests, since cognitive tests rely more on language items after 12 months of age, and children with Down syndrome are particularly delayed in expressive language.

Assessment tests

It is important to recognize that norm-referenced cognitive assessments are generally not considered a valid measure of cognitive function before about 6 months of age.

From age birth to 12 months: It is recommended that a norm-referenced or curriculum-linked assessment be used to assess cognitive level. Examples include:

- Battelle Developmental Inventory
- Hawaii Early Learning Profile
- Carolina Curriculum
- Mullen Scales of Early Learning
- Uzgiris-Hunt Scale

From age 1 to 3 years: It is recommended that standardized/norm-referenced tests be used to assess cognitive level. Examples include:

- Bayley Scales of Infant Development II (BSID-II)
- Leiter International Performance Scale - Revised
- Gessell Developmental Schedules

Assessing Communication

Communication is the process used to exchange information with others and includes the ability to produce and comprehend messages. The components of early communication that are particularly important for children with Down

syndrome are babbling, receptive and expressive language, language learning sequences, and the use of gestures.

The early vocal development of infants with Down syndrome and typically developing infants tends to be fairly similar. Differences begin to appear, however, by approximately 6 to 8 months, when typically developing infants begin canonical babbling (babbling characterized by consonant-vowel syllables that are speech-like, such as “ba”). Infants with Down syndrome typically do not develop this type of babbling until approximately 9 to 10 months of age.

Young children with Down syndrome are more likely to be able to understand language earlier than they can use it. Young children with Down syndrome also tend to use gestures more than typically developing children.



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

Importance of assessing communication

Assessing communication in children with Down syndrome is important because the child’s ability to communicate has implications for assessing cognition and other areas of development, making intervention decisions, providing a baseline for monitoring progress, and evaluating outcomes.

Components of the assessment of communication

It is recommended that a baseline communication assessment, including an objective hearing screening, be done in the first three months, and that a speech-language pathologist familiar with working with young children assess the child’s communication development at least every 6 months in the first 3 years.

In assessing communication in a young child with Down syndrome, it is important to consider the child’s:

- Cognitive level
- Hearing and vision status
- Respiratory function and breath support for vocalization
- Motor development and need for postural support for children with compromised motor development

- Primary language of the family and other language environments
- Responses to persons and not just to objects because young children with Down syndrome tend to spend more time looking at people than at objects

Audiologic assessment (hearing)

It is recommended that all newborns with Down syndrome have their hearing screened.

New York State Policy Note:

Under NYS public health law, newborn hearing screening is required for all newborn infants.

Even if there is no concern about hearing loss, it is recommended that all children with Down syndrome have ongoing monitoring of their hearing and periodic audiologic evaluation by an audiologist.



Early Intervention Policy ❖ Audiological services are an early intervention service. An audiological evaluation can be performed as a supplemental evaluation as part of the multidisciplinary evaluation process, or when identified as an area of need and can be included in the Individualized Family Service Plan.

Ongoing monitoring of hearing is important because hearing problems are much more common among children with Down syndrome than in the general population. One reason for this is that children with Down syndrome are more prone to recurrent otitis media with effusion (OME), which can result in some degree of conductive hearing loss. For children with middle ear problems, it is recommended that the child be seen by an ear, nose, and throat physician (ENT/otolaryngologist), preferably a pediatric otologist, on a regular basis.

Specific assessment approaches

When assessing communication development in young children with Down syndrome, it is important to pay attention to:

- Use of canonical babbling (babbling characterized by repeated consonant-vowel syllables such as “babababa”)
- Use of social referencing

- Functional use of spoken language (how children use words and sounds to get what they want)
- Ability to use nonverbal communication strategies, such as pointing to request or show an item, including:
 - Facility of use of gestures
 - Nonverbal receptive-expressive language

Communication assessment tests

It is important to include norm-referenced or standardized tests when assessing communication development in young children with Down syndrome. Examples include:

- The MacArthur Communicative Development Inventory
- The McCarthy Scales of Development
- The Rosetti Infant Toddler Language Scale

Use of alternative and assistive communication devices

When assessing communication in young children with Down syndrome, it is important to consider the need for alternative communication strategies, such as sign language, and assistive technology, such as personal hearing aids and FM systems. It is also important to consider the child's motor skills, as well as cognitive abilities and receptive language skills, when assessing appropriate forms of alternative communication.



Early Intervention Policy ❖ Assistive technology devices and services are included as early intervention services. Augmentative communication systems are considered “assistive technology devices.” The potential need for an augmentative communication system could be identified through the child's initial multidisciplinary evaluation, or later through a supplemental evaluation or ongoing assessment. The need for assistive technology devices must be agreed upon by the parent and the Early Intervention Official, and be included in the Individual Family Service Plan.

Assessing Social Interactions and Relationships

Social development is the ability to relate to other people. The components of social development that are particularly important for young children with Down syndrome include social attention, social interactions, attachment, and play.

Social attention skills of young infants with Down syndrome generally appear to follow a similar developmental progression as typically developing infants but at a slower rate.

Other aspects of social development in young children with Down syndrome appear to be different from those of typically developing children. For example, social interactions with young children with Down syndrome may be more difficult to elicit and interpret than interactions with typically developing children. Young children with Down syndrome tend to take less initiative in social interactions, tend to initiate and respond to interactions in a less predictable manner than do typically developing children, and tend to have social and communicative signals that are less readable to others. At play, young children with Down syndrome tend to have more limited repertoires than do typically developing children, and they tend to change the focus of their play more often.

Importance of assessing social development

It is important to assess social interactions and relationships in children with Down syndrome because of the potential impact on intervention decisions.



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

Components of the assessment of social development

When assessing social development, it is important to consider the child's cognitive skills, receptive and expressive language skills, and hearing status, as well as gross and fine motor skills because these may influence the way a child performs during an assessment.

When assessing social development, it is important to be aware that young children with Down syndrome tend to:

- Pay more attention to persons than to objects
- Have lower levels of sustained engagement/attention
- Be more responsive to directive than to suggestive requests
- Need sufficient time to respond when having their attention redirected

- Respond better when visual stimuli are provided at an eye-gaze level appropriate for facilitating performance

Because young children with Down syndrome tend to have lower levels of sustained attention, it may be useful to conduct shorter assessments (e.g., two 20-minute sessions instead of one 40-minute session).

Assessment of social interactions and relationships

Assessment of social interactions and relationships includes evaluation of:

- Social initiation (showing or giving objects to others for social purposes)
- Social imitation (imitating actions of others)
- Age expected reciprocity (turn-taking during play)
- The child's attachment behavior patterns in the presence of a caregiver (neutrality, excessive clinging, or avoidance of parent/caregiver)
- Social interactions with familiar as well as unfamiliar adults and peers
- The child's ability to make transitions from one play activity/toy to another
- Joint attention (shared interest in object or activity)

Assessments of social development of young children with Down syndrome include direct observation of the child's interactions with others, as well as information from the child's parent and/or primary caregiver.

Specific assessment approaches

Since children with Down syndrome have a tendency to focus on faces rather than objects, it may be useful to:

- Use facial stimuli to direct the child's attention appropriately
- Use a facial expression scale to assess affective expressions
- Use positive reinforcement when the child appropriately pays attention to toys and testing materials rather than to a parent or tester

Since children with Down syndrome have a tendency to change the focus of their play/activities more often than other children, it may be helpful to:

- Be flexible in response to the child's lead (unless the standardized test requires a specific order)
- Use music and singing to increase attending skills

When assessing social referencing and joint attention in children with Down syndrome, it is important to compare children with Down syndrome with other children with Down syndrome. It is also important to consider both verbal behaviors and nonverbal behaviors (facial gestures, body language, gazing), as well as to consider the child’s muscle tone and motor ability when assessing frequency of smiling.

Table 5: Social Development Milestones

Social/Self Help Activities	Age in Months			
	Down Syndrome		Typically Developing	
	Average	Range	Average	Range
Smiles responsively	2	1.5 - 4	1	1 - 2
Smiles spontaneously	3	2 - 6	2	1.5 - 5
Recognizes mother/father	3.5	3 - 6	2	1 - 5
Takes solids well	8	5 - 18	5	4 - 12
Feeds self crackers	10	6 - 14	7	4 - 10
Plays peek-a-boo/pat-a-cake	11	9 - 16	8	5 - 13
Drinks from cup	20	12 - 30	12	9 - 17
Uses spoon or fork	20	12 - 36	13	8 - 20
Feeds self fully	30	20 - 48	24	18 - 36
Undresses	38	24 - 60+	30	20 - 40
Plays social/interacting games		3.5 - 4.5 yrs.		
Uses toilet/potty without help		4 - 5 yrs.		

Adapted from: Cunningham 1996

Assessing Motor Development

Motor function is the process of sitting, standing, moving in space or place, and using our hands to play, care for ourselves, and work. Motor abilities are the skills that allow us to manipulate, move around in, and explore the world. Motor development depends on how sensory input is processed in the brain to result in purposeful movement. The components of motor development that are particularly important for young children with Down syndrome include postural

control, reflexes and reactions, gross and fine motor movements, and sensory processing.

Young children with Down syndrome tend to experience general developmental motor delays. Gross and fine motor developmental milestones are achieved at a slower rate than among typically developing children.

Young children with Down syndrome tend to experience low muscle tone, hyperflexibility, and delays in the emergence and fading of reflexes and automatic patterns of movement. Generally, the delay in motor skills is less noticeable during the first 6 months.

Children with Down syndrome have hands that tend to differ from typically developing children and these differences can affect strength of grasp, development of arches of the hands, grasp patterns, and dexterity. Children with Down syndrome have a greater dependence on visual feedback than do typically developing children, and they need a longer motor response time.

Assessment of motor development includes assessment of control of movement and posture, tone, and strength. Gross motor development refers to the ability to move the large muscle groups of the body (neck, trunk, and limbs), while fine motor development generally refers to the use of the hands and fingers.

It is important to assess motor development and functioning because of the potential impact on intervention decisions and implications for outcomes. It is also important to obtain an assessment of the quality of movements.



Early Intervention Policy ❖ An assessment of physical development, including motor development, is a required component of the multidisciplinary evaluation.

Conducting the motor assessment

It is important to obtain appropriate medical clearance before initiating a motor assessment for children with Down syndrome because these children often have underlying serious health conditions (e.g., congenital heart disease). During the assessment sessions, it is important to avoid rapid rotary or bouncing movements that may cause extreme flexion or extension movements of the neck.

While making the assessment, it is important to consider how the characteristics of children with Down syndrome may affect the assessment. For example, verbal, visual, tactile, and auditory stimulation may affect the child's movement. More

intense kinesthetic and proprioceptive stimulation may be needed to elicit a response and there may be a longer lag time between the stimuli and the response.

Components of the assessment of motor development

It is important to consider the following when assessing motor development and functioning in young children with Down syndrome:

- The interrelationship between the child's cognitive development and motor development
- The child's receptive language skills
- The child's overall health status and neurologic function
- The degree of any cardiac and respiratory distress or compromise, including:
 - Decreased muscle tone, which can lead to decreased lung power
 - Problems with feeding, sucking, swallowing, breathing, and talking
- Oral-motor function and needs
- The need for head, trunk, or lower extremity supports
- The need for appropriate adaptive equipment and/or the need to adapt the home environment
- The need for parent training/support to enhance motor development

It is recommended that assessment of gross motor skills begin by 3 months of age, and assessment of fine motor skills begin by 6 months of age (Table 6).

Table 6: Components of a Motor Assessment

Motor Attributes to be Assessed for All Ages

- Reflexes, postural reactions, protective reactions
- Postural control
- Postural alignment and symmetry
- Muscle tone
- Muscle strength
- Range of motion and joint laxity
- Pulmonary function
- Variety and complexity of movements
- Visual attention and tracking
- Sensory responsiveness to movement and touch

Activities Observed and Components Assessed

Birth to 6 months

Movements and postural control

- Supine/Prone
- Side-lying
- Supported sitting
- Supported standing
- Grasp
- Hand-to-mouth movements
- Scapula (shoulder) stability

Oral movement for sucking, feeding, and sound production

6 to 12 months

Sitting

- Postural control
- Base of support
- Ability to use hands

Mobility and exploration of environment

- Rolling
- Prone progression
- Belly crawling
- Digital (finger) grasp
- Transfers objects hand to hand
- Reaching patterns

Oral movements for eating, drinking, and sound production

Table 6: Components of a Motor Assessment

12 to 24 months:

Sitting

- Postural control
- Moving in and out of sitting
- Base of support/use of hands
- Variety of postures

Mobility and exploration of environment

- Crawling, climbing
- Pulling to stand
- Standing
- Cruising
- Taking steps
- Release of objects
- Eye-hand coordination
- Refinement of grasp
- Self-feeding

24 to 36 months:

Ability to negotiate in the environment independently

Walking on level, graded, and uneven surfaces

Stair climbing

Climbing on playground equipment

Use of coloring/drawing and writing utensils

(Continued from previous page)

Tests of motor function

The use of standardized or norm-referenced developmental motor assessment tests may be useful when assessing motor function in young children with Down syndrome. Commonly used developmental motor assessment tests are listed in Table 7.

