Building Bridges with Families: Honoring the Mandates of IDEIA

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Parent participation has been one of the key principles of the Individuals with Disabilities Education Improvement Act (IDEIA) since it was first authorized in 1975 as the Education for All Handicapped Children Act (EAHCA) (Turnbull, 1993) and has continued through the most recent reauthorization in 2004 (Mandlawitz, 2007). Parents of children with disabilities have decision making roles about their children's education mandated by law in part based upon historical lack of involvement in such decisions provided by school personnel and the resultant lack of effective education for these children (Turnbull, 1993). Beyond these legal mandates, best practice standards would suggest that services will be most effective when parents and professionals work in collaboration (Harry, 1997; Kalyanpur & Harry, 1999). The President's Commission on Excellence in Special Education (PCESE, 2002) said that a key element to achieving excellence in special education is to encourage family empowerment in relation to the special education services their child receives. Increasing collaboration with parents is also frequently mentioned as important for school reform in general (Coots, 1998; Epstein, 1990).

In order to effectively collaborate, many strategies have been suggested for use by professionals. For example, Harry (1997) suggested that for effective collaboration, professionals should practice "leaning forward" rather than "bending backwards" (p. 70) by identifying shared values between

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parents and professionals. This is not easy, as commonly held negative stereotypes or misunderstandings about different cultural groups can lead professionals to overlook family strengths and thereby create a negative atmosphere (Harry, Klingner, & Hart, 2005). By adopting a "posture of reciprocity" (Harry, 1997, p.70) whereby professionals acknowledge issues that divide them from families, Harry (1997) believed that collaboration is enabled. Bernheimer and Keogh (1995) suggested that professionals should attend to the activities that comprise a family's daily routine and attempt to weave interventions into these routines. Bernheimer and Keogh (1995) stated that if we do not attempt to weave interventions into family daily routines, they will not be implemented and sustained by the family. These metaphors of *leaning forward* and *weaving interventions into daily routines* can assist professionals in being responsive to families and help them to come together in a collaborative fashion.

A common element involved in both of these is listening to families. While seemingly a simplistic element, its importance should not be overlooked in developing collaborative partnerships with parents that will allow us to honor the intended mandates of EAHCA and IDEIA. This article will therefore discuss some of what should occur in terms of listening to families in part based upon the results of a longitudinal study of over 100 families of children identified with developmental delays at age 3. This study, Project CHILD, has focused on listening to families tell their stories (Gallimore, Weisner, Kaufman, & Bernheimer, 1989) and while not focused on providing interventions such as school-related services, the experience of listening to these families' stories provides lessons for professionals and in particular, teacher educators. Some of those key lessons will be shared here.

Lesson One

Families organize daily routines that balance their beliefs, resources, and needs and abilities (Weisner, Matheson, Coots, & Bernheimer, 2004).

The balancing act that all families engage in to organize a daily routine is a key element of the eco-cultural perspective that directed the efforts of the longitudinal study mentioned previously. The balance can be hard won as families attempt to sustain their daily routines (Weisner, et al., 2004). They may not have the resources they need to sustain a routine that incorporates their values or the needs of individual family members may be in competition. For example, in Project CHILD, one family moved to a new home that was more affordable so that the mother could stay home full-time with her children. This choice was made in particular to best meet the needs of their child with a disability. The

cost for this move was that the father had a lengthy commute meaning he could not spend the time with his family that he valued.

Another single mother went to great lengths to have her child participate in extra speech therapy as had been recommended by the early interventionists who worked with her child. She had limited financial resources and so had to use a complex city bus route to get to the speech therapist who charged affordable rates. Because she couldn't afford childcare for her older child, she took him along to the speech therapy. This meant that several days a week, they returned home close to bedtime having missed dinner. She fed each of the children 1/2 of a sandwich before bedtime as this was what she could afford. However, she quietly went back into the children's room after the younger child had fallen asleep to give the older child another 1/2 of a sandwich so that he would not go to bed hungry. This case example, while possibly extreme, shows the costs for families that can be associated with obtaining services for their child. What can professionals including teachers learn from this example? Bernheimer and Keogh (1995) might suggest that professionals could have worked with the family to deliver speech services in a way that better supported the family's daily routine.

