LEGISLATIVE REPORT

SUBJECT: Special Needs of Preschool Children with Developmental Disabilities

REFERENCE: SCR 17

ACTION REQUESTED: Report of findings and recommendations, including proposed legislation, on the educational implications of the special needs of preschool age children with developmental disabilities such as Down Syndrome, including:
- Development of guidelines for assessment, intervention, and education;
- Goals and criteria for preschool readiness, including appropriateness for developmental age and chronological age; and
- Consideration of the adoption of the December 2005, Clinical Practice Guideline: Down Syndrome, Assessment and Intervention for Young Children (Age 0 to 3 Years), sponsored by the New York State Department of Health.

DOE REPORT:
Introduction:
The National Early Childhood Technical Assistance Center (NECTAC) was contracted to complete a literature search/study to fulfill this legislative request. NECTAC is a program of the University of North Carolina at Chapel Hill, funded through a contract from the Office of Special Education Programs, U.S. Department of Education. The study was completed and transmitted to the Department on October 30, 2007. The Special Education Section has not yet generated its summary of findings and recommendations based on the report.

FINDINGS (taken from the study)
- Young children (ages 3-5) in inclusive programs generally do at least as well as children in specialized programs. Inclusion can benefit children with and without disabilities, particularly with respect to their social development. (National Professional Development Center on Inclusion, 2007)
- Children with Down syndrome are not all born with identical learning problems, health problems, appearance, and potential. (Oelwein, 1995)
- There is no one teaching method, no one behavior plan or no one Individualized Education Program (IEP) designed for all children of a certain age with Down syndrome. Many of the problems that children with Down syndrome demonstrate are faced by other children as well.
• Developmental age, in general, is how a child behaves in certain areas of development in relation to other children. Assessments of developmental ages break down children's development into different discrete areas. Children’s scores often vary in each category. The scores from all the categories are compiled into one developmental age score/number. Assigning one developmental age number is not an accurate description of the child. Developmental age is not useful in determining actual goals or outcomes to be addressed, learning styles and strengths of the child, teaching methods, or grade placement.

• None of the articles or texts reviewed indicated that a best practice would be to leave the child with disabilities in an age group that matched a developmental age, even if it was possible to attain one age across all developmental areas to describe the child.

• New York State Department of Health, “Report of the Recommendations: Down Syndrome Assessment and Intervention for Young Children 0-3 Years”
  o The report focuses on young children 0-3 years, not preschool age and older.
  o None of the 181 recommendations in the assessment section were rated as being based on strong or moderate evidence;
  o 43 of the recommendations were rated as having limited evidence; and
  o All other recommendations were based upon the opinion of the panel that developed the report.
  o There are no recommendations regarding keeping children of a specific chronological age with younger children to attempt to match developmental age.

• The Division of Early Childhood (DEC) branch of the Council for Exceptional Children (CEC) developed and published a book, DEC Recommended Practices: A Comprehensive Guide for Practical Application in Early Intervention/Early Childhood Special Education. This publication provides field verified tools and practices to help teachers, parents, therapist, administrators and others working with young children with disabilities.

RECOMMENDATIONS
1. Use the Division of Early Childhood’s Recommended Practices materials as a guide to assessment, intervention and education of preschool aged children with disabilities.
2. Placement/participation in a preschool environment should be based on an IEP team decision, not a state policy or criteria for entry.
3. Utilize the National Association for the Education of Young Children (NAEYC) support materials to provide guidance in the areas of school readiness and developmentally appropriate practices for all children.

Introduction and Purpose of Report

This report is written in response to a Hawaii Senate concurrent resolution (24th legislature, 2007) urging the Hawaii Department of Education to "study the educational implications of the special needs of preschool age children with developmental disabilities." Topics requested for study and review include: developmental age vs. chronological age; the developmental difference of young children with Down syndrome; "total communication" and other approaches, including signing for speech language services for children with Down syndrome; hearing loss and amplification support for children with Down syndrome; guidelines for assessment and intervention for all young children with developmental disabilities; and review of the "Clinical Practices Guidelines- Down Syndrome" from the New York State Early intervention Program.

The content of the study is divided into the following sections:

1) Purpose and review of the Individuals with Disabilities Education Act (IDEA) as it relates to young children with disabilities

2) Preschool (3-5 years of age) Inclusion

3) Preschoolers with Down syndrome

4) Assessment and intervention practices for all preschool children with disabilities

An extensive review of the literature and research articles including, peer reviewed articles, text books, disability organizations' standards, recommended practices and national organizational websites was conducted related to the topics listed in the resolution. Each section of this report includes a review of findings as well as direct citations. An extensive biography of all sources reviewed is included at the end of the study. The Department of Education has copies of all reviewed articles.
Section 1
IDEA

Purpose and Intent of the Law

The Individuals with Disabilities Education Improvement Act (IDEA), U.S. Code: Title 20-Education, Chapter 33- Education of Individuals with Disabilities sets forth the general provisions and purpose of the Law as:

(1) To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living; to ensure that rights of children with disabilities and parents of such children are protected; and to assist States, localities, educational service agencies and Federal agencies to provide for the education of all children with disabilities;

(2) To assist States in the implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers and families;

(3) To ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting system improvement activities; coordinating research and personnel preparation; coordinated technical assistance, dissemination and support; and technology developments and media services;

(4) To assess and ensure the effectiveness of efforts to educate children with disabilities.


Thirty years have passed since the first enactment of the Education of All Handicapped Children Act (PL 94-147). Dr. Michael J. Guralnick (2001), comments, "In that landmark and wonderfully crafted piece of legislation, the right of children with disabilities to obtain a free and appropriate public education was firmly and unequivocally established."

Over the past 30 years, the legislation has been modified, extend, amended and reauthorized first, in 1986 (PL 99-457); again in 1990 as the Individuals with Disabilities Education Act (IDEA, PL 101-336); in 1991 (PL 102-119); in 1997 (PL 105-17); and most recently in 2004. The Act is now re-titled the "Individuals with Disabilities Education Improvement Act" (PL 108-446). In each reauthorization and amendments, the foundational principle that disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in, or contribute to society (20 U.S.C. 1400 (c) (1)) is clearly stated and upheld. A second guiding principle in the law, that of improving the educational results for children with disabilities, is an essential
element of our national policy of ensuring equality of opportunity, full participation, independent living and economic self sufficiency for all individuals with disabilities and has remained at the center of thinking, law and practice.

Through all the revisions, the law continues to stress: early identification and early intervention; children educated in the “Least Restrictive Educational Environment” for ages 3-21 or the “Natural Environment” for ages birth -3 with same age peers; that every educational and related service a child receives to help them achieve their goals and outcomes are determined on an individual basis and documented on an individualized education program (IEP) or individualized family service plan (IFSP). It continues to stress the importance of family participation as team members involved in decisions regarding their child’s educational needs. Throughout the years, parents, education agencies, professionals and researchers have worked to find the “best” and most appropriate methods for supporting and teaching in order for children with disabilities to be educated and socialize together with typically developing peers in ways that meet their unique needs and learning styles. While much has been accomplished there are still many challenges that parents, providers and systems must work to improve.

Part B and Part C of the Law

IDEA sets legal statute and regulating guidelines for services for children birth-21. There are two major sections of the law applicable for providing services and supports to children. In general, Part B of the Act contains provisions and regulations for children ages 3-21. A subsection entitled “619”, further defines Part B as it applies to preschool children 3-5 years of age prior to kindergarten. Part B is viewed as an education program, providing special education services and supports for children to benefit from the general education curriculum. The US Department of Education, Office of Special Education Programs (OSEP), provides oversight through State Education Agencies (SEA). Services and supports under Part B are provided most often by local education agencies (LEAs).

Part C of the Act, referred to as the “Infants and Toddlers Program,” also called Early Intervention, is designed for families and children age birth to three. Part C, like B, receives oversight from the US Department of Education, Office of Special Education Programs, but it is administered at the state level by a state lead agency appointed by the governor. The lead agency may be a state health, human service, and disability or education agency. Part C is considered by law to be a comprehensive, coordinated, multidisciplinary interagency system of services for both infants and toddlers with disabilities and for their families.

Differences Between Part B and C

Pletcher (2002) developed a document for the Iowa Department of Education to clarify the differences between Part B and Part C of the Act. These differences are highlighted below.
Intent

- Part C focuses dually on the infant/toddler and his or her family. The legislative intent is on “enhancing the child’s growth and development AND enhancing the family’s competence and confidence in helping their own child grow and develop”. Called early intervention, the focus is on the prevention of later delays and on promoting overall child and family development so that the child may not later need more costly special education services.

