

Please share your stories about how Open Access to this article benefits you.

Until Somebody Hears Me:
Parental Voice and Advocacy in Special
Education Decision-Making

by Robyn S. Hess

Amy Molina

Elizabeth B. Kozleski

2006

This is the author's accepted manuscript, post peer-review. The original published version can be found at the link below.

Hess, R., Molina, A., & Kozleski, E. B. (2006). Until somebody hears me: Parental voice and advocacy in special education decision-making. *British Journal of Special Education*, 33, 3, 148-157.

Published version: <http://dx.doi.org/10.1111/j.1467-8578.2006.00430.x>

Terms of Use: <http://www2.ku.edu/~scholar/docs/license.shtml>

Running Head: PARENTAL VOICE AND ADVOCACY

Until Somebody Hears Me:

Parental Voice and Advocacy in Special Education Decision-Making

Robyn S. Hess Amy Molina

University of Northern Colorado

Elizabeth B. Kozleski

University of Colorado Health Sciences Center

This article appeared in the *British Journal of Special Education*, Volume 33, September, 2006,
pages 148 to 157.

Address correspondence to: Robyn S. Hess, Ph.D.

Division of Professional Psychology
C. B. 131, McKee Hall 293
University of Northern Colorado
Greeley, CO 80639
Robyn.Hess@unco.edu

Funding for this project was provided through the Merle and Marian Graham Fun in Support of the Rights of Children Committee.

Abstract

When a family finds out their child has a disability, they enter the world of special education which has its own terminology, rules, settings, and personnel. In addition to grappling with the meaning of their child's special needs, families are also thrown into the role of principle advocate for their child. This research study presents the findings from focus groups conducted with 27 diverse families on their efforts to obtain the best educational outcomes for their children. In this article, Robyn Hess, Elizabeth Kozleski, and Amy Molina bring their collective experiences as a school psychologist, special education teacher, and bilingual counselor, to bear on this topic and frame the issue from a systemic perspective. They argue that engaging in conversation with diverse families around their needs as well as assisting them in their efforts to advocate for their child is the first step in creating more equal partnerships between diverse parents of children with special needs and educational professionals.

Politicians, educators, researchers, policy analysts, and the media have all scrutinized the value of special education. In the United States, the passage of IDEIA 2004 (Individuals with Disabilities Education Improvement Act of 2004, H.R. 1350, 108th Cong., 2004), required special education to demonstrate the same accountability as that of the broader educational enterprise. Accordingly, students with disabilities are now required to demonstrate their knowledge and skills on standards-based assessments thereby ensuring that schools are held accountable for the academic progress for students with and without disabilities. By increasing accountability standards, this legislation attempts to guarantee that schools provide students with disabilities opportunities to learn within the general education curriculum. While special educators have long advocated for greater inclusion of students with disabilities, many school systems still provide separate classrooms, if not schools, to educate these students.

While on one hand, those who advocate for separate educational settings would argue that these systems allow schools to meet the special needs of children, to protect them and effectively educate all students (Barton, 2004), others would contend that these structures create barriers (Oliver, 1996) and encourage negative labels and stereotypes (Barnes, 1991 cited in Barton, 2004). Given that individuals with disabilities experience higher rates of unemployment and underemployment, higher dropout rates and more restricted community participation relative to others without disabilities (Browning, Dunn, Rabren, & Whetstone, 1995; National Center for Education Statistics, 2000); one might question the efficacy of current practices in preparing individuals for post-schooling outcomes. Of further concern, is the long history of special education in serving a disproportionate number of students of color (Donovan & Cross, 2002; Losen & Orfield, 2002). Given these shortcomings, the educational field remains deeply split on

the meaning and value of special education, and the related concept of inclusive education (Brantlinger, 2004).

As Kalyanpur and Harry (2004) note, the debates about who will be served and why, exist largely within a professional community of educators, researchers and policy makers. What is lost in this heady debate is the voice of families and their children. This paper presents the perceptions and experiences of diverse parents of children with special education needs. In particular, emphasis is given to the role that these parents played in educational decision-making and their attitudes toward different models of special education services.

The Role of Parents in Special Education

The role of parents in their child's educational treatment has changed over the years with an increasing emphasis on empowerment and decision making. For years, legislative mandates have placed an increasing emphasis on the role of parents in their child's education. IDEIA (2004) calls for 'strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home.' Unfortunately, at times the interpretation of parental involvement and its application in the schools has reflected the minimal amount required by law. In fact, some educators continue to perceive families as adversarial or even dysfunctional (Salisbury & Dunst, 1997). Despite research supporting the positive effects of parental participation on student achievement (Eccles & Harold, 1993; Henderson & Berla, 1994), schools continue to resist accepting parents as full partners.

In their review of parental involvement literature, Turnbull and Turnbull (2002) describe the progression of professional perspectives on parents from a *psychotherapy perspective*, in

which children's difficulties were presumed to be caused by the parents, to a *parent training* model where, again, families were considered to have deficits in need of "fixing" to a *family involvement* model where families were given specific, active roles in educational decision-making. Although each of these steps represents an improvement, the system and the professionals within it still hold the power by defining how and when parents are involved (Harry, 1992a). This imbalance in power is especially apparent between culturally and linguistically diverse families and school personnel (Kalyanpur, Harry, & Skrtic, 2000; Salas, 2004).

One of the difficulties in establishing collaborative relationships may be related to educators' lack of understanding of family culture or unwillingness to investigate the meaning behind certain behaviors. Through a series of qualitative interviews, Harry (1992a) found that African American parents' appearance of apathy and disinterest in their child's education was masking parents' mistrust of education professionals. Similarly, the formal channels of communication frequently used by schools (e.g., letters, forms), may actually alienate Puerto Rican families (Harry, 1992b). Given these misunderstandings, it appears true collaboration and equality between team members has yet to be realized (Kalyanpur et al., 2000; Ryndak & Downing, 1996).

