Chapter Seven

Child Care for Infants and Toddlers with Special Needs

Children come with all types of special needs, but generally, special needs can be defined as physical, mental, emotional, behavioral, or medical disabilities that require a different level of care than most children of that age. The importance of identifying infants with special needs is crucial given the importance and difference early intervention can make in the long-term outcomes for these children. Many infants will have special needs identified prior to their enrollment in the child care setting, but often child care providers are the first to suspect or verbalize a concern they may have about a child's growth or development. First and foremost, infants with special needs are children and need the same type of nurturing, supportive environment as all children.

Health Consultant and Infants with Special Needs

As the health consultant, you may play several roles to assist programs to serve infants with special needs:

- Identifying infants with special needs. If there is a concern about a child's growth, development, or behavior, you may be called upon to work with the provider and family to identify needs and refer for assessment and follow-up (see Chapter 3, Growth and Development).
- Assisting families and providers to identify the most appropriate care for an infant with special needs.
- Working with families and providers to care for infants with special needs in child care including development of a care plan to assure the child's needs are met in the child care setting (see Caregiver Tip, "Creating an Inclusive Environment," in this chapter).

Legal Issues for the Nurse Consultant

As a nurse, it is not within the scope of practice to delegate tasks (medication administration, feeding tubes, insulin injections, nebulizer treatments, etc.) to child care providers. Nurses CAN provide health teaching and information to child care providers, such as teaching infection control practices, food safety and nutrition, the importance of early brain development, how to modify the environment for a child with special needs, the purpose of certain medications, and side effects of medications, etc. Although nurses cannot teach procedures to child care providers, parents may if they choose to. If a nurse has a concern regarding how a procedure is being carried out, he/she should discuss this concern with the provider and the parent. For questions regarding the scope of your nursing license, contact the Nursing Commission at the Department of Health. A team approach is best utilized when including a child with special needs who requires medical procedures while in the child care setting. A team approach includes the parent, child care provider, and nurse. A nurse can be present while the parent is teaching the provider how to perform a task for their child. The nurse can incorporate important health information and answer questions as part of the teaching process.

What research tells us

Each child and setting should be assessed when deciding on the appropriateness of the child care arrangement for an infant with special needs. The following research findings may help you if you are called upon to help families or providers with this important decision.

Highlights of recent research include: (See References and Resources Section.)

1. Mothers of infants with special needs were less likely to enter the workforce when their child was 12 months of age than were mothers of typically-developing children.
2. When these mothers do enter the workforce, they work fewer hours.
3. When infants with special needs enter child care, they are more likely to enter at an older age and for fewer hours per week.
4. Infants with special needs who did enter child care were more likely to be cared for by a relative and less likely to be enrolled in a child care home or center.
5. Children who were chronically ill, compared with those who were not, tended to spend less time in child care homes or centers, and the care they received was of higher quality
6. Compared with other groups, children with Down Syndrome entered care at a younger age, were more likely to be enrolled in a child care center, and less likely to be in informal care; they also were significantly more likely to receive lower quality care.
7. The higher quality of care observed among children with chronic illness and the lower quality of care among children with Down Syndrome is probably a function of the type of care rather than characteristics of the child. This difference could be due to the increased caregiving demands associated with larger group sizes and child to adult ratios. Also, children with Down Syndrome are relatively passive and do not solicit attention from their caregivers, thereby resulting in less caregiver involvement.

Overall, center-based care may not be the best type of arrangement for infants with certain types of special needs because, as some research has shown, they may receive less attention than they need. However, there is current support for inclusion of infants with special needs in formal child care arrangements, and this participation can be important to the child's mental and social development as well as critical for the economic well-being of many families.

Americans with Disabilities Act (ADA) and Child Care

The Americans with Disabilities Act (ADA), passed in 1991, prohibits the discrimination towards persons with disabilities in employment, public services, public accommodations, and transportation. Licensed child care programs, whether family child care providers or centers, are considered public accommodations under the law; therefore, they cannot automatically exclude children from their services solely on the basis of the child's disability. Providers must make reasonable accommodations to meet the special needs of the infant with a disability. The provider must assess each child's needs on a case-by-case basis. According to the ADA, providers must make their facilities accessible and modify their policies and practices and procedures. They must supply auxiliary aids and services needed for communication with a child with a disability. If doing so can be done without much difficulty or expense (is not "unduly burdensome"), or if doing so would not "fundamentally alter" the nature of the child care program.