- Part B focuses on the child’s educational needs and progress in the general education curriculum. Intervention(s) is provided for a particular problem(s) impacting the child’s learning. Supplemental aides and services are provided to assist the child to progress through the general education curriculum for same age peers.

Eligibility for Services

- Part C serves children younger than the age of three who meet state eligibility guidelines for services. Eligibility requirements are different in each state. States must include children who currently exhibit delays in one or more areas of development when given a state selected eligibility assessment and evaluation process following IDEA regulations. They also include children who have known conditions that may lead to later delays in development and/or may serve children who have biological or environmental risk factors that may lead to later delays in development. Not all children served in Part C show significant delays in development.

- Part B serves children ages 3-21. The child must have a disability or be labeled “developmentally delayed” based on state approved standardized tests and eligibility requirements and procedures for special education AND be in need of special education services to benefit from the general education curriculum.

Family Involvement

- Part C is guided by “family centered practices” shaping the parent professional relationship. Families and providers work side-by-side in partnership. Families are active participants in the evaluation and the IFSP development. Family concerns and priorities for their child and family are identified together and are used to determine outcomes and services/resources the child and family will receive. Families are involved in the “interventions” and activities with their child.

- Part B families participate in the Individualize Education Plan (IEP) development, placement decision and in determining evaluation data needed. Families carry out
educational activities at home with their child to assist the home/school connection and they attend school meetings and conferences as needed.

Services

- Part C services are provided by health, education, human services agencies and other community providers. The Individualized Family Service Plan (IFSP) team meeting determines which of the required Part C services are needed, the frequency and intensity of these services, where they will be provided and how they will be paid for. Other services, which are not Part C required services by law, may also be listed on the IFSP at the family and team’s discretion. All families receive at no cost, evaluation and assessment activities, IFSP development and reviews and support and assistance from a family services coordinator.

- Part B services primarily come from local educational agency (LEA) teachers or from an Area Education Agency providing special education and related services to the LEA. Services are planned by the IEP team and can also include other agencies outside the school systems when needed. Services focus on helping the child be successful in the general education curriculum and are spelled out in the individual education program (IEP).

- All Part C services and supports for the child are provided in the “Natural Environment”—the home and/or community settings where children of the same age and without disabilities participate. Natural environments encompass the family’s community and all activities in which the family and child participate. Services can be provided in another environment only if the child’s goals can not be reached in a natural setting. This is a team (which includes the family) decision and a justification statement must be written on the IFSP as to why the goal or outcomes can not be satisfactorily achieved in a natural environment.

- All Part B services are provided in the school setting that is the “Least Restrictive Environment”, “to the maximum extent appropriate, eligible individuals in private or public institutions or other care centers are educated with individuals who are same age peers who are non-disabled.”

- Part C- Services are to be provided “year round.”

- Part B, the school calendar determines when services are provided. In addition some students may receive “extended school year” services. The IEP determines the need for extended year services for each student.

- Part C uses various models of service delivery ranging from a primary provider model where one individual supported by a trans-disciplinary team, is the main
service provider to the child and family to various other team approaches where multiple providers work with the family and child.

- Part B, the IEP team identifies the “key” person or person who is responsible for implementing the IEP. This person is usually a teacher, special education teacher or related service provider. IEP services focus on the child. Families are involved through conferences, or other meetings when requested.

Documentation

- Part C, the Individualized Family Service Plan (IFSP) is the family’s document that records how the child’s strengths and needs and the families concerns and priorities are being addressed. The IFSP can be reviewed, evaluated and changed as often as the family desires or a provider may recommend. This document has to be formally reviewed in six months and again at a year as a federal minimum requirement.

- Part B, the Individualized Education Plan (IEP) documents what special education services and supports will be provided to the child and is a communication tool regarding the child’s progress. The IEP is reviewed for changes annually but can be reviewed more frequently to ensure the child is making progress.

Funding

- Part C- There are no charges to families for service coordination activities, child find, eligibility assessment and review of the IFSP. There may be charges to Medicaid, insurance or to families for some services if the state has policies in place to use “third party” billing or has “family cost participation” legislation. Part C federal dollars are used as “payer of last resort” but no family can be denied services due to inability to pay.

- Part B- Special education services are provided at no-cost to the family (FAPE). Services are paid by federal, state or local special education dollars or could be reimbursed to an LEA or district by Medicaid or insurance if states have Medicaid and insurance plans in place for school based services.

Part C Flexibility to Serve Children 3 Years of Age until Entrance into Elementary School

IDEA 2004 (PL. 108-446), created a new provision for the Part C statewide system. Under this provision states MAY develop state policy, allowing parents of children with disabilities who are eligible for Preschool Services under section 619, and previously received Part C, to choose a continuation of Part C early intervention services. This option would need to have an additional focus to include an educational component promoting school readiness and incorporating pre-literacy, language and numeracy skills until this child is eligible under state law to enter kindergarten. The state policy and plan
to serve these children must be developed and implemented jointly by the lead agency for Part C and the State Education Agency. There are other specific conditions that the state must address spelled out in section (635 (C) (1-4)) of the Act. To date no state has adopted this option. Three states have created committees to investigate the use of this option, but have not pursued developing policies. Two other states are currently engaged in a feasibility study, including Hawaii.

The discussions regarding this option have identified challenges. The most significant challenge appears to be that no additional federal funds are earmarked for these children to remain in Part C services after age 3. The option would need to be made available to all children served in Part C who are eligible for Part B services. Early childhood educators/special education teachers trained to work with preschoolers are not always employed by the infant and toddler programs (Part C) where “special instruction” is the specified service not “special education.” This means that early interventionists may not be trained in the required “pre-literacy or numeracy activities” designed for the preschool population. Part C services may involve family cost participation while 619 B services are provided under FAPE at no charge. Families would be giving up their right to FAPE if they remained in the Part C option.

Advantages have been identified. Some parents wish to continue to receive family service coordination and other Part C services not provided under Part B. Families report they prefer the focus and intent of Part C Program. Families may wish to delay transition, or only have one transition from services, when the child would more naturally be moving into school age services at kindergarten age.

States exploring this option will need to do fiscal studies, identify potential numbers of children, review and/or revise teaching and certification requirements for personnel and develop the necessary interagency agreements and state policy and procedural documents. Currently there are no research studies documenting the advantages for childrens’ outcomes for remaining in the Part C service system.

Section II
Inclusion and LRE

The Division for Exceptional Children (DEC) Position Statement on Inclusion says:

Inclusion as a value supports the right of all children regardless of abilities to participate actively in natural settings within their communities. Natural settings are those in which the child would spend time had he or she not had a disability. The settings include, but are not limited to, home, preschool, nursery schools, Head Start programs, kindergartens, neighborhood school classrooms, child care, places of worship, recreational and other activity settings that all children and families enjoy and participate in. (Division for Early Childhood, 1996)

The entire position paper is available at:
www.dec-sped.org/pdf/positionpapers/PositionStatement_Inclusion.pdf
The National Down Syndrome Society (n.d.) defines inclusive education as:

Inclusion is more than mainstreaming. Mainstreaming implies that a student from a special education class visits the regular classroom for specific, usually non-academic subjects. Inclusion is an educational process by which all students, including those with disabilities, are educated together for the majority of the school day. With sufficient support, students participate in age-appropriate, general education programs in their neighborhood schools. Inclusion is a philosophy of education based on the belief in every person's inherent right to fully participate in society.

Guidelines to Support Inclusion (Pennsylvania Department of Public Welfare & Pennsylvania Department of Education (n.d.) states:

Belonging is a basic need of every person. In order for children to belong they need to be able to participate in every day activities with their same age peers. They need to have access to the same social and learning opportunities that they would have if they did not have a disability. Successful implementation requires appropriate supports and services to be in place. Many individuals, agencies and fiscal entities must collaborate to ensure that successful inclusive opportunities are available.

The National Professional Development Center on Inclusion (2007) has provided a summary of key “synthesis points” drawn from the research on early childhood (ages 3-5) inclusion drawn from a recent review of literature. Seventy four peer reviewed articles were included in developing the following points:

- Inclusion takes many different forms; a single definition of inclusion does not exist.

- Progress has been achieved in efforts to ensure access to inclusive programs, particularly for pre-kindergarten children (3-5 year olds). However in the US, universal access to inclusive programs for all children with disabilities is far from a reality.

- Children in inclusive programs generally do at least as well as children in specialized programs. Inclusion can benefit children with and without disabilities, particularly with respect to their social development.

- A variety of factors such as policies, resources and beliefs influence the acceptance and implementation of inclusion.

- Specialized instruction is an important component of inclusion and a factor affecting child outcomes.
• Collaboration among parents, teacher and specialist is a cornerstone of high quality inclusion.

