Caring for Children with Special Needs Training Module

version 4
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NOTE TO TRAINER

This training Module presents information on caring for children with special needs in the child care setting. The Toolkit includes a Trainer’s Guide to leading training sessions, PowerPoint slides, and materials for participant’s packets.

For more information about using the NTI materials, please read “Guidelines for Using the NTI Curriculum Materials,” available in the “Curriculum” section of the NTI Resources Website (accessed by entering your NTI username and password at http://sakai.unc.edu).
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LEARNING OBJECTIVES

After reading this Module, Trainers will be able to

- describe the role of the CCHC in assisting child care staff caring for children with special needs,

- be familiar with the Caring for Our Children standards for caring for children with special needs in child care settings,

- understand the observation process and screening tools for a child who may have special needs,

- refer a child for developmental screening and/or formal assessment,

- define “inclusion,”

- describe federal laws requiring early childhood inclusion,

- identify benefits of and challenges to early childhood inclusion,

- understand the family's perspective on caring for a child with special needs,

- list possible program considerations for children with special needs,

- describe integrated therapy and how best to work with an early intervention specialist, and

- understand how the concept of medical home relates to children with special needs.
INTRODUCTION: THE ROLE OF THE CCHC

Accepting children with special needs (CSN) into a child care facility can be daunting for both parents/guardians and child care staff. Families want to know their child will be appropriately cared for and that staff understand and are prepared to respond to their child’s needs. Child care staff may have concerns about whether they have the appropriate level of training and resources and may have questions about best practices for adapting materials and activities and the coordination of care with other care providers.

The CCHC can provide consultation to a child care facility preparing to serve a child with special needs in a number of ways and at different stages of the enrollment and care for a child with special needs. The CCHC might consult with child care facilities regarding the legal requirements for including CSN. They could help program administrators complete a self-assessment to determine how prepared they are to serve children with special needs. The CCHC could provide information about evidence-based ways to include CSN in programs. A CCHC might work with child care caregivers/teachers to ensure that they are comfortable responding to the child’s health needs. Once a child with a special need is enrolled, the CCHC may also serve as part of the team to ensure ongoing reevaluation of the care plan to meet the changing needs of the child, family, and facility. The CCHC can play a key role in facilitating access to family-centered and appropriate services and in ensuring effective transitions.

For a CCHC to be most effective in assisting child care facilities and families of children with special needs the CCHC must be knowledgeable regarding the service system for children with special needs in the county and state in which the family resides. While federal laws such as the Americans with Disabilities Act (ADA) and Individuals with Disabilities Education Act (IDEA) apply to all states, each state has adopted different eligibility requirements and modifications and has its own unique service system. As the CCHC becomes familiar with and able to navigate the early intervention system in their area, they will be better able to assist programs and families by providing education and making appropriate referrals.

There are many children with special needs in the United States and many of them will spend time in child care settings. Thus, integrating CSN into the child care facility will need to become part of regular child care practice and policy and CCHCs will need to be equipped with practical advice around what full integration in a child care program looks like and the role they play in helping families. This Module does not provide information for what to do for a child with a specific need. Instead, this Module will look to present children with special needs in an overarching manner in order to address special needs broadly and as a means to place the child care facility in a larger context of coordinated care. In addition, this Module will also support the CCHC to meet the demands for the level of care for this population and engage staff in conversations about challenges that arise.
CARING FOR OUR CHILDREN NATIONAL STANDARDS (3rd ed., 2011)

*Caring for Our Children: National Health and Safety Performance Standards: Guidelines for Early Care and Education Programs (CFOC)* is a set of 686 attainable standards that are intended for use by health care professionals, trainers, regulators, caregivers/teachers, academics and researchers, parents/guardians, and others “who work toward the goal of ensuring that all children from day one have the opportunity to grow and develop appropriately, to thrive in healthy and safe environments, and to develop healthy and safe behaviors that will last a lifetime” (*CFOC* 3rd ed., 2011, p. xxii). These standards, supported by the Maternal and Child Health Bureau, were developed by the American Academy of Pediatrics, the American Public Health Association, and the National Resource Center for Health and Safety in Child Care and Early Education.

The CCHC should become well acquainted with Chapter 8 of *CFOC, Children with Special Health Care Needs and Disabilities*. Pages 342-343 of Chapter 8 list additional standards relevant to caring for children with special health care needs that have been integrated into other chapters of the document.

The following is a list of the standards relating to caring for CSN in the child care environment, along with a short description and the page number in *CFOC* on which the standard can be found.

1.4.2.2 -- Orientation for Care for CSHCN, p. 22
Highlights that facilities should ensure that all staff members have been oriented in understanding children’s special health care needs and have the skills to work with these children in a group setting.

1.6.0.1 -- Child Care Health Consultants, p. 33
States that all facilities use a qualified child care health consultant (CCHC), and presents the necessary knowledge and skills of a CCHC.

1.6.0.5 -- Specialized Consultation for Facilities Serving Children with Disabilities, p. 39
Lists a variety of specialized consultants who can be brought on to assist facilities who enroll children with special health care needs and other disabilities.

2.1.1.1 – Written Daily Activity Plan and Statement of Principles, p. 49
Lists six elements that should be contained within a facility’s written statement of principles including health education topics and modeling by child care staff.

2.1.1.4 -- Monitoring Children’s Development/Obtaining Consent for Screening, p. 51-52
Highlights the importance of programs in developing a formalized system of developmental screening and monitoring and the need to obtain parental consent throughout this process.

2.1.2.5 – Toilet Learning/Training, p. 59-60
Details need for facility to develop and implement a plan that teaches each child how and when to use the toilet. Toileting should follow a sequential pattern and be adapted, when necessary, to accommodate a child with special health care needs.
2.3.1.1 – Mutual Responsibility of Parents/Guardians and Staff, p. 77
States that there should be a reciprocal responsibility of the family and caregivers/teachers to observe, participate and be trained in the care that each child requires.

2.3.2.3 – Support Services for Parents/Guardians, p. 80
Highlights the importance for caregivers/teachers to establish parent/guardian groups and parent/guardian support services.

2.4.3.2 -- Parent/Guardian Education Plan, p. 84
Lists over fifteen elements to include in a parent/guardian education plan, which should be individualized to meet the family’s needs.