Table 7: Developmental Motor Assessment Tests

Alberta Infant Motor Scale (AIMS)

Birth to 18 mos.
Postural control in supine, prone, sitting, standing

Battelle Developmental Inventory (BDI)

Birth to 8 yrs.
Social, adaptive, motor, communication, cognition

Bayley Scales of Infant Development II (BSID-II) Second Edition (Note: Third Edition, 2005)

Birth to 42 mos.
Cognitive, motor, behavior

Functional Independence Measure for Children (WeeFIM)

6 mos. to 7 yrs.
Mobility, self-care, communication, social, cognition

Gesell Developmental Schedules (GDS) - Revised

Birth to 72 mos.
Gross and fine motor, language, personal-social, adaptive

Hawaii Early Learning Profile (HELP)

Birth to 36 mos.
Cognition, language, gross and fine motor, social, self-help

Peabody Developmental Motor Scales (PDMS)

Birth to 7 yrs.
Reflexes, gross motor, fine motor

Pediatric Evaluation of Disability Inventory (PEDI)

6 mos. to 7 ½ yrs.
Self-care, mobility, social function

Test of Sensory Functions in Infants (TSFI)

4 mos. to 18 mos.
Tactile, deep pressure, visual-tactile integration, adaptive motor, ocular-motor, reactivity to vestibular stimulation

Toddler and Infant Motor Evaluation (TIME)

Birth to 42 mos.
Neurological function, stability, mobility, motor organization

Table 8: Motor Development Milestones

	Age in Months			
	Down Syndrome		Typically Developing	
	Average	Range	Average	Range
Gross Motor				
Holds head steady/balanced	5	3 - 9	3	1 - 4
Rolls over	8	4 - 12	5	2 - 10
Sits without support (1 minute or more)	9	6 - 16	7	5 - 9
Pulls self to stand	15	8 - 26	8	7 - 12
Walks with support	16	6 - 30	10	7 - 12
Stands unassisted	18	12 - 38	11	9 - 16
Walks unassisted	23	13 - 48	12	9 - 17
Walks up steps with help	30	20 - 48	17	12 - 24
Walks down stairs with help	36	24 - 60+	17	13 - 24
Runs	about 4 yrs.			
Fine Motor/Adaptive				
Follows object with eyes	3	1.5 - 6	1.5	1 - 3
Grasps dangled ring	6	4 - 11	4	2 - 6
Passes object hand to hand	8	6 - 12	5.5	4 - 8
Pulls string to obtain toy	11.5	7 - 17	7	5 - 10
Finds toy hidden under cloth	13	9 - 21	8	6 - 12
Puts 3+ objects into a cup	19	12 - 34	12	9 - 18
Builds a tower of 2-inch cubes	20	14 - 32	14	10 - 19
Does simple 3-shape puzzle	33	20 - 48	22	16 - 30+
Copies a circle	48	36 - 60+	30	24 - 40
Matches shapes with colors	4-5 yrs.			

Adapted from: Cunningham 1996

Assessing Adaptive/Self-Help Skills

Learning adaptive or self-help/self-care skills that include dressing, grooming (bathing), feeding, and toileting is usually one of the most important aspects of a child’s development. These skills are immediately useful, and they enable a child to be more independent, to learn more complex skills, to live in a less restrictive environment, and to be cared for more easily by family and others.



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

Young children with Down syndrome develop individual adaptive self-help skills in a progression similar to typically developing children, but they tend to do so later. These delays are probably related to problem solving, remembering steps, ability to focus on learning and completing tasks, awareness of position of body parts, postural stability, fine motor dexterity, and planning the movements needed to complete an unfamiliar motor task.

Table 9: Self-Help Milestones

	Age in Months			
	Down Syndrome		Typically Developing	
	Average	Range	Average	Range
Takes pureed solids well	8	5 - 18	7	4 - 12
Drinks from a cup	20	12 - 30	12	8 - 17
Uses fork or spoon	20	12 - 36	13	8 - 20
Undresses	38	24 - 60+	30	20 - 40
Feeds self fully	30	20 - 48	24	18 - 36
Controls urine during day	36	18 - 50+	24	14 - 36
Controls bowel	36	20 - 60+	24	16 - 48
Dresses self partially (not fasteners)		4 - 5 yrs.		
Uses toilet or potty without help		4 - 5 yrs.		

Adapted from: Cunningham 1996

Assessing Temperament and Behavior

Temperament refers to the manner in which people engage their world. Individuals with Down syndrome are commonly stereotyped as easy in temperament, affectionate, and obstinate, but this is not supported by research. Children with Down syndrome have individual personalities and can experience a wide range of feelings and emotional reactions.

In general, children with Down syndrome may be inherently less responsive to stimulation, and therefore may appear more passive than other children of similar chronologic age. Some behaviors, which might be interpreted as an aspect of the child's temperament, may have contributing factors related to other aspects of the child's development. For example, young children with Down syndrome often understand more language than they are able to express, and therefore may exhibit frustration during the communication process.

Components of the assessment of behavior and temperament

In assessing a child with Down syndrome, it is important to identify behavior patterns, relative strengths, and problem areas, including:

- Specific approaches Play skills (independent play and interactive play with parents, other adults, or other children)
- Unusual responses to sensory experiences
- Mood patterns
- Activity and behavior patterns
- Problem behaviors

The use of standardized or norm-referenced tests or scales may be helpful in assessing a child's individual temperament and may also be useful in identifying the need for parenting supports/counseling. Such tests include the Toddler Temperament Scale and the Infant Behavior Questionnaire.

ASSESSING THE RESOURCES, PRIORITIES, AND CONCERNS OF THE FAMILY

Intervention services are most effective when they are matched to the strengths and needs of the individual family. An assessment of the family's resources, priorities, and concerns may include informal discussions with families, using sensitive and focused interviewing techniques as well as assessment tools (e.g., the Parenting Stress Index) to help families identify, clarify, and communicate their goals and needs.



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

It is recommended that assessment of the resources, priorities, and concerns of the family include observation and/or discussion of:

- The family's knowledge and need for information about Down syndrome
- Family composition (including siblings and extended family)
- Family demographics, education, and specific circumstances
- Family values and culture
- The family's current support systems and resources (including extended family and their attitudes)
- The family's stressors, tolerance for stress, and coping mechanisms and styles
- Family interaction and patterns of parenting style
- Caregiving skills and sharing of caregiving responsibilities

Since family resources, priorities, and concerns may change over time, it is recommended that there be ongoing family assessment based on the individual needs of the family.

GENERAL HEALTH EVALUATIONS



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.

Health services that are needed by any child to address physical health needs (immunization, well child checkups, medical interventions) are not early intervention services and are not paid for by the Early Intervention Program.

This section describes the general health evaluation process and the general approach to assessing a few associated health conditions commonly seen in children with Down syndrome.

Primary reasons for health evaluations

There are three primary reasons for evaluating the health of children with Down syndrome. 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 with Down syndrome
- To determine the possible relevance of any identified problems to assessment and intervention

Medical conditions commonly seen or associated with Down syndrome are listed in Table 2 (page 13).

General health surveillance

It is recommended that children with Down syndrome receive the same general routine preventive health care as typically developing children. It is also recommended that the primary care physician be responsible for the child's general health surveillance, and that the primary care physician consult with other health professionals as needed.

In addition, it is recommended that physicians become familiar with and follow the general health care guidelines published by medical specialty groups, such as:

- The American Academy of Pediatrics, Committee on Genetics guidelines for providing medical care for children with Down syndrome (Table 10) (American Academy of Pediatrics 1994)
- Health Care Guidelines for Individuals with Down Syndrome: 1999 Revision (published in *Down Syndrome Quarterly*) (Cohen 1999)

**Table 10: Age-Specific Health Examination Recommendations:
Age 0 to 3 Years**

Neonatal (Birth to 1 month)

- Confirm the diagnosis of Down syndrome
- Review the karyotype with the parents; provide them with a copy
- Review prenatal diagnosis and recurrence risk
- Discuss potential clinical manifestations, including:
 - Feeding problems (including gastroesophageal reflux)
 - Middle ear problems and hearing impairment
 - Hypotonia (decreased muscle tone)
 - Facial appearance
 - Vision problems
 - Heart defects (approximately 50% of children with Down syndrome)
 - Duodenal atresia
 - Leukemia (less than 1% risk in children with Down syndrome)
 - Congenital hypothyroidism (1% risk)
 - Increased susceptibility to respiratory and sinus infections
- Perform focused medical evaluations to look for:
 - Vision problems (check for strabismus, cataracts, and nystagmus at birth or by 6 months)
 - Heart defects (echocardiogram recommended)
 - Duodenal atresia
- Discuss unproven therapies

Infancy (2 to 12 months)

- Review developmental milestones and elicit parent concerns regarding the child's development, vision, and hearing
- Refer for comprehensive audiologic assessment by 6 months. Review the risk of otitis media with effusion and associated hearing loss (60-80% risk in children with Down syndrome)
- Check vision at each visit. Check for strabismus, cataracts, and nystagmus by 6 months. Refer the infant to an ophthalmologist by 6 months
- Perform thyroid screening tests at 6 and 12 months. Thyroid screen should include measurement of TSH as well as T₄

Table 10: Age-Specific Health Examination Recommendations:

Age 0 to 3 Years

- Monitor the infant’s growth and development (see growth and development information for age 1-3 years). Monitor head growth using NCHS charts for typically developing children

Early childhood (1 to 3 years)

- Review developmental milestones and elicit parent concerns regarding the child’s development, vision, and hearing
- Have the child’s hearing checked by an audiologist every six months until age 2, and then annually
- Have the child’s vision checked annually by an ophthalmologist
- Check dental status; have dental semiannual exam starting at age 2, or sooner if indicated
- Monitor growth and development
 - Down syndrome specific growth charts can be used to assess length and weight relative to other children with Down syndrome (available at www.growthcharts.com)
 - National Center for Health Statistics (NCHS) growth charts for typically developing children can be used to assess weight to length ratio (available at www.cdc.gov/nchs)
 - Body mass index (BMI) can be used to measure weight for height beginning at approximately 2 years when an accurate stature can be obtained (available at www.cdc.gov/nchs)
- Perform thyroid screening tests annually. Screening should include measurement of TSH as well as T₄
- Screen for signs and symptoms of possible celiac disease by parent report (malabsorption, steatorrhea, failure to thrive)
- At 3 to 5 years, obtain radiographs for evidence of atlantoaxial instability or subluxation

*Adapted from: American Academy of Pediatrics 1994
(Continued from previous page)*



Early Intervention Policy ❖ Although assessment of physical development, including a health assessment, is a required component of the multidisciplinary evaluation, medical tests (MRIs, metabolic tests, and genetic tests) are not reimbursable under the NYS Early Intervention Program. The service coordinator can

and should assist the family in accessing these and other health care services through their primary health care providers. Supplemental physician evaluations may be accessed if appropriate and necessary to establish a child's eligibility for Early Intervention services or to conduct an in-depth assessment of the child's physical development if there are specific concerns or problems in this developmental area.

ASSESSMENT OF GROWTH, NUTRITION, AND METABOLISM

Growth, nutrition, and metabolism are very important for all young children, but they are particularly important for infants and young children with Down syndrome because their growth patterns are often quite different from typically developing children. Children with Down syndrome are more likely to have feeding problems and other health conditions (e.g., cardiac problems) that affect their nutrition and growth.

A standard method for assessing the growth and nutritional status of all infants and young children is to compare their length (or height) and weight to standardized growth charts. Children with Down syndrome are generally shorter than children of the same chronologic age. This is often referred to as growth delay. For this reason, researchers have developed separate Down syndrome specific growth charts for length and weight.

While head circumference also is smaller among children with Down syndrome, there is no comparably detailed Down syndrome specific growth chart for head circumference.

The role of the thyroid and growth hormone in the growth of children with Down syndrome is also important. A small percentage of children with Down syndrome will have hypothyroidism: approximately one percent has the condition at birth, and approximately 15 percent develop the condition when they are older. If untreated, hypothyroidism will affect growth and development and contribute to other health problems. The use of growth hormone therapy to stimulate the growth of children with Down syndrome is a controversial topic.

Assessment of growth

In assessing the growth of a child with Down syndrome, it is recommended that the child's length and weight be monitored and assessed using Down syndrome specific growth charts. However, it is important to recognize that the Down syndrome-specific charts reflect a tendency for children with Down syndrome to be overweight by the age of 36 months, and therefore it is recommended that weight for length be assessed using growth charts for typically developing children.

It is important to include a nutrition and diet assessment when considering the possible cause(s) of altered growth, either underweight or overweight, in young children with Down syndrome.

The graphic features the text "early intervention" in a curved, handwritten-style font above two yellow stars. The larger star is on the right, and a smaller one is on the left. A thin yellow arc connects the two stars.

Early Intervention Policy ❖ A nutrition assessment can be included as part of the multidisciplinary evaluation as a supplemental evaluation, or when identified as an area of need and included in the Individualized Family Service Plan.

Assessing nutritional status and needs

In assessing the nutritional needs of a child with Down syndrome (caloric need for growth/prevention of obesity), it is important to recognize that many children with Down syndrome may need fewer calories than a typically developing child of the same age and height. Other children with Down syndrome, such as those with congenital heart disease or breathing difficulties, may have increased energy requirements and may have poor growth.

When evaluating a child's dietary intake, it is important to include an assessment of feeding and oral motor function, including any behavioral feeding difficulties.

ORAL-MOTOR AND FEEDING ASSESSMENT

Infants and young children with Down syndrome often have a variety of oral sensorimotor and feeding problems. Some of these problems may relate to physical factors such as low muscle tone, while others may relate to other health problems that interfere with feeding.

Assessment of oral sensorimotor and feeding problems in infants and young children is often done by a multispecialty team of health care specialists that may include a speech-language pathologist, a registered dietitian, an occupational therapist, a psychologist, a pediatrician, an otolaryngologist, and a gastroenterologist. It is important that these specialists have knowledge of normal oral-motor and feeding development as well as experience and expertise in assessing young children with such problems.

In addition to oral motor function and gastrointestinal issues, it is also important to consider the feeding relationship between the parent and caregivers, and the child. It is important to recognize that while the feeding relationship may affect intake and nutrition, poor growth and poor feeding may affect the relationship.

Components of an oral-motor and feeding assessment

It is recommended that an assessment of oral-motor function and feeding skills in young children with Down syndrome include:

- Physical examination and thorough medical and feeding history
- Observation of interaction patterns between child and primary feeders, including observation of trial feeding
- Body posture and positioning effects
- Oral-motor examination, including:
 - Presence/absence of oral reflexes
 - Structure and action of lips, tongue, palate
 - Oral sensation
 - Laryngeal function (voice production)
 - Control of oral secretions
 - Respiratory control
 - Swallowing function (including effect on nutrition intake and need for measures to prevent aspiration)
 - Oral postural control
- Parents' knowledge about the progression of introducing solid foods to the child's diet
- Indications for specialized studies (such as video-fluoroscopy)
- It is important to consider developmental rather than chronologic age when evaluating feeding skills



Early Intervention Policy ❖ An oral-motor and feeding assessment can be included as part of the multidisciplinary evaluation or as a supplemental evaluation when identified as a need and included in the Individualized Family Service Plan.