As the health consultant, you can play an important role in helping child care programs serve all children who want to participate in their programs. If the family and the provider agree that the program you consult with is the best place for an infant with special needs, you will find the following information useful to help them obtain the skills, knowledge, equipment, and services to create an inclusive environment.

Costs of Caring for Children with Special Needs

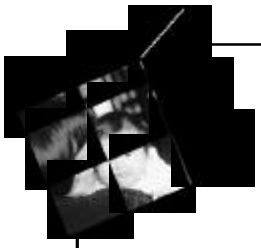
The ADA prohibits child care providers from charging a higher fee to care for an infant with special needs. Usually, caring for an infant with special needs does not require extra accommodation. The Working Connections Child Care Subsidy Program through Washington state DSHS pays a 30% higher than normal rate for caring for children with special needs (subsidy programs may offer higher rates to meet an individual child's special needs). The subsidy rate is for families who qualify based on their income. If the provider can document that caring for the child costs more than the 30% special needs rate, the provider can be reimbursed that amount. For more information contact your local Department of Social and Health Services, Community Services Office (CSO). It is located in the phone book under State of Washington Department of Social and Health Services.

Inclusive child care and its benefits

Inclusive child care means that infants with special needs participate in programs and activities along side infants without special needs. Inclusive child care promotes the growth and development of all children, focuses on the individual strengths of each child, and encourages flexibility and creativity in child care professionals.

Including infants with special needs in settings with their typically developing peers provides both with a sense of belonging, better self esteem, opportunities to form a wider variety of friendships, positive experiences about what they can do, opportunities to learn that people have different types of abilities, and ways to learn to value differences in themselves and others.

For families of children with special needs, the inclusive environment provides a real world perspective for interpreting their children's accomplishments and needs. It also provides them an opportunity to meet other parents.



Caregiver Tip

Creating an Inclusive Environment

Here are some tips for how to build an inclusive environment.

1. **Make sure policies and procedures of the child care environment do not automatically screen out infants with special needs.**
2. **Make simple changes in the activities and environment that allow all children to participate.**
3. **Use activities and materials that are accessible to all children .**
4. **Make sure there is enough space for children to move around.**
5. **Encourage children to join their own peers and support and assist children when needed.**
6. **Don't assume an infant with disabilities can't understand what you are saying.**
7. **Speak slowly and clearly and give the child time to respond.**
8. **Be as consistent as possible in routines and interactions.**
9. **Try using different cues to communicate such as photographs or pictures.**

Coordinating Special Needs Care

In 1986, Congress passed a law that encouraged states to improve early intervention services. This law is now known as the Individuals with Disabilities Education Act (IDEA). The law requires states to provide:

- Free public education from age three for children with disabilities;
- Early intervention services for infants;
- Education and services to be provided in the "least restrictive" or "most natural" environment;
- Nondiscriminatory, multidisciplinary evaluation of child to determine their needs;
- Related services, including supportive services, required to assist a child to benefit from special education
- Parental involvement and consent;
- Confidentiality of records.

Early Intervention Services in Washington State

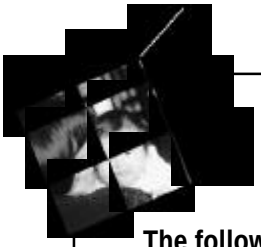
In Washington state, the Department of Social and Health Services (DSHS) and the Washington State Infant Toddler Early Intervention Program (ITEIP) direct the coordination of the statewide system of early intervention services. Children with a 25% delay in one or more developmental areas may be eligible for a range of services that may include support for the child care program. Families of eligible children will work with a variety of service providers, including the child care provider, to develop an Individualized Family Service Plan (IFSP). You can play an important role by supporting the provider's participation in the development of the IFSP so that this important aspect of the child's care is involved in planning and delivery of early intervention services. See Chapter 3 for more information about ITEIP services.

