Coping with news of a disabled child

Being told that your child has a disability can be as traumatizing as learning of a family member's sudden death. Many parents are stunned by such news. Receiving such a message can produce overwhelming emotions of shock, disbelief, anxiety, fear, and despair. Within that moment, research has shown that some parents cannot distinguish between the unconscious wish for an idealized normal child from an unthinkable, sudden reality of one who is not. For some parents, just trying to comprehend the disparity between their desires for their child and the disability that exists compounds their emotional and intellectual efforts to adjust to the situation. They may feel grief, depression, or shame. Some may also ask questions of "why me" and conclude that they are being punished for sins or bad acts of the past. Depending on the severity of the disability and the magnitude of the demand for coping, a few parents may even contemplate death for the child or themselves. These thoughts represent an all-encompassing need to achieve inner peace.

Tips for helping parents accept their child's disability

- Relay a diagnosis with compassion and an appropriate degree of hope for the child and parents. Research findings show that the manner in which a diagnosis is explained to parents can have a profound and prolonged effect on the parent's attitudes toward their child and professionals.
- Ask parents how much and what types of communication they find helpful and build rapport with honesty and caring.
- Encourage parents to ask questions and express their emotions.
- Know the resources available to assist the child and parents.
- Try to determine each time you communicate with the parents their level of adjustment and assess what they have been able to internalize and understand regarding what you have discussed.
- Reinforce the practice of parent participation in helping their child learn and develop.
- Readily admit to unknowns and seek answers to parents' inquiries.
- Understand and accept parental ascendance through the stages of adjustment as being a normal process and support them. However, adjustment can speed the process of achieving acceptance. It can, in turn, provide educators and related personnel with a majority of knowledgeable and supportive parents to assist them in the demanding tasks of reasonably meeting all children's needs.

The grieving process

Teachers and personnel in related disciplines need to know about the stages through which parents often pass when coping with the fact that their child has a disability. These same professionals also need to be available to help guide parents through the usual stages of adjustment toward reasonable acceptance of their child's condition and their fate. Until parents who are having difficulty accepting their child's disability can cope with their own pain and frustrations, their full energies generally cannot be directed toward understanding the child's
disability, level of development, readiness for instruction, or participation in the intervention process.

**Stages of adjustment**

The first point of providing support for parents should be during a period of uncertain diagnosis, which can engender confusion or bewilderment. Following the rendering of a specific diagnosis, such as autism or a less definitive determination like pervasive developmental disorder, the parents' typical stages of adjustment are as follows:

**Stage one**

The parent may be shocked, and he or she may cry or become dejected. Sometimes parents may express their feelings through physical outbursts or, occasionally, inappropriate laughter.

**Stage two**

This is an extension of stage one, and some parents may deny their child’s disability or try to avoid that reality in some other way. Some parents will search for or try to propose various actions in an attempt to change the reality. Some may "shop for a cure" or try to bargain for a different reality.

**Stage three**

At this stage, parents may feel anger. They may demonstrate their anger outwardly, in the form of rage, or become withdrawn and passive from intense feelings of guilt. Verbally attacking anyone who might be blamed for their unfortunate circumstance, including displacement of responsibility onto the original diagnosticians or any supportive professionals, is common. If the parents are feeling angry, guilty, or both, professionals must understand this stage is a very positive point to reach in the process of adjustment and not become defensive if attacked.

**Stage four**

Parents become resigned to the fact that their child has a disability. In some situations, one or more of the family may slip into depression. Feelings of shame, guilt, hopelessness, and anxiety stemming from a new overwhelming burden of responsibility can become intense. For a few parents, retreating, accompanied by an attempt to hide the child, especially from friends and persons during organized or routine social encounters may be the first sign that they have begun to accept the fact their child has a disability. However, any inclination toward or demonstration of behavior that results in abnormal isolation of one or any family members must be prevented or eliminated.

**Stage five**

This is the stage of acceptance, meaning the parents have achieved an unconditional positive regard for the child. Specialists debate whether or not this stage of adjustment includes parents who show only acceptance of their child's condition, commonly called neutrality, or a very important new stage of cognition when parents not only begin to understand and appreciate their child but strengthen their skills in coping with life's trials as well as being able to help their child, themselves, and others. Reaching this stage is highly correlated with the school inviting parents to become team members in a program with caring professionals, and often paraprofessionals, that is designed to meet all of the child's needs.

**Stage six**
Parents are able to put their lives back together and enjoy living, imagine a future, and talk of their child free of undue emotion. They can discuss and participate in designing or providing instruction objectively.

**The school's responsibility to parents**  
Because schools accept students with disabilities, they have a responsibility to provide support or see that appropriate support is available to parents as they pass through these various stages. The school may provide parent-to-parent support groups, which are divided by disability and facilitated by school personnel such as a school psychologist, counselor, or teacher. Should a parent need individual counseling, the school should provide a list of counselors with whom the parent could meet.

**Reaching acceptance**

Even after parents find acceptable ways to cope with their child and their lives by following a healthy path beyond acceptance of their child's disability, other complications can cause set-backs in adjustment, such as unanticipated experiences of being socially rebuffed by friends and strangers or being treated inappropriately by poorly informed educators. Such repeated negative experiences only aggravate the difficult process of remaining in the highest stage of adjustment. Parents, like professionals, readily perceive the inhumanity of persons who show little or no understanding or caring toward persons with disabilities or their caretakers. Peoples' actions, more frequently than events, cause parents, and the child, to regress into states of anger, frustration, or other earlier stages of feelings and behaviors. Most parents need assistance to progress positively and without debilitating delay through the stages of adjustment. Their progress toward a level of reasonable acceptance, closure, and reconstruction includes an accurate understanding of reality, at least as they reach the usual and customary benchmarks in their child's development. Professionals can help parents achieve a balance between their hopes and reality. For example, no need exists to engage in speculation about what a 4 year-old child will be able to do when s/he has reached the age of 21. While most parents want and have a need for professionals to be truthful as a prerequisite to being recognized as trustworthy persons with credibility, they do not need information that is bleak and replete with dismal prognosis. The majority of parents will come to understand the realities and implications regarding their child's achievement as the various stages of development are reached and passed. This, especially, is true if parents believe that educators put the child's needs foremost in designing appropriate educational and related services. Not every parent may experience these stages of grief, suffering, and acceptance. However, as professionals, we need to be prepared to help parents work through these stages if needed.