Ongoing monitoring when feeding

It is important to recognize that the following may be signs of a problem during feeding:

- Coughing, gagging, or gurgly voice quality

- Extended feeding times (more than 30 minutes)
- Breathing difficulties (increased effort or increased rate, blue lips)
- Food refusal at meal times (e.g., turning head away, pushing food away)
- Fatigue (falling asleep)
- Fussing/crying
- Reflux/vomiting

For feeding problems, it is recommended that both the needs of the infant and the mother be assessed and appropriate guidance given. It is important to consider the child's functional and behavioral capabilities that contribute to successful breast or bottle-feeding. Referral to a lactation specialist or other qualified professional (nurse or pediatrician) may be beneficial in assisting the mother to address breast-feeding concerns.

Assessment tests

Commercially available clinical assessment tests may sometimes be useful aids in assessing oral-motor and feeding problems in some infants and young children. Examples of such tests are the Neonatal Oral-Motor Feeding Scale, the Pre-Speech Assessment Scale, and the Schedule for Oral-Motor Assessment (SOMA).

ASSESSMENT OF HEARING AND VISION STATUS

Vision and hearing problems are seen more commonly in young children with Down syndrome than in typically developing children. Children with Down syndrome have an increased prevalence of strabismus (a muscle imbalance of the eye muscle in which the eyes do not track together), cataracts (opacity of the lens in the eye) and several other types of eye problems. Conditions such as cataracts or strabismus can be discovered on physical examination, but some literature suggests that a general pediatrician performing eye exams on young children with Down syndrome will fail to identify a certain percentage of eye problems.

It is also well known that hearing problems are much more common among children with Down syndrome than in the general population. One reason for this is that otitis media with effusion (OME) is very common in children with Down syndrome. OME is characterized by the presence of fluid in the middle ear and often results in some degree of mild to moderate temporary conductive hearing

loss. Often it occurs after an ear infection (acute otitis media). In young children with Down syndrome, the OME may persist long after the acute infection has resolved. The incidence of sensorineural hearing loss (inner ear) is also somewhat higher among children with Down syndrome than in the general population.

Assessment of Hearing

It is recommended that all newborn infants with Down syndrome have their hearing screened before they are discharged from the hospital.

New York State Policy Note:
Under NYS public health law, newborn hearing screening is required for all newborn infants.

Regardless of the results of the newborn hearing screening, it is recommended that all children with Down syndrome have ongoing monitoring of their hearing and periodic audiologic evaluation by an audiologist.


Early Intervention Policy ❖ Audiologic services are an early intervention service. An audiological evaluation can be performed as a supplemental evaluation as part of the multidisciplinary process or when included in the Individualized Family Service Plan.

Periodic audiologic assessment of young children with Down syndrome is important because:

- Hearing is a key component of oral language development
- There is a high incidence (50-70%) of conductive hearing loss that may result from the increased incidence of otitis media with effusion (OME)
- There may be progressive sensorineural hearing loss
- It is difficult for parents and professionals to detect a mild hearing loss by observation
- They influence intervention strategies

It is recommended that all young children with Down syndrome who are having middle ear problems have a comprehensive hearing assessment, including auditory brainstem response testing (ABR), by an audiologist. For children with recurrent otitis media, it is recommended that audiologic testing be considered as often as every six months during the first two years, and then annually.

Components of a comprehensive hearing assessment

It is recommended that a comprehensive hearing assessment for young children (from birth to 3 years old) include a hearing history, behavioral audiometry testing (using an age/developmentally appropriate response procedure), and electrophysiologic procedures, as needed (Table 11).

Electrophysiologic tests that may require sedation, such as the auditory brainstem response (ABR), are recommended for children whose hearing assessment results are unreliable or inconsistent or who are not able to participate reliably for behavioral test procedures.

Assessment of Vision

It is recommended that a routine vision evaluation be conducted soon after Down syndrome is diagnosed. It is important to examine children with Down syndrome for congenital cataracts at birth or as soon as the diagnosis is made because cataracts occur more frequently in infants with Down syndrome.

Vision problems are common in children with Down syndrome, so it is important to make sure that general vision checks are part of the child's routine health care visits. It is also important to check for strabismus and nystagmus as part of each general vision check.

It is recommended that all children with Down syndrome be seen by a pediatric ophthalmologist within the first six months of life and annually thereafter.

Table 11: Components of a Comprehensive Hearing Assessment

Hearing History

- History of otitis media (ear infections with fluid in the middle ear)
- Auditory behaviors (reacting to and recognizing sounds)
- Parents' general concern about hearing and communication

Behavioral Audiometry Testing

- *Behavioral Observation Audiometry* – observation of changes in behavior in response to speech and to sounds of known intensity and frequency (for example,

Table 11: Components of a Comprehensive Hearing Assessment

speech, music, specific noises)

- *Visual Reinforcement Audiometry (VRA)* and *Conditioned Orienting Response Audiometry (COR)* – used to determine threshold sensitivity in infants beginning at about 6 months of age (developmental age)
- *Conditioned Play Audiometry (CPA)* – used to determine threshold sensitivity in young children beginning at about 2 years of age (developmental age)

Electrophysiologic Procedures

- *Tympanometry* – assesses the mobility of the eardrum (it is not a direct test of hearing)
- *Acoustic Reflexes* – assesses an involuntary middle ear muscle reflex to sounds
- *Evoked Otoacoustic Emissions (EOAE)* – assesses the function of the outer hair cells of part of the ear called the cochlea by recording a cochlear echo
- *Auditory Brainstem Response (ABR)* or *Brainstem Auditory Evoked Response (BAER)* – used to estimate hearing levels and to assess the function of the auditory pathway from the cochlea to the level of the brainstem

Adapted from: New York State Department of Health, Clinical Practice Guidelines, Communication Disorders 1999

ASSESSMENT OF OTHER ASSOCIATED HEALTH CONDITIONS

In addition to general developmental delays, children with Down syndrome are also at risk for many health problems. A variety of health conditions, such as heart problems, ear infections, and hearing and vision problems, are seen more commonly in children with Down syndrome than in the general population.

A physical examination, a health history, or specific diagnostic tests can identify many of these conditions. Most of the methods for identifying and assessing these problems are the same whether or not children have Down syndrome.

It is recommended that the primary care physician be responsible for monitoring the child’s general health and for consulting with other health professionals as needed (for example, a developmental pediatrician, medical geneticist, cardiologist, endocrinologist, otolaryngologist, audiologist, and ophthalmologist).

General recommendations for routine health examinations are presented in Table 10. Medical conditions commonly associated with Down syndrome are listed in Table 12.



Early Intervention Policy ❖ Although assessment of physical development, including a health assessment, is a required component of the multidisciplinary evaluation, medical tests (MRIs, metabolic tests, genetic tests) and health care services that are routinely needed by all children, including monitoring for otitis media, are not reimbursable as early intervention services. The service coordinator can and should assist the family in accessing these services through their primary health care providers. Supplemental physician evaluations may be accessed if appropriate and necessary to establish a child's eligibility for Early Intervention services or to conduct an in-depth assessment of the child's physical development if there are specific concerns or problems in this developmental area.

Monitoring for otitis media

Because of the increased risk for otitis media with effusion (OME) and the potential for related hearing loss, it is important that young children with Down syndrome be assessed for possible middle ear infection (otitis media) whenever they have a fever or other signs of upper respiratory infection. It is recommended that neither otoscopy or tympanometry be used in isolation to diagnose middle ear effusion in infants and very young children because these tests are sometimes not reliable.

It may be difficult to visualize the eardrum of children with Down syndrome because they tend to have narrow external ear canals that may be prone to blockage from excess cerumen (ear wax), auditory canal stenosis, or thick mucus. If a child's general pediatrician is not able to clearly visualize the eardrum, or if the child has a history of recurrent OME, it is recommended that the child be referred to a specialist, preferably a pediatric otolaryngologist (ear, nose, and throat) specialist.

Monitoring for cardiac problems

Because heart defects are so common in children with Down syndrome, it is recommended that children receive a cardiac evaluation, including an echocardiogram, within the first month after birth,

Monitoring for gastrointestinal problems

Beginning in the first week of life, it is important to be on the lookout for any congenital anomalies involving the gastrointestinal tract. Symptoms might include persistent vomiting, abdominal distention, limited or no passage of stool, and failure to thrive. During early childhood, it is important to screen for signs of digestive disorders such as celiac and Hirschsprung disease.

Thyroid assessment

Thyroid disease is more common in children with Down syndrome, and symptoms of thyroid disease often mimic symptoms generally associated with Down syndrome. Therefore, it is recommended that thyroid function (T₄ and TSH) be tested as part of newborn metabolic screening, at the age of six months, and yearly thereafter.

Monitoring for other associated conditions

At age 3 to 5 years, it is recommended that radiographs be used to screen for atlantoaxial instability or subluxation.

It is also important to check the child's dental status with semiannual exams beginning at age 2, or sooner if indicated.



Early Intervention Policy ❖ Dental care is not an Early Intervention service.

Table 12: Common Associated Conditions in Children With Down Syndrome*(repeated from Table 2)*

	Percent of children affected
Congenital heart disease	40
Hypothyroidism	10–20
Joint laxity	15
Psychiatric disorders in adolescence	13
Gastrointestinal tract defect	12
Alopecia (hair loss)	10
Seizures	6
Leukemia	1
Obesity	50
Dental problems, hypodontia, malocclusion	60–100
Hearing loss	60–80
Vision problems:	
▪ cataracts	3
▪ refractive errors	70
▪ strabismus	50
▪ nystagmus	35

Adapted from: Pueschel 1990

CHAPTER IV: INTERVENTION

Planning and Implementing Interventions

Children with Down syndrome are usually identified at birth, and it is recommended that the assessment and intervention process begin as soon as possible. It is not necessary to wait for signs of a developmental delay. Beginning intervention services early may help the child’s overall development and lead to better long-term functional outcomes.



Early Intervention Policy ❖ Early intervention services should begin as soon as possible to mitigate developmental delays associated with Down syndrome. A child with Down syndrome does not need to be experiencing a developmental delay in a specific area to begin services. The Individualized Family Service Plan should include services needed to address agreed-upon goals and measurable outcomes for the child and family.

Individualizing interventions

Young children with Down syndrome may share many common characteristics, but they have different individual strengths and needs, as well as responses to specific intervention methods. There is no one specific intervention approach or plan that is effective for all children with Down syndrome. Furthermore, children have different family situations, and some families will need more support than others.

It is important that interventions for a child with Down syndrome be linked closely with the child’s assessment as well as an assessment of the family’s needs so that the intervention can be individualized to meet the strengths and needs of the child and family.



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

Selecting intervention strategies and targets

In making a decision to start or change a specific intervention for a child with Down syndrome, 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 or harms associated with the intervention
- The family's beliefs, values, and cultural traditions

It is recommended that interventions for young children with Down syndrome include:

- Multiple settings, as appropriate, such as home and/or community/center-based services (such as child care setting, playgroups, and typical social environments)
- Multiple modalities, such as using objects, pictures, sounds
- Multiple opportunities to practice developmental skills with different persons (parents, therapists, peers)

Ongoing monitoring and modification of the intervention

As the child matures, the types and frequency of the interventions may change, and it is important that changes in the intervention be based on ongoing monitoring of the child's progress and the family's needs.

It is important to monitor the child's progress and for parents and professionals to consider the need to modify or discontinue a specific intervention when:

- The child is making progress and goals of the intervention have been achieved
- The child has shown some progress, but goals have not been achieved after an appropriate trial period
- Progress is not observed 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 center-based setting)
- There is a change in family priorities



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, and included in the IFSP.

The IFSP may be reviewed more frequently upon the request of the parent(s) or if conditions warrant a review.

Periodic reassessment and evaluation

In addition to ongoing monitoring of the child's progress, it is important that there be periodic comprehensive reassessment and evaluation of the child's progress. It is important that these evaluations include both qualitative (descriptive) information and appropriate standardized testing of the child's progress. It is recommended that a child's progress be considered with respect to age-expected development for children with Down syndrome as well as for typically developing children.

Addressing coexisting developmental and health problems

It is essential that all providers who work with young children with Down syndrome:

- Understand the developmental and medical problems commonly associated with Down syndrome and the implications for the specific intervention provided
- Receive relevant information about the child's health status and associated health conditions, such as cardiac or respiratory problems, hearing loss and need for alternative communication strategies, or other considerations that may affect the way that the intervention is implemented
- Understand the importance of monitoring the child's health status and tolerance for physical activity during the intervention

Need for scientific information about interventions

In selecting interventions for young children with Down syndrome, it is important to consider any scientific evidence about the effectiveness of the intervention, especially for new or nonstandard interventions.

Including the Parents and Family in Planning and Implementing Interventions

It is recommended that parents be involved in the assessment and intervention process for their child in order to understand the intervention options, goals, objectives, and methods, and to evaluate progress and provide feedback to professionals.

When the child is very young, many of the interventions may focus more on the parents than the infant. For example, interventions may focus on the parents' need for information and support.

Parent education and support can occur formally or informally as needs/opportunities arise or in planned sessions. Methods could include verbal discussion and instruction, written material, supervision, videotapes, and hands-on training and participation in the child's therapy sessions. Formal and informal parent support can be planned or can occur in natural interactions.

It is recommended that parent training programs be included as a component of the intervention plan for young children with Down syndrome. Common elements of effective parent training programs include verbal instruction, supervised practice, feedback, and teaching the methods to other parents.

Support services are most effective if they are matched to the strengths and needs of the family. It is essential that the child's needs be considered from within the context of the family and the family's culture.



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 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, ethnic, and other family characteristics.

INTERVENTIONS FOCUSED ON SPECIFIC DEVELOPMENTAL DOMAINS

It is important to remember that while the order in which developmental skills are learned is similar in both typically developing children and children with Down syndrome, overall development tends to be delayed in children with Down syndrome. This delay in development means that young children with Down syndrome will not learn to sit, stand, walk, or talk as early as other children. It also means that children with Down syndrome may need more repetition and more consistency than typically developing children when learning new skills.

Examples of age-specific interventions for each developmental domain are listed in Table 15 (page 79).