Each local health department has a Children with Special Health Care Needs Coordinator or a Family Resources Coordinator who will know resources available to children and families in the community. CSHCN coordinators can also help coordinate a child's medical care and are knowledgeable about eligibility for publicly funded sources of health care (Medicaid, CHIP, BHP+.) Call the ASK (Answers for Special Kids) Line at Healthy Mothers, Healthy Babies for more information. The Infant Toddler Early Intervention Program (ITEIP) assists families with children from birth to three years who have developmental delays and disabilities, to access early intervention services and supports. Different agencies throughout the state coordinate a collection of services and supports for families who have infants with special needs. Family Resources Coordinators assist families to access and coordinate the services and supports available to them. Again, for information call Healthy Mothers, Healthy Babies (see Resources and References section).

Working with Families of Infants and Toddlers with Special Needs

Families are the child care provider's best resource in caring for an infant with special health care needs. All families should be seen as partners and experts in the care of their child. Child care providers can establish daily routines that are responsive to the needs of the child and family. Opportunities can be planned with families to anticipate children's changes and to help them use their new skills. It is important that child care providers remember that children and their families are dependent upon their adult caregivers to communicate important events.

Families of infants with special needs experience the stresses all families do, but they also experience stresses above and beyond those of other families. For example:



Caregiver Tip

Building a partnership with Families

The following are ideas to help build a good partnership with any family and are especially important for families with special needs.

- **Ask families to help develop a care book for their child that has information you think may be helpful – medications, allergies, emergency contacts, specific accommodations needed, types of activities the child enjoys, etc.**
- **Take time to get to know the family.**
- **Take time to talk with family members and be sure to share positive comments as well as concerns.**
- **Find creative ways to communicate with families, i.e., develop a notebook for each child that contains daily notes; write notes to families on 3x5 cards; write a note to the family each day that is written from the perspective of the child. Do this carefully, since some families might be offended by a note written in their child's voice. They may need more formal communication.**
- **Respect the relationship between the family and child.**
- **Form relationships with families based on mutual respect, cooperation, and the mutual goal of wanting to do what's best for the child.**
- **Respect and accept family diversity.**
- **Show sensitivity toward the emotional needs of the family, including the need for privacy.**
- **Design flexible schedules for families to participate in the child care setting during the day.**

1. Typical family activities and routines (like getting to child care on time) may be more stressful because of the child's additional need for care in dressing or eating.
2. Going out in public may be stressful if the child looks or acts differently from other children.
3. Families may face additional expenses related to the special needs of their child, resulting in financial stress.
4. Families may experience stress as they struggle to gain access to services and activities routinely available to other children.

It might be helpful to remind providers of these unique family stresses and that there is wide variation in how families respond to them. For example, some parents feel confident that they can obtain the services their child will need; others may need more time to understand their

Working with Families of Infants and Toddlers with Special Needs continued

child's condition or may express anger or hostility. Families of children with special needs may have unique or more specific questions about the program. For example, a parent with a child who has speech delays may ask many questions about the use of language in a center. Accessibility of bathrooms, the playground, and other areas will be a concern to families with a toddler who uses a wheelchair. Families may ask lots of questions about the food served each day if their child has allergies. Also, the experience of having a child with a special need is often alienating for families because their experience is unique and may not fit within our traditional views of parenting.

Incorporating this Chapter into Your Practice

- Ask caregivers if they have concerns about any of the children related to slowed development or other signs of possible special needs.
- Offer to assist in screening the identified infant.
- Help the providers talk with the family.
- Provide linkages and coordination, as necessary.
- If you haven't done so already, call the ASK (Answers for Special Kids) Line at Healthy Mothers, Healthy Babies for the number of the Children with Special Health Care Needs Coordinator in your county, then call that person to arrange a meeting. You can call the same number to find out the name of the Family Resources Coordinator in your area.
- Obtain copies of "A Family's Guide to Early Intervention Services in Washington State'' for the centers you consult with.
- Contact the Children's Hospital Health Consultation Program for Public Health Nurses and School Nurses who Care for Children with Special Health Care Needs.