

Working With Families: Rethinking Denial

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Young Exceptional Children: Vol. 5, Number 2

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Many years ago, Helen Keller's mother, Katie Keller, was insistent that their family not abandon the search to find the person who might be able to unlock the mystery of her daughter (Gibson, 1962). Despite the best advice and efforts of professionals and family, Mrs. Keller refused to have her daughter put in an asylum. Would Mrs. Keller be labeled "in denial" today? Well-meaning professionals might shake their heads at the IEP meeting and express their genuine concern that this mother is just not able to accept her daughter's pervasive disabilities. After all, it would be obvious to everyone that little Helen could not see or hear.

Table 1

Shifting Your Perspectives on Denial

Suggestions for professionals:

- Support parents' hopes and dreams for their child.
- Suspend judgment of families and their behavior.
- Be patient. People need time to find their own personal way through unexpected events.
- View this time as an opportunity to strengthen trust.
- Educate other professionals and family members to rethink denial.

Wasn't Helen Keller's mother right to be optimistic about her daughter's potential? Mrs. Keller was acutely aware that Helen had serious and significant limitations. After all, she was helping to care for her child at home on a full-time basis. She knew through daily experiences that Helen was not like other children. However, Captain and Katie Keller had hopes and dreams for Helen and wanted her to have a chance to fulfill those dreams. Mrs. Keller wanted the professionals to have high expectations for her daughter even if she herself did not know how to reach her, and she persevered in her fight to obtain possibilities for Helen.

Even today, with research supporting well-planned and effective interventions, no one can accurately know or precisely predict what children with disabilities will accomplish and become in their future. Still, some professionals characterize parents as "in denial" when they think the parents

do not accept their child's disabilities and limitations. It is important to explore the implications of the well-worn phrase "in denial," and to begin a discussion on reframing the concept of denial.

Stages and States of "In Denial"

Sands, Kozleski and French (2000) reviewed the literature on the impact of children with disabilities on their families, and noted the focus on the distress of having a child with disabilities. They suggest that professionals may have developed a stereotypical view of these families as being under so much stress that the family cannot meet the challenges of daily life. Others have recognized that the presence of a child with a disability in a family can have many positive effects, and can even help to strengthen families (Turnbull & Turnbull, 2001).

The use of the term "in denial" in labeling parents of children with disabilities stems from Kubler-Ross' (1969) work on death and dying in which she outlines the stages of grief, concluding with the final stage of acceptance. Many professionals in social work, psychology, nursing and education have been

taught that these stages mirror the grief that parents experience due to the lost of their “perfect” child when they learn about their child’s disability.

Howard, Williams, Port and Lepper (1997) suggest that it may not be helpful for professionals to view family members as being in particular stages of grief. Family members process information in different ways and at different times. While the feelings expressed in Kubler-Ross’ (1969) work are feelings parents may experience at given times, there are not necessarily states of feelings that parents must pass through sequentially in order to reach the next state. Some parents object to the rigidity of this model. In fact, parents report they sometimes experience feelings such as guilt, acceptance, despair, or denial all within a period of five minutes of dealing with their child with special needs. Kaster (2001) compares the feelings to a “roller coaster ride of emotions” (p.186).



Miller (1994) likewise resists the concept of a linear stage model. She reports that parents do not feel that there are clearly delineated passages they must master before moving to the next state. She instead refers to stages of adaptation to best describe the process the mothers she interviewed went through in adjusting to their children with disabilities. The four elements of adaptation she describes include surviving, searching, settling in, and separating. Miller (1994) views these stages as evolving not in a linear, developmental sequence, but rather having a circular, dynamic quality. She suggests that feelings come and go at expected and unexpected moments, some lingering, and some fleeting.

Several classic studies questioned the usefulness of a stage theory of adjustment to describe parental responses to their child with a disability. Featherstone (1980) suggested that some parents might not pass through the stages at all or might experience the stages in differing orders or at varying rates of intensities. Blacher (1984) conducted an extensive review of the existing literature and showed that families experience a wide range of responses to the diagnosis of their child’s disability. She urged that further research document parents’ feelings and responses. Winton, in 1990, reminded professionals to define “denial” as an internal coping strategy, which may be useful to some parents, rather than view the concept as a worrisome stage to be overcome before reaching the stage of acceptance.

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Turnbull and Turnbull (2001) also urge professionals to look beyond the stages of grief. They suggest that feelings of denial and grief are emotions that may disappear and reappear in all families. These feelings often occur during transition periods for families who have children with disabilities, when the children move from one set of services to another. Thus, when a family has a child with a disability, the parents may have a range of emotional responses that all family members experience at various times (Sands, Kozleski, & French, 2000).