• Families of children with disabilities generally view inclusion favorably, although some families express concern about the quality of early childhood programs and services.

• Limited research suggests that the quality of early childhood programs that enroll young children with disabilities is as good or slightly better, than the quality of programs that do not enroll these children; however, most studies have focused on general program quality as opposed to the quality of inclusion for individual children with disabilities and their families.

• Some evidence suggests that early childhood professionals may not be adequately prepared to serve young children with disabilities enrolled in inclusive programs.

The center encourages distribution of the complete document which includes all the above points with the research citations. The document is suggested to be used for parent and professional development, policy development, planning and grant writing. The document is available online at www.fpg.unc.edu/~npdei

Inclusion and the Law

The primary purpose of IDEA is to ensure that all students with disabilities are provided a free and appropriate public education (FAPE). The “right to participate in and contribute to society” is one of the two cornerstones of IDEA that supports inclusion. The second cornerstone supporting inclusion is that children with disabilities can be effectively educated within the general curriculum to the maximum extent appropriate by providing services in the general education classroom whenever necessary (Stowe and Turnbull 2001). The two cornerstones together form the platform to support FAPE in the LRE—free and appropriate public education in the least restrictive environment for all children with disabilities ages 3-21.

To receive federal funds, Section 1412(a)(5), requires that states must have policies and procedures in place to ensure that “to the maximum extent appropriate, children with disabilities are educated with children who are not disabled, and that special education classes, separate schooling, or other removal of children with disabilities from the regular education environments occurs only when the nature or severity of the disability of a child is such that education in regular classrooms with the use of supplementary aides and services can not be achieved satisfactorily.” This is known as the Least Restrictive Environment (LRE) provision of the law and requires inclusion, either full or partial, in the general education classroom, in extracurricular activities and in other school sponsored non-academic activities. The law requires that a continuum of alternative placements must be made available to support LRE. The Local Education Agency must
supply any supplemental aides and services that will allow for a greater amount of inclusion. Removal from the general education classroom may be justified only when the child’s education cannot be achieved satisfactorily after the supplemental aids and support have been tried in good faith. Placement decisions are made by the IEP team, which includes the parents.

**Part B Applied to Preschool Populations**

Stowe and Turnbull (2001) clarify a major difference for programs between the 3-5 age population and the 5-21 age population. Under Part B Local Education Agencies do not all provide preschool programs for children **without** disabilities. States do not have to create and fund preschools for **all** children simply to meet the LRE requirement of IDEA. Publicly funded pre-kindergarten programs for 3 to 5 year olds do not exist universally in most states. In the 1980’s and 1990’s many LEA’s created preschool special education programs primarily for children with disabilities in local elementary schools. This was the major option in providing quality preschool services for children with disabilities. These remained segregated settings or settings where a few children without disabilities were invited to participate. Many LEAs have moved towards employing early childhood special education teachers as “itinerate” or “consulting teachers” to work with children in more typical early childhood settings. This has helped to move some children from these preschool special education settings into community placements with typically developing peers.

Serving preschoolers with disabilities in inclusive community settings has required major restructuring of policy and service delivery models. These changes have required providing training for early care and education staff not trained in special education; improving the overall quality of early care settings; and developing financial and collaborative agreements with community partners. This has been a much slower process than anticipated when Part B services were extended to the preschool population.

In local communities, this collaborative activity most often involves working with Head Start programs, child care centers, church preschool programs, fee for services preschool programs. These programs are collectively referred to as the “early care and education network”. As inclusion of young children with disabilities into day care, private and public preschool settings expands, many in-service opportunities are now available.

**National Resources**

The National Early Childhood Technical Assistance Center (NECTAC) provides information and technical assistance and support to the state systems that provide the services and supports under IDEA Part B and Part C. A large section of their overall website is devoted to “Inclusion”. There are resources for providers, parents and state administrators including a large annotated biography on Inclusion and Natural Environments, examples of state policy, research projects and collaborative agreements and conference proceedings from the “National Inclusion Institute” from the last five years.
Implementing Part B as it applies to preschoolers has required guidance and clarification on the Law from OSEP related to this age population in 619 preschool programs. All Letters of clarification issued by OSEP’s legal counsel specific to state issues in applying Part B to preschool age children served in 619 programs can be found at http://www.ed.gov/policy/speced/guid/idea/index.html

Section III
Preschoolers with Down Syndrome

Topical Review of Literature

Seven text books and 35 research articles were reviewed for this section focusing on mental development, speech language development, hearing, and assessment and teaching strategies for young children (birth-8) with Down syndrome. An additional publication, “Clinical Practice Guideline- Report of the Recommendations- Down Syndrome Assessment and Intervention for Young Children ages 0-3 years”, developed by the New York Department of Public Health is reviewed separately in this section.

Abilities in Young Children with Down Syndrome

Down syndrome is a genetic disorder with a prevalence of 1 in 600 to 1 in 800 live births. The risk of having a child with Down syndrome increases with maternal age. The National Down Syndrome Society states this increased risk to be 1 in 101 births at age 40, and 1 in 35 births for mothers age 45. There are approximately 5,500 infants in the United States born each year with Down syndrome (Roberts, 2007). There are some common physical characteristics associated with Down syndrome that can be seen at birth. A medical diagnosis is confirmed by a chromosome analysis after birth and prenatal diagnosis is made during an amniocentesis (Leshin, 2002).

Children with Down syndrome often have high instances of heart defects, ear/hearing problems, vision problems, thyroid dysfunction, intestinal blockages, and chronic respiratory infections and low muscle tone throughout the body. Leshin (2002) and Oelwien (1995) comment that any of these conditions left untreated would affect any child’s learning. Mental retardation is also present but, as with the accompanying health conditions, can range from mild to severe. Mental retardation first manifests as delays in development of thinking, moving and talking. Genetic mapping is helping researchers to identify specific genes on 21st chromosome that cause various differences in persons with Down syndrome. Oelwein (1995) comments that the amount of genetic material that each child receives may determine if the child has mild, serious (or none at all) heart defects, intestinal blockages, vision problems, hearing problems, immune deficiencies, the degree of mental retardation, risks of leukemia and other conditions associated with Down syndrome.
While there are some physical and health related similarities, there are also many differences among children with Down syndrome. This is well stated in the following quotes:

Among the stereotypes that are being dispelled is that Down syndrome is a homogeneous condition in which all individuals are highly similar in intellectual, behavioral and other characteristics and that the expected intellectual, developmental and function outcomes are always poor. (Spiker & Hopmann, 1997)

The more children with Down syndrome you know, the more it is apparent, that not all children with Down syndrome are alike. The fewer you know, the more apt you are to generalize they are all alike. Children with Down syndrome are not all born with identical learning problems, health problems, appearance, and potential, nor are they all born in the same environment. (Oelwein, 1995)

"People first language" preferred in the field of disabilities speaks of "children with Down syndrome" not the "Down syndrome child". This reminds us to think first that these individuals are CHILDREN, not a disabling condition. As children they share many characteristics with all children. They may resemble their relatives, they learn, grow, eat, play, sleep, love and cry. They also have the same kinds of differences that all children have; differences in temperament, personality, interests, potential, needs, and health. As all children do, children with Down syndrome live in different kinds of families and communities. They have access to different kinds of care, support, cultural and educational opportunities.

**Cognitive Development of Children with Down Syndrome**

Cognition (mental development) involves the processes the brain uses to experience the world, to feel and to remember. It is the ability to think, by taking in information and using the information in a meaningful way. The aspects of cognition that are important for the growth and development of a young child with Down syndrome include attention and exploring, learning and memory, and reasoning and problem solving.

Moore, Oates, Hobson and Goodwin (2002) describe early cognitive ability as the development of abilities to form and use representations of the world and to develop "mental models" or "theory like- constructs." Cognitive tasks for babies include the ability to focus attention, to look for hidden objects, to match objects based on meanings such as shapes of animals, familiar people and daily routines. Babies can respond to simple requests, such as, "Can you find the doggie?" As the child grows and develops, language is often the way that cognition is "visible". The child can understand and do what is being asked of him/her (receptive language) and the child can use words or another behavior to tell others what he/she is thinking (expressive language). There are certain ages or stages in a child’s life where adults expect to see certain behaviors emerge. One aspect of mental retardation is slower than expected cognitive (mental) development as measured against similar age expectations. Children with Down
syndrome display varying degrees of mental retardation showing as delays in early development. Research studies indicate that cognitive development in children with Down syndrome is different than can be explained simply by the diagnosis of mental retardation, or slower development. Spiker and Hoppman (1997) reviewed studies conducted over the last decade; most recently note that young children with Down syndrome may show differences in how they take in and process information. Wishart (1992) suggests that, as early as 6 months, infants with Down syndrome engage in specific search and exploration behaviors that she describes as “counter productive” to learning. Dunst (1990) concluded that the sequence of development in infants with Down syndrome is similar to that of typically developing infants, but infants with Down syndrome have significant difficulty making transitions from stage to stage even when their slower developmental age is taken into account. Wishart (1993) reported many examples of qualitative learning difficulties experienced by young children with Down syndrome. For example, infants with Down syndrome took longer to learn contingencies and seemed more content with non-contingent reinforcement schedules than did typically developing infants. Duffy and Wishart (1994) have identified particular learning styles associated with children with Down syndrome, suggesting these individuals may be distinctively responsive to errorless learning contexts. This seems to show that the use of skills learned in one setting do not “generalize” to another setting as would be expected. Moore Oates, Hobson and Goodwin (2002) summarize their research findings on cognition and social development of infants with Down syndrome by saying evidence suggests that the development of triadic (person-person-world) social interaction may be affected by limited information processing capabilities in infants with Down syndrome, through a complex socially-mediated developmental trajectory.

