# Children with Disabilities and Other Special Needs



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California Childcare Health Program

Administered by the University of California, San Francisco School of Nursing,
Department of Family Health Care Nursing
(510) 839-1195 • (800) 333-3212 Healthline
www.ucsfchildcarehealth.org



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The names are listed in alphabetical order:

#### **Main Contributors**

Abbey Alkon, RN, PhD Jane Bernzweig, PhD Lynda Boyer-Chu, RN, MPH Judy Calder, RN, MS Lyn Dailey, RN, PHN Joanna Farrer, BA, MPP Robert Frank, MS Lauren Heim Goldstein, PhD Gail D. Gonzalez, RN Jan Gross, BSN, RN Susan Jensen, RN, MSN, PNP Judith Kunitz, MA Mardi Lucich, MA Cheryl Oku, BA Tina Paul, MPH, CHES Pamm Shaw, MS, EdD Marsha Sherman, MA, MFCC Kim To, MHS Eileen Walsh, RN, MPH Sharon Douglass Ware, RN, EdD Mimi Wolff, MSW Rahman Zamani, MD, MPH

#### **Editor**

Catherine Cao, MFA

#### **CCHP Staff**

Ellen Bepp, Robin Calo, Sara Evinger, Krishna Gopalan, Maleya Joseph, Cathy Miller, Dara Nelson, Bobbie Rose, Griselda Thomas

#### **Graphic Designers**

Edi Berton (2006) Eva Guralnick (2001-2005)

#### California Childcare Health Program

The mission of the California Childcare Health Program is to improve the quality of child care by initiating and strengthening linkages between the health, safety and child care communities and the families they serve.

Portions of this curriculum were adapted from the training modules of the National Training Institute for Child Care Health Consultants, North Carolina Department of Maternal and Child Health, The University of North Carolina at Chapel Hill; 2004-2005.

### **LEARNING OBJECTIVES**

To describe the needs of children with disabilities and other special needs.

To identify how to provide high-quality, individualized care for children with disabilities and other special needs in the early care and education (ECE) setting.

To describe three ways a Child Care Health Advocate (CCHA) can assist ECE programs in meeting the needs of young children with disabilities and other special needs.

To identify special needs resources available to assist and support ECE providers and families.

### **RATIONALE**

Because of advances in medical science and technology, more and more infants and young children with disabilities and other special needs are surviving and are no longer confined to the home or hospital. Increasing numbers of young children with disabilities and other special needs are enrolling in ECE programs. Including these children in ECE programs shows our commitment to giving all children typical childhood experiences. Their inclusion in ECE programs can be challenging for ECE providers and families. ECE providers need to learn about the unique needs of young children with disabilities and their families, and need to know how to find specific services in the community to help these families. Children with disabilities and other special needs may need special accommodations (changes to the environment) in order to participate fully in ECE programs. Another important role ECE providers play is identifying children with special needs. Since ECE providers see young children daily, they may be the first to notice when a child is not developing on a normal path similar to their peers. ECE providers can encourage a family to get help. It is important for ECE providers to recognize early warning signs that the child has developmental delays or disabilities.

# WHAT A CCHA NEEDS TO KNOW

# What Is Typical Development?

To be able to identify children with disabilities and special needs, it is important to have a general understanding of normal or typical development in early childhood. See Table 1 for a list of typical signs of development from birth to 5 years. Each child develops at a different pace, so it is hard to tell exactly when a child will learn a given skill. Children vary a lot as they grow and develop. Although developmental milestones will give ECE providers, CCHAs and parents a general idea of the changes to expect as children develop, some children develop on a slightly different path (Shelov & Hannemann, 1999). Often, it is when children do not develop a certain skill (such as talking or walking) that it becomes clear there is a developmental delay or disability (see Handout: Early Warning Signs). For example, if a child shows any of the following signs of possible developmental delay in the 8- to 12-month age range, ECE providers should encourage parents to seek help from a health care professional:

- Does not crawl.
- Drags one side of body while crawling (for over 1 month).
- Cannot stand when supported.
- Does not search for objects that are being hidden while he or she watches.
- Says no single words (such as *mama* or *dada*).
- Does not learn to use gestures, such as waving or shaking head.
- Does not point to objects or pictures.

If a child who is 18 months old cannot walk well on his or her own, does not seem curious and interested in the environment, or does not use one word at a time, ECE providers should encourage parents to seek help from a health care professional.

# Who Are Children with Disabilities and Other Special Needs?

About 18% of children have some type of cognitive, physical, speech or emotional special need. A recent national survey estimates that over 9 million (12.8%) children in the United States presently have a special health care need. One in five households includes children with disabilities and other special needs. When talking about children with disabilities and other special needs, a range of terms is used. The most common terms include disabilities, special needs and children with disabilities and other special needs. Disability is the term used by the Americans with Disabilities Act (ADA). The ADA helps prevent discrimination based on a person's differing abilities. In ADA language, disability means a "physical or mental problem" that limits one or more of the major life activities of an individual. Major life activities mean behaviors such as breathing, hearing, seeing, speaking, walking, using arms and hands, learning and working. For more information, see the Handout: Glossary of Terms Related to Children with Disabilities and Other Special Needs. In this module, we use the terms disability, children with disabilities and other special needs and children with special needs to mean the same thing, as that is how they are often used in the community. Children with disabilities and other special needs are those who have (or are at an increased risk for) a long-term physical, developmental, behavioral or emotional condition and who also require health and related services beyond those typically required by children. In fact, many children have more than one special need. This definition helps to identify children based on the severity of their special need and of their need for health and related services, rather than focusing only on their diagnosis (Maternal and Child Health Bureau, 2002).

Caring for Our Children: National Health and Safety Performance Standards: Guidelines for Out-of-Home Child Care Programs, Second Edition (CFOC) (American Academy of Pediatrics [AAP], American Public Health Association & National Resource Center for Health and Safety in Child Care, 2002) defines children with special needs as "those children with developmental disabilities, mental retardation, emotional disturbance, sensory or motor difficulty, or significant chronic illness who require special health surveillance or specialized programs, interventions, technologies,

TABLE 1: AGES AND STAGES: SIGNS OF DEVELOPMENT OVER TIME

	By 4- Months	By 8-Months	By 12- Months	By 18- Months	By 24-Months
Physical Development	<ul> <li>Holds head up when held upright</li> <li>Rolls from side to back</li> <li>Sits when supported</li> <li>Reaches for and grasps objects</li> </ul>	Rolls over, sits up, may begin to crawl     Transfers object from one hand to the other     Uses finger and thumb to pick up objects	Stands alone     Climbs     Can remove lids from containers     May prefer one hand over the other	Walks without help     Waves bye-bye and claps hands     Carries small objects while walking	<ul> <li>Walks well</li> <li>Eats with spoon</li> <li>Rolls a large ball</li> <li>Picks up toys without falling over</li> </ul>
Cognitive Development	<ul> <li>Explores objects with mouth</li> <li>Distinguishes familiar faces</li> <li>Fascinated by moving objects</li> </ul>	Experiments with simple physical relationships, like gravity and one object hitting another     Can match a happy sounding voice to a picture of a smiling face     Can imitate actions	<ul> <li>Can group objects that are alike</li> <li>Curious about small openings, objects that turn</li> <li>Can solve problems through trial and error</li> </ul>	<ul> <li>Takes things apart</li> <li>Enjoys playing peek- a-boo</li> <li>Identifies objects in a book</li> </ul>	<ul> <li>Shows preference between toys</li> <li>Points to eyes, ears, nose when asked</li> <li>Is able to listen to short stories</li> </ul>
Communication/ Language Development	<ul> <li>Responds to familiar voice</li> <li>Follows face with eyes</li> <li>Communicates needs primarily through crying</li> </ul>	<ul> <li>Follows your face with her gaze</li> <li>Laughs in response to playful interaction</li> <li>Uses gestures, eye contact, and verbal sounds to communicate</li> </ul>	Can follow your line of vision and looks at what you are looking at May begin saying first words, experimenting with word sounds  Follows conversational turn-taking when interacting with others	<ul> <li>Points or uses single words</li> <li>Looks at person talking to him</li> <li>Says hi or bye if encouraged</li> </ul>	<ul> <li>Uses 2-3 word sentences</li> <li>Tries to sing</li> <li>Says please and thank you when prompted</li> </ul>
(Adapted from B	(Adapted from Barber, Reschke, & Longo, 2002)	02)			

TABLE 1: AGES AND STAGES: SIGNS OF DEVELOPMENT OVER TIME, continued

	By 36-Months	By end of 3rd year	By end of 4th year	By end of 5th year
Physical Development	<ul> <li>Has almost a full set of teeth</li> <li>Walks backwards</li> <li>Likes to push, pull, fill, and dump</li> </ul>	<ul> <li>Develops a taller, thinner, adult-like appearance</li> <li>Sleeps through most nights without wetting the bed</li> <li>Uses the toilet with some help</li> </ul>	<ul> <li>Uses spoon, fork, and dinner knife skillfully</li> <li>Dresses self without much help</li> <li>Hops on one foot</li> </ul>	<ul> <li>Learns to skip</li> <li>May begin to lose baby teeth</li> <li>Throws ball overhead</li> <li>Catches bounced balls</li> <li>Hand dominance is established</li> </ul>
Cognitive Development	Enjoys stories, songs, and rhymes     Wants to learn how to use things     Likes to look at books	<ul> <li>Understands "now," "soon," and "later"</li> <li>Draws a circle and a square</li> <li>Matches object and picture</li> </ul>	<ul> <li>Places object in a line from largest to smallest</li> <li>Can recognize some letters if taught</li> <li>Counts 1-7 objects out loud</li> </ul>	Knows basic colors like red, yellow, blue, green     Understands that stories have a beginning, middle, and end     Understands that books are read from left to right, top to bottom
Communication/ Language Development	<ul> <li>Uses 2-3 word sentences</li> <li>Repeats words others say</li> <li>Says names of items when asked</li> </ul>	<ul> <li>75-80 percent of speech is understandable</li> <li>Talks in complete sentences of 3-5 words</li> <li>Stumbles over words sometimes</li> </ul>	Speaks fairly complex sentences     Enjoys singing simple songs, rhymes, and nonsense words     Follows two unrelated directions: "Put the milk on the table and get your coat on."	<ul> <li>Enjoys telling his or her own stories</li> <li>Enjoys riddles and jokes</li> <li>Identifies some letters of the alphabet and some numbers</li> </ul>
(Adapted from Barber,	(Adapted from Barber, Reschke, & Longo, 2002)			

or facilities" (p. 481). CCHAs should become well acquainted with *Children with Special Needs: Applicable Standards from CFOC*, as well as *Chapter 7: Children Who Are Eligible for Services under IDEA*, and pages 326 to 327, which list additional standards relevant to children with special needs that have been included in other chapters of the document.

There are many different health conditions that may define a child with disabilities and other special needs. Some of these conditions are easy to observe, such as confinement to a wheelchair or blindness, while others, such as asthma or allergies, may not be so obvious. Each child's response to his or her special need will be different so it is not helpful to generalize the symptoms, reactions, treatment or response of children and families to the specific special need. In general, a physical problem means conditions such as blindness, deafness, seizures, heart disease, cerebral palsy, asthma and diabetes (see Handout: Health and Safety Notes: Asthma in Child Care Settings, Handout: Health and Safety Notes: Diabetes in the Child Care Setting and Handout: Health and Safety Notes: Gastric Tubes in the Child Care Setting). A mental problem is defined as a condition such as behavior disorders, emotional or mental illness, learning disabilities and mental retardation. These are just some samples of different disabilities that children may have, but there are many more. If your ECE program enrolls a child with a disability or other special need, you will have to learn about all of the aspects of this child and his or her needs, as related to the health or developmental condition.

Often, children with disabilities and other special needs have a limited ability to function because of a long-term or inherited illness, a major trauma, a developmental disability, or exposure to a serious or life-threatening condition. Conditions and symptoms range from mild to severe and may be long- or short-term. Some children with disabilities and other special needs require only an accurate diagnosis and routine treatment and monitoring. Other children will need life-sustaining technology, treatment and medicines throughout their lives. It is always important to consider the unique needs of each child.

Other terms often used by programs and agencies to describe children who have been identified as having a disability or other special needs include the following (Dennis & Laveck, 2004):

- children who are developmentally disabled, developmentally delayed or at risk for developmental delays
- children with cognitive delays or disabilities
- children who are behaviorally and/or emotionally challenged
- children with hearing loss or who are hearing impaired
- children with visual impairment or who are visually impaired
- *children who are deafblind* (both deaf and blind)
- children with speech-language delays or disorders
- children who are speech-language impaired
- children with traumatic brain injury
- children with special health care needs
- children with autism and pervasive developmental disorder (PDD)
- children with physical disabilities
- children who are orthopedically impaired

# Legal Rights of Children with Disabilities and Other Special Needs

There are two federal laws that require community programs and services, such as ECE programs, to include young children with disabilities and other special needs.

# Individuals with Disabilities Education Act (IDEA)

The purpose of this law is to provide "free appropriate public education," regardless of disability or chronic illness, to all "eligible" children from birth through 21 years in a natural and/or least restrictive environment (LRE) (AAP et al., 2002). An LRE means a setting where children who are typically developing may be found, such as ECE programs, public schools, museums, shops and parks. In 1986, and in subsequent updates of Public Law 99-457, special education services provided by the public school system were expanded to include 3- to 5-year-old children with special needs. This program is commonly referred to as Part B. States were encouraged to create early intervention services for children birth through 36 months who are identified as having developmental delays or being at risk for developmental delays. This

program is known as *Part C*. Other major requirements of IDEA include the following:

- an important change in terminology from *handi*capped child to a child with a disability
- reaching out to the community and helping to identify children with special needs (i.e., *Child Find* or *Search and Serve*)
- testing by qualified professionals
- parental involvement in all aspects of testing, planning and intervention
- development of an Individualized Family Service Plan (IFSP) (early intervention services for children birth to 36 months) or an Individualized Education Program (IEP) (intervention services for children 3 to 21 years old)

CFOC standards 7.003-7.011, 2.002, 2.044, 2.051, 2.053, 2.057, 2.058, 8.013, 8.016, 8.046 and 8.053 are consistent with the requirements of IDEA (AAP et al., 2002).

#### Americans with Disabilities Act (ADA)

ADA is a law that was passed in 1991. ADA makes it illegal to discriminate against persons with disabilities in employment, public services, public accommodations and transportation. The part of this law that affects ECE programs is the section on public accommodations. In addition to hotels, theaters and restaurants, public accommodations refers to private programs that are open to the public, such as family child care homes, child care centers, after-school programs and recreational programs. Programs do not have to receive public funding to be considered public accommodations, as defined by the ADA (see Handout: Questions and Answers about the Americans with Disabilities Act: A Quick Reference). ADA requires ECE programs to consider making changes in the following areas:

- Programs must get rid of rules or policies that screen out or tend to screen out a child with a disability. For example, an ECE program should get rid of an 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.
- Programs must make reasonable changes in their policies, practices and procedures in order to in-

- clude 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.
- Programs are required to provide extra aids and services for those children with disabilities that affect hearing, vision or speech. Extra services may refer to services and devices designed to make sure children can communicate clearly. Examples include learning some sign language to improve communication with a child who is deaf or hard of hearing, and putting a Braille label on the cubby of a child who is blind.
- If there are any physical barriers in the program that prevent children with disabilities from getting to different play or eating areas, the ECE program must remove the barriers. For example, furniture may need to be rearranged to allow a child in a wheelchair to get to all areas of the program.

# Including Children with Disabilities and Other Special Needs: Inclusion

Inclusion is when children with special needs are given an equal chance to participate in the same types of programs and activities as children without disabilities or special needs (Dennis & Laveck, 2004). Inclusion means serving children with disabilities together with other children who are developing in a typical way (see Handout: Quality Inclusive Child Care Checklist). Previous words used to describe these situations have included mainstreaming, reverse mainstreaming, integration and integrated programs. All of these could be described as inclusive. When inclusion takes place, children learn and grow together, regardless of their abilities. See Handout: Health and Safety Notes: Including Children with Special Needs: Tips for Child Care Providers. Inclusion means that ECE providers have created a program where children's unique needs are met through developmentally appropriate practices and high-quality care and education. Developing a partnership with the child's family is the first step to providing child care to any child, including those with disabilities and other special needs. Families with children with disabilities or special needs want to be treated like all other families—with respect, dignity, understanding and honesty.

# Confidentiality

Protecting the privacy of children and families served in the ECE program is an important part of familycentered care and is a legal requirement (see Handout: Health and Safety Notes: Maintaining Confidentiality in Child Care Settings). A written note signed by parents or guardians is required to release or obtain information (see Handout: Consent for Release of Information Form). The release is usually effective for a limited amount of time, specifies what information can be shared or requested, and states to whom the information may be released. ECE providers should never share or discuss personal information about children or their families with any unauthorized staff. Only authorized staff (those with whom parents have agreed to share information because they "need to know" in order to provide care) should have access to specific information about a child's health and developmental needs. ECE providers should always discuss with the family the specific preferences of the family in regards to what and how information is to be shared about their child's special needs with other children and families. ECE providers should ask the family what information they do or do not wish to be shared about their child with other families, staff, volunteers or outside agency staff who may come into contact with their child.