Cognitive Development

Cognition includes the processes of the brain that allow us to remember, think, act, feel emotions, and experience the environment. Cognitive processes are complex, diverse, and highly interrelated. Important aspects of cognition include attention and exploration, learning and memory, and reasoning and problem solving.

General approach for cognitive intervention

It is important to recognize that cognitive development may be enhanced when ongoing intervention is provided at an early age and when there are many opportunities to use cognitive skills in various settings.

It is recommended that the development of cognitive skills be a component of the intervention plan for young children with Down syndrome and that strategies to develop cognitive skills be incorporated into the child's routine activities of daily life.

Cognitive intervention strategies

It is important that cognitive interventions focus on global (general) as well as specific cognitive skills. (See age-specific recommendations, page 79.)

When planning cognitive interventions, it is important to include tasks and reinforcement specific to the needs of the child, such as information processing skills and short-term and long-term memory activities. It is recommended that cognitive skills be taught using principles of learning theory (Table 13).

Table 13: Basic Principles of Learning Theory

- Simple learning consists of the association of a stimulus and a response
 - The closer together the stimulus and response occur, the faster the learning
 - The more often a stimulus and response are paired, the stronger the association between them
 - Repetition strengthens learned responses
 - Stimuli that occur after a behavior and increase the likelihood of the behavior occurring again are called positive reinforcing stimuli
 - Reinforcing stimuli may be those that satisfy basic drives like food does for hunger, or satisfy the need for social acceptance such as a smile or praise
 - Some behaviors may be learned by observation and imitation
-

Communication Development

Most children with Down syndrome will exhibit a delay in communication skills from an early age. In particular, young children with Down syndrome will usually have expressive language delays greater than expected for their receptive skills and developmental age. Expressive language delays may be compounded by speech-motor problems. Communication development in young children with Down syndrome may be further compromised because many children with Down syndrome have hearing loss.

Planning interventions for communication development for a young child with Down syndrome is similar to planning communication interventions for any child with a communication delay. It is important to take into account the specific levels of functioning and the needs of each child.

Because language development is usually delayed in young children with Down syndrome, it is recommended that some form of communication intervention be initiated shortly after birth. It is recommended that the development of communication skills be an ongoing process that is incorporated into all daily activities.

General approach for communication interventions

It is recommended that a speech-language pathologist conduct parent/child intervention on an ongoing and regular basis focusing on stimulation of vocalization, receptive and expressive language, and education about the warning signs for hearing loss.

It is recommended that early components of intervention include direct one-on-one interaction with parent and child, observation of the parent and child, and provision of verbal and written material on how to promote oral-motor function, vocalization, and language. (See Table 15, page 79, for age-specific recommendations.)

It is also important that interventions for communication development in young children with Down syndrome focus on oral-motor stimulation. Many children with Down syndrome have oral-motor problems that contribute to speech and language problems. Oral motor problems may also contribute to feeding difficulties.

Considerations for alternative communication strategies

It is important to consider the need for alternative communication strategies when planning and implementing interventions for young children with Down syndrome.

To help the child develop expressive language, it is recommended that a “total communication” approach (sign language, oral communication, and visual cues) be used. Total communication approaches are likely to result in higher levels of success for day-to-day function. When using such an approach, it is important that sign language be used simultaneously with the language spoken at home.

It is important that parents and professionals recognize that the use of sign language does not interfere with oral language development.

For children with permanent or persistent hearing loss, it is important to consider using amplification such as hearing aids or an FM system as prescribed by the audiologist.



Early Intervention Policy ❖ Augmentative communication systems and personal amplification devices are considered assistive technology devices under the Early Intervention Program.

Motor Development

Motor development is the process of learning how to sit, stand, move around, use our hands, take care of ourselves, and work or play. Motor development depends on how sensory input is processed in the brain to result in a purposeful movement. 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. Early motor intervention is important for children with Down syndrome because they tend to have low muscle tone and other problems with postural control.

Neurodevelopmental treatment (NDT)

Neuromotor therapies, such as neurodevelopmental treatment (NDT), are commonly used as a part of motor interventions. Specific handling and positioning techniques are used to inhibit incorrect movement patterns and make movement more efficient. These methods are taught to parents to use in the child's daily activities. Although NDT approaches are widely used in various therapy programs, scientific studies have not clearly demonstrated the benefits of these therapies in young children with Down syndrome.

General approach for motor interventions

It is recommended that motor interventions use techniques that:

- Use varied types of stimuli to elicit movements according to the child's response
- Facilitate movement experiences for which the child is ready but may not seek out alone
- Help the child learn to problem solve and participate in planning, initiating, and performing movement

It is important to instruct parents and other caregivers in appropriate carrying and handling techniques. For example, because of the potential for hip problems in young children with Down syndrome, it may be important to carry the child with the legs together rather than spread over the hip. It may be important to modify (or not use) backpack- or "Snuggli"-type carriers so the child's legs stay together when carried.

Using adaptive equipment and assistive technology

It is important that assistive devices or adaptive equipment be developmentally appropriate for the child. It is important to consider the child's need for adaptive equipment that will assist in postural alignment, sitting, standing, (e.g., sidelyers, standing devices, seating systems, and adapted tricycles) and independent upright forward mobility (e.g., forward walkers, postural control walkers, push toys, and ride-on toys). The use of orthotics or lower extremity

splints may help some young children with Down syndrome to maintain proper alignment in standing and walking.

Motor intervention approaches not recommended

Caution should be exerted when considering the use of activities that involve hyperflexion, hyperextension, and rapid rotary movements of the neck because young children with Down syndrome are at risk for atlantoaxial instability (dislocation of the cervical vertebrae).

The use of baby walkers, “exersaucers,” “jolly jumpers,” and other similar types of equipment are not indicated for children with Down syndrome because they encourage inappropriate movement patterns that tend to further delay motor development. Also, children with Down syndrome may lack the joint stability to maintain good alignment while using this kind of equipment.

Young children with Down syndrome generally lack the trunk, arm, or leg stability to maintain proper alignment when using weighted vests or weights. If used, they must be closely monitored.

The use of rotary movement was not found to be effective in improving motor skills in young children with Down syndrome. Range of motion exercises are also not recommended for young children with Down syndrome unless the children have a specific limitation in joint mobility.

Social Development

Interventions targeting social development focus on social attention, social interactions, attachment, and play. These interventions help parents to interact with their child. This is important because a child with Down syndrome, compared to typically developing children, usually takes less initiative, responds and initiates interactions in a more unpredictable manner, often shows less emotional expression, and gives social and communicative cues that are more difficult for others to interpret. (See Table 15, page 79, for age-specific recommendations.)

General approach for social development

When requesting actions from a young child with Down syndrome, it is important to have the child’s attention and to positively reinforce appropriate responses to those requests. It is also important to remember that the child may be more responsive to instructions that are directive (specific) than to instructions that are suggestive (not specific).

Because children with Down syndrome tend to pay more attention to faces than objects, it is important to encourage them to interact with the physical environment (e.g., toys) when in groups with other children. To increase the child's level of sustained engagement during planned activities, it is helpful to change stimuli frequently. Activities that include music may also be useful in enhancing the child's interaction, attention, and participation.

It is important to provide opportunities for the child with Down syndrome to initiate activities. It may be useful to use methods such as selective reinforcement, as well as peer and adult modeling to teach and encourage children with Down syndrome to initiate social interactions.

It is also important to provide opportunities for the child to be exposed to many social situations in different settings in order to stimulate and selectively reinforce appropriate emotional responses, facilitate language development, improve peer interactions, and promote generalization of emotional responses.

Adaptive/Self-Help Skills

Interventions focused on helping the child to develop adaptive/self-help skills are often the most important for families. These skills allow the child to function more independently in activities of daily living, including dressing/grooming, feeding, and toileting.

Feeding

It is recommended that mealtimes be kept free of other distractions, such as the television, in order to help children with Down syndrome learn to feed themselves. Consistency in mealtime routines and the opportunity to learn from observing others at mealtime can help to facilitate the learning process. It is important to provide adequate positioning and support for sitting during meals.

When the child is learning self-feeding, it is important to use utensils, dishes, and cups that are developmentally appropriate for the child's motor and cognitive abilities. Specific adaptive equipment may help some children with self-feeding. For example, it may be helpful to use a spoon with a thicker curved handle or a cup with two handles. (Note: use of cups with spouted lids may interfere with development of lip closure.)

Dressing

It is important to encourage children with Down syndrome to help with their own dressing when they appear to be ready. When teaching self-dressing, it is important to use clothing that is developmentally appropriate for the child's

motor and cognitive abilities. It is important to remember that children are usually independent in removing clothing before they are independent in putting clothes on.

Various techniques may facilitate the teaching of self-dressing skills, for example:

- Making simple modifications to clothing to increase independence (e.g., using Velcro instead of buttons, zippers, and ties, or attaching an easy-to-grip object to a zipper pull.)
- Dressing in loose, easy to pull-on/take-off clothing
- Modifying methods of dressing to make it easier for children to learn
- Using a backwards chaining approach (e.g., the caregiver completes the initial steps, and then teaches the child the last step. When the child has mastered the final step, the child is taught the final 2 steps. Add the steps expected of the child until the task is mastered.)

It is important to provide adequate support and positioning to aid the child when dressing. Proper positioning and use of appropriate supports may facilitate the child's self-dressing development.

Toilet training

It is important that the child be developmentally ready to begin toilet training. Development of motor and cognitive skills is necessary for successful toilet training. When the child demonstrates some regularity in elimination, it is often an indication of increased bladder and bowel control. It is important to recognize that children with Down syndrome often have associated conditions that may make toilet training more challenging, such as low muscle tone, which may make bladder control more difficult.

It is important to allow the child to become familiar with the bathroom and toilet before toilet training is attempted. When initiating toilet training, it is usually helpful to be consistent about which bathroom is used, if there is more than one bathroom in the house. It is also important that the potty seat or toilet is of an appropriate size and configuration to support the child and allow for as much independent mobility as possible when getting on and off of the seat.

SPECIFIC INTERVENTION APPROACHES

Behavioral and Educational Approaches

Behavioral and educational intervention approaches are programs, strategies, procedures, and techniques based on general learning and behavioral principles. The specific techniques vary, but these approaches are generally based on somewhat similar behavioral principles. Some techniques focus on what happens before a specific behavior, while other techniques focus on what happens following the behavior. Still other techniques involve skill development and procedures to teach alternative, more adaptive behaviors. These strategies often consist of building or shaping complex behaviors from simple ones.

When using behavioral techniques, it is important to recognize that there are several types of potential reinforcing stimuli. For example, there are sensory (such as music), edible (such as a favorite snack), and social (such as verbal praise) reinforcers. Important components of behavioral and educational approaches include:

- Identifying which items will serve as reinforcers for a particular child
- Varying the reinforcers
- Using visually distinctive stimuli because children with Down syndrome attend more to visual than auditory stimuli
- Simplifying complex tasks into component parts that are easier to learn

Naturalistic and directive approaches

Behavioral and educational interventions are usually a combination of directive naturalistic approaches. In directive approaches, the teacher or therapist structures the environment, the stimuli, and the consequences (which may not necessarily flow logically from the child's current activities or interests). Naturalistic approaches generally occur in the child's usual environment and use stimuli and consequences such as reinforcers that are related to the child's everyday activities. In practice, few interventions are either totally directive or totally naturalistic.

Dealing with maladaptive behaviors

Maladaptive behaviors (e.g., temper tantrums, running away, noncompliance) are usually learned behaviors. It is recommended that interventions for these challenging behaviors be determined using a functional behavioral assessment followed by a behavioral intervention that may include ignoring the behavior,

differential reinforcement of other behaviors, distracting/redirecting, and teaching other behaviors.

It is important to determine if there are identifiable triggers for maladaptive behaviors that can be addressed in the intervention plan. For example, some maladaptive behaviors may be related to hyperresponsivity to certain sensory stimuli, such as a child not allowing a toothbrush in his mouth because of oral hyperresponsivity. It is also important to remember that maladaptive behaviors may be a child's way of communicating that a task or situation is too difficult, uncomfortable, or stressful.

Other Intervention Approaches

There are many different types of intervention approaches and programs that might be considered for a young child with Down syndrome. In addition to the more standard or traditional developmental therapies (e.g., physical and occupational therapy and speech-language therapy), there is also a diverse collection of therapeutic models (e.g., sensory integration, aquatic therapy, hippotherapy, and music therapy) that are often used in conjunction with or as a part of standard therapy programs. These approaches vary greatly in the degree to which they are used, the time commitment required, cost, availability, and potential benefits and harms. Some of these approaches are also considered controversial.

Some nonstandard therapies, such as those that incorporate sensory activities (movement, music, art) into other therapeutic techniques, may be beneficial to the child's overall development. Specific therapies such as sensory integration, music therapy, art therapy, and therapeutic horseback riding are not likely to be physically harmful when implemented by knowledgeable and experienced providers and may have some benefits such as physical activity, social interaction, or generalization of developmental skills.

However, it is important to understand that the guideline panel did not find scientific evidence about the use of these therapies to improve outcomes in young children with Down syndrome.



Early Intervention Policy ❖ Music therapy and art therapy are not reimbursable services under the New York State Early Intervention Program. For some interventions, such as sensory integration, aquatic therapy, and hippotherapy, the Early Intervention Program may reimburse for the cost of qualified personnel, such as a physical therapist, as provided for in the Individualized Family Service Plan, but does not reimburse for other program expenses such as fees for the pool or horse. Qualified personnel are listed in Appendix B.

Parents and family members seek information about their child’s disability, and they are likely to find many sources of information about alternative 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 the parents need to understand how to help them make intervention decisions, especially when they are considering an unproven or controversial approach.

There will always be new theories and techniques, and new iterations of old methods, especially for conditions for which there is no known cure. It is important to recognize that if parents do not receive information about alternative therapies directly from health and educational professionals, they are likely to obtain information from the proponents of those therapies and/or other parents and that this information may be limited or biased or incorrect.

Regardless of the specific intervention being considered for a particular child, the decision-making process is generally the same. Parents might find it useful to consider the following questions in making decisions about intervention options.