3.5.0.1 -- Care Plan for Children with Special Health Care Needs, p. 129
Lists over 20 items to include in a care plan for children with special health care needs, when it needs to be updated and who will be involved in its development.

3.5.0.2 – Caring for Children Who Require Medical Procedures, p. 130
Outlines medical procedures which require a care plan from the primary care provider for the facility and the minimum level of content for the plan.

4.2.0.1 – Written Nutrition Plan, p. 152
States facility should provide food for children according to a written plan developed by a qualified nutritionist or registered dietitian. Any dietary modifications to this plan for a child with a medical condition should also be in writing and be accompanied by special instructions from the child’s primary care provider.

5.1.1.4 – Accessibility of Facility, p. 199
States that facility should be accessible for children and adults with disabilities in accordance with the ADA.

5.1.4.2 -- Evacuation of Children with Special Health Care Needs and Children with Disabilities, p. 206
States that facility should have a plan for evacuation of children with special health care needs and should ensure that all ramps and exits are accessible for children with mobility limitations. Children with medical or dietary needs should have equipment brought during evacuation.

5.4.1.7 – Toilet Learning/Training Equipment, p. 246
States that facilities should provide equipment for toilet learning/training. If modified toilet seats cannot be used, non-flushing toilets (potty chairs) meeting several requirements should be used.

5.4.6.2 – Space for Therapy Services, p. 255-256
Highlights that, in addition to accessible classrooms, programs should provide a quiet, private and accessible area within the facility for therapy services.

6.2.1.2 -- Play Equipment and Surfaces Meet ADA Requirements, p. 270
States that play equipment and play surfaces should conform to recommendations of ADA.
8.2.0.1 – Inclusion in All Activities, p. 335
States that facilities should include all children in all activities possible unless a specific medical contraindication exists.

8.2.0.2 – Planning for Inclusion, p. 335
Details that facilities must plan for the needed resources, support, and education necessary to increase the understanding and knowledge of staff, but also of parents/guardians, and children without disabilities within the facility.

8.3.0.1 – Initial Assessment of the Child to Determine His or Her Special Needs, p. 336
Highlights that children with disabilities and children with special health care needs and their families and caregivers/teachers should have access to and be encouraged to receive a multidisciplinary, interdisciplinary, or transdisciplinary assessment by qualified health providers.

8.4.0.1 – Determining the Type and Frequency of Services, p. 337
States that the parents/guardians of a child with a disability or a child with special health care needs, the child’s primary care provider, any authorized service coordinator, any provider of intervention services, and the caregiver/teacher should discuss and determine the type and frequency of the services to be provided within the child care facility.

8.4.0.2 – Formulation of an Action Plan, p. 337
Details the formulation of a plan on how to best meet the child’s needs should be based on the assessment process specified in Standards 8.3.0.1 and 8.4.0.1 and by the child’s medical care plan which is created by the child’s primary care provider in collaboration with the child care health consultant and family. Such a plan should be written, reviewed with the parents/guardians and should be maintained as part of each child’s confidential record.

8.4.0.3 – Determination of Eligibility for Special Services, p. 337
The Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP) and any other plans for special services should be developed for children identified as eligible in collaboration with the family, representatives from disciplines and organizations involved with the child and family, the child’s primary care provider, and the staff of the facility, depending on the family’s wishes, the agency’s resources, and the state laws and regulations.

8.4.0.4 – Designation and Role of Staff Person Responsible for Coordinating Care in the Child Care Facility, p. 338
Specifies that if a child has an Individualized Education Program (IEP) or an Individualized Family Service Plan (IFSP), or any plan for medical services, the child care facility should designate one person in the child care setting to be responsible for coordinating care within the facility and with any caregiver/teacher or coordinator in other service settings, in accordance with the written plan.

8.4.0.5 – Development of Measurable Objectives, p. 338
States that the individualized service or treatment plan for a child with disabilities or a child with special health care needs should include services aimed at enhancing and improving the child’s
health and developmental functioning, based on measurable, functional outcomes agreed to by the parents/guardians.

8.4.0.6 – Contracts and Reimbursement, p. 340
Specifies that if a child with a disability and/or special health care needs has an Individualized Family Service Plan (IFSP), the lead agency may arrange and contract for specialized services to be conducted in the child care facility in addition to the child’s home and other natural environments. If a child with disabilities or special health care needs has an Individualized Education Program (IEP), the local education agency may arrange and contract for specialized services to be conducted in the child care facility.

8.5.0.1 – Coordinating and Documenting Services, p. 340
States services for all children should be coordinated in a systematic manner so the facility can document all of the services the child is receiving inside of the facility and is aware of the services the child is receiving outside of the facility.

8.5.0.2 – Written Reports on IFSPs/IEPs to Caregivers/Teachers, p. 341
Specifies that with the prior written, informed consent of the parents/guardians in the parents/guardian’s native language, child care facilities may obtain written reports on Individualized Family Service Plans (IFSPs) or Individualized Education Programs (IEPs), conferences, and treatments provided.

8.6.0.1 – Reevaluation Process, p. 341
Identifies that the facility care coordinator should ensure that formal reevaluations of the child’s functioning and health care needs in the child care setting and the family’s needs are conducted at least yearly, or as often as is necessary to deal with changes in the child’s or family’s circumstances.

8.6.0.2 – Statement of Program Needs and Plans, p. 341
States that each reevaluation conference should result in a new statement of program needs and plans which parents/guardians have agreed to and support.

8.7.0.1 – Facility Self-Assessment, p. 341
States that facilities that serve children with special health care needs and children with disabilities eligible for services under IDEA should have a written self-assessment developed in consultation with an expert multi-disciplinary team of professionals experienced in the care and education of children with disabilities and children with special health care needs.

8.7.0.2 – Technical Assistance in Developing Plan, p. 342
Stipulates that the caregiver/teacher should seek technical assistance in developing and formulating the plan for future services for children with special health care needs.

8.7.0.3 – Review of Plan for Serving Children with Disabilities or Children with Special Health Care Needs, p. 342
Lists process for facility’s plan for serving children with disabilities or children with special health care needs to be reviewed at least annually to see if it is in compliance with the legal
requirements of the Individuals with Disabilities Education Improvement Act (IDEA) and Americans with Disabilities Act (ADA), as well as Section 504 of the Rehabilitation Act of 1973 (if it receives federal funding and is achieving the overall objectives for the agency or facility).