Despite these struggles, families generally view their children's schools in a positive manner. Based on a survey of over 500 parents of students with special needs, Johnson and Duffett (2002) found that the majority of these parents saw their schools as doing a good job in educating their children, felt that the special education teacher cared about them "as a person", and believed that the special education teacher knew a lot about their child's disability. However, many parents also reported difficulty in obtaining information about existing services and a

minority of parents reported extreme dissatisfaction with the available services, suggesting a continued need for more open communication and collaboration.

Issues of Programming, Partnership and Decision-Making

Once a child is identified as having a disability, the family is faced with the difficult decision of choosing the most appropriate educational program. Within the school district, the options typically range from exclusionary models such as a separate school or self-contained classroom to a full inclusion setting. Every district is different and the choices along that continuum may be limited by whether a program is offered in a child's neighborhood school, whether there are openings in a desired program and the district's philosophy toward inclusive practices. The decision-making of families and caregivers tend to reflect practical issues such as program availability, curricular preferences, placement options and social treatment rather than the philosophical soundness or research support (Palmer, Borthwick-Duffy, & Widaman, 1998). Those who had experienced successful inclusive settings for their children were also more likely to support inclusion. Still, relatively little is known about the specific role of parents in this educational decision-making, especially when we consider culturally and linguistically diverse populations whose children are frequently over represented in special education (Palmer et al.; Prater & Ivarie, 1999).

Family support and input are critical in developing programs that effectively meet the needs of families and children with special needs. In a qualitative study examining parents' perceptions of educational services for their children with moderate or severe disabilities, Ryndak and Downing (1996) interviewed the parents of 13 children about their views of self-contained and inclusive educational settings. Parents expressed frustration and unhappiness about the process used to decide where and how their child would receive services. Further, they

were amazed at the educators' lack of understanding of their child's needs for a natural social support network. These findings were consistent with those of Lake and Billingsley (2000) who reported that the main sources of conflict between parents of children with special needs and school personnel were the discrepant views that each held in relation to the child and his or her needs. This contrast was especially pronounced in those situations where the school perceived the child from a deficit perspective. Russell (2003) argued that an exploration and review of parents' expectations for their child and their child's educational services is a necessary component for increasing understanding and facilitating a stronger relationship.

Families sometimes must also make decisions regarding the "best" school for their child. Rather than simply attending their neighborhood school, families of children with disabilities are increasingly selecting schools that are further away but that provide desirable programming (Lange & Ysseldyke, 1998). Given the multiple choices that families must make around the education of their child with special needs, it is critical that families are educated about their rights and offered guidance and support as they make these difficult decisions for their child. Special education teachers are well suited to assist families in these complicated and important decisions.

The Role of the Special Education Teacher

Danielson (1996) describes teacher practice as encompassed within three overlapping structures: planning, management and instruction. Yet, special educators perform a wider variety of tasks because their services are delivered not only to students but also to other adults as an explicit part of their professional responsibilities. Collaboration with teachers and other practitioners is an essential component of a special educator's role since these other educational personnel may act as the direct service provider to the student with disabilities. The special

educator is also expected to collaborate with the families of the children in their classrooms or on their caseloads.

The current focus on teacher quality has meant higher demands on what special educators know and can do. Special education has become increasingly complex and special educators are expected to immediately transform the most current research into practice. The dual pressures of teacher quality and evidence-based practice are geared towards heightening the professionalization of special educators. Yet, the emphasis on knowledge and autonomy may actually create barriers to the type of relationship that families are seeking for their children and themselves (Ware, 1994).

Inclusive School Systems

Those who advocate for inclusive education believe that children with special needs should have access to similar educational benefits as their non-disabled peers through participation in regular education classrooms and in non-academic and extra-curricular activities (Sands, Kozleski & French, 2000). Although the degree to which inclusion should be practiced remains somewhat controversial, IDEIA has made it clear that schools have a duty to educate children with disabilities in general education classrooms. Over the last decade, inclusive models have been implemented in schools across the country based on the idea that children with and without special needs benefit from increased opportunities for interaction and that combined general and special education classrooms can better serve students and increase their educational opportunities (Ferguson, Kozleski, & Smith, 2003). Indeed, research suggests that students with special education needs placed in general education classrooms demonstrate higher levels of social interaction with non-disabled peers, receive more social support than their non-included peers (Fryxell & Kennedy, 1995) and show improved communication skills and social

competence (Bennett, DeLuca, & Bruns, 1997). Peltier (1997) concluded that inclusive education promotes all students' social growth and does not negatively impact the academic growth of students without disabilities.

Because education professionals have so much power regarding educational planning and placement of children, it is critical that they are knowledgeable about parent needs and perspectives. This willingness to investigate parents' educational values and expectations is especially important when barriers exist for family involvement such as lower levels of education, language differences and families who are not acculturated to the majority group. This study gathered parent perceptions related to special education and inclusive practices through focus groups and individual interviews with the goal of exploring the perceptions and opinions of family members (caregivers) of children with special education needs about their experiences with special educational programs. With this information, we can develop a better understanding of the similarities and potential mismatches between perspectives on the promising educational practice of inclusion.

Methodology

Context of the Study

This study was conducted in a large, urban district in a southwestern state in the United States. The district has nearly 73, 000 students and 151 schools. Of the students who attend these schools, 61% qualify for free- or reduced lunch services suggesting a majority of students reside in homes that are lower in socioeconomic status. As in many urban districts, many of the students are English language learners (20%). Of this population, 92% reported their first language as Spanish. The student population in this school district is also diverse with 19.1% reporting African American as their race/ethnicity, 57.3% Hispanic, 19.3% Caucasian, 3.1%

Asian and 1.2% American Indian. Further, 11.7% of school-aged children qualify for special education services. The district's philosophy toward special education is one of "needs based services" where the characteristics of the needs are more important than the categorical label". A Board of Education sets the overall mission and objectives for the district, but each school has a school level accountability committee that is responsible for developing, managing and evaluating the specific programming decisions at a particular school. As a result, there is quite a bit of diversity in terms of the curricula, programs and policies from school to school within this district. The district has also recently adopted a "school choice" option where families can choose the school they would like their children to attend rather than simply attending the neighborhood school.

