

Parent and Family Involvement in the Education of Children with Special Needs

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The education of any child is a very complex issue, comprising interconnected internal and external relationships (Garrett and Morgan, 2002). This is especially true when the child has been identified as one with special needs, primarily because of the wide variance of those needs and abilities. Educating these children is much more than molding a piece of clay, or drawing on a blank canvas, as some would describe child socialization. There are so many variables that impact how knowledge is imparted from one human to another, even if there are no special needs identified. In fact, the phenomenon called education is rather mysterious. When does learning begin? How is knowledge gained? By definition, who is an educated person? Who is responsible for educating children? Can all children learn? These are merely a few of the questions one might ask. In attempting to respond to these questions, it must be recognized that all children are unique. There are some children who are more different than others and have been identified as having special needs, constituting a wide array of behaviors, ability, and performance levels, as well as challenges.

In an effort to match the special needs of children with appropriate services, labels have been devised to facilitate this process. There are advantages and disadvantages to this strategy, especially if children are labeled inaccurately or if there are political motivations involved. For example, there are instances in which children with special needs are labeled differently depending on where they live. In more affluent areas, more children are labeled as learning disabled, rather than mentally retarded. These labels matter because they are connected to specified services, sometimes including fiscal support. For instance, there is currently much attention and grant opportunities focused on autism. The critical question could be asked, "Are there more students with autism or are more students, who would have received other labels a few years earlier, being labeled as autistic?" This is why teachers, service providers, and parents should be knowledgeable about the values of parent and family involvement. Children, and especially those with special needs, are educated within a societal system and not in isolation. This is a three-prong system composed of family, educators, and, collectively, other societal constituents such as social service agencies and policymakers. As with any three-legged unit, all pieces are necessary for the structure to stand. The family, in concert with educators and

others who impact this process, is a significant factor in educating children with special needs.

The late social scientist Urie Bronfenbrenner (1977) developed a classic systems model that aligns with internal and external variables which impact family functioning. In that model, the family ecosystem is divided into subsystems of micro-, meso-, exo-, and macro-levels. The family unit and school are at the micro- and meso-levels, respectively, and have regular interaction with each other. Social service agencies and policymakers are at the exo-level and attitudes, beliefs, and culture operate at the macro-level. This family systems approach should be used in educating students with exceptionalities, because these children and their families are very much interconnected with other groups. In this article, the focus is on the significant micro- and meso-subsystems as the systems components within which the family and school interact to accomplish the goal of educating children with special needs.

Identity of Family Members

In contemporary times, many forms of relationships are recognized as representative of a family. Traditionally, in some cultures, a family unit consisted of a legal union between a man and a woman and their biological children. That definition has been greatly expanded. Persons may identify themselves as family members if they are related by blood, marriage, or self-imposed affiliation. They may cooperate economically and may or may not share a common household, such as extended family members, and may not have children. If children are in the household, they may be their biological children, step-children, foster children, or adopted. In fact, the least common family structure today mirrors the traditional model. For example, in America, the fastest growing family structure is single females with children. When children with special needs are part of a single-parent household, parenting responsibilities can become overwhelming. Family structure may, in part, explain the educational outcomes of these children. There may not be time and energy for one person to work, care for the household, assist with educational programming at home, and actively participate in school functions. In addition, many of these single parents, who are mostly mothers, have parenting responsibilities with other children as well.

The list of ways that families of children with special needs differ is unlimited. To name a few, families differ in family size, socioeconomic status, number and educational level of parents as primary caregivers, ethnicity, and in the primary language spoken in the household. All of these factors influence the likelihood of family involvement with schools. Increasingly, schools are asked to serve these diverse families and accomplish parity of educational outcomes, regardless of the frame of reference with which the child enters.

Unique Circumstances Impacting Parental Participation in Schooling

It is assumed that all potential parents want the perfect child, the one who is perfectly formed, perfectly behaved, and perfectly functioning in every way. In reality, some children are born with mild, moderate, and severe congenital disabilities. Circumstances may cause children born, without these differences, to acquire physical or mentally limiting conditions. Illness or accidents are most likely the culprits in those cases. Parents may experience chronic sorrow, grief, and mourning for the loss of their ideal child (Winkler *et al.*, 1981). These feelings can recur at transitional periods such as the child's entrance into school or onset of puberty. Parents may become engulfed with bitterness or anger and wonder why this happened to them. Although unintentional, they may become consumed with jealousy of families with children identified as normal. Does society prepare families to parent a special needs child? No, there is no proactive socialization process to prepare parents for this situation. Possibly, this is one reason that the divorce rate is high for couples with a special-needs child. The caregiving demands are high and stressful, and can lead to increased feelings of depression, helplessness, guilt and blame, and decreased feelings of parental competence.

