

Levels of Awareness

A Closer Look at Communication Between Parents and Professionals

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"That mother is still in denial"; "The family is the real problem, they are demanding and unpredictable"; or "If the dad would get over his anger, we would be able to work together better." Teachers or other professionals working with students with disabilities and their parents often say things like these. Denial, anger, and depression are all common reactions to challenges faced by family members of children with disabilities (see box, "What Does the Literature Say?"). This article can help professionals and parents learn and grow together as they work together for the children in

their charge. Communication is a big part of the answer.

Importance of Communication

Communication between parents of children with disabilities and educational professionals is not only mandated but is best practice. Yet parents and professionals do not always agree what would be in the best interest of the family and child. These issues are even more challenging for parents of children with mild disabilities, who may have experienced school failure before identification. The practice of pre-referral interventions and student support teams have certainly decreased the possi-

bility that parents would be surprised that their child is experiencing problems in school, but parents may still be shocked to hear that the school has identified their child as having a disability.

This article discusses an alternative way of addressing families' adaptation to the identification of a child with a disability. This approach is grounded in a new idea about levels of awareness and transformational experiences. It is not our intent to replace one series of stages with another; rather, we suggest that each family shares a similar set of experiences in coming to grips with the challenges of living with a family member

What Does the Literature Say About Family Acceptance of Disabilities?

Traditionally, educators have applied the stages of mourning identified by Kubler-Ross (1997) to a family's adaptation to the birth or diagnosis of a child with a disability (Batshaw, 1997; Bruce, Schultz, Smyrniotis, & Schultz, 1994; Lin, 2000; O'Shea, O'Shea, Algozzine, & Hammitte, 2001). These stages of denial, anger, depression, and acceptance, however, have not been supported by research (Blacher, 1984) and are considered by many parents to be condescending and patronizing—further hindering real communication (Snow, 2001).

If families and professionals feel that using these stages of adaptation are not valid or useful, then how can we understand the adjustments families make with the identification of disability or the ongoing educational decisions that they need to make? How can parents and professionals communicate better?

Turnbull and Turnbull (2001) wrote that with the introduction of the concept of "disability" as part of the family, the "family life cycle" has been dramatically interrupted. This grieving theory does not explain all that families are going through. Turnbull and Turnbull recommended a "shoes test" for professionals—to put themselves "in the shoes" of the parent. Bauer and Shea (2003) and Allen, Petr, and Brown (1995) also recommended working with the entire family system, not just the child. In the Family-Centered Behavior Scale, Allen et al. recommend changing from a professional-centered model to a family-centered model, which affirms the strengths of the family and reframes a "grief and tragedy" paradigm with "family empowerment."

Self-advocates are beginning to write their own stories (Grandin, 1995; Williams, 1998); and parents and members of parent organizations have written books with titles like *They Just Don't Get It* (Clark et al., 1996) and *Disability Is Natural* (Snow, 2001). Just as writers have discussed the differences in communication between men and women (Gray, 1992; Tanner, 1990), Harry (1992) wrote that because of language and cultural differences, parents and professionals could be speaking different languages. Could there be differences in the ways that parents and professionals construct meaning of a common word like disability? And would these differences give us communication clues?

with a label of disability. This approach might provide a useful tool for much of the communication among families, youth, and professionals—not only to understand the family's construction of disability, but also to understand our own.

In working with families, we must also look at our own levels of awareness and our own transformational experiences. As Senge (1990) suggests, by learning to see the structures within which we operate, we begin to free ourselves from forces we were unable to see earlier and ultimately master our ability to work with them and change—or transform—them. Can we move away from the “stages of grief” paradigm and look at our levels of awareness and transformational experiences?

Levels of Awareness

According to Schaeff (1992) we all have our own level of truth or awareness, and often we are unaware of the perspective or attitudes of others. She diagrammed the concept of levels of truth or awareness as a series of steps or stages through which we progress individually. Schaeff explained the levels of truth in a series of assumptions (see box, “Levels of Awareness”).

Van der Klift and Kunc, cited in Lovett, 1996, adapted Schaeff's (1992) levels into the categories of marginalization, reform, tolerance, and diversity. Expanding on this work, Ulrich (1998) found nine categories with transformational experiences, which assist individuals to move to the next category. If we look at working with parents in view of these levels of awareness, then what a parent or professional chooses as “best” depends on the individual's “level of awareness” at that particular moment. Bogdan and Taylor (1994) have suggested that such labels as “mental retardation” and “disability” are socially constructed, so looking at a parent's or professional's “level of awareness” is a way of deconstructing his or her personal communicative intent. The professional and the parents may not be a match in the following types of awareness:

- Their feelings about the issues of disabilities.
- Their personal histories.