Participants

Twenty seven parents (or caretakers) of children with a range of disabilities (e.g., learning disabilities, cognitive disabilities, emotional disorders) participated in this study. Parents were identified for potential participation in the study by school psychologists at 8 different elementary schools within the district. Families from diverse ethnic, cultural and linguistic backgrounds were purposefully sought out to offer proportionate representation from this urban district and for the unique experiences they might share. The resulting ethnicity of our focus group participants included 15 Hispanic parents, 10 African-American parents and 2 White parents. Eight of the Hispanic parents who participated did so in three focus groups conducted in Spanish, providing us with the opportunity to learn about the experiences of non-English speaking parents. In most cases, a single parent or caregiver attended, but in two cases, two parents and/or caregivers attended for a total of 29 participants.

Focus Group Questions

Focus groups represent a qualitative strategy for data collection and are considered an effective means of gathering information from families (Wesley, Buysse, & Tyndall, 1997). This method allows the researcher to obtain more information than is typically available in survey research and provides for participant interaction (Wesley et al.). One of the key strategies to conducting an effective focus group is the development of a set of questions that will elicit rich information and will encourage interaction among group members (Morgan, 1993). The original focus group questions were developed using past research on parent views of special education. A pilot study with four parents helped us to further clarify our questions. For example, initially we simply had a question about inclusion, but found that our facilitator needed to explain this term to most participants. During the pilot study, we also found that using an interpreter for monolingual Spanish-speaking families was too time consuming and resulted in subtle (and not so subtle) input from the interpreter related to the parent's response. As a result, we enlisted the assistance of a bilingual facilitator and held separate groups for English and Spanish speaking families.

The final focus group script was structured around seven questions regarding parents' experiences and perceptions of the special education system. The questions were broad and open-ended to encourage open discussion and probes and expanders were identified for each question in order to obtain more complete, detailed information if needed. (See final focus group questions in Table 1). We translated and back translated our instructions and focus group questions into Spanish through the assistance of two different bilingual individuals who hold graduate degrees.

Procedure

After receiving all appropriate approvals, we began recruiting families for participation through the school psychologists employed by the district. If the family expressed interest and gave permission, the family's contact information was shared with the researchers. Once we had a few names of potential parent/caregiver participants from a particular school, we contacted families to set up a time for a focus group. Parents were given the choice of participating in an English or Spanish focus group. All focus groups were conducted after school at the elementary school where the child attended and/or the parent was employed. A total of 13 focus groups were held and varied in size from 1 to 8 participants. In four instances, the confirmed number of parents did not attend and our "focus groups" included only one individual or family (both parents). The groups usually lasted from 1 to 1 ½ hours and all parents were given a \$25 grocery certificate in appreciation for their time.

The focus groups were moderated by two different individuals trained in focus group methodology. The Spanish focus groups were all conducted by the same bilingual individual. Participants were given the informed consent in the language of their choice – English or Spanish. They were read a protocol explaining the content and purpose of the groups and encouraging a loosely structured format for discussion. All groups were tape-recorded using a high quality microphone and tape recorder and were later transcribed. The transcriptions were edited to reduce irrelevant information without changing the substance of the participants' comments. The Spanish focus groups were conducted in the same format as the English groups. The tapes from these groups were first transcribed into Spanish and then translated into English by a trained translator.

Data Analysis

In order to identify themes, we engaged in a series of readings of the transcripts which resulted in the generation of “open codings” consistent with procedure described by Strauss and Corbin (1998). Through a process of “constant comparison”, we began to code the data into conceptual categories. This process was facilitated through the use of the qualitative data management program, NVIVO (QSR International, 2000). In this process, the researchers identified events, actions, or feelings in the data and constantly compared them with one another to decide if the items belonged together. We did not use the actual language of the participants to define the codes and instead grouped these by the broad description of stakeholder (e.g., parent, teacher, school, child) and then by subcategories (e.g., negotiating the system, advocacy, communication). Based on this initial organization, participant quotes that were viewed as belonging to a particular category were identified and coded into that area. Quotes could be coded into as many areas as needed during this initial analysis. A subsequent analysis provided for a finer level of sorting in which those quotes that were not very clear, appeared on several different nodes, or were frequently repeated were dropped or entered in only one area. This level of analysis allowed the researchers to group the clearest statements into similar categories and rename these as appropriate. We also began to reorganize and refine our original codes as we began incorporating our interpretations into the categories. This interpretation begins early in the analysis as soon as one moves past simple description of the participants’ input (Harry, Sturges, & Klingner, 2005). During this stage, the authors read the transcripts separately, developed their ideas about the themes individually and then together, reviewed the placement of the quotes until consensus was reached. At our third level of analysis, we began to work selectively with codes and decide how they related to one another (Strauss & Corbin, 1998). In essence, we began to look for an underlying organizational schema that integrated “both complementary and

competing” data. Additionally, we identified essential “tensions” between the perspectives (both indirect and direct) of the various stakeholders as perceived by family participants.

Findings

The analysis revealed three overarching themes related to parents, teachers and schools. For parents, a dichotomy emerged between being an advocate for one’s child and being the passive recipient of decisions made by school personnel. Within this theme, parental perceptions, role in decision-making and transformation into advocate are presented. The next theme addresses teachers and their role as a “bridge” between the family and the broader school system. The final theme represents the parents’ views of the school and their struggle to find inclusive placements. From their descriptions, it is clear that they view inclusiveness more broadly than their child’s educational placement. Rather, inclusiveness for families represents a “sense of place” where their child belongs.