Different Perspectives

Miller (1994) views denial as a protective device used by a parent when he or she is not ready to deal with a problem or its implications. She suggests that parents sometimes choose to put off dealing with issues even when deep down they know something is wrong. Fialka (2001) notes that professionals may think of parents as being “in denial” when they seem withdrawn, hostile, or uninvolved. Harry (1997) proposed that professionals sometimes use the term “in denial” when actually the parent and professionals are in disagreement about the prognosis, diagnosis, program, or intervention strategy. Unfortunately, when this happens, the phrase “in denial” is sometimes applied in a judgmental way towards parents. In reality, each party simply possesses a different perspective and may not be sharing the same vision of the child and his or her future. When



parents are judged solely from the professional's perspective, the professional may not genuinely listen to or engage parents in a conversation about their dreams and hopes for their child. If professionals categorize parents as "in denial," unaccepting, or difficult, professionals may lose the chance to understand and learn from the parents.

Parents and professionals often enter into a working relationship with different expectations and perspectives. Such differences affect how each partner perceives the next step in intervention. For many professionals, a label, diagnosis, and/or prognosis can give direction and insight to their work with a child. They can consider which intervention techniques work best with children with that particular diagnosis. They know what they expect to happen with the child. During the initial diagnosis and during transition periods, parents may not appreciate the importance of a diagnosis or label. To parents, labels may be like foreign words creating chaos and a sense of inadequacy. Parents may question the meaning of the diagnosis, unsure about how it might affect the future of their child and family. They may feel unprepared for this new twist in life, and wonder how to assimilate so much information at once. Professionals should be cautious not to expect all parents to integrate new information about their child in the same manner or within the same time frame as the professional.

The professional's motivation for involvement in the field of early childhood special education may also innocently contribute to the chasm between perceptions held by parents and professionals. Many, if not most, professionals in special education typically enter into the work because they want to make a difference in the lives of children and families and make a contribution towards making the world better. During their training and education, they learn techniques, procedures, interventions, and theories that

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assist them in learning to help take care of people. This perspective is not wrong or harmful. Indeed, the desire to have a positive impact on others is noble and valuable. There are caveats, though, that accompany such a perspective. At times the desire to intervene – to do or to help – may have more relevancy to the professional than to the parent. Parents have many activities and challenges in

their lives and may not always be able to find the time or energy to do what the therapist or teacher suggests (Fialka, 2000). When a parent does not seem to take advantage of the intervention ideas offered, professionals may be puzzled and wonder why the parent won't help the child. Professionals may feel frustrated and think that since they learned to teach children with special needs and have dedicated their professional life to doing so, the parents could at least cooperate. In such moments, professionals must seek out the support of a trusted colleague to vent their worries about the family (without breaking confidentiality, or course) and to think about other ways to support this family.

Understanding the Family Perspective

Many parents and professionals have heard or used phrases such as, "that parent is in denial," or "that father can't face the reality of his child's limitations," or "that mother refuses to admit that her child won't be able to ..."

Sometimes when professionals use the phrase "in denial," the implied message is that the parents are not being realistic in their expectations of what their child can or will be able to do. Professionals should be careful not to judge a family when the family does not want to do things the way the professionals think is best.

For instance, a father may say that his hope and goal for his three-year old daughter with severe cerebral palsy is for his daughter to walk. The professionals may think that this father is "in denial" and that he is totally unrealistic in thinking that his child will ever walk! Is the father "in denial?" Perhaps not. One possible scenario is that the father knows very well that the chances of his daughter walking are not very good. Yet if there is even the slightest chance that she might walk the father will continue

to maintain that goal. Garnering all the support available to achieve this possible outcome, for his daughter to walk, is a reasonable path for this father to take.

Another possibility is that this father does understand and worries that his daughter may never be able to walk without some assistance. This thought may haunt him. His worry may be quietly and internally acknowledged, he may be able to whisper it in the privacy of his thoughts, but it may take more time and trust if he is ever to say it out loud to professionals. To formulate such worries into words is an enormous challenge, but to acknowledge them publicly to a stranger, including the caring professional, may be an unrealistic expectation for this father at this time.

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A third possible meaning is that this father, upon initially hearing the new information about his daughter, is stunned and overwhelmed with unfamiliar thoughts such as the implications of not walking for his little girl and for his family. There is not easy place to rest such nagging thoughts. People need time to find their own personal way through unexpected news. Sometimes parents “put the pause button on” to attempt to slow down the speed of change. One mother in Idaho says that “Denial” is a place for her (Thurber, 1996). She asks that professionals not shake their heads and look down upon her when she wants to retreat from the hubbub of being a parent. “I know where I am and I need to be there sometimes. Then I come back to reality,” she says.