Another example of this need for weaving interventions into daily routines is found in the family of a child who exhibited a high degree of behavioral challenges in part related to her cognitive delays. She required constant monitoring as she would eat from the refrigerator without stopping or would climb up on fences and walls jumping from dangerous heights. The mother reported that she had to repeatedly fight to obtain support for her family so they could engage in the constant monitoring. She said that service providers told her that she was already receiving more services than any other family in their area. After years of what the family perceived as a constant fight for needed support, the family made the decision to place the child outside of their family home into a state-funded group home. The mother reported that this was a difficult decision but important for the rest of the family. While this also may be an extreme example, other cases of routines being unraveled by services or lack there of can be found. Coots (1998) suggested that when service providers including teachers work with families they should insure that recommendations don't conflict with beliefs such as those about the importance of leisure time or expectations for school personnel and parents. They should also be sure that parents have resources to participate in meaningful ways and that they can respond effectively to child competencies and skill deficits.

Lesson Two

Families vary greatly in how and how much they collaborate and par-

ticipate in schooling activities (e.g., Coots, 1998; Herman & Thompson, 1995; Hoover-Dempsey & Sandler, 1997; Neely-Barnes & Marcenko, 2004).

For teacher educators, it is important to prepare teachers to understand that families vary in terms of how much they want to or are able to collaborate and participate with service personnel such as teachers. Coots (1998) and Hoover-Dempsey and Sandler (1997) along with others have found that some parents participated in their child's education to a great degree while others participated very little. For example, Coots (1998) found that one mother reported that homework was key for her child and because she wanted him to achieve at a high level, she spent 3 hours completing homework activities each and every day often needing to supplement the homework sent by the teacher. Another mother said that it was most important to spend time in enjoyable activities as a family going on bike rides together or playing board games. She felt school work should be completed at school and that her children and her family needed leisure time in their daily lives.

The level of participation is based upon beliefs, resources, and needs as found in the research of Coots (1998). Beliefs about the need for more or less attention to schoolwork at home such as those cited by the mothers above who participated in this study were examples of beliefs that mothers reported influenced their decision making about schooling participation. The mother's education level was a key indicator, with mothers who had more years of schooling participating more in school activities (Coots, 1998). For example, one mother had obtained a graduate degree in teaching and said that this helped her to support her child's schoolwork. She used the knowledge she gained in school to support and supplement her child's schoolwork. Another mother said she regularly "hung out" at her child's school so that she would have informational resources about how to best help her son achieve. This is contrasted with mothers who had less education who frequently reported feeling uncomfortable going to their child's school because of their own prior experiences. They therefore did not have the informational resources of those mothers who "hung out" at school. Another way mothers reported they stayed in touch with their child's teacher was by dropping off and picking up their child at school. This allowed them a few minutes each day to touch base with their child's teacher and therefore stay in touch and have information that would help their child succeed at school.

Coots (1998) also found that the child's needs and abilities influenced parental decisions about schooling participation. One mother said she did no homework with her child because by the time she got home from work, she just wanted to spend quality time with her child cuddling her rather than experiencing the hassle of completing homework. Since

her child exhibited significant behavioral challenges, the need to lessen hassle was important to this mother.

How can teachers use this case material to influence their decision making? One way this information can be used is simply to acknowledge there will be differences between individual families. For example, Neely-Barnes and Marcenko (2004) found that for some families, increased participation with services was helpful to the family functioning while for others, it created additional burdens. Herman and Thompson (1995) cautioned that we "must focus on the dynamic interaction of families with helping networks; investigations must focus on the social, psychological, and financial costs and benefits to families from accessing the complex system of public and private services" (p. 82). While they were discussing implications for researchers, the same message applies to teacher educators. Teacher educators must help teachers understand the complex interplay between family resources, values, and needs as families interact with the service system including schools and how there are individual costs and benefits for each family associated with this complex interplay. As Harry (1997) might say, we should bend forward to families and reach out to them as we assist them in balancing the individual costs and benefits associated with accessing services for their child.