Parents: Advocacy vs. Being “Othered”

Families’ stories at times reflected a sense of advocacy and empowerment as parents found ways to support their children’s educational needs, contrasted with a sense of having had something “done” to their family with little input on their part. When families encounter others making decisions about their children and their children’s educational program, they experience the phenomenon of being “othered”. According to Johnson, et al. (2004), othering is a process of making distinctions among individuals so that some individuals may be viewed as part of the mainstream while others are seen as different or deviant. In order for their children to receive services, families must accept the school’s position that the learning problem lies within the child (Kalyanpur & Harry, 2004). For some families, this is not an acceptable compromise and further distances them from the educational system.

Advocacy and othering is played out through the distribution of power and privilege between families and schools. Another fundamental tension is experienced in the special education team's effort to create an efficient, streamlined process and the need to personalize the process for individual families. Finally, we identified the evolution of the parents' assessment of their efficacy in dealing with the educational system in relationship to advocating for their sons or daughters. In the following section, we explore some of the features of these elements.

As parents told their stories of realizing their child had special learning needs, it was clear that the circumstances surrounding the initial referral to special education varied widely. Some parents reported knowing that their child was struggling and thus, fought hard to obtain these services as in the following example from S. M. (#1)

'Finally, I pushed and I pushed it and you know, because I work in the building and I wasn't gonna take no for an answer. They tested him and they said he was very borderline Special Ed'.

For this individual, her knowledge of learning disabilities and the special education system as well as her position as an employee of the school, provided her a level of privilege that allowed her to access the services she believed her child needed.

Others reported developing an increased awareness once the school brought the concerns to their attention. For example, one parent stated,

'They told me he was getting behind in class. And then we had him tested and he was really behind. Um, then I kind of knew because I had it also, and I could just, me having it, and then seeing him, I knew it was there because the stuff he would do and how he would react, because he would get upset if he couldn't do it'.

Her experience was one of working with the school and feeling that she was a part of the process as she uses the term “we.” Further, this parent seemed to accept the findings of the school as an accurate reflection of her child’s needs.

Finally, there was another group who expressed a sense of frustration with the lack of communication from the school, the lack of partnership and reported that they did not believe they had a voice in the process. For example, one parent described her experience,

‘And then when they called me, they’re like we need a meeting, we need to do this, we need to do that. And I sat there and I’m like okay, what’s wrong? Well, this is wrong, and this is wrong, and he doesn’t do this...and I was like well, why wasn’t I called before? Why wasn’t I informed before? Why didn’t anybody tell me? Show up, like, if he’s showing red flags up here, why didn’t I get this? I just felt like I learned...I came in at the end and I was told at the end. So it was like I was...this is how it is going to be and this is what we’re doing. And I just felt like I had to go with it’.

Parents reported different levels of experience in participating in special education eligibility and individual educational planning (IEP) meetings. For some, it was their first time and others had attended multiple meetings either because of the length of time since their child had been identified or because of older siblings who had also received special education services. In describing these IEP meetings, families portrayed the strain between obtaining needed services for their children and enduring a meeting that did not seem to include them. This tension might arise from the competing demands of developing an efficient, standardized process for identifying children and the parents’ need to understand and process the meaning of their child’s disability. In their press to create an efficient meeting, the individual needs of the family in these important proceedings may be lost. For example, one parent described her experience as:

'My first experience with an IEP, I felt like I was in a different world. I just sat there crying because it felt like, they made me feel like my son was like, so low on his scores and then it's like I had nobody there with me, and I am just looking around at everybody and I'm "he what?" They just kind of rushed through it, and all, basically all I got out of it was that it was, "My son's not up to his potential". He's not doing this and he needs this service, and that's it, sign the papers. And I just walked out of there. I mean, I was just flabbergasted'.

It is clear from this parent's words, the level of isolation, hopelessness, disempowerment and confusion that she experienced in this meeting. Other families had more positive experiences. Although initially shocked and saddened to learn of her child's special learning needs, one parent went on to say, *'But when I learned that I had so many people on my team and on my son's team, that made me feel a lot better'.*

One of the realizations that some families seemed to come to was that they needed to be advocates for their children. One parent, who had several children involved in special education and was employed as a paraprofessional (learning support assistant), described this process,

'It was really difficult for me to sit through IEP meetings and different people would start talking speech jibberish, different people would say things, and I would sit there and I would really try to focus on what's going on. But I would take that paper home, and I'd look at it and I'd be thinking, what in the world just happened? It took me pretty, several years, before I realized, I am his advocate. I have to speak up and say, okay, wait a minute, slow down, what does that mean, what did you say?'

This parent's statement also highlights parents' own growth in relation to parenting and advocating for their child. Initially, the parents of these children expressed their fear, confusion and guilt upon learning that their child had special needs. One mother expressed it like this,

'To me, this has all been overwhelming from the first day I found out that my son needed special attention. At first it broke my heart because I thought it was me. I was like, well, what didn't I do? What didn't I do as his mother and his provider?'

For some, after the initial shock, they seemed to look inside themselves and call on their own strengths in order to protect and support their child. For example, one parent noted, *'I just know that at this point in time, it's time for me to take care of my child the way that he needs to be taken care of. Nobody is to blame'*. As parents grew to understand their role as an advocate, they described both shifts in perspective (e.g., It's up to me) as well as practices that they engaged in with their children. For example, one parent noted, *'He has Ms C and me working with him, up reading every night, constantly, even on the weekends. It's better, and so I think that's why he has improved more'*. Some parents also reported changing their attitudes and expectations as well.

'And we're in the process of trying to figure out what everything is and how it's all going on. What he can understand and what he can't understand... because I...I only took everything as him being lazy or him just not putting his best foot forward'.