9.2.2.1 – Planning for Child’s Transition to New Services, p. 351
States that the designated care or service coordinator should support the transition process and review the child’s records, if and when a parent/guardian requests assistance. Any special health care need and successful strategies that have been employed while at child care should be shared with new educational setting.

9.2.3.4 – Written Policy for Obtaining Preventive Health Service Information, p. 355
States that each facility should develop and follow a written policy for obtaining necessary medical information including immunization records. A health assessment should be provided within two weeks of admission.

9.2.3.6 – Identification of Child’s Medical Home and Parental Consent for Information Exchange, p. 356
States that caregiver/teacher should ask the family to identify the child’s primary care provider or medical home, as part of the enrollment process.

9.2.3.7 – Information Sharing on Therapies and Treatments Needed, p. 357
States that written consent of the child’s parents/guardians and, where appropriate, the child’s primary care provider should be obtained before confidential information is sought for the development of an individualized health care plan.

9.4.2.1 – Contents of Child’s Records, p. 386
Lists eight elements which should be included within the child’s confidential records.

9.4.2.5 – Health History, p. 390
Lists fifteen elements that a parent/guardian should include in a child’s health history.

10.3.3.5 – Licensing Agency Role in Communicating the Importance of Compliance with Americans with Disabilities Act (ADA), p. 402
States that licensing agencies should consistently make known the requirements under the Americans with Disabilities Act that child care programs must follow.

Appendix O -- Care Plan for Children with Special Health Needs, p. 451 - 453
WHAT THE CCHC SHOULD KNOW: TERMINIOLOGY AND PREVALENCE OF CHILDREN WITH SPECIAL NEEDS

The Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as:

“Children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions who require health and related services of a type or amount beyond that required by children generally.” (http://mchb.hrsa.gov/cshcn05/)

For many federal and state agencies, the term CSHCN replaces a family of terminologies including handicapped, special, exceptional, disabled, and special needs. CSHCN represents, in part, a public health-driven evolution of the understanding of a chronic impairment affecting one or more aspects of daily living, the unique needs of the families of such children, and their need for and use of health care, educational, and other supportive services (Casamassimo, 2003).

While this broad definition seems to include children with a range of chronic health conditions and disabilities and is used widely, there remains disagreement in the field about whether the term captures children with learning disabilities or other needs less directly related to the child’s health. The term special needs covers a broader spectrum of conditions and diagnoses and, in some states, can also include children who have been deemed “at-risk” due to a variety of factors including the identification of a developmental delay. For the purposes of this Module, NTI will continue to use the term “children with special needs” to refer to a wider range of children and only use “CSHCN” when referring to a child with a chronic illness, developmental disability with health-related aspects or other special conditions, which may require medical treatment within the child care facility. The term children with special health care needs may indeed be used elsewhere in the Module (particularly in the section below) when referencing a federal study or state policy, but, when possible, the Module will attempt to make a clear distinction between the two terms.

Prevalence of CSN

In 2005, a national survey of children with special health care needs was supported by the Maternal and Child Health Bureau of the U.S. Health Resources and Services Administration and carried out by the National Center for Health Statistics of the Centers for Disease Control and Prevention (National Survey of CSHCN, 2005). Data from this survey provides detailed information on the self-reported prevalence of children with special health care needs (CSHCN) in the nation and in each state, the demographic characteristics of these children, the types of health and support services they and their families need, and their access to and satisfaction with the care they receive. The survey found a total of 13.9 percent of children under age 18 in the United States, or about 10.2 million children, are estimated to have special health care needs. At least one child with special health care needs is present in 21.8 percent of U.S. households with children.

The data from the National Survey further included the following findings:
- The children meeting the MCHB definition represent a range of functional abilities, from those who are barely affected by their condition to those who are severely impaired. However, what they all share are the consequences of their conditions, such as reliance on medications or therapies, special educational services, or assistive devices or equipment.

- The prevalence of special health care needs among children increases with age. Among preschool children (ages 0 through 5), just under 8 percent have special health care needs. The rate is 14.6 percent among children ages 6 through 11. Among adolescents (ages 12 through 17), 15.8 percent have special health care needs. The higher prevalence of special health care needs among older children is likely to be attributable to conditions that are not diagnosed or that do not develop until later in childhood.

**Action Items for the CCHC**

The CCHC should

- be familiar with terminology used to describe children with special needs and children with special health care needs, and

- be familiar with the current data and research around the prevalence of CSN.
WHAT THE CCHC SHOULD KNOW: OBSERVATION/SCREENING AND COORDINATION OF SERVICES

Observation and Monitoring Developmental Milestones

Child care settings provide daily indoor and outdoor opportunities for promoting and monitoring children’s development. Depending on the level of involvement between the CCHC and the facility, the consultant may not have any interaction with a child until well after a child enters the facility. Inevitably, much of the responsibility for monitoring a child’s development within the child care setting will fall on his/her regular caregiver/teacher, as the child care facility often represents the first time that many health and developmental issues and other special needs are observed and reported.

In observing children in a child care setting, the CCHC can highlight with child care staff the importance of key developmental milestones and, inversely, crucial warning signs of developmental delay. A child’s development can be observed in how they play, learn, speak, and behave and milestones in each of these behaviors can be observed for most children at different stages of development. Certainly variations exist depending on the child, but any concerns from the parent/guardian or caregiver/teacher when a milestone is not reached should be brought to the primary care provider. The prevalence of CSHCN is well documented and children can also have delays in language, motor control and other areas, yet less than half of children with problems are identified before starting school (Sices, 2007). The most important thing is that any developmental delay is identified as early as possible, so that children can receive the services and support they need.

The Screening Process

Programs should have a formalized system of developmental screening with all children that can be used near the beginning of a child’s placement in the program, at least yearly thereafter, and as developmental concerns become apparent to staff and/or parents/guardians. Assessing a child’s developmental progress is an on-going process that yields information about the child’s interests, preferences, strengths, and needs. This information is used to plan appropriate and meaningful activities to promote each child’s development and learning, regardless of his/her level of need.