# Individualized Family Service Plans (IFSPs) and Individualized Education Programs (IEPs)

Every infant or toddler with a disability is required by the IDEA to have an IFSP, which describes early intervention services for an infant or toddler and the child's family, including family support and the child's educational, therapeutic and health needs (AAP et al., 2002). This is a plan that outlines the child's needs and what services are suggested. IFSPs are a good way to record what is recommended for the child and then to check on how much progress is being made by looking back at the IFSP every few months.

Three- and 4-year-olds who are eligible for services under Part B of the IDEA need a written IEP. This document is developed by a team that works with the local education agency that carries out the IEP in the public or private preschool program. Even though

federal funds do not support services provided by agencies outside the public school system, local education agencies may still work with private providers. This is possible because local education agencies can contract with private providers for preschool services and can cover other educational services identified in the IEP, such as speech and language therapy, in the preschool setting. ECE providers should become as familiar with the services for a child's special needs, as identified in the IEP, as they are with the services for an infant or toddler in an IFSP. The ECE provider may wish to go to the child's IEP review meetings to share valuable insights and information about the child's special needs in the ECE program. The ECE provider may attend these meetings as long as the parents give their consent in writing ahead of time (AAP et al., 2002).

# Identifying Children with Undefined Special Needs

Many children enter ECE programs with special needs that have not yet been defined. An ECE provider may be the first person to become concerned about the child's behavior, development or health (Sokal-Guiterrez, 2001). Some developmental delays and disabilities only become clear as children develop, and some are hard to identify (see Handout: Health and Safety Notes: How to Get a Child Tested: Guidelines for Special Education Assessment). ECE providers who think a child in their care may have an undefined special need are encouraged to do the following: observe the child closely over time, write down any concerns about the child's development, talk with a mentor or supervisor to receive feedback about the concern, carefully address the issue with the parents and refer the child for testing. ECE providers who have worked in the field for many years have seen a large number of children and have become familiar with normal trends in development. Since they have this experience, they are often able to tell if a child does not seem to be developing similarly to other children of the same age. Parents often do not see the wide range of children ECE providers see. Sometimes, parents do not know what to compare their own child's development to and do not know if their child is developing the skills and abilities that are developmentally expected.

Communicating concerns about a child to the parents

is often a hard step. Sokal-Guiterrez (2001) suggests the following tips for ECE providers when talking with parents about concerns:

- Set up a meeting at a convenient time and a comfortable, private place.
- If there are any cultural or language differences, get help or get a translator to make sure communication is clear.
- Emphasize your commitment to working with the family as a team to meet their child's needs.
- Explain your concerns briefly and calmly, giving specific observations you have made.
- Allow the parents to respond to your concerns and ask questions.
- Ask the parents to consider talking with the child's health care provider.

# WHAT A CCHA NEEDS TO DO

### **Promote Family-Centered Care**

Children with disabilities and other special needs and their families do well when the care they receive is family-centered (National Center for Family-Centered Care, 1989). The Division of Services for Children with Special Health Needs of the Maternal and Child Health Bureau (2005) defines family-centered care as follows: "Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services."

CCHAs can help the ECE program focus on the following key points that support family-centered care and that make sure children have their needs met:

- Recognize that the family is the expert on their child's needs and care. They should be valued as a resource and source of information. Discuss with the family any specific needs the child may have.
- Recognize the "whole child" in the context of his or her family, culture, language, strengths and weaknesses.

- Listen to the family's vision of what they are looking for in an ECE program and what they believe are the child's needs.
- Discuss honestly and realistically the strengths and limitations of the ECE program in relation to what the family is looking for and the unique needs of the child.
- Work with parents to find solutions to challenges and barriers that get in the way of appropriately meeting the child's unique caregiving needs. Work together to make any changes in the ECE program that may be needed to include the child in the ECE program successfully.
- Work together with family, other community resources and other staff members to coordinate any necessary changes in the ECE program. The child's care requires bringing together regular and special health care systems, schools, the ECE program, early intervention programs and community services.

# Facilitate Caregiving Team Approach

The quality of life for children with disabilities and other special needs is best if they have access to broad, family-centered, culturally sensitive, coordinated and fully inclusive services at the community level (Sokal-Guitierrez, 2001). This also must include ECE programs as well as other support services.

Including a child with special needs in an ECE program makes the necessity for teamwork even greater. Using a team to coordinate the support for a child with special needs is important for the child's success. This team should be multidisciplinary, or made up of people who have different roles in the child's life, including those who work in different fields. Team members should include parents, health care professionals, community consultants or specialists, and ECE program staff working with the child. The people who make up the team will vary, depending upon the child's condition, local resources and delivery systems. However, to make sure that the information shared about the child is complete and accurate, it is important that the team be multidisciplinary. To make sure that the special needs of a child and family are met, the team members must communicate closely and regularly. The team usually chooses one agency to be in charge

of coordinating services for the family. This choice often depends on the specific needs of the child.

As a CCHA, you are an important part of this team. The CCHA will know about the child's daily activities as the child adjusts to the ECE program. It benefits CCHAs to learn as much as possible about a child who has a disability or other special need who is to be included into their program, and how to best support and meet the child's needs in the group care setting. By being an active member of the team, CCHAs can help parents feel comfortable leaving their child in the program's care, knowing that the child's needs will be met properly. Working with those involved with the child's progress will be informative and educational. CCHAs will learn new skills that can be generalized and used with all children and their families in the program.

# Help Parents and ECE Providers Develop Special Health Care Plans

The inclusion of children with special needs in the ECE program may lead to a poor experience for all involved if those caring for the child do not have enough preparation, understanding, training, resources and development of skills. Once the child has been accepted in the ECE program, a plan should be developed to prepare for the child's first day. It is important to gather as much information as possible so the ECE program can plan for a safe and healthy environment for the child. It is important to develop a "plan of care" document together with the other key individuals in the child's life. This special care plan is a written document for the care of a child with special needs (see Handout: Special Health Care Plan). It can be used for the process of ongoing communication and problem-solving, continued coordination of services with outside agency staff and the evaluation of how well the changes made in the ECE program for the child are meeting the child's and family's needs. The careful development of such a plan allows parents and the ECE providers to make sure that the child will be safe and well cared for in the ECE program.

The special care plan is written together by the entire team and must include input from the child's doctor. The special care plan should include the following parts:

- The child's health or developmental information and needs, such as medical diagnosis and the need for equipment such as hearing aids. (Information may be gathered using the *Handout: Information Exchange on Children with Health Concerns Form.*)
- Specific information about the child's health history and current health status.
- The parent's main concern while his or her child is in the ECE program.
- Any special heath care needs while the child is at the ECE program, including specific tasks or health-related procedures required of caregiving team members.
- A list of who is in charge of carrying out healthrelated procedures (such as giving insulin shots or other medication).
- Training to provide necessary health-related procedures, and the plan for monitoring these procedures by a health care professional. (Note: If a health-related procedure is necessary in the ECE program, make sure that parents have given their written permission for the procedure.)
- The "how to" of care procedures—the warning signs and symptoms of an emergency and emergency procedures, including the immediate management and treatment of potential emergencies related to the child's health condition, as well as when, how and where to transport the child to a hospital.
- Description of program planning that considers any changes needed in the ECE program which may be necessary to best meet the needs of the child and other children attending the ECE program.
- Additional things needed to make the physical environment safer.
- The need of staff to receive education and training in order to meet the child's needs. This includes getting any needed health consultation from the child's doctor, Child Care Health Consultant (CCHC) or other health care professionals.
- A list of other professionals and interested people involved in the child's care, including the services and resources being used by the child and family (how, when and where they are provided).
- Additional outside services and resources that may be needed to support the child's inclusion in the ECE program.

All staff providing care for the child should be familiar with the special care plan. The plan should be periodically reviewed to make sure that it is appropriately updated in response to changes in health and development. Staff caring for the child should initial on the form that they have read and understand the special care plan. Copies of the plan should be placed in several locations throughout the program to make sure that the information is quickly and easily accessible (see *Handout: Special Health Care Plan*).

There is a wide range of health-related conditions in young children that may affect their needs in an ECE program. Even children with the same condition may need different modifications. These changes in the environment may range from simple to complex. Decisions about care must be considered and made on a child-by-child basis and program-by-program basis. The decisions must include input from the parents or guardians, as well as the professional recommendations for each individual child.

# Training of ECE Staff to Plan for Inclusion

When an ECE program enrolls a child with special needs, the program should make sure that all staff members have been told about the child's special needs. They also need to feel competent in working with the child in the program. The education and training of ECE staff in regards to including children with disabilities and other special needs should be provided by a qualified health care professional with significant input or support from the child's parents. The staff training should address the following:

- background information about the child's needs
- condition-specific information (i.e., most children with this disability have these characteristics and needs)
- child-specific information (i.e., this child has these specific needs, strengths and weaknesses)
- the health-related procedures the child needs and the skills required to perform them (i.e., does the child need specific medication at a certain time)
- questions about what knowledge and skills will be taught, who will provide the training and who will participate in training are answered with the

- safety of the child, as well as the safety and protection of the ECE provider in mind
- arrangements confirmed for ongoing monitoring of the skills of the staff and retraining as necessary

One of the most important responsibilities for the CCHA is to make sure that enough resources are available to serve the child and the family. The CCHA has links to the community and may be the representative of the ECE program who links to the professional team of doctors and therapists serving the child and family. As the CCHA, your job is to organize ECE staff training by bringing in the appropriate professional(s) to train and assist the ECE staff and parents.

Child Care plus+ (2000), a program of the Rural Institute on Disabilities at the University of Montana in Missoula, suggests the following effective practices and policies for compliance with ADA and caring for children with disabilities and other special needs:

- Continue use of developmentally appropriate practices, which emphasize individual growth patterns, strengths, interests and experiences of children to design appropriate learning environments.
- Adopt an attitude of "how can I meet this child's needs" and adapt creatively.
- Make simple changes in the typical activities or routines in your program to meet the child's needs (use tactile play materials for a child with vision impairment, for instance).
- Include a question in your enrollment procedure that asks parents if there is anything you (or your staff) need to know that would help you care for their child (i.e., she goes to sleep with a pacifier or he wears hearing aids).
- Work closely with parents and professionals to join together the child's developmental and therapy goals into your daily routines and activities (use sign language to expand your communication with other children at snack or circle time).
- Identify and remove barriers to the child's participation (widen pathways between activity areas for walkers and wheelchairs or reposition materials at the child's level for visual or motor activities). Costly changes to the building are not required if affordable alternatives are available (provide pitchers and cups rather than lowering or raising a water fountain).

- Use community resources to make changes to your program or provide needed services or equipment. (Materials may be donated or built; recruiting volunteers may improve child-adult ratios).
- Spread added costs (e.g., insurance), if any, among all of the families, just as you do other expenses. (Under certain circumstances, a federal tax credit or deduction is available for expenses associated with accommodating special needs.)

#### **Provide Resources**

The CCHA should develop a directory of local agencies providing services to young children with disabilities and other special needs and refer ECE providers to these agencies as needed. See Handout: Resources for Including Children with Special Needs. The CCHA can also put together a list of books about children with disabilities and other special needs for ECE staff, parents and children. The National Dissemination Center for Children with Disabilities (NICHCY) has a resource list of children's literature about disability which can be downloaded from: http://www.nichcy.org/pubs/bibliog/bib5.pdf.

# Link ECE Programs with **Community Services and Resources**

Children with special needs and their families may often require more services and resources than the ECE program can provide. It is considered part of best practices for ECE programs to be aware of community services and local resources available to families with children with disabilities or special needs. CCHAs can help families to connect with local services and agencies. CCHAs should work together with community agencies and providers involved in providing services to children with disabilities and other special needs (see Handout: The Map to Services for Children with Special Needs and Their Families). CCHAs should become familiar with the services and resources available to families through the IDEA, the federal special education law that requires services to be provided to children with disabilities and their families from birth to 22 years of age. CCHAs can display brochures and have available information about these resources and services, which can be helpful for all families in the community. CCHAs can participate actively in community efforts designed to coordinate and link children's services with resources and providers, such as the state interagency council and local child care planning councils.

# Help to Develop an IFSP or IEP

The CCHA can help ECE providers in the process of developing an IFSP or IEP. ECE staff must be involved in an IEP for preschoolers and an IFSP for infant/toddler teams when the special needs child is enrolled in an ECE program. The ECE provider will usually be on the planning team to make sure that the plan is consistent and carried out in the ECE setting as well as other environments.

# **Cultural Implications**

When caring for children with disabilities and other special needs, CCHAs and ECE providers need to be sensitive to the ethnic and cultural backgrounds of children and families. Also, there is a unique culture related to each child with disabilities or other special needs. It is important to understand each family's approach and outlook about their child and the care they hope the child will receive. These may reflect their ethnic culture and the culture around a child with special needs. The ways in which disability is understood and talked about differ by culture (Stone, 2004). It is important to ask parents from other cultures how their culture understands disability in children.

# Implications for Children and **Families**

Typical family activities and routines, such as getting a child to the ECE program on time, may be more complicated and in turn more stressful because of the child's unique needs. For example, it may take more time to get dressed in the morning or to have therapy treatments in the morning, making daily life activities more complicated. Furthermore, going out in public and putting the child in care with other children and adults may cause concern for families because their child may look or behave differently than the "average" child, only adding to the family's anxiety. Some families may have more expenses related to the needs of their child and this may result in some money problems. Getting the special care and support services needed for their child may be hard and very emotional for the family. Having the support and understanding of a CCHA in the ECE program will help children and families.

# Implications for ECE Providers

A child with disabilities and other special needs provides an added challenge for the ECE provider. It is very important for the ECE provider to take the time to get to know the family and their child. The ECE provider may want to find unique and creative ways to communicate with the family. It is equally important to understand how the family works with their child as they try to maintain a consistent, supportive and loving environment for their child. Showing sensitivity toward the emotional needs of the family, including their need for privacy about their child, is essential. Respecting the diversity of families is also needed to develop a relationship that supports the child.

#### **ACTIVITY 1: BENEFITS OF INCLUSION**

(Dennis & Laveck, 2004)

The trainer will hang two signs. One that reads **YES** and one that reads **NO** in different areas in the training room.

The trainer will read a statement. If you believe that the statement is a benefit of inclusion, go stand near the YES sign. If you believe that the statement is not a benefit of inclusion, go stand near the NO sign.

#### **Statements**

- Children with special needs in inclusive settings show an increase in their rate of learning in all parts of development.
- The stimulation of an inclusive environment may increase play between children with special needs and 2. their peers.
- When compared to children in segregated settings, children with special needs in inclusive settings show an increase in their social skills.
- 4. Children without special needs in inclusive settings show an increase in their social skills.
- Positive experiences in inclusive settings may lead children without special needs to become more accept-5. ing of people who are different from them.
- For families of children with special needs, opportunities to participate in activities with families of children without special needs remove all feelings that their family is different.
- Families of children with special needs in inclusive settings may develop more positive attitudes about their child.
- For families of children without special needs, positive experiences with children with special needs may increase their knowledge and understanding of people with disabilities.
- 9. Teachers who work in inclusive settings become strong advocates for inclusion.
- 10. Experiences in inclusive settings will make sure that people with disabilities become contributing members of society.

### **ACTIVITY 2: HELEN KELLER**

(Dennis & Laveck, 2004)

The goal for this activity is for participants to do the following:

- Examine their own feelings and beliefs about people with disabilities.
- Understand the significance of "person first" language.
- Demonstrate the use of "person first" language.

Participants will be divided into two groups and asked to describe the phrase given to the group. Both groups will share their descriptions and discuss how we think about developmental disabilities.

#### **ACTIVITY 3: CASE STUDIES**

### Case 1: Managing Severe Allergies in ECE Programs

Cesar, a 4-year-old boy, will be enrolled in your program, starting 1 week from today. He will be in child care everyday from noon to 5:00 p.m. Cesar is severely allergic to peanuts.

A few months ago, he was exposed to peanuts when eating a cookie. Cesar ate the cookie because he was "sharing his snack" with another child at a playground, and the child shared her cookie with him. He had a severe allergic reaction within 5 minutes of eating the cookie, and his mother had to take him to the Emergency Room because he had difficulty breathing. By the time Cesar's mother got him to the Emergency Room, his airway was blocked; he needed rescue medications and respiratory support; and he needed to stay overnight in the hospital.

A pediatric allergist has prescribed an EpiPen® for Cesar's use in case he is exposed to peanuts or has signs of a severe allergic reaction. His mother has given the ECE program an extra EpiPen® to be kept at the program.

#### Discuss and answer the following questions about caring for Cesar:

- Who should be there when you develop the care plan (who is on Cesar's Care Team)?
- What specific questions do you have for Cesar's parents about his allergy?
- How can you be sure Cesar is not exposed to peanuts while in your care?
- Will Cesar's allergy have an effect on the other children and their families who also attend your program?
- Where will you keep the EpiPen®?
- Which staff will be trained to use the EpiPen®? Who will conduct the training(s)?
- What forms should be kept in Cesar's personal file?
- What would you do if you discovered that Cesar had just eaten a food containing peanuts a few moments ago?

### Case 2: Managing Asthma in ECE Programs

Two-year-old Sabrina has been enrolled full-time in your ECE program for the past 6 months. She comes to child care everyday. Like many toddlers, she often has a mild cold, with a runny nose and light cough.

Recently, her coughing became more serious. When she coughed, you noticed a wheezing sound, and sometimes she seemed to be struggling to catch her breath. Her parents also noticed this, and about 3 weeks ago they took her to see her doctor. The doctor said Sabrina has asthma.