Others studies imply that children with Down syndrome are “visual learners.” Oelwein (1995) used visual stimuli as a highly effective means of teaching and expanding cognitive learning. She found that illustrations, symbols, pictures and sight reading vocabulary words to be powerful tools for learning. Spoken words vanish quickly once they are said. The written word, pictures, drawings and objects, can remain for as long as the child needs them. Studies reported by Buckley (1995) also suggest that individuals with Down syndrome have strengths in visual processing centered in mental processing. Buckley’s studies in the UK suggest that many young children with Down syndrome can learn to read single words by the ages of three and four years.

Investigating the unique learning styles of children with Down syndrome is in early stages and more work needs to be done. In “Down Syndrome Visions for the 21st Century” (2002), several researchers speak to multiple intelligences, or multifaceted intelligence. In addition to linguistic and mathematical intelligence, there are other forms of intelligence including spatial, interpersonal, and musical intelligence to mention only a few. Kumin (2002) notes that many children with Down syndrome learn well using music. Oelwein (1995) has highlighted the need to consciously assist children with Down syndrome with ways in which information can be effectively filed, stored and retrieved. In her book, “Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers” she points out how important it is for teachers and parents to understand
how the child takes in and uses information (assimilates) in order to be successful, and for caregivers to be able to support that child’s particular learning style and strengths.

All of these studies imply that it is not simply that children with Down syndrome are slower than others and take longer to learn something presented in the conventional way. Teaching and intervention strategies are not about doing more of the same over and over, until the child “gets it,” or presenting materials at a slower rate. The research suggests that children with Down syndrome may learn in a different manner than other children. Thus, it would be critical to study an individual child’s learning style, interests and strengths before designing teaching and intervention methods to help each young child reach optimal development. All the above information reminds us there is no one teaching method, no one health plan, no one behavior plan or no one IEP designed for all children of a certain age with Down syndrome. Each child is a unique individual who happens to have some degree of the conditions associated with Down syndrome.

**Development of Speech and Language in Children with Down Syndrome**

For all children, the basis for all communication is social interaction. For infants, this consists of smiles, babbling, and eye contact between child and caregivers and with other young children, usually in the family. Conversation skills begin in infancy with “turn taking.” The baby makes a sound and the caregiver responds with a few words. The baby smiles and the caregiver smiles back. Playing simple lap games, such as peek-a-boo, singing nursery songs and sharing a toy in play between the infant and the caregiver are also strategies that “teach” and set up the emergence of pre-language and language skills. Single word utterances, which may or may not be close approximations to the actual word, usually follow. Caregivers who are responsive to these early attempts usually follow the attempt with the word assumed spoken back. Infants and toddlers with Down syndrome are as socially responsive in their early nonverbal and interactive attempts, with the infant using smiles, facial expressions, body movements, pointing and sounds, not unlike the attempts that infants and toddlers without disabilities use (Kumin, 2002). Most of the research points out that infants with Down syndrome are very similar to other infants in the first 6-9 months and many of these pre-linguistic activities should be a focus of early intervention with families and children. Significant differences begin to appear at the age where spoken single word utterances should be emerging at 8-12 months.

Miller, Leddy, Milo and Sedey (1995) reported that delays in language production (speech) were evident in only 50% of young children up to 24 months in their research Studies. However by 36 months, all the children exhibited language production deficits. Their research also indicates that the rate of progress in acquiring language production skills slows with advancing chronological age, although language learning continues through adolescence.

Roberts, Price and Malkin (2007) found that individuals with Down syndrome have language deficits, particularly in expressive language and syntax, and poor speech
intelligibility, relative to non-verbal cognition and comprehension skills. They noted that there is increasing evidence of specific deficits beyond mental age in some aspects of vocabulary and pragmatic skills. Language differences are evident at the onset of first words and continue throughout adolescence and into adulthood with some indication of changes in language strength throughout the individual's lifespan. Chapman's (2006) research also demonstrated that children and adolescents with Down syndrome have an "identified" specific behavioral phenotype marked by deficits in expressive language, especially in speech intelligibility, syntax and grammatical morphology accompanied by deficits in phonology and working memory with strengths in vocabulary. The expressive language and working memory deficits are more marked than comprehension skills, non verbal visual problem-solving skills, daily living skills or social skills.

Researchers, teachers, and parents are aware that children with Down syndrome are particularly at risk for language learning problems for reasons beyond the associated cognitive deficits. Fowler (1995) comments that reviewed research from many sources seems to agree, by and large, that individuals with Down syndrome will have language difficulties, but the reasons for these problems are not as clear. Over the years, different studies have focused on different reasons for delays in language development.

Children with Down syndrome have an increased frequency of middle ear infections, which can result in temporary or permanent hearing loss. They have a high rate of actual hearing deficits with some reports suggesting that 60-80% of children may have re-occurring or permanent degrees of hearing loss (Watson, 1996). Not being able to hear or hear well consistently may result in not being able to produce words clearly or to hear well enough to process and use verbal information for later learning. Second, the deficits in motor coordination associated with Down syndrome may adversely affect the synchrony of motor movements required for speech production, including respiration, phonation and articulation. Articulation involves the use of the tongue, palate, lips and jaw. Third, cognitive differences specific to Down syndrome may result in language learning problems beyond those commonly associated with mental retardation. Finally, there can be decreased expectations for performance in children diagnosed with mental retardation which frequently result in learned incompetence or lack of appropriate experiences. Any of these factors can result in deficits in language acquisition; taken together they represents a formidable puzzle to unravel in order to understand the forces affecting language growth in this population (Miller, 1987).

Mille, et al. (1995) report that persons with Down syndrome are biologically distinct as a result of the extra copy of the 21st chromosome and that almost every organ system of the body is affected. Some of these anatomical differences may be associated with speech intelligibility which includes such things as swollen vocal cords, smaller oral cavities leaving less room for the tongue, and differences in facial muscles which may be fused or even have extra muscle structures. There are also differences in the central nervous system that are likely to reduce the accuracy, speed and consistency of neural activity that may interfere with precision, sequence and timing of speech movements. All of these factors will impact the use of spoken (expressive) language.
Other research has focused on the differences in how language is acquired and used. Fowler (1999) suggested that phonological working memory, hearing sensitivity and visual short term memory are areas that may be different in young children with Down syndrome. Verbal processing is a specific area of weakness. The deficits in pre-linguistic communication emphasize a need for early intervention, while the continued growth of language during the school age and adolescent years highlights the continued need for language intervention. The uneven profile of language skills in individuals with Down syndrome suggests that interventions need to be individualized, focusing on the specific domains of language (Kumin, 1999).

There are also findings that suggest that infants and toddlers with Down syndrome at the one and two word stage of spoken language display “advanced” conversational skills not found in their same age peers without disabilities. They engage in more complex imaginative play, have mastered conversational turn-taking, make appropriate responses to questions with gestures combined with word(s), and modify their actions or behaviors when they are not understood in order to be understood. These finding indicate that receptive language is well ahead of expressive language, and the child with Down syndrome uses other strategies to compensate for what they do not clearly say “out loud” with words (Fowler, 1995).

Although there are common speech and language problems, there is no single pattern of speech and language common to all children with Down syndrome. They are not just simply learning to talk at a slower rate than children without Down syndrome. The condition itself is responsible for many of the speech and language challenges (and strengths). Many children with Down syndrome have more difficulty with expressive language than they do in understanding speech and language. Certain linguistic areas, such as vocabulary, are usually easier than grammar. Sequencing of sounds and words may be difficult for many children; many have difficulties with intelligibility of speech and articulation, while others have fluency problems.