Table 14: Questions to Ask Regarding Specific Interventions

- What do I want to accomplish with this intervention? Is the intervention likely to accomplish this?
- Are there any potentially harmful techniques or side effects associated with this intervention?
- What positive effects of the intervention would I hope to see?
- Has the intervention been validated scientifically (with carefully designed research studies) for young children with Down syndrome?

Table 14: Questions to Ask Regarding Specific Interventions

- Can this intervention be integrated into my child’s current program?
- What is the time commitment? Is it realistic?
- What are the pros and cons of this intervention? What do other parents say about it (pro and con)?
- What claims do proponents make about this intervention? (Claims of dramatic improvement are probably a “red flag.”)
- Does the provider of the intervention have knowledge about the medical and developmental issues associated with Down syndrome?
- Does the provider of the intervention have experience working with young children with Down syndrome?
- What do my pediatrician and other professionals involved with my child think about the intervention’s appropriateness?

*Adapted from: Nickel 1996
(Continued from previous page)*

It is important for professionals to provide parents with accurate information about their intervention options so they can make informed decisions. To ensure the provision of accurate information about nonstandard interventions, it is recommended that:

- Professionals be knowledgeable about alternative interventions, including the proposed benefits, the possible harms, and costs
- Professionals be open to discussing alternative interventions and schedule adequate time for this as part of the initial management plan and whenever parents ask questions about such interventions
- Professionals who discuss alternative interventions with families make sure that the discussion is informative while making it clear that the discussion is not an endorsement of the intervention

For any intervention the parents choose to pursue, it is recommended that:

- There be baseline and ongoing assessment of the child’s progress
- There be appropriate modification of the child’s progress and modification as needed

- There be defined intervention goals and objective outcome measures for the intervention
- The intervention be compatible with and coordinated with other interventions the child is receiving to avoid any potential conflicts achieving intervention goals



Early Intervention Policy ❖ All interventions must be included in an Individualized Family Service Plan (IFSP) that is agreed to by the parent and the Early Intervention Official. The IFSP must be in writing and have required components as specified in program regulations, 10 NYCRR Section 69-4.11(10). See Appendix B.

Sensory integration therapy

Sensory integration (SI) therapy evaluates children for sensory processing disturbances and provides them with the appropriate sensory stimulation. The sensory experiences used generally include goal-oriented play using activities to enhance sensory intake. These activities are often part of physical or occupational therapy approaches. The stated goal of sensory integration therapy is to facilitate development of the nervous system’s ability to process sensory input. Scientific studies were not found to support the efficacy of sensory integration as a separate therapy approach.

Music therapy and art therapy

While various music and art activities are often included within the context of standard intervention approaches, there are also some who advocate for separate, discrete programs referred to as “music therapy” and “art therapy.” Proponents of these programs suggest they may lead to improvements in social interaction and language development (music therapy) and improved motor and cognitive skills (art therapy.) Scientific studies were not found to support the efficacy of either of these therapies (as a separate therapy approach) for children with Down syndrome.



Early Intervention Policy ❖ Music therapy and art therapy are not reimbursable services under the New York State Early Intervention Program.

Therapeutic horseback riding (hippotherapy)

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

Scientific studies were not found to support the efficacy of hippotherapy for improving motor development in young children with Down syndrome. For young children with Down syndrome, as with all children in this age group, the potential for injury that may result from horseback riding needs to be considered in the decision about whether to use this intervention approach.

Conductive education

Conductive education is an educational approach focused primarily on motor function. This approach is based on the theory that abnormal motor patterns can be transformed into functional motor patterns by intensive “training” to develop alternate neural pathways. In the United States, many conductive education programs use only selective principles of this method. Conductive education has not been demonstrated in controlled scientific studies to have efficacy for improving motor development in young children with Down syndrome.

For children with motor impairments, there is some concern that unless children are closely monitored, there may be some risk for developing persistent pathological motor patterns. It is important to recognize that the conductive education approach can be time intensive for both professionals and parents, and may take time away from other therapies that might be appropriate and effective for the child. The guideline panel did not find adequate evidence to demonstrate that conductive education improves outcomes in young children with Down syndrome.

Other alternative intervention approaches

Other more health-related “alternative” interventions (such as megavitamins and fetal-cell therapy) are discussed in the section on Health-Related Interventions.

HEALTH-RELATED INTERVENTIONS

Many medical conditions occur more commonly in children with Down syndrome than in typically developing children. Some of these conditions are

listed in Table 2 (page 13). This guideline focuses on interventions related to hearing and vision, growth and nutrition, oral-motor/feeding issues, and thyroid therapy. Information about a few interventions that are generally considered “alternative,” experimental, or controversial, such as megavitamins and use of piracetam, is also included.

It is recommended that children with Down syndrome receive the same general routine preventive health care as typically developing children. In addition, it is recommended that physicians follow the general outline designed by the American Academy of Pediatrics Committee on Genetics in providing medical care for children with Down syndrome.

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 other health professionals as needed (for example, a developmental pediatrician, audiologist, medical geneticist, cardiologist, endocrinologist, ophthalmologist, or ENT specialist).

It is important that physicians discuss unproven or experimental therapies with families of children with Down syndrome to discourage misinformation and to help the family develop realistic expectations about treatment options.



Early Intervention Policy ❖ The Early Intervention Program does not cover the costs of medical interventions, or surgical procedures, or primary health services that are needed by any child (e.g., immunizations and well child care).

Nutrition Interventions, Vitamin Therapy, and Hormone Therapy

Several intervention methods focus on growth, nutrition, and metabolism because these issues are particularly important for infants and young children with Down syndrome. These methods include standard therapies (such as nutrition intervention and diet counseling by a registered dietitian) as well as several therapies that are considered more controversial (such as megadoses of vitamins, low-dose oral zinc supplementation, or the use of growth hormone).



Early Intervention Policy ❖ Nutrition services (see Appendix B) are considered early intervention services. However, the Early Intervention Program does not pay for vitamins, nutritional supplements, or growth hormones.

Components of nutrition intervention

Nutrition intervention may include:

- Ensuring a balanced diet to meet the child's nutritional needs
- Establishing appropriate foods for children with behavioral feeding problems (in order to promote oral motor development and acceptance of a wider range of foods)
- Designing appropriate diets for children with oral motor feeding problems or other associated health conditions that may affect feeding (such as celiac disease)
- Providing dietary counseling to prevent obesity
- Providing dietary management of constipation (often related to low muscle tone and dietary inadequate fluids and fiber)
- Providing dietary intervention for nutritional deficiencies

Vitamin and mineral supplement therapy

Megadoses of vitamins have not been found to improve the growth, development, behavior, or health of children with Down syndrome. There is also no clear indication for administering increased doses of vitamin B₆ (pyridoxine) to children with Down syndrome. The panel also found no evidence to support long-term, low-dose oral zinc supplementation to improve depressed immune response or to decrease infections in children with Down syndrome. Vitamin supplements for young children (other than ordinary children's vitamins) are not recommended unless prescribed by a physician to correct a diagnosed vitamin deficiency. It is important to remember that high doses of vitamins and minerals are associated with side effects and toxicity.



Early Intervention Policy ❖ The Early Intervention Program does not pay for dietary supplements.

Growth hormone therapy

The administration of growth hormone to children with Down syndrome is not standard practice. Routine use of growth hormone is not recommended for children with Down syndrome. The benefits and risks associated with the use of

growth hormone in young children with Down syndrome have not been thoroughly studied.

For a child with documented growth hormone deficiency, the risks, benefits, and long-term effects of growth hormone treatment need to be considered.



Early Intervention Policy ❖ The Early Intervention Program does not pay for growth hormone, thyroid, or other medications.

Thyroid hormone therapy

It is recommended that consultation with a pediatric endocrinologist be considered if the child's thyroid is abnormal. It is important that a child with low levels of thyroid hormone be given appropriate replacement therapy. It is important to recognize that children with Down syndrome often have transiently elevated TSH that reverts to normal without intervention. However, for children with persistently elevated TSH, it is recommended that thyroid supplementation be given, even when T₄ is normal, as there is a possibility of decompensation at any time during the first 3 years of life.

Oral-Motor/Feeding Interventions

Infants and young children with Down syndrome often have a variety of oral-motor and feeding problems. It is important that professionally guided oral-motor interventions for young children with Down syndrome be carried out by persons with knowledge and experience in the specific area of the intervention focus.

Interventions for oral-motor problems include behavioral interventions to improve tongue posture and encourage appropriate development of jaw, lip, and tongue movements for eating, drinking, and speaking, as well as teaching parents techniques to facilitate their child's feeding and transition to solid foods. When making decisions about the child's readiness to progress in feeding, it is important to consider the child's developmental level (not chronologic age).

It is important to consider the need for medical management of chronic sinus and other respiratory conditions that may affect jaw and tongue position. A chronic open mouth posture may take the jaw and tongue out of position for effective swallowing and speech production. It may also be useful to consider palatal plate therapy as an additional option to other oral-motor interventions.

Interventions for Hearing and Ear Problems

Hearing and ear problems are commonly seen in young children with Down syndrome. Children with Down syndrome are particularly prone to otitis media with effusion (OME), which can be associated with either temporary or more chronic hearing loss.

If a child has a hearing loss, it is recommended that a hearing aid or other assistive device, such as an FM system, be considered. An FM system is a type of amplification device used to help reduce the negative effects of noise and distance on the perception of speech. The main components of an FM system are a wireless microphone worn by the person talking, and an electronic receiver that receives the microphone signal (worn by the person with the hearing loss). There are several types of FM systems such as personal FM systems and sound field systems.

early intervention


Early Intervention Policy ❖ Personal amplification devices such as hearing aids are considered assistive technology devices under the Early Intervention Program.

Medical intervention for otitis media

If pressure equalization (PE) tubes to treat otitis media are surgically placed in a child with Down syndrome, it is recommended that the child have a hearing test after tube placement and the child be monitored on an ongoing basis by a physician to make sure the tubes are functioning properly. It is important to explain to parents that PE tubes for otitis media often fall out after several months and may need to be replaced.

early intervention


Early Intervention Policy ❖ The Early Intervention Program does not pay for medical interventions or surgical procedures, or primary health services such as immunizations and well child visits that may be needed by any child.

Other Health-Related Interventions

Piracetam and fetal-cell therapy are two “controversial” treatments that have sometimes been promoted for treating children with Down syndrome.

Piracetam is a drug that is purported to have cognitive enhancing properties. It has been studied in clinical trials with adults with dementia, Parkinson’s disease, and traumatic brain injury, and in children with learning disabilities. No consistent positive effects have been demonstrated in the clinical trials. No studies were found with young children with Down syndrome. The guideline panel found no evidence to support the use of piracetam as an intervention for young children with Down syndrome.

Fetal-cell therapy is the administration of freeze-dried cells derived from the fetal tissue of animals. Proponents of this therapy claim that it will improve the child’s IQ, motor skills, social behavior, height, immunologic functioning, language skills, and memory, as well as reduce some of the physical features of Down syndrome. The guideline panel found no evidence that cell therapy is effective. Cell therapy is illegal in the United States and is not recommended for children with Down syndrome.

Table 15: Summary of Age-Specific Intervention Recommendations

Age birth to 4 months

Communication Interventions

- Assess the need for facilitation of oral-motor function and feeding
- Intervention by a qualified professional with the parent and the child as indicated by needs of the child and family
- Indications for a speech-language intervention during the birth-to-4-month period may include:
 - If the child has a hearing loss
 - If there is a feeding problem
 - If the parent indicates the need for more speech/language help/support
- Educate parents about techniques or activities that may stimulate communication development, including:
 - Tracking auditory stimulation
 - Orienting to voices
 - Vocalizing when spoken to

Motor Interventions

- Begin motor intervention within the first month. The focus of early motor intervention is:
 - To prevent compensatory movement patterns that may interfere with subsequent motor development

Table 15: Summary of Age-Specific Intervention Recommendations

- To prevent the development of deformities secondary to persistent atypical postures
- To provide education and support to parents (e.g., to teach positioning and handling)
- Focus on development of postural control (ability to control head and trunk). Development of good postural control will help to facilitate future development of specific motor skills

Cognitive Interventions

- Introduce teaching of cognitive skills as soon as possible using the principles of learning theory (Table 13, page 63)
- Initiate teaching of cognitive skills with the parent/caregiver, including:
 - Having the parent move an object for the infant to visually track
 - Saying the child's name
 - Telling the child the name or label for objects in view
 - Reading and singing to the child regularly

Age 4 to 12 months

Communication Interventions

- Continue speech and language intervention with the parent/caregiver and child. Important components of therapy during this period include:
 - The encouragement of babbling
 - Use of informal gestures (such as pointing)
 - Direct intervention with child and caregiver with the emphasis on training of caregiver in language stimulation techniques appropriate for the individual child
- Provide language stimulation activities to promote development of expressive language
- Monitor oral-motor function (strength and coordination of lip, jaw, and tongue function) and assist as needed for feeding and speech

Motor Interventions

- Continue motor interventions related to postural control focusing on development of:
 - Postural control for head and upper trunk righting and upper extremity weight bearing in prone position (lying on stomach)
 - Sufficient trunk and head control for proper alignment in sitting

(Continued from previous page)

- Postural control, scapular stability and upper extremity strength to support fine

Table 15: Summary of Age-Specific Intervention Recommendations

- motor control
- Varied movements in the legs to support the development of standing
 - Transitional movements (rolling, pivoting prone, belly crawling, getting in and out of sitting, etc.)
 - The ability to move against gravity to bring hands to midline and hands to mouth
 - Begin motor interventions that focus on fine motor skills at approximately 6 months. Important components of fine motor interventions include:
 - Shoulder stability on stomach while reaching
 - Hand-to-mouth movements
 - Grip strength
 - Digital grasp
 - Transfer of objects hand to hand
 - Isolated use of index finger
 - Resistive activities (strength training) may be beneficial to increase strength in young children with Down syndrome after the age of 4 months

Cognitive Interventions

- Continue teaching cognitive skills using the principles of learning theory
- Continue teaching cognitive skills with the parent/caregiver, including:
 - Pulling a toy on a string out of reach, leaving the string within the infants reach
 - Partially hiding a toy within the child’s reach
 - Hiding a small toy in an easy-to-open box
 - Showing the infant pictures with much color or contrast
 - Providing a mobile that moves when the infant moves in the crib

