

Deborah J. Taub, Ph.D.,
is an associate professor
with the Department of
Curriculum &
Instruction, University
of North Carolina at
Greensboro.
E-mail:
djtaub@uncg.edu

Understanding the Concerns of Parents of Students with Disabilities: Challenges and Roles for School Counselors

Parents of children with disabilities share concerns common to all parents, but they also have additional concerns that are unique to their children's disabilities. Professional school counselors can be more effective in their work with parents of students with disabilities, as well as with the students themselves, the students' teachers, and other students, if they understand parental perspectives. Areas of concern are described, and implications for school counselors are discussed.

More than 6 million students with disabilities are enrolled in public schools (National Education Association, n.d.), and growing numbers are being included in general education classrooms (Sciarra, 2004). The role that school counselors play in the education of students with special needs is increasingly important (Lockhart, 2003). As school counselors work with students with disabilities within their schools, they also frequently have the opportunity, or the need, to work with the parents of those students. Parents of students with disabilities share the concerns of all parents about child-rearing and about education and also have additional concerns related to their children's disabilities. Professional school counselors can serve an important role as advocates for students with disabilities and their parents: "Professional school counselors are often the designated (and sometimes lone) advocates for children with special needs and their parents in an intricate and often intimidating educational bureaucracy" (Erford, House, & Martin, 2003, p. 18). Understanding the concerns and perspectives of these parents is essential to working with them effectively as partners in their children's education.

Just as it is unwise to generalize about students as if all students were the same or about parents as if all parents or all families were the same, so it is unwise to generalize about all parents of children with special needs, making the assumption that they are all the same. Not only is the range of special needs and disabling conditions vast, but parents and families also vary in their styles, concerns, approaches, val-

ues, involvement, and backgrounds.

Having said that, it is possible to articulate a set of issues and concerns that commonly arise for many parents of children with disabilities. Not every issue will apply to every student and every student's family; however, it is useful for school counselors to be sensitized to some common concerns that are unique to families of children with disabilities. Understanding these concerns will help school counselors be more effective in their work not only with parents of students with disabilities, but with the broader school community as well.

GRIEF, LOSS, AND THE "DREAM CHILD"

Not all children with special needs enter the educational system already identified as having a disability. Although the movement for early identification and early intervention has been successful in identifying many children with special needs at the preschool level, some students' needs may not become apparent until sometime after they begin formal school. Furthermore, a disability that is the result of an accident (e.g., traumatic brain injury) or an illness (e.g., loss of hearing or vision) may occur at any point during a child's school years. This means that issues related to the labeling of the child as disabled may arise for parents at any level of schooling.

Parents develop wishes, expectations, and dreams for their children, even before the child is born. At a minimum, parents wish for a healthy baby ("We don't care whether it's a boy or a girl, just as long as it's healthy" is the cliché that is repeated over and over), and they assume that it will be so. The discovery that the wished-for child has a disability can be seen as destroying the hopes and dreams held by the parents. Parents need to grieve the loss of these hopes and dreams (Bristor, 1991; Klein & Schive, 2001; Witt, 2004). Then, they can begin to "dream new dreams" (Klein & Schive, p. xix). However, sadness related to the child's disability may be ongoing or may recur periodically—around previously anticipated events that do not occur or around

anniversary dates, for instance (Quinn, 1998).

School counselors can respond by forming parent support groups or referring parents to existing support groups, either school based or in the community. Such groups can normalize these and other concerns for parents and serve as a source of support and encouragement. However, not all parents are able to attend or are interested in attending support groups. A lack of transportation, lack of child care, and work schedules may prevent parents from being involved in groups; therefore, the counselor should not assume that not participating in an offered group indicates that the parent “just doesn’t care” about the child. There also may not be enough parents of students with disabilities within a school or a community to form a viable group. In addition, the school counselor can recommend books, especially those with personal accounts, such as *You Will Dream New Dreams* (Klein & Schive, 2001). Such books also offer a way for school counselors to learn about the feelings and perspectives of a range of parents of children with disabilities and, therefore, to develop greater understanding and empathy for parents of children with disabilities.