Kumin (2002) implies that many of the problems that children with Down syndrome demonstrate are faced by other children as well. She believes there are no speech and language problems unique only to children with Down syndrome. This means there is a great deal of knowledge and experience that can be applied to helping a child with Down syndrome with his/her specific area of challenge which are being used by qualified and trained speech language pathologist in their work with all children with speech language delays. Others researchers have suggested specific methods to improve communication and language use specifically focusing on children with Down syndrome.
Suggested Methods to Improve Speech and Language Development in Children with Down Syndrome

Total Communication

Total Communication is an intervention method in which speech and sign language are used simultaneously by an adult communication partner in “turn taking” conversational exchanges (Gibbs and Carswell, 1991). The communication partner needs to know and use the sign language the child is learning and using. Watson (1996) has broadly defined total communication as interactions with children, adults and others that involve the combination of verbal utterances, signing, gestures and other augmentative strategies, such as pictures or written words, and computer communication devices, all with the aim to help the child be understood and to communicate. This description resembles Kumin’s (2002) definition of “transitional communication system,” which she describes as blending the variety of methods, materials and intervention strategies all with the aim of assisting the child to communicate with others what he/she wants, needs and enjoys “talking” about. Formal sign language, picture cards, word cards, communication boards with symbols, gestures and single word utterances are combined together in an effort to allow the child to continue to make progress in vocabulary development and other areas of language when he may not yet be physiologically ready to use speech. As a “transitional system” component, total communication implies that it is used to bridge or to help until the emergence of expressive language becomes more dominate in the young child’s communication strategies.

Signing and Gestures

Beginning in the early 1980’s the teaching of signing and gesturing for young children who were not using words or not using clearly articulated words and who are not hearing impaired, is well documented. In the early 1990’s researches still referred to this practice as “experimental” and felt it and must be monitored carefully by an audiologist” (Swift and Rosen, 1990)

By the mid and late 1990’s the practice was often in use with preschool children with and without disabilities. Commercial programs to teach babies to sign were marketed to parents. Many teachers and parents of young children with Down syndrome and other disabilities using signing and gesturing reported it to be useful in helping their child communicate. Watson (1996) explains that learning is most successful when the mode of teaching matches a child’s preferred learning style (perceiving and processing) and for many children with Down syndrome this would mean capitalizing on their strengths in the visual modalities. There is a fair amount of literature from researchers, clinicians and parents in support of the use of manual gestures and signs at least during the pre-linguistic and emerging language stages as a way to bridge a child’s transition to speech. Kumin (2001) strongly suggests that parents introduce signs before age one and expect that the child stop using them at around age five.
Miller et al. (1995) found that 75% of young children with Down syndrome had been exposed to manual signing at some time during their development. The usual reason for introducing sign was to improve initial communication when early verbal attempts at communication were unintelligible or absent. The use of signing suggests that signed vocabulary adds additional communication power to the child’s functioning abilities to communicate. Parents in his studies report that early signed communication reduced the child’s frustration and provided the child with a clear method for referencing objects, actions, wants needs and people in the child’s environments. This approach works as long as caregivers and other children also used and understood the signs and gestures. Parent’s reported that as the child was more successful in communicating orally, the use of signs diminished over time. Clibbens (2001) reports on studies done by Remington and Clark, show the introduction of a signed communication system, if done properly, does not inhibit in any way the development of oral language. They say that, in addition to providing a possibly temporary substitute for speech in young children, signing can help reduce frustration and challenging behavior. They suggest that signing may in fact facilitate improved interaction patterns which in turn can facilitate speech development. To be interactional assumes that the turn-taking partner understands the signs and gestures being used and can use them “back” as well.

Smaller focused studies reported by Clibbens (2001) show benefits to children using early signing as they transfer to spoken language. Children who used combinations of signing and spoken words had the largest vocabularies and were further ahead at age 8 in language comprehension, reading and writing than the children with Down syndrome in the study group who had not used signing. The majority of the children in the study by age eight were using spoken language as their preferred means of communication, although two children continued at age eight to still use manual signing. Clibbens’ studies support other findings indicating that signing is important to introduce early, and it can be thought of as a temporary expedient for children, which can be phased out as children master oral language.

Launonen (2005) notes that augmentative language development may enhance cognitive skills and that development in the two areas are closely linked. She reports that findings showed that the early signing program used in her study had significant immediate benefits for the child who took part in the interventions and that the positive results remained in the two-year follow-up. At 3, 4, and 5 years of age, the children in the research group used a far wider range of communication means and were clearly ahead in both language and general development. For some children the periods where signing was dominant lasted less than a year, and for others it remained dominate until age 5. Children also used excellent mimicry, gestures and dramatic actions, in addition to using taught signs to communicate, appearing to build on strengths in visual motor skills as a means of communication.
Hearing Aids and Amplification Devices for use in children with Down Syndrome

Infants and children with Down syndrome often suffer from mild to moderate hearing loss. Stoel-Gammon (2001) reports that 78% of children tested were found to have hearing problems in one or both ears where criteria for “a problem” were a 15dB loss. This loss may be permanent or the result from frequent bouts of Otitis Media (OME). In terms of intervention related to hearing status, the needs are clear that children with Down syndrome will benefit from aggressive treatment for hearing loss associated with middle ear pathology. Normalization of hearing through use of hearing aids is one of the treatment options suggested for those child who have losses that will benefit from hearing aids. All children with Down syndrome should receive frequent follow-up with audiologist and hearing specialist as a routine part of on-going evaluation and be fitted with hearing aids when prescribed.

Roberts (2007) recommends that children with Down syndrome should have their hearing tested when Otitis Media persists for three months or longer. Clinical practice guidelines recommend the use of tympanotomy tubes (American Academy of Pediatrics). At the same time OME is medically managed, the child’s speech and language should be carefully monitored. Because of the importance of hearing for language learning, Roberts (2007) recommends that low gain hearing aids or other amplification devices such as frequency modulation (FM) sound field systems can be useful particularly in classroom settings. She does concluded that more specific studies are needed to determine the efficiency of amplification, augmentative/alternative communication methods and language teaching methods for promoting gains in speech intelligibility, language and generalizations to everyday contexts and whether the effectiveness of intervention varies according to particular developmental stages.

The American Speech-Language Hearing Association in their published document “Guidelines for Fitting and Monitoring FM Systems” (2002) describe Frequency Modulated (FM) systems/auditory trainers as hard-wired, FM, infrared or any amplification system other than a hearing aid. These systems have been standard equipment for children with hearing loss for many years in educational settings. The benefit to the system is that the speaker wears a microphone a few inches from their mouth. The sound is then amplified and sent directly to the earphone of the listener. The resulting improvements of signal level and signal-to noise level ratio in the listeners’ ear are recognized as the primary benefits of FM use. The guidelines mention that FM/auditory trainers have been used and studied with individuals without hearing loss such as those with disorders of articulation, auditory processing, attention and learning. The guidelines only address application to persons with hearing loss not for other children with different types of auditory disabilities. The Guidelines would apply to those young children with Down syndrome who are experiencing hearing loss.

“The New York Guidelines for Down Syndrome” (New York State Department of Health, 2000), referenced in the separate section below, make two specific recommendations from their panel of experts regarding the use of hearing aids and/or
amplification. Their recommendations were based on a rating of “panel opinion without literature reviewed.” The recommendations state, “If a hearing loss is present, it is recommended that hearing aids be considered. If the loss is conductive, hearing aids can be used on a temporary or as needed basis.” “For children who have difficulty discriminating speech in a background of noise because of hearing loss or auditory processing disorder, it may be useful to consider and FM system, either to supplement hearing aids or as an alternative to hearing aids as appropriate.”