Since then, Sabrina's parents are giving her a steroid medication (budesonide) through an inhaler every night at bedtime. In addition, they use a nebulizer to deliver rescue medications (albuterol) when Sabrina has trouble breathing. The mother brings the nebulizer with Sabrina to the ECE program everyday, in case she has a problem during the day. The mother has shown you how to fit the mask on Sabrina and how to give her a treatment.

#### Discuss and answer the following questions about caring for Sabrina:

- What specific questions do you have for Sabrina's parents about her asthma?
- Will Sabrina's asthma have an effect on the other children and their families who also attend your program?
- Which staff should be trained in the use of the nebulizer? Who will conduct the training(s)?
- Where will you keep the nebulizer?
- What forms should be kept in Sabrina's personal file?
- What should you do if the family forgets to bring the nebulizer?
- Can Sabrina participate in play with other children in the program?
- How can you improve the ECE program to decrease Sabrina's risk of a problem?

### Case 3: Managing Diabetes in ECE Programs

Tyler, a 5-year-old child with diabetes, will be enrolled in your program starting in 2 weeks. He will be participating 3 days per week: Monday, Wednesday and Friday from 9:30 a.m. to 4:00 p.m. Tyler's father gives him insulin every morning at breakfast time before arriving at the ECE program. He does not normally need insulin injections during child care hours. In case Tyler ever needs insulin unexpectedly during care hours, his father, mother and a neighbor are on the call list, and they all have been trained in giving the injections.

It is important that Tyler eat regular, balanced meals and snacks. His parents send a packed lunch, and your program provides snacks for Tyler at the regular children's snack times, 10:00 a.m. and 2:30 p.m. Tyler's father has shared with you a list of acceptable foods that Tyler can have for snack. These include the following:

- four whole-grain crackers
- one piece of fresh fruit
- 1/2 cup of flavored, lowfat yogurt
- one slice of whole-grain bread, toast or bagel
- 1/2 cup of sliced or mini carrots
- one stalk of celery with peanut butter or cream cheese
- one piece of string cheese
- one cup of lowfat milk or unsweetened soy milk
- one mini pizza (4-inch diameter)
- 1/2 cup of pretzels

You are allowed to use your good judgment to give other low-sugar, minimally-processed foods to Tyler for snack. He cannot have ice cream, soda, cupcakes, candy or cookies.

Tyler's doctor has instructed that his blood sugar should be checked daily at 11:45 a.m., just before lunch. His father has shown you how to do the blood sugar check, and has given you a meter and a supply of the strips and other equipment you will need. The doctor has given these directions to follow any time you check Tyler's blood sugar:

Tyler's Blood Sugar Action Plan			
Blood Sugar Reading	Action		
Normal (70-140)	Follow routine schedule for snacks and meals. No further testing necessary during day unless he has symptoms of low blood sugar or high blood sugar.		
Low (less than 70)	Give 8 ounces of orange juice and lunch. Check blood sugar again 30 minutes after lunch.		
Slightly high (140-180)	Give Tyler his regular lunch. Recheck blood sugar in 1 hour.		
High (over 180)	Call parent—Tyler needs more insulin as soon as possible.		

#### Discuss and answer the following questions about caring for Tyler:

- Who do you call if Tyler needs insulin? What are some ways you can make sure that there is always a designated person available?
- To check Tyler's blood sugar, you must use a sterile, sharp object called a lancet to prick his finger and draw a drop of blood. What universal precautions should be observed?
- What do you do with the lancet after it has been used?
- One day around 3:00 p.m., during outside playtime, Tyler comes over and tells you he feels dizzy. He is pale and sweaty. What do you do?
- Tyler's 11:45 a.m. blood sugar reading (just before lunch time) is 225. What do you do?
- A girl in your program is turning 5 years old at the end of the month. Her mother tells you she wants to bring chocolate cupcakes with chocolate icing for the children to celebrate her daughter's birthday. What do you do?
- A boy in your program is turning 4 years old today. Without warning you ahead of time, his father has brought in an ice cream cake for the children to share at afternoon snack time. What do you do?
- What forms should you keep in Tyler's personal file?

### **NATIONAL STANDARDS**

From Caring for Our Children: National Health and Safety Performance Standards: Guidelines for Out-of-Home Child Care Programs, Second Edition

2.002, 2.044, 2.051, 2.053, 2.057-2.058, 5.097-5.099, 7.003-7.011, 7.016, 8.013, 8.016, 8.046, 8.053, Appendix T and Appendix X.

#### **CALIFORNIA REGULATIONS**

From Manual of Policies and Procedures for Community Care Licensing Division

Title 22, Division 12, Chapter 1, Article 6, Section 101226, 101223.1, 101226.

# **RESOURCES**

# Organizations and Resources

Organization and Contact Information	Description of Resources
American Academy of Pediatrics 141 Northwest Point Blvd. Box 927 Elk Grove, IL 60009 (800) 433-9016 www.aap.org	The mission of the AAP Division of Children with Special Needs is to improve the system of care for Children with Special Health Care Needs (CSHCN) by connecting them to a medical home. A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined as primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. www.aap.org/healthtopics/specialneeds. cfm.
The Arc of the United States 1010 Wayne Avenue, Suite 650 Silver Spring, MD 20910 (301) 565-3842	The Arc of the United States works to include all children and adults with cognitive, intellectual, and developmental disabilities in every community
(301) 565-3843 fax www.thearc.org	The individuals with disabilities act (IDEA): Eligibility, IEPs and placement www.thearc.org/faqs/qa-idea.html
	All Kids Count: Child Care and the Americans with Disabilities Act (ADA), by The Arc. A resource manual to help child care center operators comply with Title III (public accommodations) of the ADA. 89 pgs. 1996. Can be downloaded from http://209.183.228.233/index.asp
Asthma and Allergy Foundation of America 1233 20th Street, NW, Suite 402 Washington, DC 20036 (800) 7.ASTHMA (800-727-8462) www.aafa.org	AAFA provides a national toll free information line to help consumers and patients learn more about asthma and allergies. This line is staffed Monday thru Friday from 10 a.m. to 3 p.m. EST.
California Map to Inclusive Child Care Project 751 Rancheros Dr., Suite 2 San Marcos, CA 92069 (760) 682-0271 phone (760) 471-3862 fax map@cihs-south.org www.sonoma.edu/cihs/camap/index.html	The Map Project works under the umbrella of the California Institute on Human Services (CIHS) at Sonoma State University and is funded by the California Department of Education's Child Development Division.  The California Map to Inclusive Child Care Project seeks to expand opportunities for children with disabilities and other special needs in child care and development programs.
Child Care Law Center 221 Pine St., 3rd Floor San Francisco, California 94104 (415) 394.7144 phone (415) 394.7140 fax info@childcarelaw.org www.childcarelaw.org	The Child Care Law Center (CCLC) is a national nonprofit legal services organization that uses legal tools to make high quality, affordable child care available to every child, every family, and every community. Publications about child care and disabilities can be downloaded from www.childcarelaw.org/publications. cfm#disabilities
Circle of Inclusion Project University of Kansas http://circleofinclusion.org	Circle of inclusion Web site offers demonstrations of and information about the effective practices of inclusive educational programs for children from birth through age eight.

Organization and Contact Information	Description of Resources
Desired Results: Access for Children with Disabilites (DR Access) 311 Professional Center Drive Rohnert Park, CA 94928 (707) 285-2591 phone (707) 285-2590 fax www.sonoma.edu/cihs/ desiredresults/access/about.html	DR Access is funded by the Special Education Division (SED) of the California Department of Education (CDE) to develop a system of child outcomes and assessment methodoligies that can be used to assess the progress of children with disabilities from birth to five years of age.
Frank Porter Graham (FPG) Child Development Institute University of North Carolina at Chapel Hill CB#8180 Chapel Hill, NC 27599-8180 (919) 966.2622 www.fpg.unc.edu	FPG is one of the nation's oldest multidisciplinary institutes for the study of young children and their families.  Inclusion for young children with disabilities www.fpg.unc.edu/~ecrii/index.html The Early Childhood Research Institute on Inclusion (ECRII) was a five year national research project to study the inclusion of preschool children with disabilities in typical preschool, day care and community settings.  Individualizing Inclusion in Child Care retrieved March 23, 2005, from www.fpg.unc.edu/~inclusion/index.htm
National Early Childhood Technical Assistance Center Campus Box 8040, UNC-CH Chapel Hill, NC 27599-8040 (919) 962-2001 phone (919) 843-3269 TDD (919) 966-7463 fax www.nectac.org	A national technical assistance effort that supports programs for young children with disabilities and their families under the Individuals with Disabilities Education Act (IDEA).
National Dissemination Center for Children with Disabilities (NICHCY) P. O. Box 1492, Washington, D.C. 20013 (800) 695-0285 (voice/TTY) www.nichcy.org	List of children's literature relevant to disability www.nichcy.org/pubs/bibliog/bib5.pdf
Paraquad, Inc. 311 North Lindbergh St. Louis, MO 63111 (314) 567-1558 phone (314) 567-1552 TTY (314) 567-1559 fax www.paraquad.org	A nonprofit community-based Center for Independent Living. Paraquad was founded in 1970 and is a St. Louis organization where professional independent living services are provided by staff members with disabilities. Web site provides basic guidelines on disability etiquette including common courtesy, conversation, and people first language.
U.S. Department of Justice, Civil Rights Division, Disability Rights Section 950 Pennsylvania Avenue, NW Civil Rights Division Disability Rights Section - NYAV Washington, D.C. 20530 (800) 514-0301 phone (800) 514-0383 TTY	For information and technical assistance about the Americans with Disabilities Act (ADA) contact the ADA Information Line  Child care centers and the Americans with Disabilities Act www.usdoj.gov/crt/ada/chcaflyr.htm  Commonly asked questions about child care centers and the Americans with Disabilities Act www.usdoj.gov/crt/ada/childq%26a.htm

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#### Audio/Visual

California Institute on Human Services, Sonoma State University, Desired Results: Assuring Quality for California's Children. CIHS/SSU, 1801 East Cotati Avenue, Rohnert Park, CA 94928. Facilitator's Guide and order form can be downloaded from www.sonoma.edu/cihs/desiredresults/desiredresults\_materials.html. Or call (707) 285-2591 ext. 320.

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# HANDOUTS FOR THE CHILDREN WITH DISABILITIES **AND OTHER SPECIAL NEEDS MODULE**

# Handouts from California Childcare Health Program (CCHP), Oakland, CA

Page	Handout Title
27	Consent for Release of Information Form
29	Health and Safety Notes: Asthma in Child Care Settings
31	Health and Safety Notes: Diabetes in the Child Care Setting
33	Health and Safety Notes: Gastric Tubes in the Child Care Setting
35	Health and Safety Notes: How to Get a Child Tested: Guidelines for Special Education Assessment
37	Health and Safety Notes: Including Children with Special Needs: Tips for Child Care Providers
39	Health and Safety Notes: Maintaining Confidentiality in Child Care Settings
41	Information Exchange on Children with Health Concerns Form
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49	Special Health Care Plan

#### **Handout from Other Sources**

Page	Handout Title
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55	Glossary of Terms Related to Children with Disabilities and Other Special Needs
61	The Map to Services for Children with Special Needs and Their Families
63	Questions and Answers about the Americans with Disabilities Act: A Quick Reference

# **Consent for Release of Information Form**

I,	, give my permission for
(parent/guardian)	
	to exchange health information with
(sending professional/agency)	
(receiving professional/agency)	
This includes access to information from my child's medical re	cord that is pertinent to my child's health and
safety. This consent is voluntary and I understand that I can wi	
This information will be used to plan and coordinate the care	
This information will be used to plan and cool difface use care	
Name of Child:	Date of Birth:
Parent/Guardian Name:	
(print full name)	
Parent/Guardian Signature:	
Parents or Guardians signing this do to receive a copy of this	
to receive a copy or and	
Note: In accordance with the Health Insurance Portability and Accordance all personal and health information is priv	
Adapted from: Pennsylvania Chapter of the American Academy of Pe	ediatrics (1993). Model Child Care Health Policies.

Bryn Mawr: PA: Authors.

California Childcare Health Program www.ucsfchildcarehealth.org rev. 10/03



### **Health & Safety Notes** California Childcare Health Program

# **Asthma in Child Care Settings**







Asthma is the most common chronic disease among children who use child care. It occurs in 7 to 10 percent of all preschool and school-aged children. Therefore, it is highly likely that you will have at least one child with asthma in your program at some time. With appropriate care at the doctor's office, home and child care, most children with asthma do extremely well in child care settings and can participate in all activities.

Asthma is a condition in which the air passages of the lungs become temporarily narrowed and swollen and produce a thick, clear mucous, causing the child to have difficulty breathing. The symptoms can disappear temporarily with treatment and/or removal from whatever is causing the asthma. Asthma cannot be cured and it has been recently learned that repeated attacks can cause permanent damage to the lungs. Asthma can be controlled with appropriate care.

# Signs and symptoms of asthma

Each child may have different asthma symptoms. The parents and physician should tell you what to watch for.

- Coughing (children often have cough as an early or only symptom of asthma)
- Complaint of tightness in the chest
- Wheezing
- Rapid breathing or difficulty breathing
- Decrease in peak flow meter reading
- Unusual tiredness
- Difficulty playing, eating or talking

#### *Indications of severe asthma episode:*

- Flaring nostrils or mouth open
- Bluish color to the lips or nails (late sign: call 9-1-1)
- Sucking in chest or neck muscles (retractions)

#### Asthma triggers

Asthma episodes are usually started by "triggers," events that begin an asthma attack. Each child will have different triggers. Not every child has identified triggers.

- Allergies to substances such as pollen, mold, cockroaches, animal dander or dust mites
- Allergies to a particular food
- Infections such as colds or other viruses
- Irritants such as cigarette smoke, cleaning supplies, air pollutants or other airborne substances
- Cold air or sudden temperature or weather changes
- Exercise or overexertion
- Very strong emotions such as laughing, crying and stress

### Responsibilities of providers

Learn the basics. Read this health note and a few simple pamphlets about asthma.

Consult with the child's parents, physician and your *health consultant*. Learn about the child's triggers, symptoms and treatment. Find out the following:

- How severe is the child's asthma? Has he or she ever been hospitalized or gone to the emergency room due to asthma? How many attacks this year?
- How can you judge the severity of an episode? How will you know if the child just needs to rest, if treatment is needed, whether the parents should be called, or whether to call 9-1-1?
- What are the triggers for asthma for this child and how can they be reduced?
- What medicines does the child routinely take, and which additional medications are to be given when asthma worsens?
- How do you correctly use a nebulizer, an inhaler and spacer, and a peak flow meter if the child needs them?
- What do you need to do in an emergency (for example, administer inhaler or nebulized medications, and call the child's physician or 9-1-1)?

#### Collect and record information as required by licensing.

- California law allows licensed child care providers to administer inhaled medication for respiratory problems such as asthma.
- Have a form completed by a physician or their representative that gives you exact dosing information, including side effects and other possible concerns for each particular child. Have the asthma management plan updated every six months.
- Develop an individualized care plan with the parent and involve the child if he or she is old enough (use Licensing Form 9166).
- Develop a program-wide asthma plan (for a sample Special Care Plan check Appendix M, Caring for Our Children: National Health and Safety Performance Standard, Second Edition, 2002 at http://nrc.uchsc.edu/ CFOC/index.html.
- Enforce the non-smoking policy.
- Record medication use and your observations of the child. Share them with the parent/guardian. Call the Healthline at (800) 333-3212 for sample forms.

*Provide staff training on asthma,* including signs and symptoms of asthma, administration of medications, and the asthma emergency plan.

Modify the environment as needed. Reduce triggers.

Become familiar with signs and symptoms of worsening asthma.

*Encourage the child to drink lots of fluids daily.* This helps prevent "plugged" airways in asthma, especially when an episode occurs.

# When an asthma episode occurs

- Remove the child from known triggers, if possible.
- Help the child rest in a sitting position (sitting allows the child to breathe more easily).
- Keep the child relaxed by staying calm yourself and calming other children present.
- Administer medications as directed.
- Have the child blow into the peak flow meter, if possible, to gauge improvement as recommended by the medical provider.
- Call emergency contacts if the child gets worse or does not respond to medication in 15 minutes (parents, physician and emergency response system, if necessary).
- Stay with the child; observe closely until help arrives.
- Document the episode and use of medication.

# Responsibilities of the physician or other health care provider

- Health care providers should assess the patient's child care setting and child care staff knowledge about asthma control and request that an extra set of supplies (peak flow meter, nebulizer, spacer, medications, etc.) be kept at child care.
- Health care providers should train the parent/guardian and child care provider in observation of the child for asthma, routine medication administration, what to do if asthma worsens, what to do in an emergency situation, and the use of an asthma diary (if needed).
- Health care providers should review and approve medications, update medications / care plan at least annually, and give a signed copy to the child care provider.
- Health care providers should be a resource to the child care provider and parent/guardian and answer their ongoing questions regarding asthma management.

# Responsibilities of the parent/guardian and child

- Parents should understand their child's asthma management.
- Parents should keep a record of the child's asthma, including daily treatment and changes in response or need for medication, and share this information with the child care provider.
- Parents should ensure that their child care provider is thoroughly trained and make sure their physician knows the child is in child care and has signed a special care plan for their child.
- Parents should provide a set of equipment and medications to be kept at child care.
- Parents should regularly update their schedule, emergency contact phone numbers and special care plan.
- Parents should help their children describe their symptoms. This helps the child care provider monitor their condition and involves them in the process.