Age 12 to 24 months

Communication Interventions

- Continue to give speech/language therapy appropriate for the individual needs of the child, and continue parent training and education in language stimulation techniques
- Increase the frequency and intensity of the communication interventions from 12 to 24 months, as appropriate, because:
 - Speech language skills typically accelerate at this age, and there may be a need to facilitate this

(Continued from previous page)

- The divergence between developmental progress of children with Down syndrome and typically developing children of the same age becomes greater

Table 15: Summary of Age-Specific Intervention Recommendations

- Provide opportunities for linguistic interaction with other children to help stimulate and generalize language skills (playgroups, day care, therapeutic groups, etc.)
- Continue oral-motor interventions to address muscle-based issues that affect the child's oral-expressive output

Motor Interventions

- Continue intervention for development of fine motor skills. Important components of intervention include:
 - Prehension patterns
 - Grip strength
 - Finger and thumb control
 - Eye-hand coordination
 - In-hand manipulation
 - Bilateral coordination
 - Shoulder stability
 - Releasing objects
 - Refinement of grasp pattern
- Continue interventions for the development of gross motor skills with a focus on the use of muscles control, posture, and movement rather than compensatory positions. Components to be addressed:
 - Development of creeping on hands and knees
 - Development of sufficient postural control to move in and out of sitting in varied patterns
 - Development of pull-to-stand, standing, and cruising
 - Balance and coordination of trunk muscles
 - Use of coordinated control in hips, knee, ankles, and feet
 - Use of varied movements for transition

Cognitive Interventions

- Continue teaching of age-appropriate cognitive skills using the principles of learning theory
- Begin introduction to group learning experiences
- Continue teaching of cognitive skills with the parent/caregiver

(Continued from previous page)

Table 15: Summary of Age-Specific Intervention Recommendations**Age 24 to 36 months*****Communication Interventions***

- Continue to give speech/language therapy appropriate for the individual child and continue parent training and education in language stimulation techniques
- Provide opportunities for intervention in a structured peer group setting in order to:
 - Enhance language skills
 - Facilitate communication sessions
 - Provide opportunities for linguistic interaction with peers
- Speech language interventions for this age group should target:
 - Improving vocabulary (oral and signs)
 - Improving receptive and expressive language skills
 - Improving motor-speech production

Motor Interventions

- Continue interventions for development of fine motor skills. Important components of intervention include:
 - Use of writing materials
 - Turning knobs and lids
 - Rotating forearms
- Continue interventions for development of gross motor skills. Important components of intervention include:
 - Development of independent walking
 - Appropriate equipment/toys to provide opportunities for independent upright movement
 - Development of stair climbing
 - Development of high level motor skills

Cognitive Interventions

- Continue teaching of cognitive skills using the principles of learning theory
- Include opportunities for interaction with other children in structured and semistructured activities
- Reinforce cognitive skills through exposure to chronologic and/or developmental age peers
- Provide opportunities for generalization and exploration that enable the child to develop mastery and competencies within educational settings
- Continue teaching of cognitive skills with the parent/caregiver

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**APPENDIX A: TESTS FOR
IDENTIFICATION
AND
ASSESSMENT OF
YOUNG
CHILDREN WITH
DOWN
SYNDROME**

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Ages and Stages Questionnaires (ASQ)

<i>Type of Test</i>	Set of 11 developmental questionnaires containing 30 items each. Sent periodically to parents of children who show potential developmental problems.
<i>Purpose</i>	To identify children who need further testing and possible referral for developmental evaluation and services.
<i>Age Range</i>	4 to 48 months old. Testing is recommended at 4, 8, 12, 16, 20, 24, 30, 36, and 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>	Parent responses to questions with “yes,” “sometimes,” or “not yet” are converted to scores used to monitor the child’s development.
<i>Time</i>	Approximately 20 minutes to complete questionnaire.
<i>Standardization</i>	The test was standardized on a sample of 2,008 children (53% were male; the occupational and ethnic statuses of families were diverse). The sample included children with disabilities and those at environmental or medical risk. Information on reliability and validity testing is included in the manual.
<i>Training</i>	Parents use their observations in a natural environment to respond to questionnaire.
<i>Other Versions</i>	Spanish

Alberta Infant Motor Scale (AIMS)

<i>Type of Test</i>	A standardized assessment of infant development.
<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

Battelle Developmental Inventory (BDI)

<i>Type of Test</i>	Criterion-based and norm-referenced with hearing norms, using verbal instructions and nonvocal responses. This is a measure of developmental skills across five domains. A screening test with 28% of the items is included. Allows for multisource assessment.
<i>Purpose</i>	To identify handicapped children, strengths and weaknesses of nonhandicapped children, appropriate instructional plans for individual children, and monitor child's progress.
<i>Age Range</i>	Birth to 8 years old
<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 interview 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>	1-2 hours for entire test, 0-30 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

**Bayley Scales of Infant Development II (BSID-II) Second Edition 1993
(Note: Third Edition, 2005)**

<i>Type of Test</i>	A standardized assessment of infant development.
<i>Purpose</i>	The test is intended to measure a child's level of development in three domains: cognitive, motor, and behavioral.
<i>Age Range</i>	Birth to 42 months
<i>Components</i>	<p>The BSID-II consists of three scales: mental, motor, and behavior rating scales.</p> <p>The test contains items designed to identify young children at risk for developmental delay.</p>
<i>Scoring</i>	An "item set" based on age is presented in a specific order and scored with some examiner flexibility. Standardized scores are reported for either the Mental Development Index (MDI) or the Performance Development Index (PDI).
<i>Time</i>	From 30 minutes to 60 minutes
<i>Standardization</i>	<p>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.</p> <p>The Bayley was standardized on 1,700 infants, toddlers, and preschoolers between 1 and 42 months of age.</p> <p>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.</p>
<i>Training</i>	Appropriate training and experience are necessary to correctly administer and score the assessment.

Carolina Curriculum for Infants and Toddlers With Special Needs (CCITSN)

<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. Field-tested curriculum and assessment with details provided. Inter-rater 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.

Functional Independence Measure for Children (WeeFIM)

<i>Purpose</i>	Functional assessment for infants 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 scales 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 included lectures, rating videotape, and completing three written case studies.

Gesell Developmental Schedules (GDS) – Revised

<i>Type of Test</i>	A standardized test of a child’s general development.
<i>Purpose</i>	Intended to assess a child’s general development. Originally designed as a diagnostic developmental assessment of the integrity of the child’s nervous system.
<i>Age range</i>	Birth to 72 months Uses age equivalents over 72 months
<i>Components</i>	Test components include language, fine and gross motor, cognitive, and personal-social domains. Combines parent history and formal behavioral examination.
<i>Scoring</i>	Results can be expressed as developmental quotient (DQ) in each of five domains (gross motor, fine motor, adaptive, language, and personal-social).
<i>Time</i>	Not specified
<i>Standardization</i>	Has a normative reference group of 927 low birth weight, preterm infants. Revised and reformed in 1980. Normative values from the Gesell have been integrated into other assessment instruments (such as the Ages and Stages Questionnaire).
<i>Training</i>	Designed to be administered by physicians and others knowledgeable in central nervous system development.

Hawaii Early Learning Profile (HELP)

<i>Purpose</i>	Designed as a family-centered assessment instrument intended to facilitate comprehensive assessment by an interdisciplinary team.
<i>Age Range</i>	Children who function at or below 36 months of age
<i>Components</i>	Test based on normal developmental sequence. Seven functional areas are assessed using a checklist of 685 developmental items. Functional areas include regulatory/sensory organization, cognitive, language, gross and fine motor, social-emotional, and self-help.
<i>Scoring</i>	Infant's performance on an item is scored as pass-fail or partially successful based on examiner's judgment. Scores are used with qualitative description of the child's developmental skills and behaviors to determine approximate developmental level within major developmental domains.
<i>Time</i>	Not specified
<i>Standardization</i>	Field-tested the curriculum and assessment but details not provided. Not standardized but uses developmental sequences from standardized tests and developmental scales.
<i>Training</i>	Assessments designed to be administered by professionals from different disciplines. Formal training not required.

Leiter International Performance Scale (LIPS)

<i>Purpose</i>	Measures intelligence through testing of nonverbal items. Serves as supplementary measure of intelligence.
<i>Age Range</i>	24 months to 20 years
<i>Components</i>	Based on 2 nationally standardized test batteries: a visualization and reasoning domain battery, and a reasoning domain battery. Tests are designed to be used with motor impaired children and instructions are nonverbal.
<i>Scoring</i>	Uses age-scale format. Provides IQs by the ratio method.
<i>Time</i>	30-35 minutes to administer
<i>Standardization</i>	Norms outdated and there are concerns about standardization since there is limited information about reliability and validity.
<i>Training</i>	For use by professionals who have been trained in its use.

Peabody Developmental Motor Scales (PDMS)

<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 United States
<i>Training</i>	Not specified

Pediatric Evaluation of Disability Inventory (PEDI)

<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 and performance of 197 functional skill items.
<i>Scoring</i>	The level of assistance to complete specific activities is measured.
<i>Time</i>	Direct administration takes 20 to 30 minutes. Administration by parent report or interview can take up to 45 minutes.
<i>Standardization</i>	Standardized on 412 children and families stratified by age, gender, race-ethnicity, parent education, community size, and other socio-economic factors.
<i>Training</i>	Training requirements included in the manual.

Test of Sensory Functions in Infants (TSFI)

<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 sub-domains 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 infants 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 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.

Toddler and Infant Motor Evaluation (TIME)

<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, sitting, quadruped, and standing. 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>	15–30 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 have significant experience in developmental testing.

Vineland Adaptive Behavior Scales (VABS)

<i>Type of Test</i>	Assesses adaptive skills (personal and social sufficiency) from birth to adulthood.
<i>Purpose</i>	To assess communication, daily living skills, socialization, and motor skills domains.
<i>Age Range</i>	Newborn to 18 years
<i>Components</i>	Three forms are available: the Interview Edition Survey with 297 items, the Expanded Form with 577 items, and the Classroom Edition with 244 items.
<i>Scoring</i>	A respondent (a parent, a teacher, or another professional) who knows the individual well answers behavior-oriented questions about the individual's adaptive behavior.
<i>Results</i>	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 of age. 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>	Administration requires appropriate training and professional experience.

**APPENDIX B: EARLY
INTERVENTION
PROGRAM
INFORMATION**

New York State

B-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, play groups, 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 108). 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 says no 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 included 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 impairment).

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. And, 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 Down syndrome, 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 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 for diagnostic or evaluation purposes only
- 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, i.e., 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, play group, 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 take place 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.

REIMBURSEMENT

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.

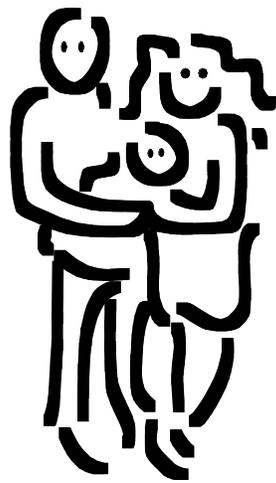
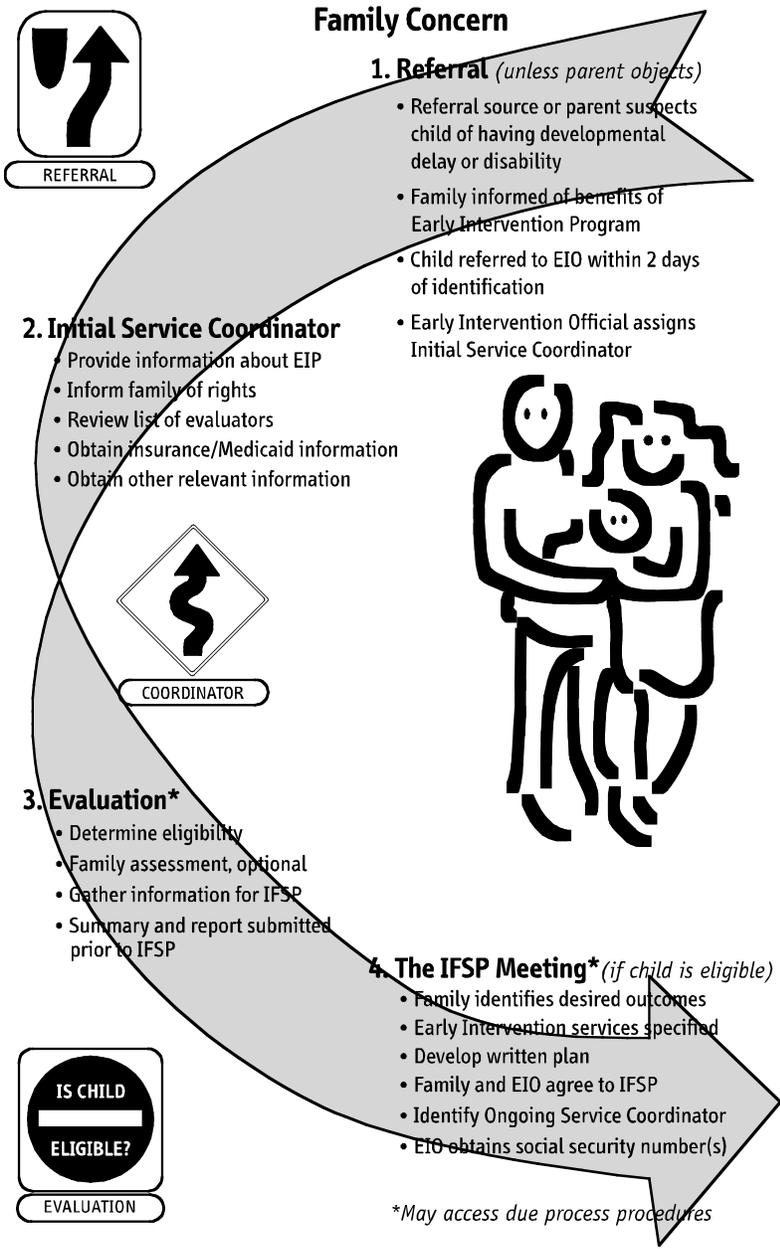
For more information about the New York State laws and regulations and administrative guidance documents that apply to early intervention services, contact the Bureau of Early Intervention.