The American Speech and Hearing Association, the professional organization for Speech and Language Pathologists offer this official statement regarding their recommendations for assessment and intervention strategies for individuals with Down syndrome:

Like all individuates with disabilities, those children with Down syndrome will show individual patterns of strengths and weaknesses. Assessment and interventions should match the individual’s developmental level. For example, if the person is non-verbal then the assessments aimed at describing the communication forms and functions present in his or her current communication would help inform an intervention approach aimed at increasing forms and functions across meaningful contexts. Probably the most pervasive and persistent communication problem associated with Down syndrome is poor intelligibility. That is, the speech of individuals with DS is often difficult to understand. Two compatible intervention approaches can help address these intelligibility concerns: interventions aimed at improving speech sound production and interventions aimed at improving child communication success through augmentative and alternative communication. For example and individual may speak with familiar communication partners but need to augment speech with pictures or print when communicating with unfamiliar partners. In addition use of contextual supports may help children compensate for memory problems that may affect language development. Some research suggests that individual with DS have more severe language impairments than one would expect, based on other cognitive skills. For example young children may appear to have better comprehension skills than what can be measures objectively. It is important to carefully evaluate both receptive and expressive communication needs as one is planning a comprehensive intervention plan for individuals with Down syndrome.” (American Speech- Language- Hearing Association,n.d.)

www.asha.org/NJC/faqs-disabilities.htm#59

National and International Organizations and Websites

Down Syndrome Online
Down Syndrome Online is a source of comprehensive, up-to-date information, guidance, and news about Down syndrome. Down Syndrome Online is published by The Down Syndrome Educational Trust a leading international charity at the forefront of research and education regarding issues related to Down syndrome.
http://www.down-syndrome.org/
National Association of Down Syndrome (NADS)
NADS is the oldest organization in the country serving individuals with Down syndrome and their families. It was founded in Chicago in 1961 by parents who chose to go against medical advice and raised their children with Down syndrome at home. Their pioneering efforts have made it easier for later generations of individuals with Down syndrome to be accepted by their families and communities, to develop their capabilities, and to work towards independence.
www.nads.org

The National Down Syndrome Society (NDSS)
The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to realize their life aspirations. NDSS is committed to being the national leader in enhancing the quality of life, and realizing the potential of all people with Down syndrome.
www.ndss.org

Developmental age vs. Chronological age used to Determine Placement Options

Chronological age is calculated based on the date of birth as it relates to a specific calendar date in time. Developmental age is more complicated. In general it is thought of as how a child behaves in certain areas of “development” related to other children. Family members, caregivers and other professionals frequently compare children in informal ways. Parents might comment that Susie talked before her brother did. Teachers look at groups of children in their classrooms and compare one child to another. Even strangers looking at a baby or young child often ask, “How old is she/he?” and then do a mental comparison of their own.

Developmental age is measured in formal ways as well. The same principles of measuring a child’s performance on tasks against how well other same-age children do is used in assigning a developmental age or an age range. Assessments or tests of developmental ages break down children’s development into different discrete areas such as cognitive (mental) skills, gross motor skills (movement), fine motor skills (hands/fingers), expressive language, receptive language, adaptive behavior and social and emotional skills. Children often attain different scores in each category. The scores are then compiled and one age is assigned. Formal tests of developmental age are norm-referenced against a comparison group of children, often without disabilities. When evaluating the usefulness of norm-referenced measures to calculate a developmental age, professionals should examine carefully the basis for which norm-referenced scores were derived. McLean (1987) suggest assigning a developmental age using norm-referenced tests may be problematic since the norms for these measures were gathered in different years on different populations and their equivalence is uncertain. Furthermore, even if individual item ages may be generally accurate, the summation of individual item scores
to obtain one developmental age is more suspect since a total score analysis was never conducted. Other measures assign age range scores, again based on tasks and expectations of when these tasks “should” be mastered. There are many different measures with variations in tasks and expected age.

Children with or without disabilities do not develop evenly in all areas at the same time. This is reflected in different scores in different developmental areas based on their strengths, interests and areas of need. Likewise, children with Down syndrome may have different scores in different areas. While mental retardation implies delays in development, it does not equate that all of areas of development will be evenly or equally delayed. Assigning one developmental age number is not an accurate description of the child.

More information on assessment, instruments and scores than can be summarized in this report is available from the federally funded Early Childhood Outcomes Project at www.fpg.unc.edu/~ECO/

A developmental age score is most often used as one aspect of determining eligibly for Part C or special education services. The score given and the degree of difference from the norm it indicates in each area of development, is used to determine standard deviation from the “norm behavior. It is not useful in determining actual goals or outcomes to be addressed, learning styles and strengths of the child, teaching methods, or grade placement.

Kathie Snow (2006), disability advocate, has fought hard against describing children (and adults) by their tested developmental age. She writes:

The development (or functional age concept) is a disability-word paradigm that should make us halt in our tracks. Many children and adults with disabilities are routinely graded against a ‘developmental scale’. If a person’s abilities are substantially lower than the norm he may be saddled with a developmental age. His chronological age-- his real age-- is disregarded as irrelevant. From then on, services, education and even the way he is treated by family members may be based on his developmental age only.

She goes on to say that:

Routinely young children (with and without disabilities) are held back in kindergarten as not ready. Many professionals and parents are recognizing the dangers of this practice. If we hold a 6 year old back or keep him/her in special education preschool with children who are 2 years younger, how will that help the child to mature? If he is six he needs to be surrounded by others who are six. However that does not mean we don’t provide additional help. If he is 6 and only talking like a two year old he needs a communication system and focus to build words and use them, if he isn’t reading at grade level he needs a modified reading curriculum and opportunities to learn through other methods.
Inclusion language uses “same age peers”, “children of the same age without disabilities” an “age appropriate activities” throughout the IDEA legislation. This implies that, in spite of test scores, children have the right to be included with peers of their own chronological age engaged in activities that children of that age enjoy. The child with disabilities is not “held back” until his developmental age reaches that of school age peers. The IEP is supposed to be the tool that adjusts the regular education curriculum and to provide the support needed to help the child make progress and be with children his or her own age. None of the articles or texts reviewed indicated that a best practice would be to leave the child with disabilities in an age group that matched a developmental age, even if it was possible to attain one age across all developmental areas to describe the child. If children were kept with developmental age groups based on lowest areas, potentially an 8 year old might be with 4 year olds, a 10 year old would be in classrooms with 5 year olds, and a 20 year old with 8 or 10 year olds. Prior to FAPE it was common to see adults in institutional settings using activities, materials and instruction designed for preschoolers based on their “developmental” age with no opportunities to engage in meaningful age appropriate activities.

Review of NYSDOH Report of the Recommendations: Down Syndrome Assessment and Intervention for Young Children 0-3 years

This 269 page document is the culmination of a multiyear effort begun in 1996 by the New York State Department of Public Health, the lead agency for New York’s Early Intervention Program (IDEA Part C). An independent, multidisciplinary panel of clinicians and parents developed the report. Another national panel of experts reviewed the document. The full document can be downloaded at: http://www.health.state.ny.us/community/infants_children/early_intervention/docs/guidelines_down_syndrome_assessment_and_intervention.pdf

This document is intended to provide parents, professionals and others with recommendations about “best practice” based on the consensus opinion of the panel and on scientific evidence about the efficacy of various assessment and intervention options for young children with disabilities. The introduction describes the key elements of the guideline development approach to include

- Ensuring multidisciplinary representation
- Developing a guideline that is valid, objective and credible
- Using a process that included a combination of systemic review of the available scientific literature, expert opinion and parent input.
Content of the report includes 10 pages on the background information on Down syndrome, 30 pages on assessment, 51 pages on interventions, and 100 pages of appendices. There are a total of 393 recommendations in two sections entitled “Assessment” and “Interventions.” Some recommendations are very broad and general and can be applied to all children, such as, “It is important to recognize that cognitive skills are an integral component of skill development in all other developmental domains.” Others are more specific such as:

“When evaluating the cognitive function of young children with Down syndrome, it is important to: Conduct evaluations at eye level with the child, provide appropriate postural supports for children who have not yet developed postural control and take into account fine and gross motor skills when methods are selected to assess cognitive status.”(pg. 50-51)

Each recommendation reported in the document was given a “Strength of Evidence Rating.” The rating scale used indicates the amount, general quality, and clinical applicability to the guideline topic of scientific evidence used as a basis for each guideline recommendation.

A=strong evidence, defined as evidence from two or more studies that met criteria for adequate evidence about efficacy and high quality and applicability to the topic, with the evidence consistently and strongly supporting the recommendation.

B=moderate evidence, defined as evidence from at least one study that met same criteria as in A.

C=limited evidence, defined as evidence from at least one study that met criteria for adequate evidence and had moderate quality or applicability to the topic, and where evidence supports the recommendation.

D=consensus panel opinion that was either

D1 based on information not meeting the criteria for adequate evidence about efficacy on topics where a systematic review of the literature was done; or

D2 consensus panel opinion on topic where a systematic literature review was NOT done.