- Their transformational experiences, knowledge, and learning about the issues.
- The contextual and systemic framework of their cultures and worlds.

These linguistic and pragmatic differences may create tension and miscommunication.

Level 1: The Ostrich Phase

The first level of awareness is actually a lack of awareness. Parents, who typically have very little experience with disability when they were growing up, may have little or no real information about mild disabilities, such as learning disabilities. Parents may not have any useful vocabulary for the difficulties their child is having, and may turn to the media for terms such as *dyslexic* or argue that the issue is one of teacher incompetence. Parents may make statements explaining behavior or achievement such as, “He's so active because he's a little boy—he just doesn't ‘get into’ school” or “She's just like my sister at that age, and she's now an attorney.”

In the “grieving” theory, the professionals would hear these statements and say, “denial.” But the parent may not be denying the presence of a problem. Rather, he or she may be operating out of a lack of information and experience of what a learning disability is, and a fear of the stigma of “disability.” At this level of awareness, the “truth” for the parent is that there is indeed nothing really wrong. They are quite happy in their “uninformed” state and wish to remain there.

At a kindergarten screening, for example, the parent may describe to the teacher how his or her child is just like “Uncle Joe,” who didn't tie his shoes until he was 9-years-old, and he is now an attorney. The teacher is confronted with a parent reassuring himself or herself with a related experience and ignoring the obvious differences. Though parents often retrospectively report that they had a feeling things weren't quite right, their level of awareness is that of an ostrich with its head in the sand.

The movement to a second, deeper level of awareness occurs following a transformational experience. In conversations with parents, they can often

specifically identify this transformation (Ulrich, 1998). For example, a father listened to a younger child reading, and realized that the younger child read far more fluently than his own son, who was several years older. A parent recounts seeing her child walking the perimeter of the playground, suddenly realizing that her child does not know how to play with other children. Parents reflecting on these experiences made statements such as, “Right then, I knew that school was going to be different for Joseph than it was for Darren.”

Level 2: Special Designation

In this second stage of awareness, parents have, through some transformational experience, recognized that there is indeed a disability. So, if there is a problem, there are professionals to fix it. If you're sick, you go to a doctor. If you can't read, you must go to some sort of reading specialist. Parents want specific services with specific numbers of minutes on individualized education programs (IEPs). Parents may seek specialists, join parent organizations, and read everything they can on their child's label

Levels of Awareness of Truth

- Each issue has levels of truth. As one grows in awareness, his or her levels of truth deepen.
- Each individual operates from a particular level of truth. This level of truth is his or her reality.
- A person must fully embrace a level of truth before moving to another level.
- Moving further along the continuum allows an individual to better understand the concept itself, as well as the level of truth of others concerning that concept.
- Each level is a significant break from the previous level, moving in the opposite direction. When one looks only at two adjacent levels of truth, they may give the appearance of a dualism.
- Understanding these different levels of truth is vital to communication.

Source: Schaeff, 1992.

Denial, anger, and depression are all common reactions to challenges faced by family members of children with disabilities.

of disability. In this level of awareness, their child becomes a “special” child for whom “special” services are needed. Parents may even be confrontational, wanting to know what the professionals are going to do about the disabilities.

In our conversations with parents, this “identify the problem and solve it” level of awareness of disability usually fades with a transformational experience having to do with the family’s quality of life. A parent stated:

Todd was going to tutoring two afternoons a week and seeing an occupational therapist. We had sticker charts on the refrigerator; a babysitter scheduled three nights a week while I was secretary of the local parent association. We drilled flash cards of some sort even in the car. One day my husband and I looked at each other and our other kids, with whom we really spent little time, and said to ourselves, “What the heck are we doing? Do we want to live like this?” We didn’t have a minute to ourselves as a couple, Todd was miserable, and his brother and sister were miserable. We decided that quality of life was more important than somehow beating Todd’s learning disability.

Level 3: Normalization

In the normalization phase, the parents minimize differences between their child and his or her classmates and siblings. They emphasize the need for normalization in their child’s life so that it begins to look like that of other children their age. At this stage, a parent may say, “I don’t think of Suzanne as have learning disabilities. I just want her to fit in.” Here’s what another parent said:

On Jan’s tenth birthday Jan announced, “All 10-year-olds get braces and go to Disney World.” So what else were we to do? The next month we were taking pictures of our child with a sparkling metal smile standing next to Mickey.

