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Living with Learning Disabilities: Strategies for Family Support

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Introduction

The incidence of learning disabilities (LD), representing half of all special education, continues to grow and affect many families. Despite these large numbers, there is a lack of consensus regarding the definition, etiology, diagnoses, and treatment (Carrier, 1986; Dudley-Marling, 2004; Reid & Valle, 2004; Rice, 2002). Generally, LD represents a complex phenomenon involving difficulties processing information, interpreting that information, integrating it with what is already known, and outputting that information verbally or through writing (Lerner & Kline, 2006; Levine, 1994; Smith, 2004).

Because there is little agreement in the field, current debate centers on considering LD as being socially constructed. Although hotly contested, experts point out that learning disabilities are not objective fact, rather they are constructs, open to interpretation (Artiles, 2004; Connor, 2005; Ferri, 2004; Neufeld & Hoskyn, 2005; Reid & Valle, 2004; Rueda, 2005). As the understanding of LD expands, there has been a major effort to consider disabilities in the broader social context of the family (Ferguson, 2002; Risdal & Singer, 2004; Turnbull & Turnbull, 2001).

Emphasizing the importance of the family is a welcome paradigm shift. The research presented here explores LD through parental eyes. First, a cultural identity model is explored, including phases of dissonance, immersion, and advocacy. Then, strategies are presented to assist professionals working with this population.

Research Methodology

Guided through the lens of social constructionist and family systems theory (Anderson & Goolishian, 1988; Becvar & Becvar, 2006; Bertrando, 2000; Gergen, 1985; Hoffman, 1993; Nichols & Schwartz, 2005; Pilgrim, 2000), this research explored how parents perceive LD within their family. The semi-structured interview guide was designed to stimulate parental responses to answer the overarching question, "What are the processes occurring when parents seek help for their children who are experiencing academic difficulties?"

To analyze the data, the constant comparative method developed by Glaser and Strauss (1967) was employed. This continuous process involved being immersed in the data, looking back over previously collected data, while at the same time considering new data and looking for common themes (Creswell, 2003; Denzin & Lincoln, 2000; Patton, 2002; Wolcott, 2001).

Analysis of Results

From the beginning to the end of this research, parents were eager to participate and share their stories. They passionately urged me to spread the word that their children are “normal,” rejecting the words “handicapped” and “disabled.” This desire to promote activism is similar to other groups who express feelings of marginalization. Thus the concept of LD cultural identity came into focus.

The majority of these parents, now strong advocates, were not always so brave and positive. The emergence of their stories often became quite emotional, to the surprise of the participants. It became apparent that two words, learning and disability, when placed side by side, possess the power to stigmatize children, leaving their parents to make sense out of this marginalization. Patterns of adjustment to living with LD lend credence to the idea of a marginalized LD culture, similar to the model of cultural identity as summarized by Sue and Sue (2003). Most of the parents traveled through phases of dissonance, immersion in factual information, to activism and desiring to share their journey with others.

Dissonance

The majority, or ideal student, display little or no school difficulties. Education is in fact an important defining norm in our culture; and indeed a good education is viewed as essential for future success. Students with LD, experiencing academic problems, are in the cultural minority. The oppressiveness of experiencing difficulties at school is well documented as seen in these parental quotes.

I was the school nurse on Friday's and I heard somebody retching in the bathroom and it was my son and it was reading time. I went to the room to tell the teacher I was going to take him out of school because he was sick and she said, “No, this happens everyday at reading time.” And I said, “You didn't think that was important to tell me?” And she said, “No, we don't want him to get positive reinforcement for these bad behaviors of not wanting to read.”

In second grade his teacher told us, “There's nothing wrong with him” and we shouldn't fight on his behalf because “he's just one of the laziest, sluggish boys; everything's a joke to him.”

We briefed his teacher before the school year started, “this is his issue, this is what we need to work on,” and she took notes. Around February of that

year he was struggling and she admitted, “yeah, I didn’t take any of your suggestions because I wanted to form my own opinion.”

Thus the theme or phase of “dissonance” surfaced as discord was noted in each parental story as well as throughout the whole of this research. Beginning with the discovery phase, the majority of these parents were surprised by the academic difficulties and the resultant learning disabilities diagnosis. Many shared how they or their spouse at first denied there was a problem. As one mother put it,

We went through the testing and they told us that he was so very LD. Well, we told the lady that she was wrong. You make excuses and you think it can’t be right. We didn’t believe it in the very beginning. I said we’ll just keep doing the work and we’ll show them.

Throughout their journey, parents related a lack of agreement from friends, family, and professionals. Dissonance continued as parents braved conflicts with the educational system. However, these parents refused to accept negative predictions and treatment towards their child, searching for answers and professionals who could assist them.

It is important to note that the parents in this study tend to gloss over the painful stories of marginalization. They do not like to think of themselves and their children as being devalued citizens. Over and over they said, “We are normal.” Disliking the diagnosis of LD, parents pointed out that all children learn differently.

Immersion

Searching for answers, the parents in this study immersed themselves in learning disabilities. These parents all spoke of voraciously searching for information from every resource they could find, whether it be from family members, support groups, medical personnel, educational staff, or professional conferences.

Beyond educating themselves, the parents spent untold amounts of time, finances, and emotional resources looking for information, assistance, and support. In the words of several parents, “time, emotions, it’s been draining and really challenging to the family in general.” “It’s exorbitant.” Despite the costs, rather than remaining stuck in their informational search, the parents chose to move forward, directing their energies toward helping their child.