Screening the Child’s Development

Developmental screening typically consists of a brief health exam, including hearing and vision evaluations, and the completion of a checklist to determine how the child is developing in other areas: gross motor, fine motor, cognitive, communication, social and emotional, and self-help. Screenings may occur in child care centers, doctors’ offices, health clinics, hospitals, and during local health fairs. Many caregivers/teachers assume children are being screened by their physicians; however, many families have inconsistent access to health care or use health care only when a child is sick. Even when children are screened during well-child visits, it is often not with an objective tool. An Illinois study found that only 39 percent of primary care providers were using a published, standardized screening tool (Allen, 2010).
CCHCs should be familiar with the tools commonly used for developmental screening of children, such as the Ages and Stages Questionnaire [ASQ] or the Parents’ Evaluation of Developmental Status [PEDS], as they may be called upon to teach others about the tools. Other examples of screening instruments for young children include the Denver - II Developmental Screening Test and the Modified Checklist for Autism in Toddlers (M-CHAT).

Newer screening tools take approximately 15 minutes to administer and are inexpensive to purchase. Parent-report tools also allow flexibility and can be completed at the facility or at home to reduce the amount of time needed to conduct a screening. Some tools allow duplication of materials without additional costs. The CCHC should be aware of early warning signs that may indicate a child’s need for screening and share this information regularly with child care staff and primary care providers. Refer to the handout Early Warning Signs in Appendix B.

Additional ways for a CCHC to support screening in a child care program include

- suggesting timing and sequencing of screening including staff administration of screenings during regular activities and natural transitions, such as when a child graduates from one room to another or when a parent/caregiver is present for a conference;
- selecting screening tools that are evidenced-based, reliable and culturally appropriate
- providing staff training on the ASQ, PEDS or other tools, when requested (McCann & Yarborough, 2003); and
- involving specialized consultants in the child’s care, with prior informed, written consent, and as appropriate to each child’s needs. 1.6.0.5

Further information on screening tools and their use is provided by the American Academy of Pediatrics at this website: http://www2.aap.org/sections/dbpeds/screening.asp

In addition to being aware of appropriate screening tools, the CCHC should be knowledgeable of the early intervention system in his/her state and names and telephone numbers for local contacts. As federal legislation requires states to locate and identify children with special needs, procedures for screening and referring a child for special services have been established by the lead agencies in each state. Public Law 99-457 requires public schools to extend special education services to children as young as 3 years old. However, the lead agency for special services for children birth through age 2 is determined by each state. The CCHC must become familiar with the lead agencies serving young children with special needs, options for screening and assessment, the eligibility requirements for children identified as having special needs, and options for service delivery. Refer to handouts Who is Eligible for Special Needs Services and Funding?, Identifying Special Needs, and Referring Children for Special Needs Services in Appendix B. Additional information on identifying the appropriate contacts for these service systems can be found at the National Dissemination Center for Children with Disabilities website at http://nichcy.org/.
Action Items for the CCHC

The CCHC should

- be familiar with typical child development and able to provide training and information on child development to caregivers/teachers as necessary,

- understand the developmental screening process and refer caregivers/teachers and families to appropriate screening sources,

- understand the eligibility requirements of lead state and local agencies providing services to young CSN and their families, and

- be able to refer families to agencies serving CSN.

The CCHC might maintain a directory of names and telephone numbers of local agencies providing services to young children with special needs, share brochures and resources that explain the early intervention system, and recommend local professionals serving children with special needs. Refer to the handout *Key Players on the Special Services Team* in Appendix B.
WHAT THE CCHC SHOULD KNOW: INCLUSIVE CHILD CARE

Definition of Inclusion
Defining inclusion can be a difficult task. In the broadest sense, inclusion embodies the values, policies, and practices that support the right of every infant and young child and his or her family, regardless of ability, to participate in a broad range of activities and contexts as full members of families, communities, and society (DEC/NAEYC, 2009). Other words used to describe inclusion in the past include mainstreaming, reverse mainstreaming, and integrated. In conversations related to early childhood inclusion, child care staff, parents and CCHCs may need to define and clarify terms to ensure effective communication. As the definition above implies, inclusion should touch on all aspects and activities within the child care program from toileting, indoor/outdoor play, meal time and beyond. Part of the conversation a CCHC has with a child care program around inclusion will likely involve assumption management. Child care staff may hold inaccurate beliefs regarding state and federal guidelines around inclusion and accessibility or feel that the effort of inclusion outweighs its benefits. While full integration of the concept of inclusion within a facility can be daunting, and it does have its challenges, there is also a great deal of available research to support this practice and alleviate concern.

Rationale for Inclusion

Social Reasons
Participating in activities with their peers who are typically developing is important for children with special needs as they learn skills that will help them get along in the world. In a review of the research on the outcomes for children with special needs, Odom et al. (2011) found that children in inclusive settings tend to have an advantage in social and behavioral areas over children in segregated settings. Children without disabilities continue to grow and develop in a typical way and can learn much about themselves by being around children who have disabilities. They may have a greater understanding of disabilities and increase their acceptance of others who are different from them (Hollingsworth & Buysse, 2009).

Educational Reasons
Young children with disabilities need the same enriching early experiences as children who are typically developing. When compared to segregated programs or classrooms, inclusive programs offer more opportunities for children to learn naturally through play, use a greater variety of materials in new and different ways, interact with other children, and explore the environment (Allen & Cowdery, 2012). Experience in inclusive settings may help teachers develop more positive attitudes toward inclusion. They may become more aware of the individual needs of all children (Guralnick, 2001). Some teachers may receive additional training for children with special needs that is beneficial to all children such as promoting social interactions (Baker-Ericzen, Muggenborg & Shea, 2008). Collaboration with specialized therapists such as speech-language pathologists, occupational therapists, and physical therapists may provide teachers with opportunities to increase their knowledge about specific developmental areas.
Legal Reasons

Two acts of federal legislation provide support to the inclusion of young children with special needs in community programs such as child care centers.