SAFETY CONCERNS AND “OVERPROTECTIVENESS”

Among the defining characteristics of the current Millennial Generation of schoolchildren (born between 1982 and 2002) is that they have been sheltered and protected to a much greater extent than the previous generation of students (Howe & Strauss, 2000). The parents of Millennial children typically desire to be involved in all aspects of their children’s development and education (Howe & Strauss). Therefore, to an even greater extent than in the past, the parents of Millennial children with disabilities can be expected to be involved and concerned about the safety of their children. Ysseldyke, Algozzine, and Thurlow (2000) indicated that many parents of students with disabilities view schools as unsafe.

Concerns about safety at school can encompass a number of areas. Parents of children with disabilities may perceive that their children are more vulnerable to accidents and injuries as a result of their disabilities (Quinn, 1998). They may worry, for instance, that their children with physical or sensory impairments are in danger of falling on stairways, on playgrounds, and in other parts of the school. They may worry about the potential for injury while using equipment in the science laboratory, art room, or family and consumer science classroom. Field trips and transportation may present other opportunities for concerns about safety and injury. In addition, parents may be concerned that school personnel

might inadvertently injure the student, due to a lack of knowledge about how to handle transfers in and out of a wheelchair, for example. Furthermore, parents may be concerned that their children with disabilities may be bullied and injured by other students, with their disabilities making them both a more likely target and more vulnerable. These concerns are more complicated for the parents of students with limited communication ability; parents may worry that such students will be unable to report injury or bullying to school personnel or to them.

Although concerns about safety are real and may be well-founded, they also can lead parents to overprotect their children to an extent that is not helpful to the students’ development. In a study of adolescents with physical disabilities, Blum, Resnick, Nelson, and St. Germaine (1991) found that the adolescents “almost without exception” (p. 280) described their relationships with their parents as good and positive. However, many of the adolescents in the study reported that they felt that their parents did not treat them in an age-appropriate manner, and about one-quarter perceived that their parents were overprotective in ways that the adolescents found objectionable.

It is important for the school counselor to respect these very real and serious parental concerns. School counselors can serve an important role in, on one hand, reassuring and educating parents regarding measures taken at school to insure children’s safety and, on the other hand, alerting school officials to safety concerns that need attention. An additional important role for school counselors working with parents of students with disabilities is to encourage parents to help their children develop independence by not *over*protecting them. Although making such adjustments may be difficult for parents, they can be helped to see that fostering independence is in the long-term best interests of the child. It may be helpful to refer parents to the research literature, such as Blum et al. (1991), cited above, and first-hand accounts, such as those contained in Klein and Kemp’s (2004) *Reflections from a Different Journey*. The Klein and Kemp book is a compilation of essays written by adults with disabilities especially for the parents of children with disabilities.

ATTITUDES OF OTHER PARENTS AND OTHER CHILDREN

The number of students with disabilities included in general education classrooms continues to increase (Sciarra, 2004; Ysseldyke et al., 2000). However, parents of students with disabilities may have concerns about the attitudes and acceptance of other, nondisabled students and those students’ parents

**Parents of students
with disabilities
share the concerns
of all parents about
child-rearing and
about education
and also have
additional concerns
related to their
children’s
disabilities.**

**The discovery that
the wished-for child
has a disability can
be seen as
destroying the
hopes and dreams
held by the parents.**

(Heward, 2003). As Heward pointed out, parents of children with disabilities “cannot necessarily depend on other’s appropriate actions and reactions” (p. 131). At a social event the author encountered a woman who expressed considerable resentment about the amount of school resources that were being “wasted” on a student with a disability who was in her son’s classroom; she further saw the money being spent on that little girl’s education as being money that could have been directed toward her own, nondisabled (and, therefore, presumed to be more worthy and more educable) child. This woman can be seen as the embodiment of what the parents of children with disabilities fear about the parents of their children’s classmates.