Advocacy seemed to take many different forms. For some, it was often in quiet, indirect ways – a statement of responsibility and teaming with the child to persevere. For others, their sense of empowerment manifested itself in an attempt to help others. For example, one parent noted:

‘Other parents have said that ‘you know, well, they said that so they really can’t help him.’ I said, ‘No, you need to go back and fight so your child has a fair shot at this education just as much as every other student in the building.’

This type of support for other parents was noted in our focus groups as well. Parents shared their ideas and experiences on how to access services, how to ask for what you need, and how to find the ‘right’ school.

Some parents clearly understood their role as an advocate and described direct actions that they could take for both their child and their child’s teacher. The perceived strength and ability to advocate was evident in one parent’s description of her introduction to her son’s new teacher,

‘And you will see me frequently, you may be coming to the point where you hate to see me. But if you need something, let me know. I will go to bat to get whatever you need. If its computers for your room, if you need Para help, whatever you need, I will be there helping. I will stand up on the table and scream until somebody hears me.’

Although some families reported a growing sense of “power” in the process, they also recognized the fragility of this balance as they described their fears for the future. Concerns ranged from their ability to let go and help their child become independent, to changing placements as their child advances in school. As one parent who, despite her role as a special education teacher, noted, *‘It’s too hard to think about the future’*.

Teachers: Relationship vs. Expertism

Parents perceived teachers as critical to their child’s success. Interestingly, it was not the teacher’s level of expertise, years of experience, degree, or research-based practice that was mentioned, rather it was a teacher’s perceived caring and openness to communication. When

expectations for professionalism were described, they concerned fairly basic levels of skill such as complying with an individualized educational plan or providing enough academic challenge. These voices seem to highlight the mismatch between parents' expectations of warmth and caring from teachers and the requirements of professional practice which place value on an objective, professional stance as suggested by Kalyanpur et al. (2000). The family perspective on the importance of relationship with educational professionals is explored in the following section.

When these parents spoke of the relative effectiveness of their children's schooling, their statements almost always included a reference to a particular teacher. Many of these statements related to the teacher's perceived "caring" for the child. One parent noted that her son seemed to be improving and attributed it to the relationship with the teacher. *'I don't know if it's just because they pamper him or if they just take care...get that little nurturing going. Cause they're always looking out for him'*. The perception of caring was also expressed in terms of the teacher's willingness to go beyond their professional role to address the child's emotional needs as well as to take the extra time simply to make sure that a child is making progress. When teachers don't demonstrate this type of disposition, family members see it as an additional barrier to their child's education. As one family member concluded, *'It's mainly about the teacher. If they don't help or care, it makes it harder'*. Another parent described the type of individual who should be a special education teacher with this statement,

'Because a teacher who takes on a special needs child, they have to have a lot of heart. They have to have an open heart and be ready to take that child and just hug them. You know what I mean? And that's what we need more of. Teachers who just want to smother those kids with showing them that they care'.

Families want to play a role in their child's education but sometimes believe that the lack of communication between themselves and the teacher acts as a barrier. Not only do did the parents state that they needed general information and support in order better understand their child's special needs, but also ongoing specific communication around academics, behavior, and general updates. Related to academics, parents wanted to know about homework expectations, curriculum goals and strategies to practice at home. Other times, the communication needs are less focused and the parent simply wants an opportunity to call and check in.

'You know, he can't tell me, so I want to know what's going on. So, I think communication, I think the biggest part of a perfect school would be a communication part. Being able to call that teacher after school and say, "Hey, what kind of a day did my son have? What did you guys do today?'

Unfortunately, this type of easy, communicative relationship does not always exist. As one parent noted in a matter of fact manner, *'My son's teachers need to talk more with the parents, some do, and some don't and that's my experience'*. When this communication isn't there, it can lead to feelings of frustration and the perception that the teacher doesn't understand the child's or family's needs, especially as related to homework. This finding was especially true in relation to families who only speak Spanish and find it extremely difficult to support their children in completing their homework.

Even though the most frequent comments related to caring and communication with teachers, the role of professionalism or competency was also mentioned. In the most outstanding instance, a parent reported that her daughter's teacher was not wearing the device that amplified her voice for her daughter who has a hearing disability. The parent had approached the teacher, the audiologist and even the principal regarding the teacher's lack of compliance with the child's

individual educational plan. The teacher reported that the device “was broken” and that she would look into getting it fixed, yet nothing had changed over several months.

In most instances, the examples were not as specific and instead, reflected a general level of concern with the type of education their child was receiving. For example, parents sometimes wondered whether their children were being challenged enough as one parent noted,

‘It’s working, but sometimes I think she needs more than what she’s having cause she’s still behind. I mean I know that she can’t catch up to be where she’s at, but at least a little higher up, you know’.

Another parent noted that her son had complained that he *‘didn’t really do anything’* in his special education classroom.

Conversely, parents also shared stories about teachers who demonstrated their professionalism by helping them to better understand their child’s disability and the kinds of interventions used in the classroom. For example, one parent noted that after talking with a teacher, she had better knowledge of her son’s disability.

‘(s)he sat down and showed me and gave me examples really...like I said, very in depth. It just made me really happy. I mean, I felt a lot more comfortable with him even being in her class because of the work that she put into it’.

When teachers care about children, communicate openly and perform their job in a professional manner, parents appreciate these efforts and appear to be satisfied with their child’s education. Unfortunately, as noted previously, the situation changes from year to year leading to uneven experiences in the interface between parents and schools.

‘Well, you know, his second grade teacher, she was so good. I mean we had a good relationship, but she told me, she said, ‘You know, I am going to work on him, you don’t

worry about it. I'm going to work on him.' But I think that third, the third grade, the first half, the teacher that he had, she just wasn't on him'.

Schools: Finding the Right Fit

The final theme focuses on family perspectives on the school, the broader educational system and their struggles to find the right “place” for their child. From the parents’ comments, it was clear that they placed a great deal of value on the services their child received, but they also wanted to find a place where their child could belong. Inclusiveness seemed to extend beyond an educational placement and also referred to a responsive school environment where their child was accepted and welcomed. Families also described some of the broader systemic issues that they perceived as facilitators or barriers to their child’s education.