Parenting is a tough and important role, maybe the most challenging in all of society. When this responsibility is coupled with parenting a child with special needs, involvement in discretionary school activities may be less of a priority. Other than the legislated involvement and meetings, or school contact initiated as a result of reported problems, these parents tend to be uninvolved. The time within their 24 h in a day, 7 days in a week, and 12 months in a year are occupied with the daily challenges of financing the needs of their child; managing a myriad of unpredictable and atypical circumstances; navigating the related legal and social systems; and handling the resulting family-relationship issues. Families experience stressful situations unknown to other families. The anticipated daily family functioning of their dreams remains a fantasy. It is amazing that they function as well as they do. For

example, some families, who parent one of the children diagnosed with autism, have experienced financial ruin in trying to secure and finance services for their child. If it is a two-parent household, one parent may have to remain outside of the labor force to care for the child's needs. This further reduces the family income! The possible genetic influence may cause some families to have more than one child with autism, especially if the siblings are twins. Government assistance is very specified and limited, if it exists at all for children with autism in some communities. In countries with socialized medicine programs, this may not be a problem. In the United States, there is no entitlement for universal healthcare. For some families, there may be government-subsidized care; in other situations, care is dependent upon the family's ability to fiscally support the health needs of the child. It must also be recognized that many of these families have typically developing children to support as well. Rather than criticize these families for the low participation in school activities, educators, social agency representatives, and policymakers should be more sensitive to the inadequacy of support that is needed for these families, and contribute to advocacy initiatives to provide more assistance.

The typical school day conflicts with the work schedule of many parents, including parents of special needs children. This fact is significantly a barrier for families of low income and those with inflexible positions that prohibit leave time to visit school settings. For these parents, this is a double disadvantage. They cannot afford absence from work to participate in many of the school functions and they are judged as being apathetic, uncaring, or uninterested with regard to their child's schooling. There are fewer high-income families and, therefore, as compared to others, many of these families are within the range of poverty, which presents a multitude of circumstances which serves as a barrier to their participation in school activities.

Children with special needs are members of families from all social classes. Parents at all economic levels should perceive that they have the opportunity for participation in some form of school activity, but social class is an issue. The social stratification results in many of the parents of the same income having children clustered in the same school. In schools where a large majority of the children are from families with low income, there is low parental participation. Conversely, children from families with high income, tend to attend the same schools. As their parents are more likely to have professional careers with flexibility of schedules, their participation in school events is higher. The attention that these parents give to the child and school interaction is not a signal that they love their child any more than parents with inflexible work schedules. It does signify that there is more of an opportunity for them to be involved. Being concerned about a child's education is not a function of income level.

Family members of children with special needs, like everyone else, are impacted by past experiences. Memories of the school experiences of family members influence their attitudes and perceptions about school. Those with positive experiences tend to be more open to school interaction, than family members with memories of negative events during their own school years. Similar to any other situation, persons tend to avoid unpleasant situations and embrace positive ones. There are parents, especially those with less education than school officials, who feel intimidated by school personnel. Insecurity, inferiority, and embarrassment are emotions they feel when in the presence of teachers or school administrators. Their response to avoiding these feelings is merely to limit school visits to mandated appearances. Overall, parental involvement is a result of the family's perceived skills and abilities, their employment and other obligations, and opportunities provided by the school.

Family Participation in Schooling Children with Special Needs

A primary responsibility of schools is to educate students, but students are connected to some part of a family unit, in which most of their time is spent. Family members are actually the first teachers. Collectively, considering the child's total being of time and influence, school is dwarfed by home and family impacts. There is a role in educating students that is occupied only by family members and cannot be replaced by school faculty, administrators and staff, school board members, or legislators. School personnel and others making important decisions about schooling may have degrees from the best colleges and universities, but lack crucial information known only to family members.