In 1986 and in subsequent reauthorizations of Public Law 99-457, the Individuals with Disabilities Education Act (IDEA), special education services provided by the public school system were extended to children with special needs ages three to five years. This program is commonly referred to as Part B. States were encouraged to create early intervention services for children birth through age 2 who are identified as having developmental delays or who are at risk for developmental delays. This program is known as Part C. Other major provisions of IDEA require states to find and identify children with special needs, provide a nondiscriminatory, multidisciplinary evaluation performed by qualified professionals, provide related services including transportation and such supportive services as are required to assist a child to benefit from special education, encourage parental involvement and consent in all aspects of the educational process, and inform all participants of their right to confidentiality (Allen & Cowdery, 2012). An Individualized Family Service Plan (IFSP) is developed for every infant and toddler determined eligible for Part C services. Likewise, an Individual Education Program (IEP) is developed for every child who is determined eligible for Part B services. A special services team that includes the child’s family develops these plans. (Refer to the handouts entitled Key Players on the Special Services Team and Developing and Implementing Individualized Education Plans in Appendix D). Services for young children identified as having special needs are to be provided in the most natural environment or least restrictive environment. For many children, this environment is their child care setting.

The Americans with Disabilities Act (ADA), passed in 1991, prohibits the discrimination of persons with disabilities in employment, public services, public accommodations, and transportation. The part of this law that affects child care programs is the section on public accommodations. In addition to hotels, theaters, and restaurants, public accommodations refers to private programs such as family child care homes, child care centers, nursery schools, and preschools. Programs do not have to receive public funding to be considered public accommodations.

Title III of the ADA requires child care programs to make changes in the following areas:

- First, child care programs must eliminate eligibility criteria that screen out or tend to screen out a child with a disability. For example, a child care program may eliminate a provision in the admissions policy which refuses enrollment to children who have not been toilet trained. Such a policy discriminates against children who, because of their disability, have not yet been toilet trained or may never be toilet trained.

- Second, programs must make reasonable modifications in their policies, practices, and procedures to accommodate the child with a disability. For example, a program may make a schedule change for a child who takes medication and needs a morning nap.
- Third, child care programs are required to provide auxiliary aids and services for those children with disabilities affecting hearing, vision, or speech. Auxiliary aids and services refer to services and devices designed to ensure effective communication. Examples include learning some sign language to improve communication with a child who has a hearing impairment, and putting a Braille label on the cubby of a child who has a visual impairment.

- Finally, architectural barriers that prevent access to services must be removed if removal is readily achievable. For example, furniture may need to be rearranged to enable a child in a wheelchair to access all areas of the facility.

CFOC standards 5.1.1.4, 6.1.0.1, 6.2.1.2, 8.2.0.1, 8.7.0.1, are consistent with the requirements of ADA.

Challenges of Inclusion

Values and Beliefs
Pre-existing values and beliefs of individuals can make the acceptance of an inclusive child care setting difficult. For example, a family’s feelings of guilt regarding their child with special needs may lead them to accept any placement at all. Some families may fear that children who are typically developing will mock their child with special needs. Early care and education staff may fear that typically developing children will imitate inappropriate behaviors of children with special needs resulting in behavior problems. Attitudes and beliefs about persons with special needs may be reflected in the words that individuals use to talk about them.

Personnel Preparation
Several issues related to personnel preparation present challenges to effective inclusion. Many caregivers/teachers know little about developmental disabilities. Fear of the unknown often becomes the greatest obstacle to including a child with special needs. Until recently, special educators and specialized therapists received no training in providing services in the natural setting of the child care center or in consulting with child care staff about the child’s goals. Successful inclusion requires a team approach, and frequently involves many people from various agencies in addition to the family. Few early childhood professionals have received adequate training on building successful teams and partnerships with families.

Policies
Policies at the state, local, and program level may present challenges to inclusion. For example, public school systems struggle with blending funds to create classes for preschool children with and without disabilities (Title I blended with Exceptional Children funds). A child care center may not have a diapering area in the 4-year-old classroom, resulting in a 4-year-old child with spina bifida who may never be able to control urination and bowel movements being refused enrollment.
Resources

Finally, a lack of resources may present challenges to inclusion. Unfortunately, there is a lack of quality placements for children with special needs. Parents frequently have few options and funding constraints may prevent special services from being provided in the child care setting. Early childhood special educators, early interventionists, and specialized therapists frequently have large caseloads that prevent them from providing the amount of support needed to ensure the successful inclusion of some children. Finally, a lack of transportation to an inclusive program may impact a parent’s selection of care for their child.

See Appendix D in this Module for additional materials about inclusion.

Program Considerations for Care of Children with Special Needs

As the above section indicates, inclusion and participation of children with special health care needs requires proactive planning. When a child care facility enrolls a child with special health care needs, the facility should ensure that all staff members have been oriented in understanding that child’s special health care needs and have the skills to work with that child in a group setting. Developing a care plan for a child with special needs at the time of enrollment is an ideal place to begin the planning process in order to identify the extent of the child’s needs and how those needs may relate to accessibility, medical requirements or other issues. In addition to the regular health report or health history taken at enrollment, the care plan should include the following information:

- a list of the child’s diagnosis/diagnoses,
- contact information for the primary care provider and any relevant sub-specialists,
- medications to be administered on a scheduled basis,
- medications to be administered on an emergency basis with clearly stated parameters, signs, and symptoms that warrant giving the medication written in lay language,
- procedures to be performed,
- allergies,
- dietary modifications required for the health of the child,
- activity modifications
- environmental modifications,
- stimulus that initiates or precipitates a reaction or series of reactions (triggers) to avoid,
- behavioral modifications,
- suggested special skills training and education for staff, and
- emergency response plans- both if the child has a medical emergency and special factors to consider in programmatic emergency, like a fire.

This last point is important to highlight as CFOC, the ADA and many local building inspectors have specific standards and guidelines for the emergency evacuation of children with special needs, particularly those children with mobility issues. Children who have special medical or dietary should have their medical equipment brought along during an evacuation. All care plans, whether basic or more specialized, should be completed by the parents/guardians, primary care provider and any additional qualified health professionals. CFOC states (p. 130) that “the child care health consultant may help in creating the care plan, through developing a draft and/or
facilitate the primary care provider to provide specific directives to follow within the child care environment. The child care health consultant should write out directives into a “user friendly” language document for caregivers/teachers and/or staff to implement with ease.” Appendix O in CFOC provides a sample care plan for CCHCs and child care staff to use when beginning this process.