Families viewed the services that their children received as effective and nearly every one could identify very specific academic, behavioral and emotional changes that they had seen in their children. For example, one parent noted how pleased she was with her son’s growth since receiving special education services,

‘But now he’s working on his motor skills. He wants to hold a pencil and a spoon and fork and stuff of that nature. And so to me, the school has made my son come a long ways as far as him picking up a pencil because that amazed me. I mean my heart just like hit the floor to see my son doing something like that. Because I was...I was shocked and just...it made me very happy’.

Even a parent whose son had recently started receiving special education services voiced a sense of hope, *‘I haven’t seen tremendous change yet, it’s still a work in progress’*. Overall, parents believed that special education is an effective method for meeting their children’s needs.

There was also general agreement among the families around the manner in which these services were provided. By and large, parents of children with special needs wanted their children to have the opportunity to learn with other children who did not have special education needs. One parent described her son as “scarred” by the time he had spent in a self-contained classroom. In fact, some parents expressed concern about labeling and segregating children for any reason. As one parent considered her own experience, she said,

‘I don’t think it’s good to segregate kids just because one person is smarter than the other. It just seems to put, to start labeling them when they’re just that young and they pick up on that. Like when I was in school, you know, they had the gifted and talented and you’d see all the kids going to the gifted and talented, and you just automatically thought they were better’.

Parental voices were more divided when defining how services should be provided to their children. Some felt their child was best served by a “pull out” model where the children could receive services in a small group format outside of the regular classroom. For example, one parent noted,

‘I think he gets pulled out 45-50 minutes a day. And so, I kind of like that because then it gives him a chance to still be a part of a class and yet still get his help that he needs, even though he still kind of struggles in the classroom’.

Other parents articulated their support for a more inclusive model where the special education teacher or an LSA provided the additional support in the classroom setting.

‘I like it better because they are in the classroom, instead of having them pulled out. Because, like I said, when I was in school, they pulled me out. And like I said, this is the first here at [name of school] where they had it in the class. And I think its way, much

better than last year with them pulling him out, bringing him in, pulling him out, and I just, I like this much better. Him in the class and they come in there and work with him in there'.

Some parents believed that their children liked a more inclusive model better as well. For example, one parent said, *'He didn't really like it when he got pulled out. They used to tease him and stuff and I guess now that she's coming into his classroom, he works'.*

Some parents still had lingering concerns about these more inclusive settings because they thought their children might not get enough attention or that the programming was not specific enough to meet a child's needs. One parent who was new to this model of services was beginning to see the benefits of this approach.

'And it's still a concern of mine, but seeing that my son's getting better, I'm not as worried when I leave him at school and stuff. I'm not as worried about him acting up like he did when he first got here because the teacher's said he's gotten better'.

Unfortunately, even within "inclusive" classrooms, exclusion can happen. One parent noted how her son's desk was routinely placed in the corner of the room and said,

'Now, how does that make you feel as a mom? Everybody else's desk is nicely lined up, but your son's desk is way over here in the corner of the room'.

In addition to valuable educational services, families also voiced their appreciation of schools that were responsive to the needs of their children by providing them with opportunities for success and recognition of their accomplishments. One of the ways in which schools met children and family needs was through additional programs such as after school tutoring and student recognition programs. As one parent noted,

‘With them after school programs it actually, it helps them, because they help them with their homework, with the problems that they’re having, they sit and talk about it, discuss it, and they try and take them on a field trip like every two weeks. It helps them out a lot’.

Within the school day, parents appreciated the ways that schools reinforced their children’s behavior and gave them opportunities to be recognized despite their different learning needs. For example, one parent reported,

‘[My son] was more excited when they had an award ceremony and he got the most improvement award. And he told everyone about that because we’ve been working hard on his reading, so he was really excited about that’.

Beyond the “extras” offered to children in the schools, parents described the climate of responsive schools as welcoming and as places where their children belong. For example, one school was described as,

‘The school, the whole atmosphere, you know when you’re in a school that has a lot of special needs kids . . . the entire staff has a different kind of (outlook). It’s a fairer idea of how to look at those children, I guess. It’s part of the school culture. So we fought really hard to get him here, and you know, we were thinking about moving, but we won’t move till he’s too old to go here anymore’.

This parent also described the degree of communication, partnership and perceived caring from the teachers within this school.

When parents can’t find a good match between their child’s needs and the school, their options may seem limited. Some parents described simply going along with the recommendations of the school, despite their disagreement, while others reacted by removing their child from the situation. For example, one parent described placing her child on medication

so that he could go to the “mainstream” kindergarten, whereas another parent in a similar situation described pulling her child out of a particular school.

‘We actually, when he was in Kindergarten, they started working with him, but they, they demanded that he be on Ritalin to stay in that school. It was just back and forth with me and the teacher so I had to pull him out of that school’.

Some parents participated in the district’s school choice option and described spending a great deal of energy and time finding a school that would provide the right fit for their children’s needs. For example, one parent noted,

‘And I think probably you need to just be a consumer as a parent, you need to go around and shop and say, this is the kind of place that I know where the people will care my child, you know’.

Parents also described the broader, systemic level barriers that they faced in attempting to guide their child’s education. Wedell (2005, p. 4) referred to these barriers within our schools systems as “rigidities that hamper inclusion.” Parents described their struggles related to class sizes, program offerings, and to a lesser degree, teacher preparation. As a result, finding the “right fit” became an annual challenge, depending on the variables noted above. One of the most often mentioned systemic issues noted by parents was the size of the classrooms. Parents wondered whether either students or teachers were really getting a fair shake when they were trying to conduct class with such large numbers of students.