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

(518) 473-7016

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

bei@health.state.ny.us



6. Transition

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

Areas of Development

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

5. IFSP – Review Six Months /Evaluate Annually

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

Early Intervention Services*

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

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

Revised 12/04

B-2: OFFICIAL EARLY INTERVENTION PROGRAM DEFINITIONS

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

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

Sec. 69-4.10 Service Model Options

1. 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

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:
 - (vi) a twelve month delay in one functional area; or
 - (vii) a 33% delay in one functional area or a 25% delay in each of two areas; or
 - (viii) if appropriate standardized instruments are individually administered in the evaluation process, a score of at least 2.0 standard deviations below the mean in one functional area or score of at least 1.5 standard deviation below the mean in each of two functional areas.
- (ag) *Parent* means a parent by birth or adoption, or person in parental relation to the child. With respect to a child who is a ward of the state, or a child who

is not a ward of the state but whose parents by birth or adoption are unknown or unavailable and the child has no person in parental relation, the term “parent” means a person who has been appointed as a surrogate parent for the child in accordance with Section 69-4.16 of this subpart. This term does not include the state if the child is a ward of the state.

- (aj) *Qualified personnel* are those individuals who are approved as required by this subpart to deliver services to the extent authorized by their licensure, certification, or registration, to eligible children and have appropriate licensure, certification, or registration in the area in which they are providing services, including:

Qualified Personnel:

- (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 Individualized Family Service Plan

(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 statement 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.

B-3: TELEPHONE NUMBERS OF MUNICIPAL EARLY INTERVENTION PROGRAMS

Please visit our Web page at

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

**APPENDIX C: ADDITIONAL
RESOURCES**

APPENDIX C

The Arc of the United States (Association for Retarded Citizens) 1010 Wayne Avenue, Suite 650 Silver Spring, MD 20910	(800) 433-5255 (301) 565-3842 (301) 565-3843 (fax) www.thearc.org
The Association for Children With Down Syndrome 4 Fern Place Plainview, NY 11803	(516) 933-4700 (516) 933-9524 (fax) www.acds.org
Council for Exceptional Children 1110 North Globe Road Suite 300 Arlington, VA 22201	(888)-CEC-SPED (703) 620-3660 (703) 264-9494 (fax) www.cec.sped.org
Down Syndrome Parent Network 3226 Church Road Easton, PA 18045	(610) 432-3776 www.dspn.org
Easter Seals National Headquarters 230 West Monroe, Suite 1800 Chicago, IL 60606	(800) 221-6827 (312) 726-6200 www.easterseals.com
Educational Resources Information Center 4483-A Forbes Boulevard Lanham, MD 20706	(800)-538-3742 www.eric.ed.gov
International Foundation for Genetic Research 500A Garden City Drive Pittsburgh, PA 15146	(412) 823-6380 (412) 829-7304 (fax) www.michaelfund.org
March of Dimes Foundation 1275 Mamaroneck Avenue White Plains, NY 10605	(914) 428-7100 (914) 428-8203 (fax) www.modimes.org
National Down Syndrome Congress 1370 Center Drive, Suite 102 Atlanta, GA 30338	(800) 232-6372 (770) 604-9500 (770) 604-9898 (fax) www.ndsccenter.org
National Down Syndrome Society 666 Broadway, 8th Floor New York, NY 10012-2317	(800) 221-4602 (212) 460-9330 (212) 979-2873 (fax) www.ndss.org

**National Information Center for Children and
Youth with Disabilities (NICHCY)**
P.O. Box 1492
Washington, DC 20013-1492

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

Special Olympics International
13256 G Street, NW
Suite 500
Washington, DC 20005

(202) 628-3630
(202) 824-0200 (fax)
www.specialolympics.com

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

Cognitive Development

General development

1. Children with Down syndrome, ranging from 1 month to 2 years of age, compared with typically developing children matched for gender, age, and social class, when evaluated for general cognitive and motor development:
 - Have moderately lower mental and motor development scores at 6 weeks and 6 months of age
 - Show a drop in scores at 10 months and 15 months and a flattening out of scores by 2 years of age
 - Exhibit greater fluctuations in mental developmental scores (Carr 1970)

Attention and exploration

2. Compared with typically developing children matched for chronologic age, 1-year-old children with Down syndrome who are presented with novel objects tend to:
 - Spend a similar amount of time in visual exploration
 - Spend less time mouthing and manipulating objects
 - Spend less time manipulating each new object when multiple objects were introduced sequentially (Bradley-Johnson 1981)
3. Compared with typically developing children matched for mental age, 1- to 3-year-old children with Down syndrome who are presented with new objects tend to spend less time looking at and touching the new objects (Lewis 1982).
4. Children with Down syndrome from 1 to 3 years old and typically developing children matched for mental age who are presented with new objects react similarly in the following ways:
 - Children gaze at objects longer when the object was touchable
 - Children gaze at and touched 3-dimensional objects less than flat objects
 - Older children both gaze at and touch objects more than younger children do (Lewis 1982)

5. Compared with typically developing children matched for either developmental or mental age, 2- to 3-year-old children with Down syndrome, when playing with toys, tend to:
 - Have similar levels of sustained attention during play
 - Have similar amounts of developmentally appropriate play
 - Display more throwing behaviors
 - Glance up less during play
 - Look less at people when not engaged with toys
 - Spend more time unoccupied when not engaged with toys (Krakow 1983)
6. Compared with typically developing children matched for mental age, children with Down syndrome over 18 months old, when given a task to find an object:
 - Use a greater number and variety of exploratory behaviors
 - Attempt fewer active but incorrect strategies to complete the task
 - Need similar amounts of prompting
 - Take similar amounts of time to complete the task (Loveland 1987/Loveland 1987A)
7. Mental age is the best predictor of whether a child will successfully complete a learning task for both children with Down syndrome over 18 months old and typically developing children (Loveland 1987/Loveland 1987A).
8. Compared with typically developing children matched for mental age, children with Down syndrome over 18 months old, when placed in front of a mirror, tend to:
 - Spend a greater amount of time looking in the mirror
 - Be more attentive to and less likely to lose interest in the mirror (Loveland 1987/Loveland 1987A)
9. Compared with typically developing children matched for mental age, 9-month-old children with Down syndrome, when presented with new objects, tend to:
 - Spend equal time attending to the new objects
 - Spend more time looking at the new object
 - Spend less time exploring the new objects (MacTurk 1985)

Learning and memory

10. Compared with typically developing children matched for chronologic age, 4-month-old children with Down syndrome tend to:
- Have a similar ability to learn operant conditioning tasks
 - Display a similar temperament when learning new tasks
 - Be less likely to be positively reinforced by visual and auditory stimulation (Ohr 1991, 1993)

Reasoning and problem solving

11. Compared with typically developing children matched for mental age, 3- to 4-year-old children with Down syndrome, when performing a problem solving task of removing toys from a lock box, show less success in the task. As with typically developing children, competence and organization tends to increase with increases in mental age (Berry 1984).
12. Compared with typically developing children matched for chronologic age, 3- to 4-year-old children with Down syndrome, when performing a problem solving task (removing from a lock box), tend to:
- Exhibit more unsuccessful attempts
 - Exhibit fewer aimless actions when mother is present
 - Exhibit less exploration with fewer problem solving strategies
 - Be less likely to repeat strategies (patterns of actions that were previously successful) (Berry 1984)
13. Compared with typically developing children matched for chronologic age, when measuring the progress in sensorimotor development, children with Down syndrome tend to:
- Take less time to move to the next stages for gestural imitation and spatial relation
 - Take more time to move to the next stages in all other domains (Dunst 1988)
14. Compared with typically developing children matched for chronologic age, 3- to 4-year-old children with Down syndrome, when given a problem solving task using progressively difficult repeated trials, tend to:
- Improve with each session
 - Be lower with the first session but equal in the following sessions

- Exhibit false fails (purposely responding incorrectly) less frequently (Wishart 1987)

Communication/Language Development

Early vocalization

1. Children with Down syndrome develop canonical babbling later than typically developing children, although the ranges of onset overlap (Cobo-Lewis 1996, Lynch 1995). Ages of onset of canonical babbling (observed at home) were:
 - 6.6 to 13.3 mos. for children with Down syndrome (mean = 9 mos.)
 - 4.3 to 8.4 mos. in typically developing children (mean = 6 mos.) (Lynch 1995)
2. There is a great deal of variability in a child's use of early vocalizations both for children with Down syndrome and typically developing children. Children with Down syndrome tend to use canonical babbling less consistently than do typically developing children. There are also differences between time of onset of canonical babbling in the home and in the laboratory. Therefore, a one-time assessment may be misleading (Lynch 1995, Steffens 1992).
3. In children with Down syndrome an earlier onset of canonical babbling is correlated with more advanced social and communication development at 27 months (Lynch 1995).

Gestures and nonverbal communication

4. Children with Down syndrome and typically developing children both tend to increase their use of gestures as the level of receptive language (word comprehension) increases (Caselli 1998).
5. Compared with typically developing children at similar levels of language development, children with Down syndrome use more gestures (Caselli 1998, Franco 1995).
6. Children with Down syndrome show deficits in nonverbal communication skills (gestures) that are considered necessary precursors for developing verbal communication (Mundy 1988).
7. Compared with typically developing children at similar levels of language or cognitive development, children with Down syndrome use gestures differently. Specifically, children with Down syndrome:

- Use more nonverbal social interactions
 - Use more social referencing when pointing
 - Use a similar frequency of reaching for objects
 - Use less nonverbal requesting behaviors (Franco 1995, Mundy 1988)
8. Children with Down syndrome tend to use gestures differently than do other children with cognitive delays. Children with Down syndrome:
- Use more nonverbal social interactions
 - Use less nonverbal requesting behaviors (Mundy 1988)

Verbal language development

9. Compared with typically developing children, children with Down syndrome show delays in both receptive and expressive language development. The degree of delay becomes greater as children get older (Caselli 1998, Harris 1983, Mahoney 1981, Mundy 1988).
10. Even when compared with typically developing children matched for mental age, children with Down syndrome show delays in expressive language development. Children with Down syndrome show a greater delay in expressive language than in receptive language (Mahoney 1981, Mundy 1988).
11. At an early stage of verbal language development (single-word utterances), children with Down syndrome have an expressive vocabulary similar in size to that of typically developing children matched for level of word comprehension (Caselli 1998).
12. For children with Down syndrome, a higher level of:
- Receptive and expressive language is associated with development of object permanence
 - Receptive language is associated with gestural imitation (Mahoney 1981)
13. As children advance from single-word to multiword utterances, children with Down syndrome use different types of words and have different patterns of language compared with typically developing children matched for mean length of utterance. Specifically, children with Down syndrome:
- Use fewer single-word utterances that make use of operators
 - Use fewer multiword utterances that make use of operators

- Use fewer words indicating nonexistence or disappearance (such as gone, no more)
 - Use more rote utterances (Harris 1983)
14. Mean length of utterance may not be an accurate predictor of other language abilities (Harris 1983).
 15. Children with Down syndrome who have better verbal expressive language tend to have better nonverbal communication skills (Mundy 1988).

Auditory preferences

16. The majority of infants with Down syndrome, as well as the majority of typically developing children matched for mental age, prefers to listen to a human voice rather than to musical instruments (Glenn 1981).

Communication and language milestones

17. Developmental milestones for communication and language have been established for typically developing children. These milestones specify the age at which most typically developing children will have displayed a particular communication skill or behavior (NYSDOH Communication Disorders Guidelines 1999).
18. Compared with typically developing children, the average age when children with Down syndrome reach each specific communication milestone is later, and the range of ages for attaining each milestone is broader (Cunningham 1996).
19. The broader age range of communication milestone attainment may be at least partly because children with Down syndrome vary greatly in their degree of cognitive delay (Carr 1970, Cunningham 1996).

Social Development

Social attention

1. Compared with typically developing children matched for chronological age, infants with Down syndrome from 4 to 9 months of age spend more time gazing at their mothers when engaged in play with their mothers (Crown 1992, Gunn 1982).
2. Compared with typically developing children matched for mental age, children with Down syndrome from 16 to 28 months of age, when engaged in play with an unfamiliar adult, tend to:

- Show similar levels of joint attention
 - Spend more time looking at the adult's face and spend more time looking away from the interaction
 - Spend less time looking at objects that are not the main focus of play
 - Use less social referencing
 - Have more shifts in affect (facial expression) (Kasari 1990, 1995)
3. The extent to which children with Down syndrome (from age 16 to 28 months) engage in play with an unfamiliar adult generally correlates with:
- Expressive language skills at 16 months of age
 - Nonverbal joint attention skills at 28 months of age (Kasari 1990)
4. Compared with other children with developmental delays matched for mental and motor age, 12-month-old children with Down syndrome, in responding to their mothers' attempts to direct the child's attention during play:
- Are equally likely to respond with a look or with no response
 - Are less likely to respond by manipulating a toy introduced by the mother (Landry 1989)
5. When engaged in play with toys, 7- to 8-month-old children with Down syndrome tend to:
- Spend more time looking at their mothers and less time looking at toys
 - Show more positive affect (facial expressions) during independent play than during joint play (Landry 1990)
6. Compared with high risk infants matched for mental and motor age, 7- to 8-month-old children with Down syndrome engaged in play with toys:
- Spend more time looking at their mothers and show a more positive affect when engaged in independent play than during joint play
 - Are less responsive to their mothers' attempts to redirect attention during joint play (Landry 1990)
7. When presented with two social interaction situations with an adult, children with Down syndrome, compared with typically developing children matched for language level:
- Are more likely to attend to and participate in a verbal social interaction (singing a song with an adult)
 - Are less likely to play independently with toys presented by the adult

- Are less likely to smile when given toys, but equally likely to smile during verbal social interaction (Ruskin 1994)

Social interaction

8. When presented with unfamiliar and ambiguous situations in the presence of their mothers, children with Down syndrome age 1 1/2 to 3 1/2 years, compared with typically developing children matched for mental age:
 - Look at their mothers less often and for a shorter period of time
 - Are less likely to match their mothers' fearful expressions
 - Show similar intensity and liability of facial expressions (Knieps 1994)
9. Children with Down syndrome who are 2 to 4 years old and typically developing children matched for developmental or mental age respond similarly to their mothers' requests when engaged in play. Children in both groups:
 - Are more likely to respond to requests when there is a higher contingency
 - Have more appropriate and higher quality responses (i.e., the child is more likely to attempt or complete a task) when requests are less difficult and have higher contingency (consequence) (Bressanutti 1992)
10. Children with Down syndrome tend to have a similar quality of play as that of typically developing children matched for developmental or mental age, when both playing with their mothers and playing independently (Cielinski 1995).
11. When engaged in play with their mothers, children with Down syndrome, compared with typically developing children matched for developmental or mental age, tend to:
 - Spend less time in play
 - Have shorter bouts of play, but more bouts of play per minute (Cielinski 1995)
12. Compared with typically developing 3- to 14-month-old infants matched for chronologic age, infants with Down syndrome tend to:
 - Spend less time smiling at their mother when engaged with their mother in normal play

- Spend a similar amount of time smiling at their mother when the mother both was and was not interacting in play activities (Carvajal 1997)
13. For children with Down syndrome, the amount of time a child spends engaged with toys tends to increase when the mother is more directive (Cielinski 1995).
 14. Compared with mothers of typically developing children matched for developmental age, the mothers of children with Down syndrome tend to be more directive in social interactions with their child, especially when the interaction setting is less structured and more open-ended (Cielinski 1995, Landry 1994, Mahoney 1990, Tannock 1988).
 15. When engaged in play with their mothers (either carrying out difficult tasks or engaged in pretend play), children with Down syndrome, compared with typically developing children matched for developmental age, tend to:
 - Be less likely to comply to requests initiated by their mothers
 - Be more likely to comply to a directive request than to a suggestive request from their mothers
 - Have fewer social interactions in both types of play situations (Landry 1994)
 16. When engaged in play with their mothers, 1- to 5-year-old children with Down syndrome, compared with typically developing children matched for developmental age, tend to have a similar frequency of utterances or turns taken (Tannock 1988).