**Action Items for the CCHC**

The CCHC should

- assist child care facilities in defining inclusion as it applies to their program,

- share benefits of inclusion with child care programs that may be interested in enrolling children with special needs, and

- use his/her knowledge of the challenges of inclusion to assist programs in addressing these issues if they arise.
WHAT THE CCHC SHOULD KNOW: MEDICAL HOME AND INTEGRATED INTERVENTION

The Medical Home Model
The child care health consultant is an important link in a complex array of supportive relationships; one who has the opportunity to make connections and referrals among those who care for children with special needs, yet may not necessarily provide direct services or treatment to an individual child. The National Survey on CSHCN documented the breadth and extent of the medical and support service needs of this population, including prescription medications (needed by 86 percent of CSHCN), specialty medical care (52 percent), vision care (33 percent), mental health care (25 percent), specialized therapies (23 percent), and medical equipment (11 percent). Most CSHCN receive the services they need. However, 16 percent report at least one unmet need for services; the most commonly mentioned is preventive dental care. Often times, based on several factors including the unique needs of the CSN, availability of local/state resources and access to regular health insurance, a child with special needs may be under the care of one or more health or specialized support providers and may require a level of care which spans multiple settings, including the child care environment.

By providing only routine preventive and acute care services, the current primary pediatric care system does not meet the needs of children with special health care needs. Rather it is best designed for children who need a single health care service, in other words, for those children who do not have special needs (AAP, The National Center for Medical Home Initiatives for Children with Special Needs, Shriners Hospitals for Children, 2003). The medical home concept is designed to address and ensure the provision of a variety of coordinated services to meet the needs of children with special needs and their families.

Defining “Medical Home”
A medical home is not a building, house, or hospital, but rather a partnership approach to providing quality and cost-effective health care services for children (AAP, 2002). The following seven components define what a medical home should be:

- **Accessible**: Health care should be provided in the child’s community, and at a facility that accepts all types of insurance, including Medicaid. Also, a well-trained primary pediatric health care provider (hereafter referred to as the medical home provider) should be available to speak directly with the parents/guardians when requested.

- **Family-Centered**: The health care facility should recognize that the parents/guardians are the experts about their child and his/her health care needs.

- **Continuous**: The child’s medical home provider delivers health care throughout childhood. Should a transition be necessary, the medical home provider, the parents/guardians, and the child should all be included in the process.

- **Comprehensive**: Health care is available at all times, 24 hours a day, 7 days a week, 52 weeks a year. All types of health and dental health care services, including preventive, primary, and tertiary needs, are provided. Also, parents/guardians are given information
about community resources that provide services that the medical home provider is unable to offer.

- **Coordinated**: The child’s health care plan is developed by the medical home provider, the parents/guardians, and other agencies or services the child or family currently receive (i.e., child care center).

- **Compassionate**: The child’s and family’s well-being and the perspective of the child and family are always of concern when providing health care services.

- **Culturally Effective**: Information about the family’s cultural background, including beliefs, rituals, and customs, is incorporated into the child’s health care plan. Efforts are made by the medical home staff and other health care providers to ensure the child and parents/guardians understand the health care plan and any other medical encounters. This includes the provision of language translators and interpreters. (AAP, 2002).

In summary, the primary source of a child’s health care comes from a well-trained medical home provider in partnership with the parents/guardians (AAP, 2002). This person is involved in providing both the primary care, and the facilitation and management of all aspects of the child’s care. This person also provides these services throughout childhood, and is someone whom the child and parents/guardians grow to know and trust. Health care within the medical home concept can be provided in a variety of locations (i.e. physician’s offices, community health centers, hospital out-patient clinics, etc.). This, along with the components discussed above can “help the children and their families achieve their maximum potential” (AAP, 2002, p. 1).

As part of the enrollment of a child, the caregiver/teacher should ask the family to identify the child’s primary care provider, his or her medical home, and other specialty health care professionals. "Knowing who is treating the child and coordinating services with these courses of service is vital to the ability of the caregivers/teachers to offer appropriate care to the child." 9.2.3.6

**Integrated Intervention**

Many times the full inclusion of a child with special needs will involve one or more specialized therapists in addition to services provided by an early interventionist or preschool special education teacher. Traditionally, this therapy has been provided to each child individually in a therapy room or some space outside of the regular classroom. A recent approach to providing therapy advocates for providing the therapy within the daily routines and activities of the child. This approach is called integrated intervention.

Integrated intervention is a parallel concept to medical home in that it seeks to bring services and coordinated care to a child and family’s primary environments. Integrated intervention works best when the family, child care caregiver/teacher and therapists collaborate to embed the child’s therapy goals in naturally occurring activities or interactions. Therapists work with the child in the classroom during the daily routines and activities. This approach enables the child care staff to observe strategies and adaptations used by the therapists to elicit and practice targeted skills. In addition, consultation provided by the therapists to the child care staff ensures that
opportunities for the child to use and practice new skills occur daily, not just on days when the therapist is present. Integrated intervention increases the opportunities for communication among the child care staff and therapists regarding the child’s goals and progress. Refer to *Integrating Intervention into the Classroom* in Appendix D for more information.

**Action Items for the CCHC**

The CCHC should

- consult with child care facilities to ensure each child has a medical home and caregivers/teachers are active participants in the medical home,
- assess and/or develop policies that help ensure every child has access to a medical home; for example, these policies may reflect how the facility should ensure that each child has a medical home or how child care staff interact with medical home providers;
- advocate within the community for greater access to a medical home for every child,
- educate child care teachers/caregivers and parents/guardians about the medical home model,
- assist child care teachers/caregivers in maintaining a current local/state list of medical home providers and related resources,
- serve as a liaison between medical home providers and child care staff to develop child care policies related to medical home, coordinate advocacy efforts, and connect health services to children and families.
WHAT THE CCHC SHOULD KNOW: WORKING WITH PARENTS/CAREGIVERS AND SUPPORTING TRANSITIONS

Ultimately, the family is responsible for the health, developmental, social, and emotional needs of their child. Under the best circumstances, parenting can be challenging. For the family of a child with special needs, additional challenges may be present. Families of a child with special needs may need to spend a greater than average amount of time coordinating or providing care, change their employment status, and deal with increased stress.

Having a child with special needs can directly influence a family’s day-to-day routine. Family members may need to stay home to provide direct care, such as administering medication or therapies and providing transportation to appointments, or may have to spend time coordinating the care that their child receives by ensuring that appointments are made, medication supplies and equipment are maintained, and that information is shared between providers. The amount of time allocated to these types of activities will vary according to the needs of the child. More than 47 percent of families with children with special health care needs report spending an hour or less per week on these types of activities, but 34 percent of families need 2 to 5 hours a week to do these tasks and 10 percent of families spend 11 hours a week or more on these activities (The National Survey of CSHCN, 2005).

