

The Emotional Experience of Families of Children with Disabilities

Many families who have children with special needs or disabilities describe caregiving for their child as challenging yet extremely rewarding. Others feel as though caring for their child is no different than caring for any other child. Regardless of how families feel about their caregiving responsibilities, it's important to recognize that they often have additional roles and responsibilities specific to their child's needs. This can be extremely stressful for primary caregivers; it is important that you understand the impact on families' stress and well-being. We must also consider the impact on the entire family unit and how roles may be re-defined compared to how we usually think about family members.

You've already learned about the importance of asking individual families for feedback on the language they prefer you use to **discuss** their child's disability. For ease, you will see the terms "disability" or "disabilities" used in this information. Having a "disability" is what allows children and adults in the United States to have access to certain rights and services (IDEA, 2004; ADA, 1990).

Disabilities affect individuals in different ways. Some people have disabilities that are life-long and will require care into adulthood; while others will learn and develop in ways that allow them to live independent lives or even "outgrow" a diagnosis. Disabilities can be visible or invisible and affect all of a person's ability to learn or impact just one specific learning area. You may see the term developmental delay used to describe a child's gap in development that is not linked to a specific diagnosis or condition or specific to development in early childhood (birth to six). For example, speech delays are common in young children with developmental delays, but many of these children catch up to their peers by the time they enter kindergarten.

Learning the News

The path for how one learns they are a parent, grandparent, sibling, or other family member to a child with a disability is different for every family. We will use the term "primary caregiver(s)" to refer to the person(s) most central to a child's care. Primary caregivers are usually a child's mother, father, grandparent, relative, or foster parent.

You might see how some primary caregivers come to know that their child is developing differently from other children the same age. They may ask you questions about their child's behavior or development to learn if the differences they notice are typical. You may even be the one to first share concerns and recommend the family speak with a doctor or specialist. Though rare, there may be times in your work with children where you are devastated and shocked to learn that a child in your care has a serious condition or has been involved in a traumatic incident such as a car accident. Some families discover before their child is born or at birth that there is a risk of or that a child will be born with a condition. While it may seem as though families who have known about their child's disability for some time have adjusted and are accepting of the situation, it's important to remember that every individual's emotional experience is different and is deeply impacted by their culture, relationships, and environment.

Emotional Responses to Disability

Think about what it must be like to first learn that your child has a disability. How would you react? Who would you turn to for support? Although rare, some families will not experience strong emotions and immediately embrace the situation. Others will be filled with a range of emotions and may react in ways that are not usual for them. Grief is included in the range of emotions often felt by primary caregivers. Grief is a deep feeling of sorrow, and we often think of it as what one feels after the death of a loved one. Most children with disabilities thrive but on rare occasions some children, despite a loving family and access to evidence-based intervention, are very slow to make minimal progress. These families may grieve for the child they thought they would have, but with time and support, they develop new hopes and dreams for their child.

Below are stages of grief that families with children with disabilities commonly experience. There is no specific order for these stages, nor do all families experience every single one of these emotions (The IRIS Center, 2008). Some families may feel these emotions on the inside but try to mask their feelings to others.

Denial: Families may not believe the news that their child has a specific condition or learning need. This can be especially true when the news is a surprise. An individual's culture, acceptance of people with disabilities, and knowledge of a specific condition can impact how one copes with the news. Those in denial may try to discredit the doctors or specialists involved in the process. Family members in denial may make statements about how their child, "never acts that way at home" or "that doctor doesn't know how to be around kids." This is especially true when the condition is based on a behavioral assessment rather than by an objective test such as bloodwork or genetic workup.

Guilt: Some families feel as though they did something wrong or are responsible for their child's disability; as a result, these families can begin to question their past decisions. Families may feel as though professionals talk down to them or are critical of their decisions and parenting, which may increase any existing feelings of guilt. While professionals do not intentionally make families feel this way, be aware of your own biases towards families and their decisions. It can be difficult to hide your feelings and opinions when you communicate with families, but keep in mind that your role is to be supportive of their decisions.

Anger: Parents and caregivers may feel angry about their child's disability. Some describe feeling as though it's not fair to their child or that they have bad luck. They may take their anger out on others. Remember that this anger may help families cope and eventually create plans for how to help their child in the future.

Depression: There is evidence to suggest that mothers of children with developmental disabilities are at increased risk for depressive symptoms due to the stress of parenting compared to parents of children without disabilities (Zeedyk & Blacker, 2017). While there is generally less research on fathers, some evidence suggests that those with children with disabilities also experience an increased risk of depression.