Van der Klift and Kunc, cited in Lovett, 1996, suggested that resignation and benevolence characterize this phase. Parents may argue for a reduction of requirements in favor of more typical peer activities.

As parents move through this level, their transformational experience may again occur related to what their child can or cannot do. The transformational experience may also be related to the child’s moving from one educational environment to another. Parents may make statements like this:

He was fine in the primary grades. They did everything he needed. But now, we’re moving to fourth grade. Long division. Ink pens. I thought to myself, we can’t keep pretending that he’s going to be fine or outgrow this.

Thinking back on it, it was like before he was identified. The IEP, in the name of inclusion, didn’t really have any meat. I don’t think he learned anything all year. All of the requirements were reduced, and he was just “one of the kids”—one of the kids who didn’t seem to be improving in any of his academic skills.

Here we see a huge transformation, going from denial of disability to not only acknowledging it but asserting that the other students can learn from their child with a disability. Teachers may wonder what happened—almost overnight, parents may be saying contradictory statements.

Level 4: Self-Actualization

In this level of awareness, parents recognize that children with disabilities need supports; and not only do they need supports, but they may have their own perspectives on how these needs should be met. Parents and professionals do not perceive that being different is either better or worse, but just differ-

ent. They recognize the value of equal work, and emphasize the mutual benefits that come from celebrating diversity (Van der Klift & Kunc, cited in Lovett, 1996).

In this level, parents and teachers support their children in learning about themselves and their disability. Because the culture still has much stigma associated with “disability,” parents and teachers prepare the students to be self-advocates. Information and experience with disability culture and self-determination advocacy teaches individual equilibrium. We hear statements like this from students: “I am Shanisha, and I am smart. I have a learning disability, which means I have to use my Palm Pilot to schedule my day, but I am good in math and want to be a teacher.”

Parents stop expressing their dreams and begin to express realities. The young adult who loves stories may never be an English major at Harvard, but may be happy unpacking books at the library.

Using the Levels of Awareness in Working With Families

Schaeff (1992) stated that the first step involves “naming.” Covey (1989) suggested looking “inside-out.” Reflecting on your own individual definition of disability may give you insights into the parent’s current “level of awareness” of disability. Is there a current match between the teachers’ and parents’ semantic definition?

We asked six teacher/parent dyads (T-Teacher, P-Parent of primary school-age child with a disability) from two school districts (E-East, W-West) to fill in a visual display of the first things that came to mind when they heard the word “disability.” Although almost all the parents’ responses were similar to each other in that they mentioned their child’s name, several were quite different from their child’s teacher.

We need to be aware that the learning and growth process includes transformational moments.

**As educators, we must look
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Suggestions for Practice

When miscommunication occurs between the parent and teacher, it could result from a mismatch in the levels of awareness. If the parent is on Level 2: Special Designation, and the teacher is on Level 4, or vice versa, then even though each may be earnestly doing their best to communicate, it may be challenging. We need to be aware that the learning and growth process includes transformational moments. When statements from parents or teachers are inconsistent with what they said previously, they may have experienced a change in their level of awareness. For instance, the parents demand more

therapy (Level 2) on one day and suddenly change their mind and say they just want their child to be included in general physical education (Level 3).

First, we each need to know ourselves. Second, "transformational experiences" will happen and may cause each of us to grow and change. Shared "aha" moments on both sides help us process what is happening and more accurately find shared meaning. Third, we can build trust and communication if both parties make it a priority.

After years in Nazi concentration camps, psychotherapist Viktor Frankel wrote in *Man's Search for Meaning* (1984) that each of us must find our own larger sense of what is happening to us, a "guiding truth" for our attitudes, beliefs, and actions, and then we must be willing to take responsibility for the choices we make. Certainly we must look in retrospect and think about our personal knowledge, our past transformational experiences, and our motivation to really listen and communicate. More important, we must focus on our future and how we can bring real learning, real

community, real inclusion and belonging, and real communication to life.

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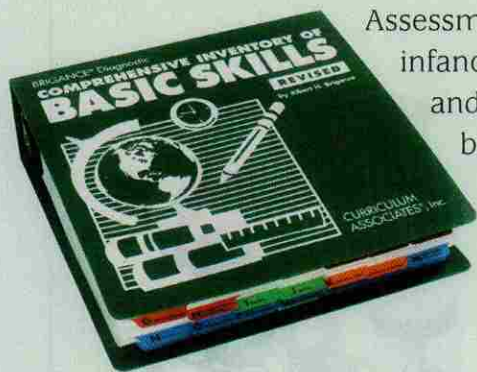
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