In another instance, a parent noted how the lack of program availability for children in the upper elementary grades at her neighborhood school negatively affected her child. This parent lamented,

‘And he’s being mainstreamed into a classroom, but he is doing so well here. He has learned to write his first and his last name. He has learned to count, I mean he’s doing so much here that I didn’t expect, you know, and I am just so happy, but we’ve got to move on. He’s old, too old for the special ed class here’.

The degree of preparation and experience of teachers assigned to special education classrooms was also identified as a systemic issue. One parent made the following observation, *‘It’s an ironic thing that happens in education where the hardest of the kids tend to get the least experienced (teachers)’*. She went on to note how many young teachers taught for a year or two in this urban district before moving on to neighboring suburban districts that were perceived as having fewer difficulties and more resources.

Discussion

The tensions expressed at the national level between politics, advocates and researchers are played out in many ways at the local and direct level between schools, families and teachers. Schools follow legislative directives and attempt to create systems that standardize and assembly line the process of identifying and placing children in special education. The advocates, or families, attempt to support their child’s individual needs, seeking justice in the form of equal opportunities for their children. Finally, we have the teachers, the researchers, who are split in their valuing of their role as a collaborator with families or the removed expert. Some of these individuals seem to embrace their role and go beyond expectations to communicate and support families, while others seem to begrudgingly resist, perhaps viewing the process as outside the scope of their professional role. Still, we are left with how to reconcile these differences since each of these stakeholders is dependent on the other.

Our primary goal for this work was to clarify the issues as voiced by the parents of culturally and linguistically diverse families in relation to the special education of their child. We heard common themes shared among the parents regardless of their ethnicity, language and the school their child attended. In addition to hearing parent views, we wanted to use these stories to generate recommendations for practice. At the most fundamental level is the need to assist families in learning to be advocates for their children through education, support and family mentors. If we only give voice to the idea of empowerment without taking action, we are not truly providing families with opportunities to become equal partners in decision-making for their children. Empowerment is often defined as a process that enables families to gain control over their interpersonal and social environments (Parsons, 1991). To do so, families must have access to information related to their options, their rights and to supportive individuals who can help them reflect on the advantages and disadvantages of various options.

Families need the opportunity to talk and share their hopes and concerns related to their children. In fact, many parents commented that they were happy to participate in a study that might add to understanding of inclusive education and assist other families in similar situations. After the groups ended many expressed relief at having the opportunity to share their feelings and experiences with other parents; they found that they had many commonalities and were not alone in their struggle to navigate the system and to advocate for their children. This observation supported our contention that families need support not only from professionals, but from family advocates or other families who have successfully participated in the special education process.

To attain the goal of equal partnership with families, change is also needed within the contexts of our schools at K-12 and university levels. Kalyanpur et al. (2000) suggested that within teacher preparation programs we engage in discourse on the cultural assumptions

underlying the field of special education in order to help future educators understand the fundamental mismatch between a knowledge hierarchy and authentic partnerships. Established professionals should be encouraged to advance their own beliefs and attitudes toward more equality in family-school collaboration.

Finally, there are the schools and the tension between meeting the needs of children and their families while providing the most efficient education to the greatest number of students. Once, special education was seen as a way to accomplish both goals, addressing the needs of children with learning difficulties while educating the masses. Today, however, these two separate educational tracks might only serve to separate children from their peers and create unnecessary barriers for families. Families want a responsive school marked by a welcoming atmosphere and open communication, while receiving needed and valued special education services for their children. Unfortunately, until schools can find a way to resolve this tension, families may find themselves once again searching for a place where their child can belong.

References

- Barton, L. (2004) 'Historical influences: Disability and "special" schooling', in L. Ware (ed) *Ideology and the politics of (in)exclusion* (pp 63-75). New York: Peter Lang.
- Bennett, T., DeLuca, D. & Bruns, D. (1997) 'Putting inclusion into practice: perspectives of teachers and parents', *Exceptional Children*, 64 (1), 115-131.
- Brantlinger, E. (2004) 'Ideologies discerned, values determined: getting past the hierarchies of special education', in L. Ware (ed) *Ideology and the politics of (in)exclusion* (pp 11-31). New York: Peter Lang.
- Browning, P. L., Dunn, C., Rabren, K. & Whetstone, M. (1995) 'Post-school outcomes for students with disabilities: a U.S. synopsis', *Issues in Special Education and Rehabilitation*, 10 (1), 31-37.
- Danielson, C. (1996) *Enhancing professional practice: a framework for teaching*, Alexandria, VA: Association for Supervision and Curriculum Development.
- Donovan, S., & Cross, C. (2002) *Minority students in special and gifted education*, Washington, DC: National Academy Press.
- Eccles, J. S. & Harold, R. D. (1993) 'Parent school involvement during the early adolescent years', *Teachers' College Record*, 94 (3), 568-587.
- Ferguson, D. L., Kozleski, E. B. & Smith, A. (2003) 'Transforming general and special education in urban schools', in F.E. Obiakor, C. A. Utley & A. F. Rotatori (eds) *Advances in Special Education, 15: Effective Education for Learners with Exceptionalities*, (pp 43-74). Stamford, CT: JAI Press.