A final category coded [dc] was used to denote the recommendation was from studies about the developmental characteristics and was used after the A, B, or C rating. Of the 181 recommendations in the assessment section none were rated A or B. Forty three were rated with a C [dc] and the remaining recommendations were based upon panel opinion. The section on intervention contained 212 recommendations with similar
Recommendaions for Selected Areas of Intervention

General:

It is important to recognize that while young children with Down syndrome may share many common characteristics, they differ in terms of their individual strengths and needs as well as in their responses to specific intervention methods or techniques. There is no one specific intervention approach or plan that is effective for all children with Down syndrome. Further, children have different family situations and some families will need more support than others. It is recommended that any intervention for a child with Down syndrome be based upon assessments of the specific strengths and needs of the child and family [D2]

Hearing and Ear Problems

- It is important to use intervention strategies that facilitate the acquisition of listening behaviors. For example, useful strategies might include: providing opportunities for exposure to a variety of sounds, drawing the child’s attention to sounds in the environments.[D2]

- If a hearing loss is present, it is recommended that hearing aids be considered. If the loss is conductive, hearing aids can be used on a temporary or as need basis. [D2]

- For children who have difficulty discriminating speech in a background of noise because of hearing loss or an auditory processing disorder, it may be useful to consider an FM system, either to supplement hearing aids or as an alternative to hearing aids as appropriate [D2]

Communication Development

- It is important to remember that no one type of speech or language intervention is the best for all young children with Down syndrome. As with all intervention, it is recommended that the type, frequency/intensity and setting of speech/language intervention for a young child with Down syndrome be based on an assessment of the child’s overall development (in all domains) and the specific strengths and needs of the child and family [D2]

- It is recommended that some form of communication interventions be initiated shortly after birth (oral motor and parent training) as most children with Down syndrome exhibit a delay in communication skills from early on, including vocalization, speech and language [C]

- It is recommended that principles of learning theory be applied to intervention for communication development [D2]
• It is recommended that development of communication skills be an ongoing process that is incorporated into all activities by professionals and by the family during the course of the intervention and during all daily activities [D2]

• Although it is important to consider the parent's preference in determining the language used in an intervention, it is recommended that any speech language intervention be conducted in the primary language used in the home [D2]

• It is important to consider the need for alternative communication strategies when planning and implementing interventions for the young child with Down syndrome [D2]

• To facilitate development of expressive language it is recommended that a total communication program (sign language, oral communications and visual cues) be used. This is important as most children with Down syndrome exhibit delays in expressive language that is not commensurate with their developmental level. When using a total communication approach it is important that the sign language system be one that can be used simultaneously with spoken English (or other language spoken in the home) and the child receive speech/language therapy to support and enhance speech production and oral communication [C]

• It is important for parents and professionals to recognize that the use of sign language does not interfere with oral language development. When sign language is included as a communication strategy, it is important that the families/caregivers and those working with the child learn the same signs and be encouraged to use them and, that the signs and oral vocabulary being taught have practical/functional and cultural value to the family [C]

• When planning for alternative communication strategies, such as sign language or augmentative communication systems, it is important to consider the cognitive level of the child, the gross and fine motor skills of the child and the preference of the family [D2]

• Amplified sound as provided through a hearing aid or other personal or group listening device may be beneficial for young children with Down syndrome who have hearing loss [D2]

• It is important to consider the use of amplification for children with permanent or persistent hearing loss. Amplification may take the form of hearing aids or an FM system. It is important that the child use amplification as prescribed by an audiologist [D2]

• When the child participates in a group setting, it is important to consider the acoustic environment. The use of an FM system may be recommended for children with Down syndrome who have hearing loss, as well as for some with normal
hearing, because children with hearing loss and/or Down syndrome often need a very favorable and highly redundant auditory signal [D2] (pg 126-127)

There are no recommendations regarding keeping children of a specific chronological age with children younger to attempt to match developmental age.

The remainder of the document contains charts, tables and other resources that families and professionals may find useful. There is no plan included or explanation of either how the document will be distributed and used, or how it potentially can be incorporated in personnel preparation, in-service training, or policy redesign. New York is the only state to have developed extensive guidelines and recommendations for infants with Down syndrome. Several states have developed policy or practice briefs for infants and toddlers with Autism spectrum disorders in the last few years.

Section IV
Assessment and Intervention for all Young Children with Disabilities

Special Education teacher preparation focusing on young children includes course work on assessment and specific intervention practices. Teacher education programs sometimes offer practicum before graduation in which special education pre-service teachers spend time in preschool classroom, if this is their area of concentration. Special education credentials and teacher preparation programs may differ from state to state. Individuals graduating from these programs may be employed by early intervention programs or IDEA 619.

Many states which have chosen a “blended” certification process for individuals who wish to work with the preschool age population also complete course work focusing on identifying, assessing and teaching young children with disabilities, as well as a similar course work for those without disabilities. Individuals with blended certificates are often employed in state funded pre-K programs or private preschool programs. Other personnel employed in early care and education centers such as day care, preschool or Head Start may not have teaching degrees and rely on in-service training opportunities to know how to manage and teach young children with disabilities.

Recommended Practices Division of Early Childhood (DEC)

Perhaps the most ambitious effort to improve practices for working with young children with disabilities has come through the Division of Early Childhood (DEC) branch of the Council for Exceptional Children (CEC). In the early 1990’s the Division published a document of recommended practices in early intervention/early childhood special education. A decade later, the Division decided to revise the practices document. Inspired by the goal of improved outcomes for young children with disabilities and their families, the board designed a new project, building on the earlier work, to improve outcomes. They took a direction for ensuring the practices were shared widely across the field and encouraged administrative support and policy change.
The new project created a team of experts from the field, which included administrators, faculty in higher education institutions, researchers, providers, therapists, parents and administrators. This team reviewed the research literature, integrated the literature with those practices identified as critical by various stakeholders, developed and disseminated user-friendly products and addressed the administrative and systems change foundation necessary for long-term adoption and use of quality practices. Focus groups of key stakeholders, researchers, and administrators then verified the practices that were most important related to better outcomes for young children with disabilities and their families from “evidence-based practices.”

The identified practices are grouped into two broad headings:

- Direct Services consisting of practices for
  1. Child assessment
  2. Child focused interventions
  3. Family-based practices
  4. Interdisciplinary models
  5. Technology application.

- Indirect Support referring to
  1. Policies, procedures and systems change

Several products have been developed and published as a result of this project. The first is a book, “DEC Recommended Practices: A Comprehensive Guide for Practical Application in Early Intervention/Early Childhood Special Education.” This book provides a number of tools to help teachers and parents, therapists, administrators and others working with young children with disabilities. Each practice is illustrated with several examples meant to clarify the practice representing only some of the ways the practice is used. The practices are all followed by an annotated list of resources and additional materials that can be used in implementing the practices. Part III of the book is designed to give the reader information on how to use these principles, both at the individual and program level. The final chapter provides specific tools for administrators and for families.

A second product is a workbook that can be used at the local program level to determine which practices are being implemented and which need to be improved. Third, a collection of articles describing the research basis of the practices was published in several of the early intervention and special education journals. The list of research articles reviewed is published on the DEC website. [http://www.dec-sped.org/](http://www.dec-sped.org/)

**DEC Recommended practices (Sandall, Hemmeter,Smith and McLean 2005)**

**Assessment-(46 recommended practices)**

Professional and families collaborate in planning and implementing assessment.
Examples:

- Professionals provide families with easy access by phone or other means for arranging initial screening and other activities.

- Professionals ensure a single point of contact for families through the assessment process.

- Families receive a written statement of program philosophy regarding family participation in assessment planning and activities.

- Professionals meet and collaborate with families to discuss family preferences and reach consensus about the process, methods, materials and situations of assessment that will meet the child's best needs.

- Professionals solicit information from families regarding the child's interests, abilities and special needs.

- Professionals review, with parental consent, agency information about the child and family.

- Professionals and families identify team members and the team assessment style that best fits the needs and goals of the child and family.

- Families participate actively in assessment procedures.

- Families choose their roles in the assessment of their child.

- With each family's agreement, professionals help families identify their resources, concerns, and priorities related to their child's development.

Assessment is individualized and appropriate for the child and family (8 practices)

Examples:

- Professionals use multiple measures to assess child status, progress and program impact and outcomes (e.g., developmental observations, criterion/curriculum based, interviews, informed clinical opinion, and curriculum-compatible norm-referenced scales).
• Professionals choose materials and procedures that accommodate the child's sensory, physical, response, and temperament differences.

• Professionals rely on materials that capture the child's authentic behavior in routine circumstances.

• Professionals seek information directly from families and other regular care givers using materials and procedures that the family themselves can manage in designing IFSP/IEP goals and activities.

• Professionals assess children in environments that are familiar to the child.

• Professionals assess children after they have become familiar to the child.

• Professionals gather information from multiple sources (e.g., families, professional team members, other agencies, service providers and regular caregivers).

• Professionals assess the child's strengths and needs across all developmental and behavioral dimensions.

Assessment provides useful information for interventions. (9 practices)

Examples:

• Professionals use functional analysis of behavior to assess the form and function of challenging behaviors.

• Professionals appraise the level of support that a child requires in order to perform a task.

• Professionals choose and use scales with sufficient item density to detect even small increments of progress.

• Professionals report assessment results in a manner that is immediately useful for planning program goals and objective.