#### **Sources**

The American Lung Association, Project Exceptional, PA Chapter of the American Academy of Pediatrics, The Allergy & Asthma Network, Mothers of Asthmatics, and Asthma Charts & Forms by Thomas F. Plant and Carla Brennan, NEA Health Information Network, Caring for Our Children: National Health and Safety Performance Standards, Second Edition, 2002.

by Lyn Dailey, PHN (rev. 06/04)

California Childcare Health Program • 1333 Broadway, Suite 1010 • Oakland, CA 94612-1926

Telephone 510-839-1195 • Fax 510-839-0339 • Healthline 1-800-333-3212 • www.ucsfchildcarehealth.org



# **Health & Safety Notes** California Childcare Health Program

# Diabetes in the **Child Care Setting**



#### What is it?

Diabetes is a serious illness in which the body is unable to properly change sugar from food into energy. A simple sugar called glucose is the main source of energy for our body. Insulin, a hormone produced by the pancreas—a large gland behind the stomach helps the body to use the glucose for energy.

Diabetes happens when the body does not produce enough insulin (Type 1 or insulin-dependent), or use it properly (Type 2 or non-insulin-dependent). As a result glucose begins to builds up in the blood, creating high sugar levels in the body.

Children with diabetes usually have Type 1 diabetes, in which the body does not make insulin. They therefore need daily injections of insulin.

# Who gets it and how?

Approximately 127,000 American children, including 15,000 in California, have Type I diabetes. At some time, child care providers are likely to have a child with diabetes in their care.

Diabetes is not contagious. People cannot catch it from each other. At present, scientists do not know exactly what causes diabetes, but they believe that both genetic factors and viruses are involved. Diabetes can run in families.

# What are the symptoms?

Two kinds of problems occur when the body does not make insulin:

1. Hyperglycemia, or high blood sugar, occurs with both types of diabetes when the body does not have enough insulin. Symptoms include frequent urination, excessive thirst, extreme hunger, unusual weight loss, irritability and poor sleep, nausea and vomiting, and weakness and blurred vision.

2. Hypoglycemia, or low blood sugar, is more common in people with Type 1 diabetes. It is also sometimes called "insulin reaction" or "insulin shock." Symptoms may include hunger, pale skin, weakness, dizziness, headache, shakiness, changes in mood or behavior (irritability, crying, poor coordination), sweating, and rapid pulse. Treatment commonly involves quickly restoring glucose levels to normal with a sugary food or drink such as cola, orange juice, candy, or glucose tablets.

If not treated properly, it can result in loss of consciousness and life-threatening coma.

# What factors affect blood glucose level?

The amount of blood sugar changes and can be affected by many factors such as diet, exercise, emotional stress, illness, and medicine.

Exercise helps to lower blood sugar. Regular exercise is important because of the need to balance the effect of exercise with food and insulin. If possible, the child should test blood glucose levels before taking part in a game or sport to determine when to eat a snack and how much food to eat.

Types, amount, and frequency of meals and snacks have different effects on blood sugar. Children with diabetes need special diets in reasonable amounts, and on regular schedules. Crackers with peanut butter or cheese, pretzels, apples, and juice make ideal snacks.

A child with diabetes may need to eat a snack before, during, or after energetic exercise.

Stress from a cold, sore throat, or other illness may increase the level of blood glucose.

#### The law and diabetes

The Americans with Disabilities Act, a federal law, considers diabetes a disability, forbids discrimination against the disabled, and puts legal responsibility on child care providers to care for the special needs of children with diabetes.

Effective January 1, 1998, child care providers in California are allowed to perform a blood-glucose test (using a finger-stick test) on a child in their care. However, they are not required to give an insulin injection to any child in a child care facility.

### **Blood glucose testing**

Regular testing of blood glucose levels is a very important part of diabetes care. Testing is done by taking a drop of blood, usually from a finger, and placing it on a special test strip in a glucose meter. Glucose meters are easy to use, and most children quickly learn how to do their own blood glucose tests. A normal blood glucose level is between 70 and 120 mg/dl. Keeping blood glucose levels within

this range is rarely possible in children with diabetes. A health care provider will often identify a target range for blood glucose levels – for example, 80 to 180 mg/dl.

# How is it managed?

Care for diabetes is more flexible than it used to be. It requires self care or assistance with care if the child is very young. Children with diabetes can participate in all child care activities. Except for paying attention to their special care

plan, you do not need to treat them differently just because they have diabetes.

The goals for treatment of diabetes in children are to:

- (a) Maintain normal growth and development
- (b) Keep blood glucose levels within a target range (not too high, not too low)
- (c) Promote healthy emotional well being.

Child care providers in coordination with parents and health care providers can prepare a special care plan to meet the special needs of children with diabetes, and help them lead healthy, active, and fulfilled lives without having to change their regular program. A written, special care plan should include:

- When to test blood glucose and take insulin
- Regular meal and snack times
- Preferred snacks and party foods
- Usual symptoms of hypoglycemia and preferred treatments
- When and how to notify the child's parents of problems
- When and how to contact the child's health care provider
- Who will give insulin injections when nedded

Preschool-age children with diabetes often need fre-

quent blood glucose tests because they have not yet learned to recognize the symptoms of low blood sugar, can't tell what they feel, or may try to avoid or delay finger-prick and insulin injections. They may also drink and urinate a lot, so make sure they can go to the bathroom as often as they need.

Providers considering or already performing the fingerstick test must follow "universal precautions" at all times. For more information on diabetes, please call our toll-free

Healthline at 1-800-333-3212 or American Diabetes Association 1-800-DIABETES.

# **Summary of key points**Good diabetes care practices

Good diabetes care practices include:

- eating reasonably, consistently, and on schedule
- testing blood glucose levels regularly
- adjusting insulin as glucose levels and activities warrant
- exercising regularly

#### References

American Diabetes Association

Assembly Bill (AB) 221 Chapter 550, Statutes of 1997, Section 1596.797 of the Health and Safety Code.

By A. Rahman Zamani, MPH (2/27/98)

California Childcare Health Program • 1333 Broadway, Suite 1010 • Oakland, CA 94612–1926

Telephone 510–839–1195 • Fax 510–839–0339 • Healthline 1–800–333–3212 • www.ucsfchildcarehealth.org



# **Health & Safety Notes** California Childcare Health Program

# Gastric Tubes in the **Child Care Setting**



# What are gastric tubes?

Gastric tubes—also called gastrostomy tubes or Gtubes—are feeding tubes for the purpose of administering liquid nutrients, medications, or both. Unlike nasogastric tubes (plastic tubes that stretch from the nose down the back of the throat to the stomach) gastric tubes are surgically inserted directly into the stomach.

There are many types of gastric tubes. The most common, called button tubes, are level with the skin. A tube or syringe is attached to the button opening in order to deliver the formula or liquid nutrients and/or medication. Some children with gastric tubes may receive a slow, continuous infusion with the help of a small pump device.

# How are gastric tubes inserted?

They are inserted into the stomach through a surgical opening in the abdomen. A gastric tube is kept in place by either sutures (stitches) or an inflated balloon, just inside of the stomach. One end of the tube is in the stomach and the other end is outside of the body. Once the incision is healed the child usually does not experience any discomfort at the tube site.

# Who will need a gastric tube?

Infants or children who are not able to eat normally because of problems with their mouth, throat, stomach or intestines may require a gastric tube in order to take in enough nutrients to grow normally and stay healthy. Infants or children with sucking or swallowing difficulties could require a gastric tube as well.

# Can gastric tubes come out accidentally?

Yes, they can be dislodged if pulled on and should be kept protected from hazards that could cause snagging. Most gastric tubes have an anchoring device, but extreme care should always be taken to prevent trauma or accidental injury to the site. Gastric tubes should be kept away from the hands of young children and infants—including the child with the gastric tube—to avoid them accidentally pulling out the tube. It is recommended that the child wear a onepiece shirt with the gastric tube tucked inside. If the G-tube comes out accidently, don't panic. Cover the site with a clean piece of gauze or a washcloth, and call the parent. The child care provider should not attempt to reinsert the G-tube.

# Does the ADA cover gastric tubes in child care?

The Americans with Disabilities Act (ADA) gives children with special health care needs the right to participate fully in child care programs. The law mandates that child care programs make reasonable modifications in order to accommodate children with special health care needs so that they are fully included in the child care setting.

# What should I do if I have a child with a gastric tube in my care?

Understand the reasoning for the gastric tube. Children that have a gastric tube usually have had some other medical problem requiring it. Respond to the whole child so that your focus is not only on this one area.

Develop a written daily plan for the special care of the child with a gastric tube. Involve the parents and all staff members who care for the child in the creation of this plan (a Special Health Care Plan form example is available on the CCHP Web site). If available, involve your Child Care Health Consultant or public health nurse for guidance, resources and continued consultation.

Daily assess the child as he or she enters into care to make sure the gastric tube is not dislodged, infected or causing local irritation of the skin.

Communicate with the child's family about the gastric tube care on a regular basis. Your open and positive attitude will let them know that their child's needs are being meet and that their child is being cared for responsibly and lovingly. Let the family show you how to hold the child during feedings. Ask if they provide any sucking, texture or taste stimulation in the mouth during feeding that you might do as well.

Provide opportunities for the other children in care to be part of the planning for the participation of the child who uses a gastric tube. Children are naturally curious about a child who is different than themselves. Encourage them to share their anxieties and fears, explore their questions and interests, and discuss the issue with each other and in play. Answer their questions with simple and factual answers, using examples that they will understand. Share children's books, songs and other materials that promote the acceptance of individual differences.

# **Does Community Care Licensing** allow feeding by gastric tube in child care?

There is nothing in Community Care Licensing (CCL) in California to prohibit child care personnel from administering routine gastric tube feedings, or administering routine liquid medication through a gastric tube to a child in care, as it is not considered a medical procedure. However, child care personnel are prohibited from administering crushed medication (pills) to a child through a gastric tube.

Licensed facilities *must* notify CCL in writing of their intent and provide a plan of operation to provide gastric tube care. This must include information on how staff are to be trained in gastric tube care. The facility must obtain approval from CCL to provide gastric tube care for a child [Section 101173(c)].

Written permission from the child's parent/guardian *must* be obtained to provide gastric tube care. It must include parental consent to be able to contact the child's health care provider. Licensing form LIC 701B, "Gastrostomy-Tube Care Consent / Verification (Child Care Facilities)" is to be used to document this permission and must be kept on file at the facility [Section 101226(e)(3)(B)].

A qualified health care professional must properly instruct staff personnel who provide gastric tube care about the procedure for the child. This designated person may be the child's parent/guardian if the physician approves. Licensed facilities must ensure that personnel who give gastric tube feedings are competent to do so and that there is written verification that the personnel completed the necessary training/instruction in gastric tube care. Form LIC 701A, "Gastrostomy-Tube Care: Physician's Checklist (Child Care Facilities)," is to be used for this purpose and must be kept on file at the facility. A separate form must be used for each person who provides gastric tube care. It is important to ensure that there is trained back-up staff available to assist if necessary [Section 101216(a)].

Personnel who provide gastric tube care must follow specific written instructions from the child's health care provider The instructions including what to do, who to notify if complications occur, and how to receive training should be attached to the child's LIC 701A form and keep on file at the facility. These instructions must include the exact steps needed to provide gastric tube feeding or liquid medication to the child and provide related necessary care. This includes, but may not be limited to: limitation or modifications to normal activity, frequency of feeding and amount/type of formula or liquid medication, hydration with water or other liquids, method of administering nutrients or medications, positioning of the child, potential side effects, how and when to flush the gastric tube and what to do if becomes clogged, proper sanitation/ cleaning procedures, proper storage of equipment and emergency procedures and contact information. These instructions must be updated by the child's health care provider annually, or whenever the child's needs change, by the child's physician or health care provider working with the physician [Section 101226(e)(3)].

Call the Healthline at (800) 333-3212 if you need additional information or materials.

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# **Health & Safety Notes** California Childcare Health Program

# How to Get a Child Tested: Guidelines for Special Education Assessment



If you suspect a child may be having difficulties, the following guidline will help you understand the screening and assessment process. Only parents or guardians may initiate this process.

# Children ages 0 - 3

Children birth to three who have or who are at risk of having a developmental delay may be eligible for early intervention services provided by a regional center or a local education agency (school district). School districts are primarily responsible for providing services to children who are blind, deaf, deaf-blind, or have a severe orthopedic disability (low-incidence disabilities). The parents or legal guardian should contact their local regional center for assistance or call 800-515-BABY (800-515-2229) for local California Early Start services and Family Resource Centers and Networks.

Early intervention services are provided based on the developmental needs of the child, the concerns and priorities of the family, and the resources available to them. Services are provided within the context of the child and family's daily activities and routines. Early Start services are provided at no-cost to eligible families. Early intervention services can:

- Improve both developmental and educational gains
- Reduce the future costs of special education, rehabilitation and health care needs
- Reduce feelings of isolation, stress and frustration that families may experience
- Help children with disabilities grow up to become productive, independent individuals
- Strengthens families' capacity to advocate and care for their children with special needs

# Children ages 3 - 21

In order to determine whether a child 3 to 21 years old qualifies for special education services, she or he must be tested by the school district. Child care providers concerned about how a child moves, thinks, communicates,

hears or sees should talk to the parent. The parent then contacts the school district, as well as their health care provider if appropriate, since the parent or legal guardian may make the initial referral and must sign the forms.

- 1. To initiate the process the parent or legal guardian should contact their local school district, ideally in writing. If writing a letter, it should state specific concerns and if possible, include observations made by the child care provider. The parents should date the letter and make a copy for their records. The parent may also want to provide a copy of the letter to the child care provider.
- The school district must contact the parent within fifteen calendar days to sign an assessment plan and any releases of information to talk to other professionals involved with the child. The parent may also want to sign a release of information between the schools and the child care program to enable open communication and input.
- 3. The assessment plan is the written permission to allow the child to be tested. It should indicate which areas of development will be tested and the types of tests that will be used. Once the assessment plan is signed, a legal timeline begins for the school district to test the child.
- 4. Testing can take several hours, and young children may need to be assessed in phases, over a period of days or weeks. Parents should encourage the school district staff to observe the child in all settings, including in the child care and the home. Testing should be done in the primary language of the family and at no cost to the family.
- 5. If the child qualifies for special education, the school district has 50 calendar days to develop an Individualized Education Plan. Generally, a pre-schooler must have a significant delay in one developmental area or a moderate delay in two areas compared to their chronological age, or have a disabling condition or established medical disability.

Assessment includes the following developmental areas and should identify strengths and abilities as well as delays:

Adaptive: how children take care of themselves, including toileting, feeding, and dressing.

Communication: how children understand, speak and use language.

Cognitive: how children think and solve problems.

Fine and gross motor: how children use their muscles, eye-hand coordination, and other large and small motor tasks, including walking, running, jumping, and writing.

Social-emotional: how children interact with adults and peers, how they feel about themselves, how they make their needs known.

The child's health history is also taken into account and vision and hearing screenings may be recommended depending on the child's needs.

The IEP team determines the most appropriate services to meet the child's needs. The parents can invite anyone to attend the IEP with them, including the child care provider. Participating in these meetings may help child care providers coordinate services for the child and better understand the child's strengths and needs.

Special education services can be provided in a variety of settings, including a child care center, family child care home or in the child's home. The IEP team determines the type and quantity of services.

Once the parents sign the IEP, services can begin.

Even if the child does not qualify for special education services, the parents can ask the school district to make recommendations as to how the parent and child care provider can help improve the child's skills—suggested programs, activities, etc. The child's health insurance or another agency may cover services that could help, such as occupational therapy or counseling.

Parents should always request and keep copies of all reports, test results, and any other completed forms. With permission from the parents, child care providers may also want to keep copies of these forms on record.

The assessment process itself may help answer questions about the child's development and how to work with him. Assessment should be an ongoing collaborative effort between professionals and parents to understand warning signs.

### Resources

Handbook on Developing Individualized Family Service Plans and Individualized Education Programs in Early Childhood Special Education Programs, and Handbook on Developing and Implementing Early Childhood Special Education Programs and Services, California Department of Education, Sacramento (2001). These handbooks may be ordered at (800) 995-4099 or www.cde.ca.gov/cdepress.

Early Warning Signs, California Department of Education, in collaboration with the California Childcare Health Program. Free pamphlet describing indicators which suggest that a child may need help.

Special Education Resources on the Internet at http:// seriweb.com. This site offers a collection of Internet accessible information for those involved in fields related to special education.

The National Information Center for Children and Youth with Disabilities at www.nichcy.org. NICHCY is the national information and referral center that provides information on disabilities and disability-related issues for families, educators and other professionals.

Idea Practices at www.ideapractices.org. This Web site has technical information about the federal law that guides special education, including the process of assessment, IEPs, and services.

The Healthline at (800) 333-3212 is a toll-free number available to the child care community for consultation on a number of different health and safety issues, including children with disabilities and other special needs.

Early Start for Infants and Toddlers with Disabilities and their Families at (800) 515-BABY.

Special Education Division, California Dept of Education at (916) 445-4613.

### References

Handbook on Developing Individualized Family Service Plans and Individualized Education Programs in Early Childhood Special Education, California Department of Education, Sacramento, 2001.