The complexity of a child’s special needs and the parents’ need to devote time to the child’s care sometimes requires parents cut back on the number of hours they work or stop working completely to care for their child. Overall, the parents of nearly 24 percent of CSHCN report having to stop work, cut back on their hours at work, or both, because of their children’s needs.

Of course, giving up a job is likely to reduce a family’s income. Therefore, it is not surprising that children in lower-income families are more likely to have parents who have sacrificed work hours: one-third of CSHCN in poverty and 29 percent of those with family incomes between 100 and 199 percent of poverty have parents who reported they cut back on work or stopped working to care for their children, compared to 17 percent of children with family incomes of 400 percent of poverty or more.

A change in employment status is also more apt to occur in families who have a child who is more severely affected by his or her condition. The parents of 47 percent of children whose activities are affected usually, always, or a great deal by their conditions report cutting back on work or stopping work completely to care for their children, compared to 9.1 percent of children whose daily activities are never affected by their conditions (The National Survey of CSHCN, 2005).

Having a child with special needs can also influence a family’s mental health, as parents learn to navigate often confusing service and payment systems. Parents may spend a great deal of their free time figuring out how to access the system, determining if their child is eligible for services, and making sure their child is getting the services that they need. Parents must learn to advocate for their child and work to ensure those in contact with their child—including physicians, therapists, child care providers, and others—understand their child’s unique needs, share the information they have, and are working toward the same agreed-upon goals. Families might also feel isolated from their extended family and from friends with typically developing children.
When a child care facility is preparing to serve a child with special needs, it is important the family and child care staff communicate so that both sides know about the needs of the child and are clear about the expectations for care. The CCHC might facilitate this process by acting as a resource for information about possible adaptations or accommodations and consulting on the development of a comprehensive care plan for the child. The CCHC could also assist the child care teachers/caregivers as they work to ensure their services are family-centered.

Family-centered services

- recognize that family is constant in a person's life, while service systems fluctuate;
- facilitate family/professional collaboration at all levels of services;
- honor racial, ethnic, cultural and socioeconomic diversity of families;
- recognize individual family strengths and respect different methods of coping;
- share complete and unbiased information with families on a continuing basis and in a supportive manner;
- encourage family-to-family support and networking;
- recognize and meet developmental needs of infants, children, and their families;
- create policies and programs that offer families emotional and financial support; and
- offer accessible, flexible, culturally competent and responsive services.

Adapted from: Handbook of School-Family Partnerships 2010.

Read the handouts entitled The Benefits of Working with Families, Strategies for Building Partnerships, Children with Special Needs: The Family’s Perspective, and Family Stressors When a Child Has Special Needs in Appendix E to gain a better understanding of the benefits of building strong partnerships with families, and how caring for a child with special needs may affect the family.

Supporting Transitions

Arguably, one of the most stressful times for a child with special needs in an early care and education setting is the transition out of early intervention services (Part C) and into preschool special education services (Part B). This difficulty is built into the systems themselves as both have different eligibility requirements and are managed by separate state and federal entities. In Part C, family involvement is mandatory and parents/caregivers are expected to be the decision makers for their child's services. Throughout the infant/toddler years, families are taught and encouraged to provide and advocate for their children's needs. Then when they enter Part B programs at age 3, the school assumes the primary educational responsibility.

The IDEA requires a minimum 6 month transition period from early intervention to preschool and from preschool to public school. During this time, the family and child care staff will participate in a number of evaluations and meetings required by the law. A multi-disciplinary team of qualified professionals will complete an evaluation that must include comprehensive, formal and informal information from multiple sources in the following domains: cognitive, physical, communication, and social/emotional. There will also be a voluntary, family-directed assessment of resources, priorities and concerns. During this time, parents/caregivers will need information about their child's potential services and about the transition process. A child care
health consultant may be well-positioned to provide information and assist in this process. They might help by reviewing the child’s records to identify needs, learning style preferences, necessary supports, and future goals. With proper consent from the parent/guardian, the CCHC might share this information and any additional recommendations at a transition meeting with staff from the preschool or public school system. The CCHC might also ensure that any special health care need of the child and successful strategies that have been employed while at child care are shared.

The CCHC can play a key role in the transition process either by meeting individually with families to answer questions or by helping child care facilities in developing policies and procedures around transitions that can be modified to fit the needs of a variety of families in this situation.

Important points for a CCHC to consider in preparing for transitions include the following:

- maintain consistent and effective communication with all parties involved,
- establish roles and expectations together, and
- ensure flexible programs and schedules (Johnson, 2001).

**Action Items for the CCHC**

The CCHC should

- help child care staff understand the perspective of families of children with special needs. The CCHC should consult with child care teachers/caregivers in supporting families to function as primary decision makers, caregivers, teachers and advocates for their child;

- be aware of family support agencies in their area and be able to refer families to these services as appropriate,

- be familiar with the principles of family-centered care and be able to provide training and consultation to child care teachers/caregivers as appropriate, and

- support transition planning between child care and preschool programs (or preschool to kindergarten) and make connections to outside resources when necessary.
WHERE TO FIND MORE INFORMATION

General

Able Play
http://www.ableplay.org

Georgetown University
MCH Library
http://mchlibrary.info/KnowledgePaths/kp_CSHCN.html

One of the Family (DVD)

Topics in Early Childhood Special Education
IDEA – Powerful Vision and Pesky Details
http://tec.sagepub.com.libproxy.lib.unc.edu/content/early/2011/11/22/0271121411429077.abstract

Observation/Assessment in Child Care

Assessing Child Development Through Play

Brazelton Touchpoints
Model of Development

Centers for Disease Control and Prevention
Developmental Screening
http://www.cdc.gov/NCBDDD/child/devtool.htm

Centers for Disease Control and Prevention
Learn the Signs, Act Early
http://www.cdc.gov/ncbddd/actearly/index.html

Early Head Start
Developmental Screening and Individualized Curricula
http://www.ehsnrc.org/PDFfiles/T4A.pdf