Despite the movement toward classroom inclusion, many classmates without disabilities may have had little or no exposure to people with disabilities. The former may be curious or fearful or rejecting or respond in yet other ways. School counselors have a role to play in the education of all students about disabilities in general and about a classmate’s disability in particular. As Sciarra (2004) stated, “Accurate information is one way of reducing bias in our schools and in the larger society” (p. 194).

Parents of children with disabilities may have concerns about the content of the information being presented to their child’s peers about disabilities or about the manner in which it is presented. Among these concerns may be accuracy of the information presented, potential violations of the child’s privacy, whether the focus is on what the child cannot do versus what the child can, and whether emotions such as pity are likely to be evoked. The school counselor should consult with parents about information to be provided to the student’s classmates, respect concerns that the parents may raise, and make appropriate adjustments if requested. The question of whether the student with a disability should be present for the presentation or excused from the classroom may arise. Although it is respectful and appropriate to include parents in this decision, the optimal approach is also to give the child himself or herself a voice in the matter.

Events such as back-to-school nights, school open houses, and parent-teacher organization meetings provide opportunities for school counselors to present information and education about students with disabilities to the broader parent population of the school. Such presentations might include general information about disabilities, the law governing the education of students with disabilities, and how one’s school is approaching the inclusion of students with disabilities. School counselors may want to consult with the parents of students with disabilities within the school about any concerns they may have about such a presentation. Again, such concerns

need to be heard and responded to with care and respect.

School counselors should take care not to violate the confidentiality of individual students in such presentations. Both the Family Educational Rights and Privacy Act (FERPA; U.S. Department of Education, 2005a) and the Individuals with Disabilities Education Improvement Act of 2004 (IDEA; U.S. Department of Education, 2005b) protect the confidentiality of all information contained within a student’s Individualized Education Program (IEP). Information contained in students’ IEPs may not be shared outside the IEP team without consent from the student’s parents. Members of the team have access only to those portions of the IEP that are essential for each individual to provide educational programming and/or services to the student (typically, the pertinent goals and objectives). Care must be taken not to disclose information that would make a student personally identifiable; the confidentiality of this information is protected by FERPA and IDEA. Therefore, individual students should not be identified in such presentations nor should information about their diagnoses or their educational programs be shared. Particularly in small schools or in small communities, it takes very little information to make an individual student identifiable even when the name is not used.

Finally, school counselors may want to invite parents of children with disabilities and students with disabilities themselves to be part of their educational efforts. Parents and/or students may be interested in making presentations to classes, teachers, or groups of parents. Often, such presenters, speaking from personal experience, are particularly effective educators.

FRIENDSHIPS

Friendships play an important role in the life of the developing child. Relationships with peers play an integral role in adolescents’ identity formation (Erikson, 1963; Quinn, 1998). All parents want their children to have friends. Parents of children with disabilities may be particularly concerned about their children’s abilities to make and keep friends.

These concerns may have a variety of origins. Children with mild disabilities, such as learning disabilities or mild mental retardation, may be socially immature (Heward, 2003; Sciarra, 2004). Children with disabilities may have communication difficulties, such as little or no speech or speech that is difficult to understand, making it more difficult for them to converse with peers and to make friends. Children with chronic health problems or frequent surgeries may have frequent school absences, making it difficult for them, as well, to make friends. In

addition, paraprofessional teaching assistants who are with a child with a disability during the school day may serve as an obstacle to making friends, as peers communicate with the aide rather than with the child or as children are inhibited by the hovering presence of an adult. In addition, the student with a disability may, in turn, be more comfortable and accustomed to interacting with adults than with peers and may have difficulties understanding how to relate to peers. Peers without disabilities also may be frightened of the child's adaptive equipment (such as a wheelchair or walker) or of the child's different appearance or behavior (Heward). Furthermore, children with visible disabilities may be concerned that their classmates will reject them because of their differences; Mattingly (2004) related that as a child he was convinced that the special shoes that he needed to wear as a result of cerebral palsy were responsible for making him the target of classmates' teasing and bullying.