By Pamm Shaw, MS, Disabilities Specialist (June 15, 1999) (Revised April 2003)



# **Health & Safety Notes** California Childcare Health Program

# Including Children with Special **Needs: Tips for Child Care Providers**

The following suggestions are intended to help include children with disabilities and other special needs in your care. It is important to remember that children are children first and each child is different, regardless of whether or not he or she has a disability. When considering adaptations and modifications, it may be helpful to take into account the severity of the disability, the child's age and the child's developmental level. Each child with special needs requires a "Special Care Plan" to identify how you will meet the child's individual needs in your program. A sample special care plan is available at the CCHP Web site at www.ucsfchildcarehealth.org, or by by calling the Healthline at (800) 333-3212.

# **Developmental delays**

- Teach in small steps.
- Give clear directions, speaking slowly, clearly and using only a few words.
- Move the child physically through the task, so she can feel what to do.
- Stand or sit close to the child so you can help as needed.
- Help the child organize his world by providing structure and consistency and by labeling things with pictures and words.
- When moving from one activity to the next, let the child know ahead of time and allow plenty of time for the transition
- Work closely with other agencies and personnel who provide specialized services (such as early interventionists, therapists and psychologists). These specialists are a great resource for answering questions and brainstorming when problems arise.

# Speech and language delays

- Be a good listener and observer.
- Engage infants and toddlers in back and forth conversations by reading their sound, gestures, facial expressions and body language.
- Give directions using as few, simple words as possible and in complete sentences.
- Talk about what you or the child is doing as you do it.
- Use everyday activities such as singing songs, read-

- ing books and dramatic play to encourage language development.
- Encourage the child to talk about what she or he is doing by asking specific questions.
- Repeat what the child says and add missing words, or ask the child to repeat what you are saying.
- Expand the child's language skills—build on what the child says by adding new information.
- Praise the child's efforts at communicating even if he or she doesn't do it exactly right.

### Visual disabilities

- Use lots of communication during activities such as dressing and eating to help the child orient to the activity.
- Think about the physical space of the room: be wary of sharp edges on tables, curled up edges of rugs and other potential hazards.
- Once you've found an arrangement of furniture that works for the room, try not to change it too much as the child may rely on furniture to help navigate the
- Give specific directions and use descriptive language.
- Call children by their names. Address them directly, not through someone else ("Juan, do you want some banana?" not "Do you think Juan wants some banana?").
- Avoid glaring lights. Increase or decrease the room lights gradually and try not to change the light suddenly.
- Display simple, clear, uncluttered pictures that are easy to see.
- Avoid standing with your back to windows: the glare may make you look like a silhouette.
- Encourage hands-on and sensory experiences such as touching, holding, exploring, tasting, smelling and manipulating.
- Ask first if the child needs assistance—try not to assume you should help.

# Physical/neurological issues

Consider the physical space: are there any obstacles that prevent the child from moving safely in the area?

- Are the pathways wide enough to accommodate special equipment such as walkers or wheelchairs?
- Know the child's strengths and needs so that independence is realistically encouraged and supported.
- Assist the child with activities she or he may not be able to do alone, such as kicking a ball.
- Ask any therapists involved with the child to show you proper positioning techniques and how to use and care for any special equipment.
- If you are having difficulty with positioning, feeding, etc., consult with the child's parents or guardians for suggestions they have found helpful at home.
- Give all staff opportunities to hold and position the child to ensure everyone is comfortable.
- Help other children understand why "Lauren can't walk" and emphasize what Lauren can do.
- Try to experience the disability yourself so that you can better understand the child's perspective.
- Work closely with other agencies and personnel who provide specialized services such as early interventionists and therapists.
- Ensure that the child's positioning is similar to what other children in the class are doing whenever possible (such as floor time).
- If the child is unable to use playground equipment, schedule some other outdoor activities that the child with a disability can participate in such as blowing bubbles, flying kites, etc.

# Deaf or hard of hearing children

- Find out from the parents/guardians the degree of the child's hearing loss and what that means for the child.
- Ask the child's parent or guardian how to use and care for the hearing aid or other special equipment.
- Support the child socially.
- Be sure you have the child's attention before giving instructions.
- Speak in full sentences, at normal speed, to the child's face—and smile.
- Use visual cues such as pictures or gestures as you talk.
- Encourage the child to let you know when he or she doesn't understand by using a special signal.
- If the child doesn't understand at first, rephrase your comment rather than repeating it.
- If the child uses sign language, learn some simple sign language symbols.
- Provide opportunities for the child to talk.

# Social/emotional/behavioral issues

Try not to change activities abruptly. Warn the child

- of any changes in schedule ahead of time.
- Provide routine and structure for the child. Use cues such as timers, bells and lights.
- Allow the child time to practice new activities away from the group or allow withdrawn children to watch new activities first.
- Seat the child close to you. Give occasional physical and verbal reassurances and encouragement.
- Let the child bring a familiar object when entering new situations or beginning a new activity.
- Help the child make choices by limiting the number of choices available.
- Allow the child to have a safe emotional outlet for anger, fear or frustration.

# Techniques for managing behavior

- Ignore negative behavior when you can.
- Notice and praise positive behavior as much as possible. Focus on what the child can do and accentuate the positive.
- Acknowledge the child's feelings.
- Children follow your example: model the kind of behavior you want to see in them.
- Prevent problems when possible by considering how the schedule, structure and physical space support your goals for children.
- Help children to talk about, act out and understand their strong feelings and behaviors.
- Follow through with realistic consequences.
- Be aware of what behaviors are your "hot buttons" and work with other staff to make sure you have the support you need. Seek additional help if the behavior persists or you feel the need for support.
- Give children reasonable choices.
- Provide developmentally appropriate activities in a safe, nurturing environment.
- Give the child enough time to comply with your request.
- Develop a plan for how you will handle difficult behavior the next time.
- Try to be consistent with the way the child's family and culture handles behavioral issues and their social and emotional goals for the child.
- Remember to have fun with the children!

### Resources

National Network for Child Care at www.nncc.org.

Circle of Inclusion at www.circleofinclusion.org.

By Pamm Shaw, MS, Disabilities Specialist (rev. 04/2003)

California Childcare Health Program • 1333 Broadway, Suite 1010 • Oakland, CA 94612-1926

Telephone 510-839-1195 • Fax 510-839-0339 • Healthline 1-800-333-3212 • www.ucsfchildcarehealth.org

# **Health & Safety Notes**



# **Maintaining Confidentiality** in Child Care Settings



### What is confidential information?

Confidential information is personal details from our lives which we may not want to share with others. It can include our address, phone number, birth date, employment history or other personal information. It may also include information about our past or present health and development. Individuals have the right to keep information of this type private.

Child care programs routinely handle confidential information about enrolled children, families and staff. When managing sensitive information, it is important for child care directors, administrators and staff to be aware of their ethical and legal responsibility to protect the privacy of individuals and families.

# Legal requirements

California Community Care Licensing (CCL) Regulations for Child Care Centers require that licensed providers ensure the confidentiality of all records pertaining to enrolled children (CCL, 2002). Files containing confidential information should be accessible only to program staff who must know the information in order to care for the children. Each child's records must also be made available to that individual child's parent/guardian, CCL personnel, or police officers upon request. CCL further requires that programs must inform the parents/guardians of enrolled children that their information will be kept confidential. Programs must explain to enrolled families that their records will be shared only as described above, unless the family gives the program written consent to disclose specific information to others (CCL, 2002).

# Confidential contents of records in child care settings

Programs keep individual files for each enrolled child, including but not limited to the following:

- enrollment forms
- family's health insurance information

- health screenings and records, including immunization records
- emergency contact information
- contact information for those authorized to pick up child
- emergency care consent forms
- consent forms (permission slips) for outings or special activities
- names of regular medical or dental providers who know the child
- nutritional restrictions
- progress reports
- child observation logs
- parent conference logs
- medication logs
- documentation of medical, behavioral or developmental evaluations, referrals or follow-ups, addressing issues relevant to the child's participation in the program
- documentation of any injury occurring at the program site and the steps taken to address the situation

# How can child care programs ensure confidentiality?

Caring for Our Children, National Health and Safety Performance Standards (2002) recommends that programs create and abide by a written policy which describes how confidential information should be documented, stored and handled. All staff should be familiar with this policy, which should cover all of the specific types of confidential information kept at the program site. Below are some examples of how a program can protect confidential information while providing quality care.

Notification of communicable illnesses. When any child in care is diagnosed with a communicable illness or condition, such as chicken pox, impetigo, head lice and many others, programs are required to notify the program staff and the families of any children who may have been exposed. Notified families should be instructed to monitor their own children for the development of any symptoms, and to seek medical attention if symptoms do occur. This type of notification can and should be done without mentioning the identity of the diagnosed child.

Children with special needs. Enrolled children may have special needs due to disabilities or chronic health conditions. To ensure their safety, programs often institute policies that have an effect on all of the families in the program. A common example of such a policy is one that prohibits families from bringing some types of food to the program site, to accommodate the restricted diet of another child. A program may institute a peanut-free policy, to protect a child with a life-threatening reaction to peanuts. Or, a program may create a policy prohibiting sugar-laden cakes and cookies at birthday celebrations, to accommodate a child with diabetes, for whom such foods are dangerous.

When creating such policies and notifying other families, keep the affected child's right to confidentiality in mind. Notifications of policies should explain that there is a child in the program whose serious health condition makes the policy necessary. The notification need not mention the affected child by name.

# When is it appropriate to disclose personal information?

While the rights and desires of families to keep their personal details private are important, there are also some circumstances under which identifying information should be shared.

Program staff and the "need to know." To ensure the health and safety of children with special needs, teachers, caregivers, and other program staff who interact with the children should be informed of the identities of children with special health concerns on a "need to know" basis (AAP, 2002).

For example, staff who prepare and serve food should be fully aware of which children have food allergies and what each affected child is allergic to. Staff members who monitor the children in the playground should be aware if any children are allergic to bee stings, or if any children have a chronic

condition which warrants especially close monitoring during play (such as poorly controlled epilepsy, or diabetes treated by insulin injection). Primary caregivers and back-up staff need to know if any children in care have been prescribed medications, for what reasons, and what the possible side effects are, since they are likely to be administering the medications and monitoring the reaction. Program directors and teachers need to know if there are any un- or under-immunized children in care, so that appropriate measures can be taken in the even of exposure to a vaccine-preventable illness.

Outbreaks of reportable illness. Community Care Licensing Regulations provide a list of certain serious infectious diseases which are reportable in California (CCL, 2005). This means that a child care program *must* report to both the local Public Health Department and to Community Care Licensing whenever there is a known or suspected outbreak of any of these illnesses. During such reporting, identifying information about the affected child, including name, age, and how to contact the family, should be reported.

Known or suspected child abuse. Licensed child care providers are mandated reporters of child abuse. If a child in your care shows evidence of abuse or neglect, you must call Child Protective Services and report the situation. The CPS intake process requires disclosure of the child's name, address, parents or guardian's names, and possible additional details. In this situation, the child's safety and welfare come before the family's right to confidentiality.

### References and resources

California Department of Social Services, Community Care Licensing (2004). Title 22 Regulations for Child Care Centers. Accessed May 6, 2005 at www.dss.cahwnet.gov/ ord/CCRTitle22\_715.htm.

American Academy of Pediatrics (2002). Caring for our children; Health and Safety performance standards for out-ofhome child care programs, 2nd edition.

California Childcare Health Program (2003). Child Abuse Prevention. Accessed May 6, 2005 at www.ucsfchildcarehealth.org/pdfs/healthandsafety/childaben081803.pdf.

California Childcare Health Program (2003). Maintaining child health records in child care settings. Accessed May 6, 2005 at www.ucsfchildcarehealth.org/pdfs/healthand safety/recorden081803.pdf.

by Eileen Walsh, RN, MPH (06/05)

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# Information Exchange on Children with Health Concerns Form

Dear Health Care Provider:

We are sending you this Information Exchange Form along with a Consent for Release of Information Form (see back) because we have a concern about the following signs and symptoms that we and/or the parents have noted in this child, who is in our care. We appreciate any information you can share with us on this child in order to help us care for him/her more appropriately, and to assist us to work more effectively with the child and family. Thank you!

	Child Care Provider:
Facility Name:	Telephone:
Address:	
We would like you to	evaluate and give us information on the following signs and symptoms:
Questions we have re	garding these signs and symptoms are:
Date//	Child Care Provider Signature:
	Child Care Provider Printed Name:
To be filled out by	Health Care Provider:
	s Name: Telephone:
	•
	i:
Recommended Treatn	nent:
Major side effects of a	ny medication prescribed that we should be aware of:
Should the child be ter	mporarily excluded from care, and if so, for how long?
What should we be av your instructions, sign	ware of in caring for this child at our facility (special diet, treatment, education for parents to reinforce s and symptoms to watch for, etc.)?
Please attach additional	pages for any other information, if necessary.
Date / /	Health Care Provider Signature:
	Health Care Provider Printed Name:
	California Childcare Health Program www.ucsfchildcarehealth.org rev. 04/05

# **Quality Inclusive Child Care Checklist**

Are families and children welcomed, and are children greeted in a loving, respected way? Are parents welcome at anytime during the day?	
Is the overall atmosphere bright, cheerful and child-focused, without being overwhelming?	
Do you notice caregivers/teachers really listening to children and families?	
Are caregiving and teaching practices responsive to differences in children's abilities, interests and experiences?	
Are the sounds of children predominantly happy? Does it appear that the adults and children enjoy being together?	
Is the physical environment safe, secure and free of barriers that limit or prevent access and mobility (e.g., ramps, outside play area, bathrooms)?	
Is there a fenced-in outdoor play area with a variety of safe equipment? Can the caregivers/teachers see the entire play yard at all times?	
Are learning materials and toys sufficient, safe, clean and within reach of all children? Are there enough for the number of children?	
Are there different areas for resting, quiet play and active play? Is there enough space for the children in all of these areas?	
Is there a daily balance of active and quiet activities (e.g., play time, story time, activity time and nap time)? Are the activities appropriate for each ability and age level?	
Are the majority of planned developmental activities individualized or in small groups?	
Do learning materials, books and pictures reflect diversity, including children with special needs?	
Do caregivers/teachers use a variety of instructional strategies to meet the individual needs of children?	
Do caregivers/teachers facilitate or enhance interactions between children with and without disabilities?	
Are children with disabilities included socially and engaged in meaningful activities throughout the day?	
Are children with disabilities given support and assistance when needed, and is it unobtrusive?	
Does the program accept children who are not yet walking or toilet-trained?	
Are therapeutic and/or support services such as OT, PT and Speech Therapy welcomed and provided on-site?	
Are parent's ideas welcomed? Are there ways for families to be involved in the program?	
Does communication between parents and staff seem open and ongoing? Are events and information shared with families regularly?	
Is the program licensed by the state? Is the program accredited or working towards national accreditation?	

M.Lucich 11/03

# When observing and listening, pay particular attention to these five key indicators of quality inclusive child care:

### A POSITIVE AND HAPPY LEARNING ENVIRONMENT

- Are the children engaged?
- Are staff involved with children at eye-level?
- Are the rooms bright and cheerful without being overwhelming with too many sights and sounds?
- Do the adults speak positively about all children?

### THE RIGHT NUMBER AND MIX OF CHILDREN AND ADULTS

- Are all children receiving individual attention?
- Do adults call children by name?
- Are children comforted, when needed, by staff or other children?
- Does staff overuse the "time-out" tactic?



### TRAINED AND SUPPORTED PERSONNEL

- Are caregivers trained in early childhood education and special needs?
- Are teaching staff available to attend school district educational meetings with families who have children in their program who are receiving special education services?
- Do those who work with children themselves receive positive support?

### A DEVELOPMENTAL FOCUS ON THE CHILD

- Do you see and hear a variety of developmental activities taking place?
- Do the children have opportunities to control objects and events in their environment?
- Are activities based on the children's level of functioning?
- Are learning materials accessible to children with special needs?

### PARENTS TREATED AS PARTNERS

- Does child care personnel help families develop goals for children and plans to achieve them?
- Does the program provide families with regular schedules of activities and events?
- Does the child care staff describe their communication practices as "open"?
- Do parents actively participate with the children?