Activism and Advocacy

Parents, armed with an abundance of information, decided and defined for themselves what LD meant and looked like. Realizing that all families experience difficulties, these parents view their lives as being no different. “We are typical,” echoes over and over. They have become strong advocates.

Beyond advocating for his or her own child, each parent articulated their reason for participation in this research was to help other parents get the needed information, assistance and support. It is as if their anger has solidified into a sense of great passion as

they encourage others facing LD to become assertive. These parents urged me to share my findings with other parents and professionals. In the words of one mother, “My faith is that whatever you and I discuss, it’s going to be just that much easier for the next mom.”

The parents are adamant about spreading the message of normalcy; the child is “not defective.” Other parents of children with LD are passionately urged to get educated and advocate on behalf of their child. In the words of the parents, “You have to advocate because they can’t.” “You have to fight for everything and be proactive.” “Don’t stop asking questions.” “Be aggressive.” “If you hear negative stuff, say something, [people] need to be accountable.” The ultimate goal is not to be considered a minority group, but rather, simply part of the human race, struggling and desiring the best for his or her child and family.

Integration

The final phase, integrative awareness, as delineated by Sue and Sue (2003), is considered necessary for health and stability. This stage is characterized by “an inner sense of security [as people] now can own and appreciate unique aspects of their culture as well as those in the U.S. culture” (Sue & Sue, 2003, p. 225). While some of the attributes of integrativeness are documented, this phase cannot be clearly identified by this research.

As described above, these parents, having resolved many conflicts, do exhibit a positive view of their families and a sense of control. However, one does not perceive a sense of peacefulness. Instead, a sense of conflict remains; parents knowing they will have to continue fighting for acceptance for their child with LD. From previous experiences, parents know conflicts and discomforts which were resolved can easily rise to the forefront. Thus, parents may revert back to anger and strong activism. It is my conjecture that these parents would not be happy or content to be considered a minority culture, preferring instead to actively pursue change which would lead to a cultural attitude of normalcy towards learning differences.

Limitations

Following a social constructionist paradigm, it would be incorrect to say that all parents travel the same path as delineated above. Nor would it be correct to say that parents and their children pass through these phases in the same sequence. A cultural identity model, however, can serve to organize disparate research findings, thus facilitating meaningful dialogue.

It must be remembered that these reflections are based on a very small sample size. It would be important to interview parents at different phases of the journey. It would also be informative to interview parents further along the road, perhaps with college aged and adult students.

Recommendations for Professionals

Inherent in this research are many suggestions for professionals who work with students facing learning disabilities and their families. The myriad of professionals associated with LD include teachers, administrators, diagnosticians, tutors, language therapists, counselors, and pediatricians. Generally, the parents in this study agree that professionals continue to “have a ‘detached and clinical’ understanding of disability” (Azzopardi, 2000, p. 1067). Suggestions to combat this professional detachment fall into categories emanating from the affirmative practice counseling paradigm (Colon, Appleby, & Hamilton, 2007; Ritter & Terndrup, 2002). The areas identified from this research are awareness, knowledge, and skills.

Awareness

Of utmost importance, it is crucial to remember that parents do not want to be approached from a stance of pathology. Rather, just as all people experience difficulties, the families and individuals living with LD desire to be thought of as normal people with normal families. This perception can be facilitated by listening to individuals and families as they describe what their lives are like. By bearing witness to their stories, you assure them that you as a professional are indeed aware, interested, and caring.

It is also important to remember that these families face difficulties that are unique to the world of LD. These general concerns typically revolve around issues related to obtaining accurate and useful educational assessments and procuring needed modifications. In addition, each person and each family face their own unique circumstances and changing family dynamics. Thus, it is also important to explore each individual situation.

Knowledge

The importance of increasing personal knowledge regarding LD and surrounding issues cannot be overstated. Exploring the importance of the family will lead to an expanded perspective of LD. Also, keeping in mind that everybody learns differently, it is important to expand personal knowledge via collaboration with others, web search, attending workshops, and visiting classrooms. Next, it is helpful to understand LD first hand. Place your pen in your non-dominant hand, tap your foot and write your name in cursive. Or, hold writing up to a mirror and read the mirror image. Notice, analyze, and spend time with your frustration. Share your new knowledge and insights with parents and kids.

Skills

Perhaps the most important ability when providing assistance is to approach issues from a non-pathological stance. Explore from a stance of genuine curiosity rather than making deficits the focal point. It is first important to examine any pre-conceived notions related to LD and the family. Thus, self-awareness is potentially the biggest asset in working with this group of people.

With self biases in check, explore for solutions from a stance of partnership. Remember that parents and children bring important parts of the LD puzzle to the table. Be open and learn from parents, they have wonderful insights.

Regardless of what services the professional is supplying, thoughts, and findings should be shared respectfully, in terms parents and students can understand. Whether providing the initial diagnosis or continuing assistance, remember that being faced with the LD world is a huge paradigm shift for most families. Realizing that parents need time to digest new life changing information, be patient, willing to share findings on more than one occasion. Talk over the stigma associated with diagnoses. And, perhaps most importantly, help parents by providing practical advice.

It is important to view parents as human beings with self care and time needs of their own. Time for themselves may sound ludicrous to overburdened parents as they are faced with incredible time demands. Professionals can help by facilitating support within families, social network or local agencies.

Lastly, support parents as they advocate for their child. Encourage parents to share their experiences. It appears to be very beneficial for parents to share their experiences and provide support for others traveling the same road. Endeavor to make a dent in society, striving for the day when everybody is looked at first and foremost as a person, a living human being. By focusing on our shared humanity, great strides can be taken towards acceptance of all regardless of learning style.

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