In addition, parents may perceive some of the avenues for making friends to be less open to their children with disabilities. Children with physical disabilities may be unable to participate in games and activities that lead to the development of friendships. These children may not be invited to play dates and birthday parties, as other parents are uncertain about what would be necessary to facilitate the child's participation. After-school and out-of-school programs may not appear accessible; parents of children with disabilities understandably worry about specialized transportation, safety issues, and whether staff members are adequately trained. School-sponsored extracurricular activities also may appear inaccessible, and parents may not realize that access to such activities must be provided and can be included in their student's IEP. Witt (2004) pointed out the difficulties that typically keep children with disabilities out of organized group activities and deny them the valuable lessons that they can learn from participating in such groups, including making friends, communication skills (listening and speaking), responsibility, and independence.

School counselors can be active in many ways in helping students with disabilities to establish friendships within the school community. Educating the school community, discussed above, is an important step toward breaking down attitudinal and informational barriers that might impede the development of friendships for students with disabilities. In addition, as part of a small-group counseling program, school counselors can create friendship groups and include students with disabilities in those groups along with their nondisabled peers. School counselors also can work with individual children with a focus on their difficulties in forming friendships, helping them to identify the source of their difficul-

ties and ways to overcome them. School counselors can serve as a source of information and evaluation in terms of students' progress toward social development goals in their IEPs. School counselors can communicate these possibilities to parents of students with disabilities, partnering with them to help students with disabilities make friends.

POTENTIAL FOR DISCOUNTING CHILD'S ABILITIES

Parents also may be concerned that the child's disability may overshadow the child's abilities in the eyes of teachers. Perhaps the teacher will focus on the child's "label" and not see the learner. Maybe the teacher will see the student's struggles with math but miss his or her gift for art. Perhaps the teacher will be unable to see past the wheelchair to the bright and eager young person using it (see Heward, 2003). Parents may have concerns that the teacher will make erroneous assumptions about the child's ability to learn because the child has some kind of disability—perhaps a disability that does not affect the child's cognitive functioning at all. Parents also will likely be concerned that teachers may focus on what the child *cannot* do to the exclusion of what the child *can* do. School counselors can serve as advocates for children with disabilities within their schools and can help to educate teachers to look beyond the child's disability to his or her abilities.

The underestimate of the child's abilities may be an area of particular concern to the parents of twice-exceptional children, who have a disability and are gifted. Identification of giftedness in children with disabilities is problematic, because the methods commonly used for identification such as standardized tests may not be appropriate for use with students with disabilities without modifications and adaptations (Olenchak & Reis, 2002; Willard-Holt, 1998). Another common method of identification is referral and recommendation by teachers, which also may be less likely to occur for students with disabilities whose potential may be hidden (Willard-Holt). Giftedness may be expressed differently in students with disabilities (Willard-Holt). In cases in which students have paraprofessional instructional aides, teachers may have concerns about whether classroom work is that of the student or of the adult aide (Willard-Holt), or parents may worry that the teacher will have these concerns.

These same concerns also may carry over to homework and fuel debate over whether work represents the student's efforts or the parents'. Further, in the case of twice-exceptional children, parents may be concerned that their children will be penalized for mistakes made by the aide, such as misspellings that occur when the aide is scribing for the

**School counselors
can serve as
advocates for
children with
disabilities within
their schools and
can help to educate
teachers to look
beyond the child's
disability to his or
her abilities.**

**Understanding the
concerns of parents
of children with
disabilities is an
important first step
to school counselors
serving as an
advocate for
students with
disabilities and
their parents.**

child who cannot write independently. Finally, in cases in which the student's giftedness has been identified, teachers may see accommodations for the student's disability as unnecessary because the child is so bright; Sibley (2004) related such an incident from her own school experience as a twice-exceptional student.