Adapted from "Choosing Quality Child Care for a Child with Special Needs," a Child Care Aware brochure. 1-800-424-2246 www.childcareaware.org



# TRAINING, CURRICULUM AND PROFESSIONAL DEVELOPMENT RESOURCES

CHILD CARE PLUS+: THE CENTER ON INCLUSION OF EARLY CHILDHOOD is a federally funded project that shares knowledge, fosters skills and encourages attitudes that promote inclusion as a core component of excellence in early childhood through expanding child care options for children with disabilities and their families, providing training and technical assistance for child care providers and other early childhood professionals (including specialists in early intervention and special education), and seeking ways to improve the quality of the child care experience for all children.

http://www.ccplus.org

CIRCLE OF INCLUSION is a Web site for early childhood service providers and families of young children which offers demonstrations and information, including training and technical assistance about the effective practices of inclusive educational programs for children from birth through age 8.

http://www.circleofinclusion.org

BEGINNING TOGETHER offers training institutes that focus on issues pertinent to the field working with infants and toddlers with disabilities and special needs in inclusive settings. The institutes feature a variety of sessions including a parent panel, time to preview and purchase relevant books, videos and materials, opportunities to dialogue with faculty and other participants, and in-depth, interactive workshops. Early intervention specialists, Program for Infant/Toddler Caregivers (PITC) early childhood faculty and parents of children with special needs collaboratively present specific workshops.

http://www.sonoma.edu/cihs/BT/Beginning.html

CENTER FOR PREVENTION & EARLY INTERVENTION (CPEI), WestEd's newest center in Sacramento, is recognized as the premier source of training, technical assistance, and resource development and provision supporting early intervention services for infants and toddlers with disabilities and at-risk conditions and their families. CPEI provides high-quality training, technical assistance and resource development, dissemination, and support for successful education, special education, early intervention and child care.

http://www.wested.org/cs/cpei/print/docs/230

ALL OF US TOGETHER: MOVING TO INCLUSION provides three-day intensive training institutes which are a project of WestEd's Center for Prevention and Early Intervention and are sponsored by the California Department of Education, Child Development Division. The institutes prepare child care providers to serve preschool-age children with disabilities and other special needs. The project is designed to facilitate teams of early care and education providers, special education and regional center staff, and other related service providers to develop community collaboration plans, facilitate the development of new skills and strategies for inclusive practices, and provide limited follow-up technical assistance.

http://www.wested.org/cs/wew/view/pj/202

KIDS TOGETHER, INC., a nonprofit agency co-founded by parents and organized by volunteers, is designed to promote inclusive communities where all people belong. This site contains a variety of helpful information and resources for inclusion, and sections for individuals with disabilities, parents, siblings, educators, businesses and communities. http://www.kidstogether.org

# PARENT, FAMILY AND PROVIDER RESOURCES

THE ARC is the national organization of and for people with mental retardation and related developmental disabilities and their families. It is devoted to promoting and improving supports and services for people with mental retardation and their families. The association also fosters research and education regarding the prevention of mental retardation in infants and young children. The ARC is an online resource that has been developed to provide easy access to facts, contacts and news updates.

http://www.thearc.org

CORNUCOPIA OF DISABILITY INFORMATION (CODI) serves as a community resource for consumers and professionals by providing disability information in a wide variety of areas. It consists of both an Internet Directory of Disability Information and a repository of electronic disability documents, dating back to the early 1990s. http://codi.buffalo.edu/children

INTERNET RESOURCES FOR SPECIAL CHILDREN (IRSC) is dedicated to children with disabilities and other health-related disorders worldwide, acting as a central starting point that integrates information, resources and communication opportunities. Their mission is to improve the lives of these children by: providing valuable information to parents, family members, caregivers, friends, educators and medical professionals who provide services and support; creating positive changes and enhancing public awareness and knowledge of children with disabilities and other health-related disorders; providing Online Communities (a place to ask questions or connect with others who may have the same questions, thoughts and/or experiences); and provide access to recent news articles and books. www.irsc.org:8080/irsc/irscmain.nsf

CHILDREN WITH DISABILITIES offers families, service providers and other interested individuals information about advocacy, education, employment, health, housing, recreation, technical assistance and transportation covering a broad array of developmental, physical and emotional disabilities. http://www.childrenwithdisabilities.ncjrs.org

SPECIAL EDUCATION RESOURCES ON THE INTERNET (SERI) is a collection of Internet-accessible information resources of interest to those involved in the fields related to special education. This collection exists in order to make online special education resources more easily and readily available in one location. It is continually updated, and additional informative links are added when available.

http://www.seriweb.com

CENTER FOR EARLY EDUCATION & DEVELOPMENT (CEED) provides information regarding young children (birth to age 8), including children with special needs, in the areas of education, child care, child development and family education. The Web site contains information about CEED activities, including research, training and publications geared toward improving professional practices, supporting parents and informing policy development. http://education.umn.edu/ceed

KIDNEEDS.COM is a worldwide resource that provides children with special needs, families and other caregivers with access to comprehensive information and resources. Includes professional opinions on important topics, and information about public health policy initiatives and local, statewide and national advocacy efforts on behalf of children with special needs and their families.

http://www.kidneeds.com

INFANT DEVELOPMENT ASSOCIATION OF CALIFORNIA (IDA) is a multidisciplinary organization of parents and professionals committed to optimal developmental, social and emotional outcomes for infants, birth to 3, with a broad range of special needs, and their families. IDA advocates for improved, effective prevention and early intervention services, and provides information, education and training to parents, professionals, decision-makers and others. http://www.idaofcal.org

COUNCIL FOR EXCEPTIONAL CHILDREN (CEC)-DIVISION FOR EARLY CHILDHOOD (DEC) is a nonprofit organization advocating for individuals who work with or on behalf of children with special needs (includes those who have disabilities, developmental delays, are gifted/talented, and are at risk of future developmental problems), birth through age 8, and their families. Founded in 1973, it is dedicated to promoting policies and practices that support families and enhance the optimal development of children. http://www.dec-sped.org

# EDUCATIONAL RESOURCES

CENTER FOR PREVENTION & EARLY INTERVENTION POLICY is a project of the FSU Center for Prevention and Early Intervention Policy. Its mission is to influence public policy by enlarging the knowledge base about families and young children. The Center's work focuses on practices and policies which prevent poor birth outcomes, build strong families, promote maternal and child health and development, and prevent disabilities. http://www.cpeip.fsu.edu

EARLY CHILDHOOD RESEARCH INSTITUTE ON INCLUSION (ECRII) was a five-year national research project funded by the Office of Special Education Programs, U.S. Department of Education to study the inclusion of preschool children with disabilities in typical preschool, day care and community settings. The project ended on August 31, 2000. http://www.fpg.unc.edu/~ecrii

NATIONAL INFORMATION CENTER FOR CHILDREN & YOUTH WITH DISABILITIES (NICHCY) is a national information center that provides information on disabilities and disability-related issues for families, educators, administrators, journalists and students. The agency's special focus is children and youth (birth to age 22). NICHCY has information about: specific disabilities, special education and related services for children in school, IEP/IFSP, parent materials, disability organizations, professional associations, education rights and what the law requires, early intervention services for infants and toddlers, and transition to adult life. http://www.nichcy.org

NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE CENTER (NECTAC) supports the implementation of the early childhood provisions of IDEA. The mission is to strengthen service systems to ensure that children with disabilities (birth through five) and their families receive and benefit from high-quality, culturally appropriate and family-centered supports and services. Includes the Adjunct ERIC Clearinghouse on Early Intervention and Early Childhood Special Education, which links people and knowledge. Through working relationships with knowledge producers and users at all levels, including researchers, policy makers, practitioners, families and advocates for young children with special needs, the Center identifies new information resources and enters them into the ERIC database, for retrieval by anyone through library or Web access. http://www.nectac.org

NATIONAL PARENT INFORMATION NETWORK (NPIN) a project of the ERIC system, which is administered by the National Library of Education in the U.S. Department of Education, provides access to research-based information about the process of parenting, and about family involvement in education. Designed and maintained by two ERIC clearinghouses: the ERIC Clearinghouse on Urban Education at Teachers College, Columbia University, New York City; and the ERIC Clearinghouse on Elementary and Early Childhood Education at the University of Illinois at Urbana-Champaign.

http://npin.org

### **GOVERNMENTAL RESOURCES**

CALIFORNIA EARLY START is for children with or at risk of developmental delay or disability, as they can receive an "Early Start" in the State of California. Teams of service coordinators, health care providers, early intervention specialists, therapists, and parent resource specialists can evaluate and assess an infant or toddler and provide appropriate early intervention services to eligible children.

http://www.dds.ca.gov/EarlyStart/ESHome.cfm

UNITED STATES OFFICE OF SPECIAL EDUCATION (OSEP) is dedicated to ensuring the rights of and improving results for infants, toddlers, children and youth with disabilities, ages birth through 21, and their parents by providing leadership and financial support to assist states and local districts. OSEP administers the federal legislation Individuals With Disabilities Education Act (IDEA). IDEA authorizes formula grants to states, and discretionary grants to institutions of higher education and other nonprofit organizations to support research, demonstrations, technical assistance and dissemination, technology and personnel development, parent training and information centers. http://www.ed.gov/offices/OSERS/OSEP/index.html

CALIFORNIA DEPT. OF EDUCATION-SPECIAL EDUCATION DIVISION (CDE-SED) SED is the department that is responsible for special education services to children with special needs throughout the state. http://www.cde.ca.gov/spbranch/sed

CALIFORNIA DEPT. OF DEVELOPMENTAL SERVICES (DDS) is the agency through which the State of California provides services and supports to children and adults with developmental disabilities. These disabilities include mental retardation, cerebral palsy, epilepsy, autism and related conditions. http://www.dds.ca.gov

### ADVOCACY AND LEGAL RESOURCES

PROTECTION & ADVOCACY, INC. (PAI) works in partnership with persons with disabilities to protect, advocate for, and advance their human, legal and service rights. http://www.pai-ca.org/Index.htm

CHILD CARE LAW CENTER (CCLC) is a national nonprofit legal services organization that uses legal tools to make high-quality, affordable child care available to every child, every family and every community. Devoted exclusively to the complex legal issues that affect child care, encompassing public benefits, civil rights, housing, economic development, family violence, regulation and licensing, and land use. http://www.childcarelaw.org

DISABILITY RIGHTS EDUCATION DEFENSE FUND (DREDF) was founded in 1979 by people with disabilities and parents of children with disabilities. DREDF is a national law and policy center dedicated to protecting and advancing the civil rights of people with disabilities through legislation, litigation, advocacy, technical assistance, and education and training of attorneys, advocates, persons with disabilities, and parents of children with disabilities. http://www.dredf.org

Compiled by Mardi Lucich, MA (4/03) California Childcare Health Program www.ucsfchildcarehealth.org

# **Special Health Care Plan**

The special health care plan defines all members of the care team, communication guidelines (how, when, and how often), and all information on appropriately accommodating the special health concerns and needs of this child while in child care.

Name of Child:	_ Date:
Facility Name:	_
<u>Description of condition(s)</u> : (include description of difficulties associated with each condition	ion)
Team Member Names and Titles (parents of the child are to be included)	
Care Coordinator (responsible for developing and administering the Special Health Care Plan):	
① If training is necessary, then all team r	members will be trained.
☐ Individualized Family Service Plan (IFSP) attached ☐ Individualized Education	eation Plan (IEP) attached
Outside Professionals Involved	<u>Telephone</u>
Health Care Provider (MD, NP, etc.):	
Speech & Language Therapist:	
Occupational Therapist:	
Physical Therapist:	
Psychologist/Mental Health Consultant:	
Social Worker:	
Family-Child Advocate:	
Other:	
Communication	
How the team will communicate (notes, communication log, phone calls, meetings, etc.):	
How often will team communication occur:	□ Bi-monthly □ Other
Date and time specifics:	<del> </del>

Sp	ecific Medical Information				
*					
	Information Exchange Form completed by health care provider is in child's file on site.				
*	Medication to be administered: ☐ Yes† † ☐ No††				
	Medication Administration Form completed by health care provider and parents are in child's file on site (including: type of medications, method, amount, time schedule, potential side effects, etc.)				
	y known allergies to foods and/or medications:				
Spo	ecific health-related needs:				
_					
_					
_					
_					
	nned strategies to support the child's needs and any safety issues while in child care: (diapering/toileting, outdoor play, circle time, /sleeping, etc.)				
_					
_					
Pla	n for absences of personnel trained and responsible for health-related procedure(s):				
_					
_					
Otl	ner (i.e., transportation, field trips, etc.):				
Ou	(i.e., aunsportation, note also, vie.).				
<u>Sp</u>	ecial Staff Training Needs				
Tra	nining monitored by:				
1)	Type (be specific):				
	nining done by: Date of Training:				
	Type (be specific):				
	nining done by: Date of Training:				
	Type (be specific):				
	nining done by: Date of Training:				
<u>Eq</u>	uipment/Positioning				
	The second secon				
Spo	ecial equipment needed/to be used:				
_					
Pos	sitioning requirements (attach additional documentation as necessary):				
Eq	uipment care/maintenance notes:				

# **Nutrition and Feeding Needs**

Behavior Changes (be specific when listing changes in behavior that arise as a result of the health-related condition/concerns)						
Additional Information (include any unusual episodes that might arise while in care and how the situation should be handled)						
Su	pport Programs the Child Is Involved with Outside of Child (	<u>Care</u>				
1.	Name of program:	Contact person:				
	Address and telephone:					
	Frequency of attendance:					
2.	Name of program:					
	Address and telephone: Frequency of attendance:					
	rrequency of attendance.					
3.	Name of program:					
	Address and telephone:					
	Frequency of attendance:					
<u>En</u>	nergency Procedures					
	Special emergency and/or medical procedure required (additional documents	tion attached)				
En	ergency instructions:					
Em	ergency contact:	Telenhone:				
2						
Fo	llow-up: Updates/Revisions					
This Special Health Care Plan is to be updated/revised whenever child's health status changes or at least every months as a result of the collective input from team members.						
Du	Due date for revision and team meeting:					

☐ Nutrition and Feeding Care Plan Form completed by team is in child's file on-site . See for detailed requirements/needs.

# Early Warning Signs

ll children develop at different rates and in different ways. Some children are born with special needs that can affect their growth and development. Other children may not show developmental problems, delays, or differences until later in childhood. Fortunately, many of these children can get the support they need to reach their potential if parents and child care providers recognize the signs of need early and get help.

The Early Warning Signs described on these pages are only a few of the indicators that a child may need further observation and assessment. If, for any reason, you suspect that your child or a child in your care may have special needs, we urge you to seek help immediately. The period from birth to age three is the best time to help the child and you may prevent more serious problems from occurring later. DON'T WAIT until the child enters kindergarten before you ask for assistance!

If you suspect that your child or a child in your care may have special needs, call or help the child's parents call the local school district or the special education program of the county office of education. Representatives of those agencies may schedule an assessment to see if the child qualifies for services. Parents must give written permission for the child to be tested and receive special education. All services are confidential and provided at no cost to the family.

For concerns regarding children birth to age three, call the California Department of Developmental Services at 1-800-515-BABY (2229). You will be provided with information on resources in your local community or your Family Resource Center for parent-to-parent support.

### **Risk Factors**

The following situations place children at greater risk for health and developmental difficulties:

- Prematurity and/or low birth weight
- Prenatal or other exposure to drugs, alcohol, or tobacco
- Violence in the community or home
- Poor nutrition
- Family stress (for example, poverty, poor housing, homelessness, death in the family)



### **General Behavior**

Some behaviors may be causes for concern or just part of the child's temperament or personality. The following behaviors should be looked at in light of the whole child.

- By six months of age, avoids being held or talked to or resists being soothed and comforted.
- Does not pay attention or stay focused on an activity for as long a time as other children of the same age do.
- Avoids or rarely makes eye contact with others.
- Gets unusually frustrated when trying to do simple tasks that most children of the same age can do.
- Often acts out; appears to be very stubborn or aggressive.
- Acts extremely shy or withdrawn.
- Does not like being touched.

- Does not like having certain types of materials or clothing next to body.
- Treats other children, animals, or objects cruelly or destructively.
- Tends to break things a lot.
- Displays violent behavior (tantrums, fighting, screaming, or hitting other children) on a daily basis.
- Stares into space, rocks body, or talks to self more often than other children of the same age.
- · Often bangs head against an object, floor, or wall.
- Does not recognize dangerous situations, such as walking in traffic or jumping from high places.
- Tends to be sick often; complains of headaches or stomachaches.
- Has sleeping, feeding, eating or toileting problems.
- Is overly impulsive, active, or distractible.
- Does not respond to discipline as well as children of the same age.
- Has difficulty putting thoughts, actions, and movements together.
- Does not seek approval from parent or caregiver.

### **Hearing**

### The child...





- Has had many ear, nose, or throat infections or allergies.
- By four months, does not look at the source of sounds or voices or react to
- Talks in a very loud or very soft
- Seems to have difficulty responding when called from across the room, even when it is for something interesting.
- Turns body so that the same ear is always turned toward a sound.
- Breathes through mouth.
- Has difficulty understanding what is said.

# That your child or a child in your care may need help

### Moving

The child...

- Has stiff arms or legs.
- Has floppy or limp body posture.
- Uses one side of the body more than the other.
- Has poor coordination or moves in a disorganized, clumsy manner compared with other children of the same age.
- At three months, still has difficulty holding head up.
- By age one, has difficulty sitting without help, standing up, reaching for objects, or picking up objects with thumb and index finger.
- By age two, has difficulty walking without help, kicking a large ball, scribbling, or building a tower with two or three blocks.
- By age three, does not walk up or down stairs, run without falling frequently, or turn pages of a book.
- By age four, has difficulty with such activities as standing on one foot, jumping from a bottom step, pedaling a tricycle, catching a large bounced ball, closing a fist, or wiggling a thumb.
- By age five, has difficulty skipping using alternate feet, pumping self on a swing, or cutting with scissors.

### Seeing

The child...

- Rubs eyes frequently.
- · Seems to have difficulty following objects or people with eyes.
- · Has reddened, watering, or crusty eyelids.
- Holds head in a strained or unusual position when trying to look at an
- · Has difficulty focusing or making eye contact.

- Seems to have difficulty finding or picking up small objects dropped on the floor.
- Closes one eye when trying to look at distant objects.

### **Communicating**

The child...

