

## Editorial

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# Family and disability

Even now television, advertisements, and societal views often still paint a picture of a certain type of family, one where a father, mother, and children all live under the same roof. In reality many families within today's society look very different from this traditional view, although most educators and counselors continue to assume that children and youth live with two biological parents. In fact, this traditional picture accounts for less than one third of all families. Actually, over 60% of all children and youth will live in single-parent homes at some point in their lives. A family is usually comprised of one or more individuals who provide support and play a significant role in the life of an individual with or without a disability. Children will approach school in a positive fashion when they feel secure in their family. A family may include parents (both natural and foster), sisters, brothers, cousins, aunts, uncles, guardians, advocates, or authorized representatives of the individual. Cousins can play a very important role for children with special needs if they are allowed to be actively involved.

There are many different family members who may eventually play a critical role in the life of a child with special needs; often the mother cannot provide the greatest amount of involvement due to work responsibilities. As many women continue to enter the work force, some fathers are becoming more involved from birth as their children's caregiver. Fathers increasingly play a major role in the raising of children.

Those of us in the helping professions must learn to direct questions or comments to fathers in a situation with both the mother and father present. How many times have human service workers called the home and asked the father if he or she could speak with the mother, instead of addressing the issue with the parent on the telephone? How often are fathers included in communications about their child when the mother and father are separated? However, fathers who want the opportunity to play a significant role in the life of their son or daughter should be supported and given the opportunity to do so. This is the problem which all too many fathers face in trying to participate in the care of their child with illness or disability.

The grandparent as the primary care giver also presents another change for contemporary families. More and more children are being reared by one or both grandparents and unfortunately, there is a clash between the old and the new way of doing things. Usually, grandparents do not have the energy and vigor that they once had when they reared and cared for their own children. Therefore, they may not do things the way professionals think they should be done or respond to requests as quickly as if parents were directly involved. Grandparents who are heavily involved in the care of their grandchildren have special needs, too, and these need to be recognized by educators and others in social service positions.

When professionals and families initially meet, they should strive to reach a consensus about the services and supports that will be needed for the child as well as the family. Regardless of who represents the individual in the program planning process, there should be ample opportunity to participate. Involvement of all family members should be equally encouraged. Some parents and family members will also be practitioners in the helping professions, and the situation in their own family will call upon them to play very different roles in familiar issues. There is a need to be open minded and prepared to provide support and information that is in the best interest of the child.

Most parents want to be involved in the decisions that are made on behalf of the child they love and support. However, families and their individual members have a variety of ways of showing their interest and involvement in the process. It is unfortunate that some teachers and other professionals will hold negative stereotypes about families and parents because these assumptions may exert a negative influence on the child's program and even performance at school. Many professionals will characterize families as being either uninvolved or overly involved in the process. For parents who are assumed to be uninvolved, professionals will make most decisions for the child and his or her family with no consent agreement. For families and parents who are assumed to be overly involved they are labeled as trouble makers in the system.

As children grow older, parents want to know what happens to their child after the mandated school services are over. They want to know if there will be a long waiting list for adult services. In like fashion, they want to know what types of services are available for the individual in school. Most families want professionals to help them find the answers to these questions. Parents will assist in the identification of resources and will truly appreciate any help that the professional can give them. This ability to be a solid resource to the family will greatly foster trust on other issues related to helping the child.

Families have to make decisions very early on, regardless of whether an individual has a disability. As soon as parents become involved with any outside entity, decisions become more complicated and often have

to be made immediately. When individuals from outside of the family are involved in decision making, various interests and levels of commitment influence the decisions to be made. For many families, outside-of-the-home childcare becomes a reality. Decisions about private care versus preschool or day care centers become variables in the decision making processes. As soon as outside-of-the-home childcare becomes an issue, families must make decisions about what's best for the individual. The more parents can be given help in how and where to get professional support for this decision making process, the more satisfied they will be with the process.

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