There are a number of ways that school counselors can respond to the concerns of parents of twice-exceptional children. School counselors have a role to play as advocates for twice-exceptional children. Schools may need to be encouraged to broaden the ways in which students are identified for and referred to gifted programs in order to identify gifted children with disabilities. School counselors can consult with special education teachers or school psychologists about assessment options or with teachers in gifted education about the characteristics of gifted children, and they can communicate with parents about alternative methods for student identification. School counselors also can advocate for twice-exceptional students with teachers, reminding them that both the disability and the giftedness need to be accommodated. Twice-exceptional children may benefit from small-group counseling or individual counseling (Moon, 2002a). Moon (2002b) pointed out that parents of twice-exceptional children need to learn about their children's disabilities and about giftedness. School counselors can invite parents of twice-exceptional children to participate in support groups for parents of gifted children as a way of gaining greater understanding of issues related to giftedness and of the stresses giftedness can create for families (Moon, 2002a).

TRANSITIONS

School transitions, whether from one level of schooling to another (such as from elementary to middle school) or into a new school (such as after family relocation), are stressful for all families. However, these transitions typically are easier for students without disabilities than for their peers with disabilities (Ysseldyke et al., 2000). Therefore, transitions may raise particular concerns for the parents of students with disabilities. School transitions mean establishing new relationships with principals, teachers, support-service providers, other school personnel, and students and their parents. Parents may feel depressed, pessimistic, and overwhelmed about the need to start all over again with this new cast of characters. These new people will need to be educated about the child's disability and trained in all pertinent special procedures or equipment. Meanwhile, the child will need to adapt to the new school, new people, and new schedules and routines (Ysseldyke et al.). These changes may be particular-

ly unsettling to a student with a disability who already feels little control over many aspects of his or her life. The accompanying stress may manifest in previously unseen behavioral problems in school or in verbal or somatic expressions of anxiety at home or in school.

School counselors can be extremely helpful in easing these transitions for students with disabilities and their families. Opportunities to visit and become familiar with the new school before the transition can be beneficial. Including future classmates (current students) of the incoming student in these visits can help to build familiarity in both the incoming student and the future classmates. It also is important for the incoming student to meet teachers during such visits. If appropriate to the age of the student, parents can be included in such a visit, or parents might be accommodated in a separate visit to allow the student more independence. These pre-entry visits should be in addition to, not in place of, new-student orientations attended by all new students to the school. To leave students with disabilities out of the regular new-student orientation programs singles them out and deprives them of the opportunity to participate in an important school event and the opportunity to make social contacts.

Careful, thorough transition planning, including pre-entry training for school personnel, will be reassuring to parents. School counselors also should acknowledge that school transitions are stressful and normalize those stress reactions for parents and students. Transitions offer another appropriate opportunity to invite parents to participate in parent support groups.

CONCLUSIONS

It is all too common to hear complaints in the schools that parents—or some particular category of parents (e.g., low-income parents or parents of children with special needs)—just do not care about their children's education. In fact, most parents do care about their children and the education that their children receive (Cicero & Barton, 2003). Barriers may exist, however, to parental involvement in their children's education. Such barriers might include job and family demands (Cicero & Barton), limited English proficiency (Cicero & Barton), and discomfort with the school setting due to previous negative school experiences. School counselors will be best served by acting from the assumption that parents care about their children and their education. School counselors can help parents overcome such barriers by encouraging their school involvement, offering alternative times for meetings, conducting home visits or work-site visits (Cicero & Barton), and joining with parents as partners in their

children's education.

Understanding the concerns of parents of children with disabilities is an important first step to school counselors serving as an advocate for students with disabilities and their parents. The common concerns outlined in this article provide school counselors with a starting point for listening and responding empathically to the parents of students with disabilities. It is from this point of understanding that school counselors can work to become effective partners with and advocates for the parents of students with disabilities and the students themselves. ■