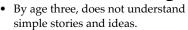
- By age six months, rarely makes sounds like cooing or gurgling.
- Is unusually quiet.
- Does not shake head no.
- By age one, does not understand first words, such as milk, bottle, or
- By age one, does not say mama or dada.
- By age two, rarely names family members and/or common objects.
- By age two, does not speak in twoword phrases.
- By age two, does not point to objects or people to express want or need.
- By age three, does not know last name, gender, or common rhymes.
- By age three, does not follow simple directions or speak in three- or fourword sentences.
- By age four, does not tell stories, either real or make-believe, or ask frequent questions.
- · By age four, does not speak in fouror five-word sentences and has speech that is not understandable by adults.
- By age five, does not know age and cannot answer who, what, where, when or why questions or use various types of sentences.

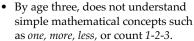
### **Thinking**

The child...

- By age one, has a hard time figuring out simple problems, such as finding an object after seeing it hidden.
- By age two, does not identify simple body parts by pointing, match

similar objects, or recognize self in a mirror.



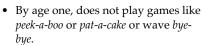


- By age four, does not give correct answers to questions, such as What do you do when you are sleepy or hungry?
- By age four, cannot tell the difference between different shapes or
- By age five, does not understand the concepts of today, tomorrow, or yesterday.

### **Playing**

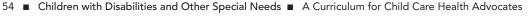
The child...

• By three months, does not coo or



- By age two, does not imitate parent or caregiver doing routine tasks such as washing dishes, cooking, or going to work.
- By age three, tends to play alone more than with other children.
- By age three, does not play purposefully or initiates play through pushing and hitting.
- By age three, does not interact with adults and children outside the
- By age four, does not play makebelieve games and group games such as hide-and-seek with other children.
- By age five, does not share and take
- By age five, does not express concern or compassion, when appropriate.
- By age five, does not show off occasionally.





# GLOSSARY OF TERMS RELATED TO CHILDREN WITH DISABILITIES AND OTHER SPECIAL NEEDS

Abduction wedge (or splint): an adaptive device made of firm foam used to keep the legs apart.

**Abrasion:** a wound in which the surface layers of the skin have been scraped away.

Acquired immune deficiency syndrome (AIDS): a group of symptoms developing in a person who is HIV-positive, arising from severe impairment of the immune system.

Adaptive equipment: any assistive device, commercial or homemade, used to maximize the ability to function and minimize efforts needed to interact with one's environment.

Americans with Disabilities Act (ADA): federal legislation that gives civil rights protections to individuals with disabilities, including equal opportunity in employment, public accommodations, transportation, government services and telecommunications. ECE programs fall under the public accommodations category.

Apnea: a condition in which breathing stops for 20 seconds or longer. An apnea monitor is a mechanical device used to document stoppages of breathing in infants.

**Atonic:** lacking muscle tone.

Autism: a form of a pervasive developmental disorder characterized by disturbances of social, language and thinking skills.

**Catheter:** a flexible tube to administer fluids to or drain fluids from the body.

Cerebral palsy (CP): a disorder of movement and posture control resulting from nonprogressive damage to the brain during fetal life, the newborn period or early childhood. Both genetic and acquired factors may be involved. It may be caused by a lack of normal fetal brain development or by injury to the brain.

**Colostomy:** a surgically created opening to allow the colon to pass feces directly through the abdominal wall, bypassing part of the digestive tract. To collect the waste, a colostomy bag is attached to the skin at the point where the colon is brought through the abdominal wall.

Congenital/birth defect: a problem present at birth, such as congenital heart disease or cleft palate. Birth defects can be inherited (genetic); occur due to a factor of the pregnancy (such as maternal illness, drug use, x-ray or physical factors in the uterus); occur due to a chromosomal abnormality; or occur during childbirth.

Cystic fibrosis (CF): an autosomal recessive disorder characterized by abnormally thick secretions, which contribute to chronic lung damage, and lack of the enzymes needed to break down and absorb fats, which causes malnutrition. Cystic fibrosis is a serious illness that nearly always shortens a child's life expectancy.

**Developmental delay:** the condition of an infant or young child who is not achieving new skills in the typical time frame or is exhibiting behaviors that are not appropriate for his or her age.

Developmental disability/disorder (DD): any physical or mental condition (such as mental retardation, cerebral palsy, epilepsy, autism or neurological disorder) that begins before the age of 18 years, causes the child to acquire skills at a slower rate than his or her peers, is expected to continue indefinitely and impairs the child's ability to function normally in society.

- Diabetes mellitus: a chronic disorder of carbohydrate metabolism characterized by abnormally high sugar levels in the blood and sugar in the urine; excessive urination and thirst; and sometimes by an abnormally large intake of food, weight loss and excessive acidity of body fluids. Diabetes mellitus results from inadequate production or utilization of insulin (a hormone that regulates the metabolism of blood sugar). Some children with diabetes mellitus are insulin-dependent (because the body produces little or no insulin) and therefore require insulin therapy (this is referred to as Type I). Others are noninsulin-dependent (the body produces more insulin), and the disease can usually be controlled by diet and medication, although insulin therapy is sometimes needed (this is referred to as Type II).
- **Down syndrome:** a genetic disorder caused by a chromosomal abnormality. Down syndrome results when there is an extra (a third) chromosome 21, or extra part of chromosome 21, in the body's cells.
- **Early intervention:** specialized services provided to infants and toddlers who are at risk for, or are showing signs of, developmental delay. Services emphasize the continued development of basic skills through planned interactions that will minimize the effects of the child's condition.
- **Early interventionist:** a professional who is trained to assess or plan and implement a program that addresses the infant or young child's developmental need.
- **Early Periodic Screening, Diagnosis, and Treatment (EPSDT):** The EPSDT is a schedule of recommended well-child preventative health visits to a health care professional. The EPSDT chart advises the health care professional on the types of screening and exams that are recommended at each well-child visit.
- **Epilepsy:** a condition characterized by recurrent seizures that is caused by abnormal electrical activity in the brain. Seizures can occur for many reasons, including damage to the brain due to infection, injury, birth trauma, tumor, stroke, drug intoxication and chemical imbalance.
- **Febrile seizure:** the most common type of seizure in children under the age of 5 that is associated with a high fever, occurring especially when the temperature is rapidly rising. These seizures are not considered a form of epilepsy.
- **Fetal alcohol syndrome (FAS):** a combination of congenital abnormalities that is caused by maternal consumption of alcohol during pregnancy. Characteristics may include growth deficiency, mental retardation, attention deficit/hyperactivity disorder, motor delays and congenital anomalies, such as characteristic facial appearances.
- **Fine motor:** the developmental area that involves skills, which require the coordination of small muscles of the body, including those of the hands and face.
- **Gross motor:** the developmental area that involves skills, which require the coordination of large muscle groups, such as those in the arms, legs and trunk.
- **Hydrocephalus:** an abnormal accumulation of cerebrospinal fluid in the ventricles of the brain. Hydrocephalus occurs when too much cerebrospinal fluid is produced, when the circulation of blood is blocked or when both conditions are present. It can occur as a congenital anomaly or as a result of brain injury, infection, bleeding or tumor. Persons with hydrocephalus are treated by draining away the excess fluid via a shunt that channels the fluid to another part of the body where it is absorbed.
- **Inclusion:** the full and active participation of children with disabilities with, and in programs for, typically developing children. Inclusion is when a child with a disability is included in a setting in which children who do not have disabilities participate (the program or classroom setting would exist even if there were no children with special needs enrolled).

- Individualized Education Plan (IEP): a written plan required by the Individuals with Disabilities Education Act (IDEA) for all children in special education, ages three years and up. The IEP includes a statement of the child's current level of development (abilities and difficulties) and an individualized plan of instruction, including the goals, specific services to be provided, the people who will carry out the services, the standards and time lines for evaluating the progress made, and the amount and the degree to which the child will participate with nondisabled peers in school. The child's parents and the professional who evaluated the child develop the IEP.
- Individualized Family Service Plan (IFSP): a written early intervention plan describing the child's current level of development; the family's strengths and needs related to enhancement of the infant's or toddler's development; goals for the child and the other family members, including criteria, procedures and time lines used to evaluate progress; and the specific early intervention services needed to meet the goals. The IFSP is developed and implemented by the child's parents and a multidisciplinary early intervention team.
- Individuals with Disabilities Education Act (IDEA): federal legislation mandating special education for all eligible children. IDEA guarantees children with disabilities a free appropriate public education, an education in the least restrictive environment, related services and fair assessment in the delivery of special education services to children with disabilities from birth to age 21. The law has four parts: (1) Part A covers the general purpose of the law and definitions; (2) Part B addresses the requirements for the education of all children with disabilities from age 3 to 21 years; (3) Part C addresses the specific requirements for services to infants and toddlers (birth to 36 months of age) with disabilities and their families; and (4) Part D authorizes national activities to improve special education services (research, personnel development, technical assistance and state improvement grants).
- Informed consent: parents or legal guardians have been fully informed of all information relevant to the requested activity for which consent is being sought, understands the activity and agrees in writing to the implementation of the activity. A signed, written consent must be obtained prior to any information released to or shared with other agencies. Informed consent must be given prior to an initial evaluation and all other evaluations, and prior to the implementation of the initial IEP/IFSP. All information must be in the parents' first or primary language.
- **Least restrictive environment (LRE):** Required by IDEA, it applies to children receiving *special education* services in a setting and through activities where children who are typically developing may be found (e.g., regular class placement, child care setting).
- Mental impairment: conditions such as behavior disorders, emotional or mental illnesses, learning disabilities and mental retardation.
- **Nebulizer:** a device used to administer medications in mist form for inhalation.
- Occupational therapy (OT): therapeutic treatment aimed at helping children who are ill, injured or disabled develop and improve self-help skills and adaptive behavior and play. The goal is to address a child's motor, sensory and postural development with the overall objective of preventing or minimizing the impact of impairment and developmental delay, and promoting the acquisition of new skills to increase the child's ability to function independently.
- Oxygen therapy: treatment in which oxygen-enriched air is supplied to the child who has hypoxia (a lack of sufficient oxygen in the body cells or blood) or breathing difficulties.
- **Phenylalanine (PKU):** a genetic disorder in which the ability to break down phenylalanine (an amino acid) causes a buildup of amino acids in the body. If the condition is not diagnosed soon after birth, the buildup leads to mental retardation.

- Physical impairment: conditions such as blindness, deafness, seizures, heart disease, cerebral palsy, asthma and diabetes.
- Physical therapy (PT): therapeutic treatment designed to prevent or alleviate movement dysfunction through a program tailored to the individual child. The goal is to develop muscle strength, range of motion, coordination and endurance; to alleviate pain; or to attain new motor skills.
- **Referral:** a formal request to evaluate a child to determine if he or she is in need of early intervention or special education services.
- Regional centers: private, nonprofit agencies responsible for providing services to persons with developmental disabilities from birth through adulthood. Some share primary responsibility for coordinating or providing local-level early intervention, developmental and educational services for children less than 3 years of age with local education agencies.
- Resource and referral (R&R) programs: agencies that provide information to the community, including referrals and coordination of resources for parents, and public and private providers of child care. Services include, but are not limited to the following: technical assistance for providers, toy-lending libraries, equipment-lending libraries, staff development programs, health and nutrition education, and referrals to social service.
- Respite care: skilled caregiving service that can be provided to the parent of a child who is disabled or seriously ill. Respite care allows parents time away from home for several hours or overnight to rest or attend to other needs. Respite care is provided in the family's home or the home of the care provider.
- Seizure: involuntary movement or changes in consciousness or behavior brought on by abnormal bursts of electrical activity in the brain.
- **Sensory integration:** the ability of the central nervous system to receive, process and learn from sensations (such as touch, movement, sight, sound, smell and the pull of gravity) in order to develop skills.
- **Shunt:** a surgical procedure in which a catheter (tube) is placed to divert an accumulation of fluid.
- Sickle cell anemia: an autosomal recessive hemoglobin abnormality characterized by the presence of crescentor sickle-shaped red blood cells. It is a serious disease, which can render the child vulnerable to bacterial infections (because the spleen functions poorly), painful cries (periods of obstructed capillary blood flow and inadequate oxygen supply that are symptomized by fever and pain in joints and abdomen) and apastic anemia. Sickle cell anemia occurs primarily in African-Americans and is an incurable disease.
- Special education: specialized instruction and needed related services modified or designed, at no cost to parents or legal guardians, to meet the individual needs of a child with disabilities, from age 3 through 21 years. A major goal of special education is to teach the skills and knowledge the child needs to be as independent as possible. Consequently, the focus is not just on academics, but also includes special therapeutic and other related services to help the child overcome difficulties in all areas of development. Special education and related services may be provided in a variety of educational settings, but are required by IDEA to be delivered in the *least restrictive environment*.
- **Speech disorder:** a condition that affects the ability to speak. Speech disorders include articulation problems, such as sound substitutions (saying wan instead of ran); rate and rhythm problems, such as stuttering; and voice production (resonance) disorders, such as a voice that is too soft or hypernasal. Speech disorders are often associated with another disorder, such as cerebral palsy, but can occur on their own.

- Spina bifida: a birth defect in which part of the spinal column (one or more vertebrae) fails to close completely, exposing membranes covering the spinal cord, or the membranes and the spinal cord. Sometimes the membranes and cord protrude out through the back of the spine. The severity of the damage depends on the degree and placement of the exposure, and can range from no apparent damage to paralysis below the level of the protrusion and severe brain damage. Spina bifida is often associated with hydrocephalus.
- Support/related services: specialized services designed to promote the healthy physical, mental, social and emotional growth of children. Appropriate services which a child with disabilities needs in order to benefit from his or her educational program as required by his or her IEP/IFSP. These include, but are not limited to the following: protective services, parent training, provider and staff training, transportation, parent and child counseling, child development resource and referral services, speech-language therapy, physical therapy and child placement counseling.
- Tactile defensiveness: an abnormal sensitivity to touch indicated by an infant's avoidance or rejection of touching or handling. Tactile defensiveness may be a result of having difficulty with processing and discriminating tactile stimulation.
- **Tracheostomy:** a surgical procedure in which an opening is made through the base of the throat and into the trachea to create an airway. A tracheal tube (the tube through which the child breathes) is inserted into the opening and the child will then either breathe room air or, if he or she cannot breathe without assistance, have the tube connected to a ventilator.
- **Ventilator:** a mechanical device used to provide assisted breathing for the child who cannot breathe on his or her own. The ventilator pumps humidified air (with a measured amount of oxygen) into the lungs via an endotracheal tube or tracheostomy tube.

Coleman, J. (1999). The Early Intervention Dictionary: A Multidisciplinary Guide to Terminology, Second Edition. Bethesda, MD: Woodbine House, Inc.

Torrey, V., Krajieck, M., Steinke, G., Hertzberg, D., Anastasiow, N., & Sandall, S., Eds. (1998). First Start Program for the Care of Infants, Toddlers, and Young Children with Disabilities and Chronic Conditions. Austin, Texas: Pro-ed Publisher.

# The Map to Services for Children with Special **Needs** and Their Families

Created by Pamm Shaw, Consultant, WestEd

Many families and child care providers have questions about children's development. Although many resources are available to both families and providers, trying to navigate and understand the system for delivering services can be confusing and overwhelming. Both legal and practical information is provided to help you. This chart has been developed and reviewed by parents, providers, and professionals to help other parents understand the system for delivering services to children with special needs. Please call the California Child Care Healthline at 800-333-3212 if you have questions or comments about the information or have a concern about your child.

### **OUESTIONS OR CONCERNS**

# **Birth**

Child appears to have difficulty relating to caregiver or does not meet typical developmental milestones or demonstrate age-appropriate behavior.

### Providers can:

- · Observe the child and provide developmental information to the parent.
- · Share information regarding the child's interests, interactions, and behaviors at home and in the child care setting.
- Work closely with families to identify specific areas of concern.
- · Refer to medical provider to rule out any physical causes, including vision and hearing problems.
- · Discuss with the family the option to refer their child to the California Early Start Program. Call the Babyline at 800-515-BABY for information and referral sources
- Call the California Child Care Healthline at 800-333-3212 for more information.

Children from birth to three years may qualify for early intervention services in the Early Start Program.

The parents may refer their child directly to an Early Start Program or have their health care provider or other professional make the referral. Parents do not have to make that first call. After the referral, the parents will be contacted, informed of their rights as parents under the law, and asked whether they wish to initiate services. A service coordinator will be assigned to assist the family.

Parents have the right to an evaluation of their child's performance. Referrals should be made to the local regional center or school district. Call the Department of Developmental Services at 800-515-2229 to obtain the phone numbers in your area.

### **EVALUATION AND ASSESSMENT**

Evaluation may determine whether the child has a delay or disability; identify the child's strengths and concerns about development; and help in planning for intervention.

Children referred to the Early Start Program are evaluated by means that are not racially or culturally discriminatory. Evaluation is conducted in the following developmental areas: physical (includes vision, hearing, and health status), cognitive development, communication development, social or emotional development, and adaptive skills.

Evaluation and assessment:

- · Are conducted by a multidisciplinary team of qualified personnel that consist of a nurse, psychologist, educator, or therapists.
- Identify the infant or toddler's unique strengths and needs.
- · With family consent, identify their resources, priorities, and concerns in the language of the parents' choice.
- Must be completed within 45 days of referral.
- · Should be ongoing as child develops and grows.