The school needs to take the lead on whether the parent will be afforded only a passive role, or encouraged to assume an active role. The participation has to go beyond the traditional model of parent-teacher association (PTA), established in 1924, and the school climate must be welcoming and encouraging of parental involvement. To accommodate this involvement, schools can structure opportunities for parents to participate in schooling (Epstein, 1986). There are some situations in magnet schools in which family members are required to volunteer a specified number of hours at the school. As mentioned earlier, some level of involvement is mandated for parents of children with special needs. In the United States, the Individuals with Disabilities Education Act (IDEA) of 1990, Public Law 101-476 provided the opportunity for the parents of children with special needs to influence the education of their children. Parents of children in special-education programs are legally required to

participate in the child's individualized educational plan. Public Law 101-476 and its 1997 amended version, especially addressed parents and educational resources for minority children (Prater and Ivarie, 1999).

For many parents, they are invited to the school to assist the teacher in the classroom, raise funds, chaperone field trips, or possibly help coach a ball team. For parents of special-needs children, the involvement tends to be more focused. The educational process can be a 7-days-a-week, 24-hours-a-day process, depending on the nature of the birth or acquired differences. The parent and teacher partnership is much more significant than baking cookies for a class party. Of course, parents often help with homework, but parental assistance with homework for a special-needs child is more intense, more focused, and more than likely, more time consuming.

Parents who can navigate the political and educational system are empowered to get the best services for their children. Schools that seek to empower parents assume that parents are capable of influencing the outcome of their child's educational process.

However, sometimes there is a disconnect between families and school personnel. Society is becoming more diverse, not less diverse. Considering that families reside within a global society, this diversity includes racial, ethnic, language, and cultural differences, but must also include differences in cognitive, emotional, and physical functioning. When there were more homogeneous school populations and neighborhood schools, empowerment of parents did not seem to be a concern. The incidence of children in need of special education was not much of an issue, because children with special needs were not sent to school. They were mostly kept at home and shielded from public view.

Family involvement is a certainty for parents of children in special-education programs, if only indicated by parents signing a consent form, rather than actively participating in policymaking. This formal, one-way communication, from school to home is limiting and does not empower parents. When families are empowered, they feel that their views have value. When families are not empowered, there is a feeling of powerlessness, followed by intimidation that prohibits them from asking important questions on their child's behalf. To empower parents, parental involvement should include roles such as advocates and policymakers.

School personnel must view each child and family within a framework that encompasses the entire political, social, economic, cultural, and spiritual experiences that shape the identity and behavior of the families and children with special needs. For more than any other population of school-age children, the one-size-fits-all approach is inappropriate, which is exactly why the individualized educational program emerged. For these children and families, there are endless variances.

Teachers, like everyone else, may tend to avoid situations in which they perceive rejection as the outcome. Sensing negative reactions from parents, there could be instances in which teachers are more passive in seeking parental involvement because they fear an unsuccessful result. Some of this fear could be based on biased pre-judgments, myths, or stereotypes couched within Urie Bronfenbrenner's macro-level inclusive of attitudes, beliefs, and cultures. In these circumstances, parents can sense the feelings of teachers and reciprocate with feelings of isolation, alienation, and disengagement.

In establishing a support system for parent involvement, school personnel should become familiar with the child's uniqueness, the family, and the school's community to determine those activities that are more likely to solicit the desired outcome of parental involvement. As parents are afforded a greater role in defining involvement, they will gain greater confidence leading to increased participation in educational decision making focused on their child with special needs. Aside from meetings to discuss the individualized educational plan, family members have few avenues by which they can challenge curriculum choices, instructional strategies, or additional educational resources for their child.

In too many situations, educators continue to exclude families, devalue their suggestions, primarily use the ideas of experts, and value more the opinions of those who have possibly never even met the students. [Prater and Tanner \(1995\)](#) completed a case study report that detailed the tragedy of such practices, and the subsequent result of sabotaging parental aspirations and curtailing educational opportunities for youth in special-education programs. It is a mistake to rely solely on the ideas of experts and ignore the real people most knowledgeable about the child, the families. It is vital that parents are empowered and parental involvement is integrated into the instructional plans for students in special education, beginning with early childhood special education and continuing throughout the educational process.