Suggestions for Professionals

Is there a better way to understand the family perspective when parents and professionals have different expectations for children with special needs? Recently, one of the authors asked her husband to explain his early impressions of their son with developmental disabilities who is now a teenager. During the first year of their son’s life, she saw a child who was not progressing and appeared unable to accomplish most of the milestones of a typical one-year-old. Her husband, on the other hand, remembered their son as a bit slower but basically doing okay. She asked her husband if, during those early years, he was “in denial.” He paused and replied, “No, I wasn’t in denial. I was in hope.” He needed to be optimistic about his son’s future. As delineated in Table 1, ways for professionals to rethink denial might include the following:



- ***Support parents’ hopes and dreams for their child.***

Professionals can reframe “in denial” as the parents’ way of being “in hope.” They can help parents explore their dreams, hopes, and fears for their child. Professionals can encourage the parents’ dedication to, determination, and high expectations for their child. This doesn’t mean that professionals can’t help the parents understand and be realistic about their child and the disability. Professionals can support parents in their many roles as teacher, advocate, record keeper, and morale booster. Professionals can encourage parents to have hopes and dreams for their child. When parents and professionals work together as a team, the role of optimist can be a shared responsibility.

Parents can be the best advocates for and supporters of their children with special needs when they are armed with information, encouragement, and optimism. As one mother said, “Anna is 14 now but I still hope that she will change and be okay. I know that is not realistic and I’m not denying that she is severely disabled, but I still like to have hope. It helps me get through the day and night sometimes. Hope is my time to just dream.” Professionals can help by giving parents information and encouragement.

Another mother explained, “Each small step today paves the way for future opportunities. The other day my 12-year-old daughter spontaneously wrote the first two letters of her name for the first time. I watched with interest as she concentrated, saying the words her teachers and I have said to her over and over during practice. After eight years of hope, challenging therapists who wanted to eliminate prewriting skills from her IEP because she will never be a functional writer, I thought ‘you go, girl.’ The accomplishment buoyed me to face the next challenge.”

- ***Suspend judgment of families and their behavior.***

Parents do not like to feel that professionals are intentionally or unintentionally judging them. An example of the real difference between denial and hope can be found in the story of a mother who set aside college funds for each of her children, including her daughter with disabilities. While the mother was aware of the extent of her young daughter’s cognitive limitations and knew that her child’s test scores indicated that she would not likely ever be a candidate for higher education, from the mother’s perspective, the college fund represented hope for the future. However, from the therapist’s perspective, this college fund was evidence of the mother’s denial. When questioned about her decision to have a college fund, the mother exclaimed, “Well, maybe not, but I can always hope.”

No one would suggest that the therapist withhold information or not offer alternative ways of viewing the child’s future. But to focus on the college fund was to miss the essence of the real goal, which is to support the child to reach her highest potential and to support the parent to remain hopeful in order to continue to work with her child. It is important to examine the full range of the actions and behaviors of the parents before assuming that a parent is in denial.

- ***Be patient. People need time to find their own personal way through unexpected events.***

Sometimes parents attempt to slow down the speed of change, particularly when they are integrating new, and sometimes painful and uninvited, information about their child. Learning and understanding is a personal and private process that continues over time.

Professionals can help parents use time and optimism to their advantage. Parents should not be made to think they have to share everything or progress according to someone else’s timetable!

- ***View this time as an opportunity to strengthen trust.***

Some parents report that they find themselves distancing from professionals, thinking, “They are not going to understand.” Others may discount professional advice that does not consider their hopes and dreams for their child. As a professional, take the opportunity to learn from each family and understand family differences. Families and individuals within families cope differently. The professional can carefully listen to and understand the parent’s perspective and can encourage the parent to talk about his or her concerns, doubts, and worries. Knowledge, acceptance, patience, and shared understanding increase trust.

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- ***Educate other professionals and family members to rethink denial.***

The opportunities open to people with disabilities are expanding in ways that seemed unimaginable even a decade ago. People with disabilities, even severe disabilities, are living in their own homes, authoring books, attending colleges, holding jobs, starring in television shows,

marrying, and having children. Not all people, whether or not they have a disability, will achieve the same dreams. The current vision is a hopeful one that invites a fuller participation for all people in a variety of dreams. Over time, most parents rebuild their hopes and dreams for their child, learn to adapt to the circumstances in their lives, and remain steadfast in their concern for and commitment to their child with disabilities. The ways in which professionals understand and respect parents' efforts can significantly contribute to this process. Parenting a child with disabilities requires energy, determination, and perseverance. Perhaps hope provides the emotional fuel to persevere. We encourage professionals not to extinguish this hope by misrepresenting the parent's response as "in denial."

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Professionals have the opportunity to educate others about the concept of denial. Talk to parents and other professionals and challenge them to think about how they are using the term. There can be another way to think about denial. Our hope is that through conversation and collaboration, parents and professionals will grow in their understanding of the many paths to acceptance and respect for the parents' own journey of rebuilding their dreams for their child.

Note

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