### Child is having difficulty at home or in child care and is 3 to 5 not developing as are other children of the same age. Child care providers can:

Use the brochure Early Warning Signs as a guide. Concerns for preschool children may include the

- Has limited understanding and use of language
- · Does not play with other children
- Has very short attention span
- · Overly aggressive or frequently hurts self or others
- · Frequently falls, is clumsy, has poor motor coordina-

Discuss parents' perception of child's strengths and any

Have parents observe their child in the child care

Maintain open and ongoing communication with the family and school.

Parents should call the local school district or county office of education to make a referral. Other agencies and child care programs may contact the schools, but only with written consent of the family.

- · The family should contact the regional center (call 800-515-BABY for the local contact) if a developmental disability is suspected. Regional centers have 15 working days to complete the intake process.
- A referral to the health care provider should be made to rule out physical or health causes.

School districts evaluate children to determine whether they qualify for special education and related services. Written parent permission is required for the evaluation.

Health care and other professionals should stay informed and involved. Information from child care staff may be included as part of the assessment

- Must be done in the primary language of the child by a team of professionals
- May be conducted in group care settings, including child care.
- Should be unbiased.
- · Should be completed in all areas of the suspected disability.

Parents have the right to request an assessment of their child for eligibility with the regional center if a disability is present. There are legal timelines to the process. For information regarding all parental rights and entitled services in the regional center system, call Protection & Advocacy, Inc., at 800-776-5746.

# 5 and

School-age children are typically identified because of behavior or academic problems in school, such as the following:

- · Not doing well in school, even after accommodations are made and educational support is provided in the regular classroom
- Does not complete or forgets to turn in homework frequently
- Has learning or behavior problems
- Not reading by second grade

### Child care providers can:

- Support families listen and share what works.
- · Identify key areas that may be cause for concern.
- · Maintain open and ongoing communication with the family and school.

For older elementary and middle school children:

- · Problems may occur as children enter a new school or change classes.
- Social problems may give parents and providers cause for concern beyond the typical entry into adolescence.
- · Child care for children with special needs is more difficult to obtain because typical children of this age are often not in group care settings.

Parents may contact the special education department in their local school or district office to make a referral.

If a child has a developmental disability, parents should also contact the local regional center.

Child care providers may obtain written consent from the family to allow communication between the child care program and the school district to coordinate referral and possible serSchools evaluate children with written consent of the parent.

### Assessment:

- · Can identify differences between the child's ability and how well s/he is doing in school.
- Identify social problems.

Student study teams (SSTs) are available at most schools to observe and assess children. SSTs are not required to follow any timelines or provide due process rights for parents, unlike special education. Parents may bypass the SST and make a referral directly to special education.

The law requires a functional behavioral assessment by mental health professionals for children with severe behaviors. The assessment must be conducted before a child is suspended or expelled from school.

### **ELIGIBILITY**

Eligibility for services is based on the results of the evaluation and includes one or more of the following conditions:

- 1. Significant delays in one or more of the following developmental areas: cognitive; physical and motor, including vision and hearing; communication; social or emotional; or adaptive (self-help).
- 2. "Established risk conditions" means having a high probability of leading to developmental delay (e.g., Down syndrome).
- 3. High risk of having a developmental disability due to a combination of biomedical risk factors (e.g., low birth weight, prematurity, or medical complications).

For children who do not qualify for services, a meeting is held to discuss the evaluation results. Families and providers can request specific suggestions for working with the child. The child care provider may attend the meeting if the parent so requests.

### PROGRAM PLANNING

Individualized family service plans (IFSPs) are developed for infants and toddlers who qualify for the Early Start Program and include the following information:

- Child's present level of development
- If the family consents, the resources, priorities, and concerns of the family
- Major outcomes desired for the child/family
- Specific early intervention and other appropriate services necessary
- Dates for initiation and duration of services
- Name of the service coordinator responsible for implementation and coordination with other agencies and persons
- · Planning for the child's transition at age 3 to a preschool program or other community services
- Informed written consent of parents or guardian

Child care providers may attend IFSP meetings if the parent requests their presence.

The IFSP meeting is conducted in the language of the family or through the use of interpreters.

### SERVICES

A variety of services may be offered to promote the child's development and support the family.

Services are provided in natural environments, such as:

- · The child's home
- · The child care center and/or family child care homes
- Other settings where there are typically developing children

A listing of services for children who are eligible can be found on the following page.

### TRANSITION OR PERIODIC REVIEW

The IFSP must be reviewed every 6 months or as needed or requested.

The Early Start Program ends when the child turns 3. A transition plan to preschool is written as part of the IFSP when the child is 2 years, 9 months (or earlier if needed) to prepare for the change in program.

The service coordinator facilitates the transition and the exchange of information between regional centers, schools, and other agencies.

Transition steps may include:

- Obtaining parental consent for a referral to the school district for special education services
- Obtaining parental consent for referrals to other community agencies
- Arrangements for evaluations to determine eligibility for special education services at age 3
- Developing an individualized education plan (IEP) to be implemented by age 3

At the request of parents, child care providers may give recommendations for the transition process, information to preschool programs, and support to families.

To qualify for special education services, children  $3\ to\ 5\ years\ of\ age\ must\ meet\ one\ of\ the\ following$ criteria:

- I. The child has a significant delay in one of the following skill areas: gross or fine motor development, receptive or expressive language, social or emotional development, cognitive development, or visual development.
- 2. The child has a moderate delay in any two areas above.
- 3. The child has a disabling condition or established medical disability that can include autism, deaf-blindness, deafness, hearing impairment, mental retardation, multiple disabilities. orthopedic impairment, other health impairment, serious emotional disturbance, specific learning disability, speech or language impairment, traumatic brain injury, or visual impairment

Individualized education programs (IEPs) are developed for children who qualify for special education and contain the following information:

- · Present levels of educational performance
- Measurable annual goals and short-term objectives
- · Services related to special education
- Supplementary aids and services and program modifications or supports provided for school personnel
- Explanation of why child will not participate in the regular class
- · Individual modifications needed to participate in state and districtwide assessments
- Projected dates to begin services, the frequency, location, and duration; dates of modifications
- How child's progress is measured and how parents will be regularly informed

School districts develop a "504 Plan" for children with a disability who require adaptation or services but do not qualify for special education. This can be used for children with health problems (e.g., asthma, diabetes, seizures) and attention deficit disorder.

Regional centers develop an individualized program plan (IPP) for children who qualify for their services. Services are provided in the least restrictive environment as decided by the IEP team, which may include the home, preschool, or child care setting.

A listing of preschool special education services for children who qualify may be found on the following page.

Regional center services are based on the child/family needs as identified on the IPP. The services are listed on the following page.

Child care providers may invite special education and other specialist staff to observe the child in your program, show you what to do, and give you information on how to best improve the child's skills and meet his/her needs. The specialists can also learn by seeing the child in a "typical" setting with "typical" children.

An appropriate reassessment should be conducted before the child enters kindergarten to determine whether s/he still needs special education and to plan for the appropriate services and supports

Families should visit sites and determine the best program based on the child's strengths and family concerns

Child care providers help families by:

- Providing support,
- Preparing the child/family for change,
- Accompanying the parent on site visits, and
- Talking with staff of special education and other programs regarding the child's strengths and

Children qualify for special education services under the following categories:

Hearing impairment

Visual impairment

Language or speech disorder

- · very difficult to understand
- · abnormal voice
- fluency disorder (stuttering)
- · language disorder (speaking or understanding)

Severe orthopedic impairment

Other health impairments (chronic or acute health problems)

Autistic-like behaviors

Mental retardation

Emotional disturbance

Specific learning disabilities Traumatic brain injury

If the child has a developmental disability, s/he continues to be eligible for services at the regional center

Child care providers can:

- · Get parents' permission to share relevant information about the child between the service providers and the child care staff.
- · Request assistance and communicate with specialists to get information about children to plan better and support them.
- · Ask for help by inviting the special education staff to visit the child care program and offer recommenda-
- Participate as part of the team to develop and implement the IEP.

Specialized programs and vocational and recreational services are available in communities. Some programs provide services before and after school. Contact the local parks and recreation programs, Special Olympics, or AYSO (American Youth Soccer Organization).

Since most children of this age are in school, special education services are typically provided in school during school hours.

- · Children may be bused to other service providers (e.g. CCS-Medical Therapy Units for occupational and/ or physical therapy).
- Services must be provided in the least restrictive environment (e.g., school, home, or private school). Special education consultation or services are allowed to be provided in a child care setting.

Regional center services continue for children who remain eligible.

As children in special education go from one service to another or one class to another (e.g., from speech therapy to resource room or learning center or to a special day class), they make transitions.

For older children with special needs, transition to high school may be difficult; children and families need much support at this time. Beginning at age 14, each child with a disability must have a transition plan in the IEP.

221 PINE STREET, 3<sup>RD</sup> FLOOR ◆ SAN FRANCISCO ◆ CALIFORNIA 94104 TELEPHONE: 415.394.7144 ◆ FAX: 415.394.7140 ◆ E-MAIL: info@childcarelaw.org

# **Questions & Answers about the Americans with Disabilities Act: A Quick Reference** (Information for Child Care Providers)

### 1. What is the ADA?

The Americans with Disabilities Act (ADA) is a federal civil rights law which was passed in 1990. Among other things, the ADA prohibits discrimination by child care centers and family child care providers against those individuals with disabilities. States may provide greater protection for people with disabilities than what is guaranteed by the ADA. In California, the Unruh Civil Rights Act prohibits all business establishments, including child care providers, from discriminating on the basis of disability. <sup>2</sup> The Unruh Civil Rights Act goes much further than the ADA in its protections for children with disabilities.

# 2. Who is protected by the ADA?

Four groups receive protection under the ADA. They are:

People with a physical or mental impairment which substantially limits one or more major life activities (when determining whether one has a substantial limitation, one takes into account any

- corrective measures they use, such as medication);
- People with a **history of** a physical or mental impairment which substantially limits one or more major life activities;
- People who are **regarded as** having a physical or mental impairment which substantially limits one or more major life activities: and
- People who are associated with people who have a physical or mental impairment which substantially limits one or more major life activities.

# 3. What does the ADA require of providers?

The ADA requires that providers not discriminate against persons simply because they have disabilities. Instead, they are to make a case-by-case assessment of what the person with the disability requires to be fully integrated into the program. Once they know what is needed, they must assess whether reasonable accommodations can be made to allow this to happen.

<sup>&</sup>lt;sup>1</sup> 28 Code of Federal Regulations § 12201(b).

<sup>&</sup>lt;sup>2</sup> California Civil Code § 51 (West 2000).

# 4. Who determines if the accommodation is reasonable?

The ADA sets out three primary types of accommodations (changes in policies, practices, or procedures, removal of barriers in existing programs, and provision of auxiliary aids and services—special equipment and services to ensure effective communication). Making these accommodations is required unless:

- In the case of changes in policies, practices or procedures, the accommodation would fundamentally alter the nature of the program;
- In the case of auxiliary aids and services, the accommodation would fundamentally alter the nature of the program or pose an undue burden (significant difficulty or expense)
- In the case of the removal of barriers in an existing program, the accommodations are not readily achievable (cannot be done without much difficulty or expense).<sup>3</sup>

What is "reasonable" will vary, depending on the accommodations requested and the resources available to the program. Generally speaking, less will be required of a family child care home which typically has fewer resources and staff than a center, but individualized assessments of the child's needs and the program's ability to accommodate always need to occur to determine what is reasonable.

The most important thing is to undertake a process of dialogue with the parents to determine what accommodations are necessary and whether they are reasonable to the program. It should be the goal of both the parents and the provider to reach an informal resolution whenever possible.

Ultimately, if the parent and the provider cannot agree, it is a court that determines if the accommodation requested is reasonable.

# 5. Are there situations in which care can be refused?

These situations will be very limited. They include situations in which a child poses a direct threat—a substantial risk of harm to others (which must be documented by objective professional evidence) or where the accommodations needed would not be reasonable for the program to provide (see question above for the standards used to determine if an accommodation is reasonable).

# 6. Can I be sued by other parents for taking a child with disabilities?

Not successfully. In fact, the law is to the contrary. Anyone who would interfere with a program's rightful compliance with the law (for example, enrolling a child with disabilities) can be sued for violating the ADA. A high quality program will provide opportunities for parent education which in turn should include discussions of the benefits to all children of inclusive child care.

# 7. What do I do when another parent makes inquiries about a child with disabilities?

Information about a child's disability is confidential and should not be shared with others unless you have consent from the parents of the child with the disability. If you have a respectful relationship with the parents, you may be able to have a conversation with them about how they would like to see you handle inquiries about their child's disability from the parents and the children. Some parents will prefer that information about their child's disability continue to be kept confidential while others may welcome the opportunity to share with other families the nature of their

<sup>&</sup>lt;sup>3</sup> If you are making major renovations or are constructing a brand new facility, the facility must be readily accessible to a child with a disability, almost without exception.

child's disability. When a family is open about a child's disability, not only does the child benefit, but there are also many benefits and advantages for the staff and children in the center.

Once again, one of the best ways to respond to families is outside of the context of a particular child and in the general context of information about what quality care is all about. High quality programs will provide opportunities for parent education, which in turn should include discussions of the benefits to all children of inclusive child care.

# 8. Is there a certain number of children I may care for if I care for a child with special needs?

There is no particular number of children you may care for when you care for a child with special needs, as each child with special needs is different, and there are no special ratios. The provider must evaluate his/her own program keeping in mind the special needs of each child before making the determination of how many children with special needs their program can accommodate.

# 9. Can I charge more for a child with special needs because they require more individualized attention? If I can't how will I survive financially?

When an accommodation is above and beyond a reasonable accommodation, an additional fee may be imposed but a legal consultation should be made with someone knowledgeable with the ADA laws. Programs may not charge the parents of children with disabilities more for providing reasonable accommodations. Programs are free to raise their fees to all families, use tax credits or deductions available from the IRS, or seek resources from outside their programs. Programs may charge parents for the cost of providing additional, non-child care

services, such as physical therapy, occupational therapy and the like. Keep in mind that in many instances, the reasonable accommodations which are necessary are not very costly and/or in the case of improving ratios, could benefit all the children in care.

# 10. I understand that programs may not discriminate, but in addition I want to be clear that my program welcomes children with disabilities. How do I say that in my brochure?

Your materials may include language that states that your "program is fully accessible" or that your teachers "have experience in caring for children with disabilities."

# 11. When I care for a child with special needs who receives a subsidy, may I receive any additional money?

Yes, there are special needs rates and additional funding that may be obtained when caring for children with exceptional needs and severely handicapped children. However, the additional money cannot be charged to the parents, but must be billed to the funding entity. Also, the definitions of "children and with special needs" are interpreted differently from county to county. You should check with your local alternative payment program to determine the practice in your county.

# 12. How can I care for children with disabilities if I am not trained? If I work on my own?

Many of the accommodations children need are not complicated and can be easily learned. In other instances, where training is helpful or necessary, it may be available from the parent, from early intervention or special education specialists, from health professionals, from disability organizations, resource and referral agencies or community colleges. The important thing

is to identify community resources that can assist with inclusion.

# 13. May I automatically decline to serve a child with disabilities and simply refer them on to another provider who I think is better able to serve them?

No. A parent may prefer your care and if it is possible for you to make the reasonable accommodations necessary to serve that child he or she may not be turned away and referred to another program. If a program can document that it undertook an individualized assessment of the situation and found that accommodating the child would not be reasonable the program may then offer suggestions for other potential care.

# 14. Shouldn't providers get to choose who they enroll since it is their business?

By deciding to become professional caregivers, providers become responsible for complying with many types of laws tax laws, licensing laws—as well as civil rights laws, which in the case of ADA, protects people with disabilities from discrimination. It is worth remembering that any of us could become a person with disabilities at any time, and we too may benefit from the ADA's protections.

# 15. If a parent of a child with a disability has conflicts with the provider or the parent fails to comply with rules applied to all families can the family be terminated from the program?

Yes, if it can be documented that the reasons for termination have to do with failure to comply with rules or standards that are: uniformly applied to all families, not relevant to any potential required accommodations, and are not used as pretexts for discrimination. So for example, a recent case found that a mother's belligerence and total lack of cooperation, coupled with her failure to comply with rules imposed on everyone which had nothing to do with her child's disability, would cause her ADA claim to fail.

This document is intended to provide general information about the topic covered. It is believed to be current and accurate as of 10/30/01, but the law changes often. This document is made available with the understanding that it does not render legal or other professional advice. If you need legal advice, you should seek the services of a competent attorney.

### **Useful Resources**

- Call the Child Care Law Center at (415) 394-7144 if you would like information about child care issues. We are a national and California child care support center for legal services programs. We also provide counsel and advice over the telephone. The following are some of our legal services:
  - Answer legal questions regarding child care legal issues during our telephone intake hours: Monday, Tuesday and Thursday from 12p.m. to 3p.m.
  - Publish many useful publications. Visit our website at www.childcarelaw.org.
  - Conduct trainings for parents, teachers, community agencies, and others regarding legal issues affecting child
  - Occasionally we provide legal representation in impact cases.
- Contact your local family resource center. Internet search keywords: family resource center [insert type of disability].
- Department of Justice Hotline (between 11 a.m. and 5 p.m. EST weekdays) at (800) 514-0301 or (800) 514-0383 (TDD). DOJ Disability website: http://www.usdoj.gov/disabilities.htm. "Commonly Asked Questions About Child Care and the ADA" at: http://www.usdoj.gov/crt/ada/childq%26a.htm.