First Signs
http://www.firstsigns.org/

Frank Porter Graham- North Carolina Technical Assistance Preschool Project
http://www.fpg.unc.edu/~pfi/
IDEA Infant and Toddler Coordinators Association
About Early Intervention
http://www.ideainfanttoddler.org/about_early_intervention.htm

National Association for Child Development
http://www.nacd.org/

National Association for State Health Policy
http://www.nashp.org/node/111

Inclusion


Child Care Law Center
http://www.childcarelaw.org

Council for Exceptional Children
IDEA Policy Resources

Disability Rights Wisconsin
A Thinking Guide to Inclusive Childcare

Kids Included Together
http://www.kitonline.org/index.html

Special Quest Birth to Five
http://www.specialquest.org/
To view materials, click on “Library” tab at top of page

US Department of Education
IDEA 2004 Resources
http://idea.ed.gov

U.S. Department of Justice, Civil Rights Division, Disability Rights Section
Child Care Centers and the Americans with Disabilities Act
http://www.usdoj.gov/crt/ada/chcaflyr.htm

U.S. Department of Justice, Civil Rights Division, Disability Rights Section
http://www.usdoj.gov/crt/ada/childq%26a.htm
Medical Home

American Academy of Pediatrics
Early Identification in the Medical Home
http://aappolicy.aappublications.org/cgi/content/full/pediatrics;118/1/405

Healthy Child Care America (HCCA)
Child care and role of medical home
www.healthychildcare.org/PPT/PP-MedicalHome.ppt

National Association of Pediatric Nurse Practitioners (NAPNAP)
History of Medical Home Concept
http://www.napnap.org/Files/HistoryoftheMedicalHomeConcept.pdf

National Center for Medical Home Implementation
http://www.medicalhomeinfo.org/about/medical_home/

Understanding the Family’s Perspective and Working Together

Centers for Disease Control
Tips for Talking With Parents

Federation for Children with Special Needs
http://fcsn.org/index.php

National Network for Child Care
http://www.ces.ncsu.edu/depts/fcs/pdfs/nc07.pdf

South Carolina Department of Disabilities and Special Needs
Working with Families with Special Needs

Wisconsin Child Care Information Center
Together Children Grow
http://www.dpi.state.wi.us/ccic/pdf/together_ch_g.pdf
REFERENCES


Wesley PW, Dennis BC, Tyndall ST. (2007). QuickNotes: Inclusion resources for early childhood professionals (2nd ed). Chapel Hill: UNC, FPG, PFI.
APPENDIXES

Please note: Appendix A is included here. Appendices B-E have been reproduced with permission and are available electronically on the NTI Training website.

Appendix A: Defining Children with Special Needs
Definition of Children with Special Health Care Needs – Maternal and Child Health Bureau
Definition of Children with Special Needs – IDEA

Appendix B: Assessing a Child’s Need for Special Services
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Early Warning Signs
Who Is Eligible for Special Needs Services & Funding?
Identifying Special Needs
Sample Observation Chart
Referring Children for Special Needs Services
Key Players on the Special Services Team
Developing & Implementing Individualized Education Plans

Appendix C: Materials for Developmentally Appropriate Practices
Using the Environment to Promote Positive Self-Concept
Using the Environment to Promote Independence
Using the Environment to Promote Social Interaction among Children
Using the Environment to Promote the Child’s Appropriate Behavior
Using the Environment to Promote Adult/Child Interaction and Supervision

Appendix D: Inclusion
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Adapting the Environment for Children with Disabilities
Including Children with Autism
Including Children with Challenging Behaviors
Including Children with Hearing Loss
Including Children with Visual Impairment
Including Children with Physical Disabilities
Including Children with Severe Disabilities
Assistive Technology
Integrating Intervention into the Classroom

Appendix E: Materials for Understanding the Family’s Perspective and Working Together
The Benefits of Working with Families
Strategies for Building Partnerships
Children with Special Needs: The Family’s Perspective
Family Stressors when a Child Has Special Needs

Appendix F: Additional Resources
Choosing Words the “People First” Way
Available from: http://www.nc-ddc.org

Individuals with Disabilities Education Act Fact Sheet
Available from: http://www.nectac.org/idea/idea.asp

Commonly Asked Questions about Child Care Centers and the Americans with Disabilities Act
Available from: http://www.ada.gov/childq%26a.htm
Appendix A

Defining Children with Special Needs

- Definition of Children with Special Needs -- Maternal and Child Health Bureau
- Definition of Children with Special Needs -- Caring for Our Children
- Definition of Children with Special Needs -- Individuals with Disabilities Education Act
Defining “Children with Special Needs”

The Maternal and Child Health Bureau defines Children with Special Health Care Needs (CSHCN) as:

“They who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” (M McPherson, P Arango and H Fox et al., A new definition of children with special health care needs, *Pediatrics* 102 (1998), pp. 137–140.)

The Individuals with Disabilities Education Act makes eligible for special services:

“Children with mental, physical, or emotional disabilities, who, because of their disability or chronic illness, require special instruction in order to learn.” (The Individuals with Disabilities Education Act Amendments of 1997, 20 USC § 1400 (1997).)
Appendix B

Assessing a Child’s Need for Special Services

- Assessing Child Development
- Early Warning Signs
- Who Is Eligible for Special Needs Services & Funding?
- Identifying Special Needs
- Sample Observation Chart
- Referring Children for Special Needs Services
- Key Players on the Special Services Team
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Developmentally Appropriate Practices

- Using the Environment to Promote Positive Self-Concept
- Using the Environment to Promote Independence
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- Using the Environment to Promote Adult/Child Interaction and Supervision
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Inclusion

- What is Early Childhood Inclusion?
- Adapting the Environment for Children with Disabilities
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- Including Children with Challenging Behaviors
- Including Children with Hearing Loss
- Including Children with Visual Impairment
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- Including Children with Severe Disabilities
- Assistive Technology
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Understanding the Family’s Perspective and Working Together

- The Benefits of Working with Families
- Strategies for Building Partnerships
- Children with Special Needs: The Family’s Perspective
- Family Stressors when a Child Has Special Needs
Appendix F

Additional Resources

- Choosing Words the “People First” Way
- Individuals with Disabilities Education Act Fact Sheet
- Commonly Asked Questions about Child Care Centers and the Americans with Disabilities Act