Creating a School Environment to Empower Families

There is a mistaken notion that involvement and empowerment are synonymous terms. Involvement may merely imply some form of contact, but empowerment is more of a reciprocal partnership that includes decision making and influences outcomes. In order for parents to be empowered in special-education programs, they must assume roles as assessors, presenters of reports, policy-makers, advocates, and peer supporters. Educators will not be a vehicle for empowering parents unless they respect the fact that parents are themselves empowered

with an understanding of the system within which families of children with special needs exist and function. Coupled with educators' need to understand, is the need to avoid stereotyping families based on a presumption of uniformity of experience, culture, and knowledge. Often, there is cultural and educational dissonance between school governance professionals and the families they serve. If there are no deliberate attempts to eliminate, or at least bridge these poles, a barrier develops that will cause families to avoid school participation. This cultural divide is very evident in America, where school-governing bodies tend to be male, White, and middle class. By contrast, minorities comprise the majority of children enrolled in special-education programs.

The school environment can facilitate or impede successful relationships between the school and families. Perceptions based on gender, sexism, and social stratification can reinforce dissonance between parents and teachers, causing some educators to view parents as the cause of problems with schooling their children. These perceptions marginalize parents and inhibit parental empowerment, and discourage involvement. There must be trust between families and school personnel. Without trust, little will be accomplished. To benefit the educational goals for the child, this trust must be mutual and must be earned to be acquired.

One might ask, How can educators earn this trust? For parents to trust school personnel, there must be a consistent pattern of positive experiences, resulting in a strong foundation of credibility rooted in honesty and practices targeted to the sincere well-being of the child. For whatever the reason, this does not always occur. If a child is misdiagnosed, misplaced, mislabeled, or miseducated, trust is compromised. If there are unanswered questions as to why certain groups are overrepresented in remedial programs and rarely in gifted programs, it may be difficult to accomplish a comfortable level of trust. One might assume that because a child is assigned to a special-education classroom that he or she is appropriately placed. This might not necessarily be the situation. As described previously in Bronfenbrenner's systems model, the macro-level comprises attitudes and beliefs. Despite their academic credentials, educators have personal biases which serve to influence behavior in their professional activities.

Benefits of Family and School Partnerships

Regardless of the challenges, schools must seek to engage parents. There are positive outcomes involved in reaching out to parents. By any measure, students in special-education programs benefit from the partnership. The academic outcome is more positive and the availability of the joint resources provides additional assistance. Time and

energy lost in disruptions between the family and school are costly, with the child being the biggest loser. With the help of school personnel, parents who can navigate the political, educational, and social systems are empowered to get the best services for their children. Unfortunately, some parents do not even know their rights. When parents know the laws and have political expertise, they can create happenings. For example, in one mid-Western town in the United States, parents lobbied state legislators to get millions of state money allocated to serve children with autism in their district. This occurrence would not have happened without parental collaboration and intervention.

Summary

An effective relationship between family and school impacts school adjustment and progress. As there are so many variables in the education of children with special needs, all opportunities must be explored to create and sustain effective partnerships between families and the schools, even those options that have never been used before, or may seem atypical. To address the fact that families are different, there should be more development of projects targeted to specific groups, such as grandparents raising grandchildren, single fathers, foster parents, and other groups of identifiable populations parenting children with special needs.

Institutions preparing teachers must include sensitivity to the role of parents in their teacher-training curriculum, because current and future educators must empower parents. This sensitivity must include knowledge of multicultural factors. Otherwise, it may be assumed that a culture different from the educator implies a lower status of cognitive functioning and educational deficits for the children and families. Currently, school professionals are not prepared for these diverse families.

If parents are not empowered, they cannot and will not advocate for the child. Intimidation may prohibit them from asking important questions or seeking social service support. More importantly, a systemic network of negative attitudes will serve to victimize parents and retard the likelihood of parents establishing a partnership in the education of their children. Empowered parents ask questions and insist on accountability.

The model used by schools for involving parents is outdated. It has not changed, but the family structures and lifestyles have changed. Rather than expecting parents and the child to modify their behavior, it is imperative that educators modify their behavior and attitudes toward students in special education and their families. The complexity of family functioning must be considered in order for families to be repositioned as active, equal partners in schooling. Educational systems nurturing special-education programs must establish a web of support

for its students. Students, parents, educators, employers, lawmakers, and other community entities must be totally focused on an integrated goal of educating all of the students with special needs.

See also: Child Rearing and Early Education: Parents and Professionals: Theoretical and Historical Influences; Educating Students with Special Needs: An Overview; Parent Support in Early Childhood – Approaches and Outcomes.

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