References

- Blum, R. W., Resnick, M. D., Nelson, R., & St. Germaine, A. S. (1991). Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics*, 88, 280–285.
- Bristor, M. W. (1991). The birth of a handicapped child—a wholistic model for grieving. In R. P. Marinelli & A. E. Dell Orto (Eds.), *The psychosocial impact of disability* (3rd ed., pp. 59–69). New York: Springer.
- Cicero, G., & Barton, P. (2003). Parental involvement, outreach, and the emerging role of the professional school counselor. In B. T. Erford (Ed.), *Transforming the school counseling profession* (pp. 191–207). Upper Saddle River, NJ: Merrill Prentice Hall.
- Erford, B. T., House, R., & Martin, P. (2003). Transforming the school counseling profession. In B. T. Erford (Ed.), *Transforming the school counseling profession* (pp. 1–20). Upper Saddle River, NJ: Merrill Prentice Hall.
- Erikson, E. (1963). *Childhood and society* (2nd ed.). New York: Norton.
- Heward, W. L. (2003). *Exceptional children: An introduction to special education* (7th ed.). Upper Saddle River, NJ: Merrill Prentice Hall.
- Howe, N., & Strauss, W. (2000). *Millennials rising: The next great generation*. New York: Vintage.
- Klein, S. D., & Kemp, J. D. (Eds.). (2004). *Reflections from a different journey: What adults with disabilities wish all parents knew*. New York: McGraw-Hill.
- Klein, S. D., & Schive, K. (Eds.). (2001). *You will dream new dreams: Inspiring personal stories by parents of children with disabilities*. New York: Kensington.
- Lockhart, E. J. (2003). Students with disabilities. In B. T. Erford (Ed.), *Transforming the school counseling profession* (pp. 357–409). Upper Saddle River, NJ: Merrill Prentice Hall.
- Mattingly, R. (2004). Listening is the key. In S. D. Klein & J. D. Kemp (Eds.), *Reflections from a different journey: What adults with disabilities wish all parents knew* (pp. 175–178). New York: McGraw-Hill.
- Moon, S. M. (2002a). Counseling needs and strategies. In M. Neihart, S. M. Reis, N. M. Robinson, & S. M. Moon (Eds.), *The social and emotional development of gifted children: What do we know?* (pp. 213–222). Waco, TX: National Association for Gifted Children/Prufrock Press.
- Moon, S. M. (2002b). Gifted children with attention-deficit/hyperactivity disorder. In M. Neihart, S. M. Reis, N. M. Robinson, & S. M. Moon (Eds.), *The social and emotional development of gifted children: What do we know?* (pp. 193–201). Waco, TX: National Association for Gifted Children/Prufrock Press.
- National Education Association. (n.d.). *Special education and the Individuals with Disabilities Education Act*. Retrieved January 11, 2006, from <http://www.nea.org/specialed/index.html>
- Olenchak, F. R., & Reis, S. M. (2002). Gifted students with learning disabilities. In M. Neihart, S. M. Reis, N. M. Robinson, & S. M. Moon (Eds.), *The social and emotional development of gifted children: What do we know?* (pp. 177–191). Waco, TX: National Association for Gifted Children/Prufrock Press.
- Quinn, P. (1998). *Understanding disability: A lifespan approach*. Thousand Oaks, CA: Sage.
- Sciarra, D. T. (2004). *School counseling: Foundations and professional issues*. Belmont, CA: Thompson Brooks/Cole.
- Sibley, K. A. (2004). Twice exceptional. In S. D. Klein & J. D. Kemp (Eds.), *Reflections from a different journey: What adults with disabilities wish all parents knew* (pp. 156–160). New York: McGraw-Hill.
- U.S. Department of Education. (2005a). *Family Educational Rights and Privacy Act (FERPA)*. Retrieved January 11, 2006, from <http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html>
- U.S. Department of Education. (2005b). *IDEA 2004 resources*. Retrieved January 11, 2006, from <http://www.ed.gov/policy/speced/guid/idea/idea2004.html>
- Willard-Holt, C. (1998). Academic and personality characteristics of gifted students with cerebral palsy: A multiple case study. *Exceptional Children*, 65, 37–50.
- Witt, N. (2004). Groups offer valuable life lessons. In S. D. Klein & J. D. Kemp (Eds.), *Reflections from a different journey: What adults with disabilities wish all parents knew* (pp. 184–188). New York: McGraw-Hill.
- Ysseldyke, J. E., Algozzine, B., & Thurlow, M. L. (2000). *Critical issues in special education* (3rd ed.). Boston: Houghton Mifflin.

Earn CEUs for reading this article.
Visit www.schoolcounselor.org, and
click on *Professional School Counseling*
to learn how.