

# Supporting Families of Children With Disabilities

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## ABSTRACT

Advanced technology combined with improvements in neonatal care have increased the survival rates of low-birth-weight infants and infants born with severe birth defects. These infants are at greater risk for long-term health and developmental problems. The effect of having a child with a disability on the family is described, and emerging interventions and resources available for these families are provided.

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Advances in technology and neonatal care have increased the survival rate of premature infants, especially those born at very-low birth weights and infants born with severe birth defects (Reichman, Corman, & Noonan, 2008). In 2010, approximately 500,000 infants were born preterm. Due to the American with Disabilities Act and the Individual with Disabilities Education Act (IDEA), the number of children with disabilities living at home has doubled since 1960. In addition, these changes in governmental policy have affected the number of children with disabilities living at home and attending school (Reichman et al., 2008; Wall et al., 2005).

Premature infants born at fewer than 38-weeks gestation have a greater risk of dying within the first few weeks of life than infants born at term, and according to Doyle (2011), "If they survive, they have a greater risk of neurological impairments, blindness, deafness, or cognitive dysfunction (either developmental delay, or intellectual impairment) and a greater risk of substantial disability as a result of these neurological impairments" (p. 3). For those infants who live beyond the first few weeks after birth, annually in the United States, approximately 28,000 infants will die within the first year of life (MacDorman & Mathews, 2008). The loss of an infant takes a serious

toll on the well-being of families (Xu, Kochanek, Murphy, & Arias, 2014).

Infants born with birth defects have abnormalities of structure, function, or metabolism that result in physical or mental disability or death (Parker et al., 2010). According to the March of Dimes (2015), disabilities such as cardiac anomalies, cerebral palsy, and Down syndrome affect 120,000 infants each year. One out of every five deaths in the first year of life is caused by a birth defect, and if the infant survives it may experience lifelong problems with infections, physical movement, learning, and speech (Centers for Disease Control and Prevention, 2008).

## The Diagnosis

When parents learn that a child may be born prematurely or may have a birth defect, the experience during pregnancy changes from hopeful expectation to fear, which creates stress for the parents (Doyle, 2011). While some disorders are diagnosed shortly after birth, others may take a year or longer to diagnose (Glidden, Billings, & Jobe, 2006). Cerebral palsy (CP) and autism are examples of diagnoses that would not be evident in the newborn period. Parents who discover birth defects during pregnancy can develop more

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effective coping strategies than parents who discover the diagnosis months later (Glidden et al., 2006).

After diagnosis, a multidisciplinary approach to care is needed. Multidisciplinary teams comprising physicians, geneticists, nurses, pharmacists, nutritionists, social workers, and occupational therapists are required to support the family and should be involved in patient care conferences. It is imperative when planning these meetings to recognize and acknowledge the stress and fear of the parents during difficult conversations regarding the care of their infants (Izatt, 2008). These conferences usually focus on the initiation and continuation of care and delivering unfavorable news regarding diagnosis and prognosis for the infant or child (Izatt, 2008). Additional factors that should be taken into consideration by the multidisciplinary team include potential language barriers and cultural diversity (Izatt, 2008).

A communication tool developed for oncology patient that is useful for conveying unfavorable information is the SPIKES protocol (setting, perception, invitation, knowledge, empathy, strategy, and summary). This tool provides a framework that can be applied across specialties and follows six steps during difficult conversations with parents: (a) preparing for the family meeting, (b) assessing the family's understanding of the situation, (c) delivering the information, (d) responding to the family's emotions, (e) discussing the implications and future directions, and (f) summarizing the discussion. Often, parents have a difficult time processing all information they receive in these meetings, so following these steps provides the family with the information at the pace that allows for the assimilation of information. Nurses are ideally positioned to reinforce and clarify any information not completely understood following the meeting (Buckman, 2005; Izatt, 2008).

## **The Family**

Having a child with a disability can have a significant effect on the entire family. Researchers prior to the 1980s assumed that families with children with disabilities were dysfunctional and continued to grieve the loss of the perfect child (Lightsey & Sweeney, 2008). Recently, researchers have shown that though parents do experience grief, shock, and hopelessness at the initial diagnosis, these emotions do not predict the ability of the family to adjust and cope (Lightsey & Sweeney, 2008). Trute, Benzies, and Worthington (2012)

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evaluated the positive effects of having a child with a disability on the family and found that many parents responded with positive coping and resiliency. It is common for parents raising a child with a disability, much like parents of normal children, to experience joy and sadness (Trute et al., 2012).

Parents of children with disabilities who thrive or flourish have been found to utilize internal and external resources and support systems (Krstić & Oros, 2012). Internal resources are within the family or the parents themselves. These resources can include personality strengths or learned responses in difficult situations. Reframing priorities is a method used by parents to reevaluate the situation from a different perspective. Reframing is one of the coping strategies most often used by parents of a child with a disability (Krstić & Oros, 2012). Researchers have shown that the parents' ability to cope influences family time, routines, respite care, care coordination, family satisfaction, and cohesion (Giallo & Gavidia-Payne, 2006). Families with effective communication and problem solving skills demonstrated an increased ability to deal with stressful situations (Giallo & Gavidia-Payne, 2006). Baker, Blacher, and Olsson (2005) indicated that the characteristics associated with the diagnosis, such as behavior or temperament rather than the diagnosis itself, may be key in predicting stress and negative family adjustment.

Emotional support for parents leads to improved adjustment within the family. Parents who see the positive aspects of the disability can often counterbalance some of the negative effects of the stressful situation (Trute et al., 2012). Stress without support can lead to depression, anger, anxiety, substance abuse, or child abuse. Developing connections with other parents in similar situations can also diminish some of the negative consequences. The ability to cope with negative life events often involves finding meaning through the positive benefits and personal growth the life event has caused. Many factors affect the ability of families to cope. Parents, especially mothers, can find the role of parenting a child with a disability rewarding and difficult (Willingham-Storr, 2014).

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