Anxiety: Once families begin to learn more about their child's disability, worry can set in. Questions such as, "How am I going to go to work and take my child to all of these appointments?", "Will my child have a normal life?", and "Will my child be bullied or made fun of?" are common worries that

families think about. Anxiety can make it difficult for people to move forward or make changes. Be thoughtful when making assumptions about primary caregivers who struggle to follow through with recommendations for their child. Lack of action or seeming uninterested doesn't mean they love their child less or are any less involved as caregiver. Anxiety can be crippling; it can prevent individuals from being able to move forward or make adjustments.

Bargaining: This is the stage of magical thinking and unrealistic expectations. Primary caregivers may think that if they work hard enough to help their child, they will be rewarded by having their child "cured" or that symptoms of their child's disability will go away. Primary caregivers may expect program staff to provide for their child in ways that are out of the scope of practice for childcare settings or are unrealistic given the program's adult-to-child ratio.

Fear: Parents of children who have a lot of medical needs may fear for their child's life or fear that other caregivers will not know how to keep their child safe. Some primary caregivers fear that no one will love and care for their child the way they do. If a primary caregiver of a child with a disability seems critical of your care for their child, know that fear may be the root cause of such behavior or beliefs.

Other Roles

Primary caregivers often feel as though they take on extra roles when parenting a child with a disability. Consider these roles and reflect on how these responsibilities impact the well-being of primary caregivers. Also think about how you can partner with the primary caregiver to help ease the stress of additional roles.

Advocate	Ensures that the child has full access to rights and services on behalf of the child
Case Manager	Coordinates all care, appointments, specialists, doctors, and teachers, and informs all parties of updates and important information
Expert	Has a wide scope of understanding about a specific diagnosis or condition and is available to answer questions and provide assistance to others when issues arise
Trainer	Responsible for training professionals and caregivers how to properly carryout a recommendation or task for the child
Financial Planner	Researches and coordinates long-term care plans to ensure the child will maintain quality of life when primary caregivers can no longer continue their roles

Impact on the Family

As you reflect on the emotional experience and many roles of primary caregivers of children with disabilities, think about the impact on the entire family.

Siblings, especially as they become youth, will sometimes take on caregiving-like tasks and roles. Some siblings of children with disabilities will thrive in this role and feel a sense of pride. Other siblings may feel jealous of or annoyed toward the sibling with a disability, especially when the family's schedule and priorities seem to be made around caring for the other child. Primary caregivers may feel like so much of their time goes to caring for their child with a disability that they don't get to give individual attention to their other children. If siblings are close in age, they may not have a "playmate" relationship that primary caregivers often think of if they planned the spacing of their children.

When children have more than one primary caregiver, much thought and energy is used to make decisions about shared responsibilities. This is true for all families that have more than one primary caregiver but can be especially stressful for families with a child with a disability. Whether the individuals co-caregiving are marital partners, mother and daughter, or any other arrangement, they may not have planned for the additional tasks and time needed to care for their child. Some families may have additional caregiving needs and may have a relative or babysitter that is very involved in supporting the family who may not have otherwise been needed if they did not have a child with disability.

Due to the diverse cultural views on disability, some core families choose to not share with extended family and friends that their child has a disability. They may feel shame or unsure of how others will react. Some may fear that important people in their lives will be unaccepting of their child with a disability. Among families who are open with others about their child's disability, how much and what information they share varies. It can be difficult for primary caregivers who are in various stages of grief or have grown their acceptance to hear opinions and answer questions about their child. For example, a father who has learned to embrace that his daughter has autism may have a brother and sister-in-law who don't believe "girls can get autism" and that their brother needs to show his daughter "who is in charge of the family." This can create rifts within families that disrupt support systems and relationships.

Families with children with disabilities may feel they cannot take part in community activities. Some caregivers feel embarrassed about their child's development when in public or feel the need to apologize or explain for their child. Seeing children who are typically developing and of a similar age to their child can be emotional, especially as those children reach expected milestones that their child with a disability is delayed in developing. This can re-trigger the various stages of griefs discussed above.

References & Resources

The IRIS Center. (2008). *Collaborating with families*. Retrieved from

<https://iris.peabody.vanderbilt.edu/module/fam/>

Seligman, M. & Benjamin Darling, R. (2007). Effects on the Family as a System. *Ordinary Families, Special Children* (pp. 181-217). New York, NY: The Guildford Press.

Zeedyk, S.M. & Blacher, J. (2017). Longitudinal Correlates of Maternal Depression Among Mothers of Children With or Without Intellectual Disability. *American Journal of Intellectual and Developmental Disabilities, 122(5)*, 374-391.