Another important element for teachers to be aware of in regards to varying levels of parent participation is that some families choose to customize their child's education while some accept generic services (Lareau, 1989). Lareau (1989) found that this was related to socioeconomic status with higher SES families assertively customizing their child's education while lower SES families accepted generic services as offered. The children in higher SES families therefore received a wider array of supports than those in the lower SES families. Lareau (1989) found this pattern for families of children without disabilities but Coots (1998) found the same pattern for families of children with disabilities even though those latter families had legally mandated forms of participation. Since patterns of participation were similar for families of children with and without disabilities, legal mandates did not emerge as a salient factor differentiating these forms of participation. If as the PCESE (2002) suggested parent empowerment is a key element to excellence in special education, then moving beyond the requirements of legal mandates will be important for effective education since the legal mandates were not found to lead to increased participation by families.

Lesson Three

Listen to families (Weisner, Coots, & Bernheimer, 2004).

Project Child, the longitudinal sample described in this paper, focused on listening to families and asked families to tell their story (Gallimore et al., 1989) including a description of their daily lives and how they achieved a sustainable daily routine (Weisner et al., 2005). Over the first[t] 10 years of the study, 91% of the original sample continued to participate in interviews held every few years (Weisner et al., 2005). This is an unusual attrition rate for longitudinal studies. Why was the attrition rate so low? There is not specific data available to answer this question but an anecdotal comment from families was that participating in this study was one of the most helpful services they had received since their child was identified as potentially having a disability. What was the service? The only service the project provided was to have someone come to the family every few years and listen to them tell their story.

This is a simple lesson that has been played out in the literature in many ways. It is however a complex lesson to put into action. For example, Dennis and Giangreco (1996) suggested that educators should attend to cultural differences in communication when interviewing families. Lynch and Hanson (2004) suggested using cultural consultants or parent liaisons who are knowledgeable about cultural differences in a broad sense, as well as in the area of communication differences, to provide support to professionals as they communicate with families in order to design effective educational interventions. Futures planning processes such as the McGill Action Planning Systems (MAPS) can also be helpful tools to use in listening to families (Falvey, Forest, Pierpoint, & Rosenberg, 2002). Home visits, working with cultural consultants and parent liaisons, and using the MAPS process are all helpful tools but the common elements are listening to families talk about what is important to them.

Discussion of daily routines might be a good way of listening to families. Gallimore, Weisner, Bernheimer, Guthrie, and Nihira (1993) reported that families readily talked about these routines and the challenges they faced in organizing them. They also stated that listening to families talk about these adaptations is an important part of assessing families and understanding the contexts in which they operate, including their cultural context. In addition to the families who participated in Project CHILD, this method of discussing daily routines has been found to be an effective method to gain knowledge from a variety of families from varied cultural backgrounds (Coots & Hitchin, 1997; Kuaidar, Goldberg-Hamblin, & Coots, 2004; Nihira, Weisner, & Bernheimer, 1994; Rayfield, 2001). As noted by Weisner et al. (2004), the construction of a daily routine is a universal problem, and from an anthropological perspective, has been studied extensively. It may also be the method that allows us to lean forward with families (Harry, 1997) and avoid misunderstand-

ings and negative stereotyping (Harry, Klingner, & Hart, 2005). If we do this, it may also encourage early conflict avoidance as promoted by the PCESE (2002) and as a way to promote excellence in education. A first step in conflict avoidance would seem to be understanding what is sustaining each family's daily routine or what aspects of their daily routine make them hard to sustain or vulnerable as described by Weisner et al. (2004). Then, based upon what families tell us when we carefully listen, appropriate educational interventions can be designed (Bernheimer & Keogh, 1995).

Conclusion

Though parent participation has been a legally mandated aspect of special education since the IDEIA was first enacted in 1975, the information presented here supports the idea that this mandate has been difficult to honor. Certainly, the legal mandate alone has not led to full participation. The PCESE (2002) stated that increased parent empowerment in the area of involvement was key to improving special education services. A variety of models and strategies are available to assist educators in embracing this mandate, but the simple act of listening to families and providing opportunities for participation that fit with their often hard won daily routines may allow us to collaborate with them most effectively and to build bridges to them. As we honor this 30th anniversary of the 1st enactment of IDEIA, we must acknowledge that we have made much progress in improving the lives of individuals with disabilities but that we have a long way to go in terms of fully honoring the original intent of the mandates of this pioneering legislation.

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