- Fryxell, D. & Kennedy, C. H. (1995). 'Placement along the continuum of services and its impact on students' social relationships', *Journal of the Association for Persons with Severe Handicaps*, 20 (4), 259-269.
- Harry, B. (1992a) 'Restructuring the participation of African-American parents in special education'. *Exceptional Children*, 59 (2), 123-132.
- Harry, B. (1992b). Making sense of disability: Low income, Puerto Rican parents' theories of the problem. *Exceptional Children*, 59 (1), 27-40.
- Harry, B., Sturges, K. M. & Klingner, J. K. (2005) 'Mapping the process: An exemplar of process and challenge in grounded theory analysis', *Educational Researcher*, 34 (2), 3-13.
- Henderson, A. & Berla, N. (1994) '*A new generation of evidence: the family is critical to student achievement*', Washington, DC: National Committee for Citizens in Education.
- Individuals with Disabilities Education Improvement Act of 2004, H.R. 1350, 108th Cong (2004) [online at <http://nasponline.org/advocacy/IDEA2004.pdf>].
- Johnson, J. & Duffett, A. (2002) 'When it's your own child: a report on special education from the families who use it', New York: Public Agenda [online at www.publicagenda.org].
- Kalyanpur, M., Harry, B. & Skrtic, T. (2000) 'Equity and advocacy expectations of culturally diverse families' participation in special education', *International Journal of Disability, Development and Education*, 47 (2), 199-136.
- Kozleski, E. B., Ferguson, D. L. & Smith, A. (2005) 'Paths for change: the systemic change framework and inclusive schools', *TASH Connections*, 31, 12-14.
- Lake, J. & Billingsley, B. (2000) 'An analysis of factors that contribute to parent-school conflict in special education', *Remedial and Special Education*, 21 (4), 240-251.

- Lange, C. & Ysseldyke, J. (1998) 'School choice policies and practices for children with disabilities', *Exceptional Children*, 64 (2), 255-281.
- Losen, D. J. & Orfield, G. (eds) (2002) '*Racial inequity in special education*', Cambridge, MA: Harvard Education Publishing.
- Morgan, D. (ed) (1993) '*Successful focus groups*', Newbury Park, CA: Sage.
- National Center for Education Statistics. (2000) '*Dropout rates in the United States: 1998*' Washington, DC: U.S. Department of Education, Office of Educational Research and Improvement.
- Oliver, M. (1996) 'A sociology of disability or a disablist sociology', in L. Barton (ed) '*Disability and society: Emerging issues and insights*', Harlow, UK: Addison Wesley Longman Ltd.
- Palmer, D., Borthwick-Duffy, S, Widaman K. & Best, S. (1998) 'Influences on parent perceptions of inclusive practices for their children with mental retardation', *American Journal on Mental Retardation*, 103 (3), 272-287.
- Palmer, D., Borthwick-Duffy, S, & Widaman K. (1998) 'Parent perceptions of inclusive practices for their children with significant cognitive disabilities', *Exceptional Children*, 64 (2), 271-282.
- Parsons, R. J. (1991) 'Empowerment: purpose and practice principles in social work', *Social Work with Groups*, 14 (2), 7-21.
- Peltier, G. L. (1997) 'The effect of inclusion on nondisabled peers: A review of the research', *Contemporary Education*, 68 (4), 234-238.

- Prater, L., & Ivarie, J. (1999) 'Empowering culturally diverse parents in special education program' in F. Obiakor, J. Schwenn & A. Rotatori (eds) *Advances in Special Education* (pp 149-166). Stamford, CT: JAI Press Inc.
- QSR International. (2000). NVIVO.
- Richardson, M. D. & Jordin, C. S. (1999) 'Implementing the inclusion model: perceptions and observations of elementary principals', *Journal of At-Risk Issues*, 6 (1), 14-19.
- Russell, F. (2003) 'The expectations of parents of disabled children', *British Journal of Special Education*, 30 (3), 144-149.
- Ryndak, D. L. & Downing, J. E. (1996) 'Parents' perceptions of educational settings and services for children with moderate or severe disabilities', *Remedial and Special Education*, 17 (2), 106-118.
- Salas, L. (2004) 'Individualized educational plan (IEP) meetings and Mexican American parents: Let's talk about it', *Journal of Latinos and Education*, 3 (3), 181-192.
- Salisbury, C. L. & Dunst, C. J. (1997) 'Home, school, and community partnerships: Building inclusive teams', in B. Rainforth & J. York-Barr (eds) *Collaborative teams for students with disabilities* (pp 57-88). Baltimore, MD: Brookes.
- Sands, D. J., Kozleski, E. B. & French, N. K. (2000) '*Special education for the twenty first century: Making schools inclusive communities*', Belmont, CA: Wadsworth.
- Strauss, A. L. & Corbin, J. (1998) '*Basics of qualitative research: Grounded theory procedures and techniques*'. Newbury Park, CA: Sage.
- Turnbull, A. P. & Turnbull, H. R. (2002) 'From the old to the new paradigm of disability and families: Research to enhance family quality of life outcomes', in J. L. Paul, C. D.

- Lavelly, A. Cranston-Gringas, & E. L. Taylor (eds) '*Rethinking professional issues in special education*' (pp 83-117). Westport, CT: Ablex.
- Villa, R. A., Thousand, J. S., Meyers, H. & Nevin, A. (1996) 'Teacher and administrator perceptions of heterogeneous education', *Exceptional Children*, 62 (1), 29-45.
- Ware, L. P. (1994). Contextual barriers to collaboration. *Journal of Educational and Psychological Consultation*, 5 (4), 339-357.
- Wedell, K. (2005) 'Dilemmas in the quest for inclusion', *British Journal of Special Education*, 32 (1), 3-11.
- Wesley, P. W., Buysse, V. & Tyndall, S. (1997) 'Family and professional perspectives on early intervention: an exploration using focus groups', *Topics in Early Childhood Special Education*, 17 (4), 435-456.

Table 1: Focus Group Questions

1. Tell us about your children's school experiences - their classes and their classmates.
2. Tell us about how you first learned that your child might need special help.
3. Tell us about what's happening now with your child. Is he or she continuing to get special help and how is it working out?
4. How does your child fit in with his classmates?
5. To what extent has school been good for your child?
6. There's an idea that some people have that all kids should learn together in the same class, even if they have a disability. That's so that all kids grow up with the same choices and opportunities, even when they are different. The thought is that all teachers need to know how to work with all kids. This is often called inclusive education. In what ways has your child has had an inclusive school experience?
7. What would the perfect school be like for your child?