Social milestones

17. Compared with typically developing children, the average age when children with Down syndrome reach each specific social development milestone is later, and the range of ages for attaining each milestone is broader (Cunningham 1996).
18. The broader age range of social development milestone attainment may be at least partly because children with Down syndrome vary greatly in their degree of cognitive delay (Carr 1970, Cunningham 1996).

Patterns of maternal interactions with child

19. Compared with mothers of other children with developmental delays matched for mental and motor age, mothers of children with Down syndrome, when engaged in play with their child:
 - Are more likely to introduce a toy when the child is not involved with anything
 - Are more likely to physically reorient the child (Landry 1994)
20. Mothers of children with Down syndrome who are engaged in play with their children tend to use more requests for action and fewer requests for attention when interacting with their child. The opposite pattern was found for mothers of typically developing children matched for developmental age (Mahoney 1990).
21. Compared with mothers of typically developing children matched for developmental age, the mothers of children with Down syndrome tend to show greater control in turn-taking and in choosing the topic of the interaction when interacting with their children (Tannock 1988).

Motor Development*Postural reactions*

1. Motor delays or motor deficits can be observed in infants with Down syndrome as early as 3 to 5 months of age (Rast 1985).
2. Focusing on only motor milestones while neglecting postural reactions (such as head righting) may give a false impression that motor development is progressing normally in young infants with Down syndrome (Rast 1985).
3. Infants with Down syndrome have difficulty adjusting their heads in space against gravity and have less antigravity control of lower extremities (Rast 1985).
4. Children with Down syndrome may exhibit atypical movement patterns that may interfere with future motor development. Some of these atypical patterns may reflect the child's efforts to compensate for low muscle tone (hypotonia), which is common in children with Down syndrome (Rast 1985).
5. The times of onset for postural reactions are closely associated with the level of motor development in both children with Down syndrome and

typically developing children, but the association is greater with children with Down syndrome (Haley 1986).

6. By 4 months of age, differences in postural reactions can be seen between children with Down syndrome and typically developing children. After 5 months of age, the rate of development of postural reactions is slower in infants with Down syndrome than in typically developing infants matched for chronologic age (Haley 1986).
7. The level of motor development is more closely associated with chronologic age for typically developing infants, compared with infants with Down syndrome (Haley 1986).
8. There is no significant difference in rank in which righting and equilibrium factors (indicators of postural control) appear in children with Down syndrome and typically developing children (Haley 1987).
9. Well-developed postural reactions (protective, righting, and equilibrium reaction), which allow an individual to maintain body alignment when stationary and during movement, are a necessary precursor to later motor development including crawling, standing, and walking, as well as adaptive skills. Children with Down syndrome are delayed in developing all postural reactions compared with typically developing children of the same chronologic age (Haley 1986, Haley 1987, Rast 1985).
10. Children with Down syndrome develop protective reactions relatively sooner in the sequence of motor development, and righting and equilibrium reactions develop later, compared with typically developing children. This delay in development of righting and equilibrium reactions may lead the child with Down syndrome to develop atypical compensatory movement patterns (for head righting, standing, etc.) (Haley 1986, Haley 1987, Rast 1985).

Spontaneous movements

11. The frequency and duration of spontaneous movements does not differ between 5-month-old infants with Down syndrome and typically developing infants matched for either chronologic or motor age (Ulrich 1995).
12. Children with Down syndrome at 5 months of age have less complex spontaneous leg movements compared with typically developing infants matched for either chronologic or motor age (Ulrich 1995).

13. Five-month-old infants with Down syndrome who display more complex spontaneous kicking movements tend to walk at an earlier age compared with Down syndrome children who do not show these kicking movements. This suggests that repeated complex spontaneous movements may be important for facilitating the later development of stable motor behavior patterns in infants with Down syndrome (Ulrich 1995).
14. Infants with Down syndrome who have a greater range of motion at the hip and the knees at 5 months of age tend to have a later onset of walking than do other children with Down syndrome. This may be because increased joint flexibility combined with general hypotonicity may make these children less stable when standing and walking (Ulrich 1995).
15. Both the type of environmental stimulation and order of stimulation affect movement frequency. There is more movement with verbal than with visual stimuli (Ulrich 1995).
16. When confronted with different physical situations affecting motor movements, infants with Down syndrome require a higher threshold of sensory input in order to adapt to situations and display less intense changes in motor output when compared with typically developing infants matched for chronologic or motor age (Ulrich 1997).
17. It is possible that children with Down syndrome have a reduced sensitivity to their own “internal dynamics,” which could explain why they develop functional motor and adaptive skills later than typically developing children (Ulrich 1997).

Motor milestones

18. Compared with typically developing children, the average age when children with Down syndrome reach each specific motor milestone is later, and the range of ages for attaining each milestone is broader (Cobo-Lewis 1996, Cunningham 1996).

Temperament/Behavior Styles

1. In general, a young child’s temperament appears fairly stable as the child grows older, both for children with Down syndrome and for typically developing children (Huntington 1987).
2. Children with Down syndrome show less persistence in activities than do typically developing children when matched either on chronologic or mental age (Bridges 1982, Gunn 1985, Huntington 1987, Marcovitch 1986).

3. Compared with typically developing children matched for mental age, both infants and toddlers with Down syndrome need less stimulation to elicit a response (i.e., have a lower threshold for stimulation) (Bridges 1982, Gunn 1985).
4. Compared with typically developing children matched for chronologic age, 2 1/2- to 3-year old children with Down syndrome need higher levels of stimulation to elicit a response (Gunn 1985, Huntington 1987, Marcovitch 1986, Vaughn 1994).
5. Compared with typically developing children matched for either chronologic or mental age, children with Down syndrome are more approachable (Marcovitch 1986).
6. Compared with typically developing children matched for either chronologic or mental age, children with Down syndrome are less adaptable in new situations (Vaughn 1994).
7. Compared with typically developing children matched for chronologic age, children with Down syndrome:
 - Are more likely to be seen as having “easy” temperaments
 - Are less likely to be considered “difficult” or “slow to warm up” (Marcovitch 1987)
8. Infants with Down syndrome and typically developing infants who are matched for mental age appear to have similar temperaments in terms of level and intensity of activity, adaptability, distractibility, rhythmicity of behaviors, and mood (Bridges 1982).
9. Compared with typically developing children matched for either chronologic or mental age, children with Down syndrome who are 2 to 3 years old tend to show:
 - More rhythmicity in behaviors
 - Less intensity of behaviors
 - A more positive mood (Gunn 1985)
10. Children with Down syndrome age 2 to 3 years old and typically developing infants matched for mental age appear to have similar temperaments in terms of their levels of activity, adaptability, and distractibility (Gunn 1985, Huntington 1987, Marcovitch 1986).

Thyroid and Growth Hormone Function

Thyroid function

1. Of the children in the Down syndrome group who ranged in age from 4 months to 3 years:
 - Twenty-seven percent had elevated TSH and normal T₄ values
 - Ten percent had significant thyroid disease (Cutler 1986)
2. Compared with typically developing children matched for chronologic age, children with Down syndrome ranging in age from 1 to 3 years of age:
 - Have similar levels of T₄
 - Have elevated levels of TSH when under 1 year of age (transient elevation) (Cutler 1986)
3. Children with Down syndrome ranging from 1 to 7 years of age, compared with typically developing children matched for chronologic age:
 - Have higher TSH levels
 - Have similar T₃ and T₄ levels
 - Have similar thyroid antibody results (negative)
 - Exhibit similar differences in basal and peak TSH levels between the two younger age groups (less than 1 year and 1 to 3 years of age) compared with the oldest age group (3 to 7 years of age) (Sharav 1991)

Growth hormone function and growth retardation

4. Children with Down syndrome ranging from 1 to 5 years of age, compared with typically developing children, tend to:
 - Have smaller heads (microcephaly)
 - Have growth retardation (Castells 1996)
5. Compared with typically developing children, children with Down syndrome (from age 1 to 5 years) have an abnormally low response of serum GH concentration when given the pharmacological stimuli of levodopa and clonidine. This is an indication of hypothalamic dysfunction (Castells 1996).
6. Compared with typically developing children, children with Down syndrome (from age 1 to 5 years) have a normal GH response when given GHRH. This indicates normal pituitary function (Castells 1996).

Behavioral/Educational Intervention

1. Starting intervention programs early (within the first month after birth) appears to be more beneficial than starting later in infancy (Sanz 1996).
2. Early educational programs individualized to the needs of the child and family can benefit young children with Down syndrome (Bidder 1975, Connolly 1976, Connolly 1980, Connolly 1984, Connolly 1993, Kysela 1981).
3. Children with Down syndrome generally show a decline in standardized scores of development (such as developmental quotients) as they get older (Carr 1970). There is some evidence that participation in early intervention programs may reduce these declines in cognitive and social functioning scores (Connolly 1976, Connolly 1980, Connolly 1984, Connolly 1993, Kysela 1981).
4. Instructional methods using techniques based on learning theory (such as graduated guidance, decreasing assistance, and other prompt fading procedures) can be effective in teaching young children with Down syndrome (Bidder 1975, Bruder 1987, Schoen 1988, Sloper 1986).
5. A six-month program of one-hour biweekly therapy sessions combined with instructions to parents for follow-up may not be an intensive enough program to reduce the declines in developmental quotients for young children with Down syndrome (Piper 1980).
6. Training parents as primary interventionists can result in improvements in their teaching skills (Bruder 1987).
7. Training parents, either as part of an intervention program or as primary interventionists, can result in improvements in their children's performance (Bidder 1975, Bruder 1987, Kysela 1981, Sanz 1996, Sloper 1986).
8. Effective elements in training parents include verbal instruction, practice, feedback, and teaching the methods to other parents (Bruder 1987).

Communication/Language Intervention

1. For an infant with Down syndrome, a parent can increase the infant's vocalization rate by smiling, making eye contact, and playing with the infant during or immediately following a vocalization. The parent's social behavior serves as a reinforcer (Poulson 1988).

2. Interventions that involve training parents in a social-conversational language program can result in improvements in parent communication patterns when interacting with their children (Girolametto 1988).
3. For young children with Down syndrome and other developmental delays, training parents to modify their communication patterns can result in improvements in children's communication abilities such as turn-taking and responsiveness (Girolametto 1988).
4. For young children with Down syndrome and other developmental delays, more extensive training of the children and their parents in sign language can result not only in a significant increase in the number of signs acquired by the children but also in improvements in their expressive language scores on a standardized test (Jago 1984).

Motor Therapy Intervention

1. Motor therapy based on the neurodevelopmental treatment (NDT) approach may be effective in improving motor performance in young children with Down syndrome if this improvement is measured by the number of individualized therapy objectives attained (Harris 1981/Harris 1981A).
2. Adequate research evidence was not found to demonstrate the effectiveness of interventions based on either NDT or vestibular stimulation for improving outcomes on standardized tests of motor development in young children with Down syndrome (Harris 1981/Harris 1981A, Lydic 1985).

Oral-Motor Intervention

1. For young children with Down syndrome, palatal plate therapy (used for 1/2 to 1 hour a day for 9 to 12 months) in combination with regular oral-motor exercises can be effective in reducing oral-motor dysfunction, including reducing inactive tongue protrusion and improving mouth closure (Carlstedt 1996).
2. Oral-motor treatment based on either NDT principles or behavior modification techniques can be used to reduce tongue protrusions in young children with Down syndrome (Purdy 1987).

Vitamin Therapy

1. High dose vitamin/mineral supplements do not appear to improve the developmental progress of young children with Down syndrome and may have detrimental side effects (Bidder 1989).

APPENDIX D

2. High dose vitamin/mineral supplements have frequent undesirable side effects, such as flushing, tightness of the skin, and vomiting (Bidder 1989).
3. Long-term administration of vitamin B6 does not appear to improve the rate of development of young children with Down syndrome (Coleman 1985/Frager 1985).

REFERENCE LIST

REFERENCE LIST

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

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GUIDELINE VERSIONS

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

The three versions are

THE CLINICAL PRACTICE GUIDELINE:

Quick Reference Guide

- summary of major recommendations
- summary of background information

Report of the Recommendations

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

The Guideline Technical Report

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

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