Additional Headings for assessment practices include:
Professionals share information in useful and respectful ways. (7 practices)

Professionals meet legal and procedural requirements and meet recommended practice guidelines. (10 practices)
Child Focused Interventions

Adults design environments to promote children’s safety, active engagement, learning, participation and membership (11 practices)

Examples:

- Play routines are structured to promote interaction, communication and learning by defining roles for dramatic play, promoting engagement, promoting group friendship activities and using specialized props.

- A variety of appropriate settings and naturally occurring activities are used to facilitate children’s learning and development.

- Interventionists facilitate children’s engagement with their environment to encourage child-initiated learning that is not dependent on the adult’s presence.

Adults individualize and adapt practices for each child based on ongoing data to meet children’s changing needs (5 practices)

Examples:

- Practices are individualized for each child based on
  (a) the child’s current behavior and abilities across relevant domains instead of the child’s diagnostic classification,
  (b) the family’s views of what the child needs to learn,
  (c) Interventionists’ and specialists’ views of what the child needs to learn and,
  (d) the demands, expectations, and requirements of the child’s current environments. The practices are individualized.

- Practices target meaningful outcomes for the child that build upon the child’s current skills and behavior and promote membership with others.

- Practices are used to teach/promote what ever skills are necessary for children to function more completely, competently, adaptively and independently in the child’s natural environment. (home and community)

Adults use systematic procedures within and across environments, activities and routines to promote children’s learning and participation (11 Practices)
Examples:

- Systematic naturalistic teaching procedures such as models, expansions, incidental teaching, and-model procedures and naturalistic time delay, are used to promote acquisition and use of communication and social skills.

- Peer mediated strategies are used to promote social and communicative behaviors.

- Promoting and prompt fading procedures (e.g., modeling, graduated guidance, increasing assistance, time delay) are used to ensure acquisition and use of communicative, self-care, cognitive and social skills.

- Specialized procedures are embedded and distribute within and across activities.

- Recommended instructional strategies are used with sufficient fidelity, consistency, frequency and intensity to ensure high levels of behavior occurring frequently.

Other chapters of the books contained:
Family Based Practices (17 Practices),
Interdisciplinary Models (19 Practices), and
Technology Application (22 Practices)

The DEC Recommended practices do not include any recommendations regarding grouping children by developmental age or holding children back until they reach standard developmental age goals.

The practices do not address specific methods of teaching language or use of specific devices such as hearing aids or amplification devices. However, several practices in the Technology Applications section recommend the use of assistive technology for improving services and list communication and language as an area that AT can be used to improve results for the child. Another practice area addresses collaboration between families and professional in planning and using assistive technology to help the child reach goals and outcomes.

**Definition of some of the instructional models (teaching methods) mentioned in the DEC practice recommendations that are common in programs designed for all young children with disabilities:**
Embedded- Identifying the times and activities when a child’s goals and the instructional procedures for those goals can be inserted into children’s ongoing activities, routine or transitions in a way that relates to the context. It involves distributing opportunities to learn skills and apply those skills across different activities, and transitions of the child’s day.

Expansions- Listening to what the child says (or gestures) and after the child speaks, repeating what the child has said and expanding by adding new words to the child’s statement.

Generalization- Refers to learning to use a skill outside of the context in which it was first learned and then using it again in a meaningful context. This is often thought of as performing a behavior in another setting, with other people and/or materials different from those used in the initial instruction.

Graduated guidance- A response promoting procedure used with a series of behaviors sequenced together to form a more complex skills. It involves promoting the child with the amount and intensity of prompts needed to ensure the behaviors occur, and then immediately removing those prompts (but reapplying them as needed) to ensure the series of behaviors are done correctly. As the child becomes more proficient, the adult “shadows” (follows the child), ready to immediately apply and remove prompts as necessary.

Incidental teaching- The environment is structured to increase the probability that a child will initiate to the adult. (Talk to, gesture to, play with, etc.). When the child initiates, the adult requests more elaborate behavior. If the elaborate behavior is forthcoming from the child, the adult praises the child and responds to the context of the child’s initiation. If more elaborate behavior is not forthcoming, the adult prompts the child, allows the child to respond, and then responds to the context of the child’s initiation.

Mand-model procedure- This procedure involves observing the child’s focus of attention and asking non-yes/no questions of the child about the focus of his or her attention and waiting for an answer from the child. If no answer is forthcoming, then a model of the answer is provided. The procedure is embedded into children’s play or other interactions.

Peer-mediated strategies- A collection of procedures, all of which involve using peers to promote the behavior of a child with disabilities. This may involve having peers model specific behaviors for the child with disabilities to imitate; it may involve teaching the children to initiate social interaction to the child with disabilities; it may involve teaching the children to respond to social initiations by the child with disabilities; it may involve teaching children how to give appropriate help to the child with disabilities.
Another model of working with young children with disabilities call **Responsive Teaching (RT)** was reviewed for this report. RT was first developed and researched with young children with Down syndrome but now has been researched on other young children with a variety of disabilities. Mahoney and MacDonald (2006) describe RT as an early intervention curriculum that is intended to be used by parents and other caregivers who spend significant amounts of time with the child. It helps the adult to maximize the potential of each of their daily interactions with the child so they support and enhance the child’s well-being and learning.

RT is based on research and theory that shows that parents promote their children’s development in thinking, communicating and feelings by engaging in highly responsive interactions. These occur throughout the daily activities that the child and adult engage in, rather than in directing or “teaching” the child a specific task or skill that the child does not know out of context. Parents (or teachers) who are responsive focus primarily on encouraging children to say and do things they already know (and enjoy doing). They support their children by joining in with the child during the activity by doing or saying things that are similar to what the child is engaged in. The strategies are based on “active learning principles.” Mahoney and colleagues have developed a curriculum to be used by parents and caregivers which includes 66 responsive teaching strategies and 16 pivotal behaviors that are targets areas of developmental intervention objectives based on his earlier work with young children with Down syndrome. They have reported successful gains in young children with disabilities whose parents have been taught this model.

**Other National Centers which focus on Intervention Research for Children with Disabilities**

**Frank Porter Graham Child Development Institute**  
[http://www.fpg.unc.edu/](http://www.fpg.unc.edu/)

For the past 40 years, FPG Child Development Institute research and outreach has shaped how the nation cares for and educates young children. FPG has a proud history of serving as an objective, knowledgeable force for social change to enhance the lives of children and families. Researchers focus on parent and family support; early care and education; child health and development; early identification and intervention; equity, access and inclusion; and early childhood policy. Projects at FPG of major relevance to this study include:

**National Center on Early Development and Learning**  
NCEDL focuses on enhancing the cognitive, social and emotional development of children from birth through age eight  
[http://www.fpg.unc.edu/~ncedl/pages/research.cfm](http://www.fpg.unc.edu/~ncedl/pages/research.cfm)
National Professional Development Center on Inclusion
The National Professional Development Center on Inclusion (NPDCI) is working with states to create a system of high quality, cross-agency, accessible professional development for early childhood personnel. While NPDCI will serve as a resource to all states, the Center will select eight states for more intense collaboration.

www.fpg.unc.edu/~npdci

Partnerships for Inclusion
PFI provides training and consultation to support the inclusion of young children with disabilities, age’s birth through five, in all aspects of community life. PFI collaborates with state, regional, and local agencies to develop policy and program initiatives that facilitate full community inclusion of children with disabilities and their families.

http://www.fpg.unc.edu/~pfi/

Puckett Institute: Center for Evidence Based Practices
The Orelena Hawks Puckett Institute is a not-for-profit organization engaging in activities that enhance and promote healthy child, parent and family functioning. Their goal is to foster adoption of evidence-based practices that build on the capacities and strengths of children, parents and families, communities, and public and private organizations

www.puckett.org

Research and Training Center on Early Childhood Development
The major aim of the Research and Training Center (RTC) on Early Childhood Development is to implement a coordinated and advanced program of applied research on knowledge and practice that improves interventions associated with the healthy mental, behavioral, communication, pre-literacy, social-emotional, and interpersonal development of infants, toddlers, and preschoolers with or at risk for developmentally disabilities.

http://www.researchtopractice.info/

National Individualizing Preschool Inclusion Project
The Individualizing Inclusion approach hinges on three critical components: functional intervention planning, integrated therapy, and embedded intervention. Functional intervention planning is carried out principally through a routines-based assessment, featuring an interview of the family and the teaching staff. Integrated therapy consists of specialists using models we have labeled individualized within routines and group activity to provide special education and related services. Embedded intervention involves the use of proven instructional principles, especially incidental teaching, in the context of developmentally appropriate activities.

http://www.vanderbiltchildrens.com/interior.php?mid=1173
REFERENCES


in cooperation with National Association of State Directors of Special Education (NASDSE).


