

Parents and Professionals: Bridging the Gap

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Several years ago, I wrote a chapter entitled "Parent-Professional Interaction: The Roots of Misunderstanding," for a book about disability in the family (Darling, 1983). The chapter addressed the gap between the perspectives of parents of children with disabilities and the professionals who worked with them. At that time the literature contained numerous horror stories of physicians, teachers, and other professionals who treated parents as pathological, and who treated their children as less than human (see, e.g., Gliedman & Roth, 1980). A common theme was the tendency of professionals to define disability in negative terms and to adopt the stigmatizing attitudes and behaviors of the rest of society. These views resulted in the Baby Doe decisions of the 1970s and 80s and other actions that denied the rights of children with disabilities. Such discriminatory and inappropriate treatment fueled a movement among parents to create social change. The results included stronger educational legislation (amendments to the Individuals with Disabilities Education Act) and greater consumer involvement in medical education. These changes have now been in existence for over a decade, which raises the question: Have they had a positive effect on the attitudes of professionals and the opportunities available to parents and children? A related and broader question concerns whether professionals can be allies of persons with disabilities and their families.

Current research has yet to provide a definitive answer to the first question. Some studies of parents' and teachers' views, with regard to educational inclusion (Bennett, DeLuca, & Bruns, 1997; Yasutake & Lerner, 1997), suggest that a gap continues to exist; most parents favor inclusion, whereas many teachers do not. Clearly, though, more parents are aware of their rights and are willing to enlist the aid of advocacy groups to obtain needed services for their children. The field of early intervention, in particular, has moved toward a family-centered approach, in which the family's perspective is taken seriously by professionals and serves as the basis for service plans (see Darling & Darling, 1992, for a discussion of the movement toward this approach).

Changes in medical education have also been encouraging. At a national conference several years ago (Darling & Peter, 1994), a variety of preservice and inservice models were presented. These models help medical students and physicians to understand the family's point of view. One student wrote that his experience as a first-year medical student at the University of Connecticut, participating in the required home visits to patients/families with chronic health conditions, helped him to remember that "behind all these abnormal cells and diseases, we are learning about are real people" (Lewis & Greenstein, 1994, p. 90). Similarly, at the University of Vermont, parents of children with disabilities serve as teachers for third-year medical students, and a number of pediatric residency programs likewise incorporate the family's perspective into their curriculums. This perspective is now commonly included in continuing education programs for practicing physicians.

Future research will reveal whether these innovations result in a convergence between the views of parents and professionals. Complete convergence seems unlikely, however. As I have noted elsewhere (e.g., Darling, 1983), the world views of parents and professionals are shaped by their experiences; while professional training emphasizes universalism and functional specificity. In other words, professionals learn to apply the same treatment principles to everyone and to focus on the aspects of a person that relate to their professional specialty. As a result, they may overlook individual concerns and may not recognize their patients, students, or clients as holistic human beings. A parent, on the other hand, tends to focus on her or his child's and family's particularistic needs, and to regard the child in diffuse terms, rather than simply as a child with disabilities. Even when professionals are able to understand the parents' views to some extent, their own views are

more likely to prevail, because of the power imbalance that characterizes almost all professional-client interactions.

Although professional dominance has been declining as consumerism has grown, in various areas of social life, many clients still feel intimidated by professional authority. This authority derives from professional status and expertise, as well as from the fact that the professional controls the consumer's fate to some extent. Parents are usually cautious about antagonizing teachers who issue their children's grades or about physicians who might be able to provide treatments that will improve their children's functioning.

Another argument against rapprochement between parents and professionals comes from adults with disabilities. Recent writings by disability rights activists (e.g., Branfield, 1999) argue that people without disabilities can never truly understand the meaning of disability or the experience of oppression that disability engenders. Such views suggest that nondisabled professionals, as representatives of an oppressive society, cannot be allies of the oppressed. In fact, proponents of this position argue that those without disabilities are not welcome to join the disability rights movement or to advocate for people with disabilities. Such views are likely to discourage enlightened professionals from becoming allies.

Certainly, nondisabled professionals can never completely share the experience of disability and oppression. However, parents of children with disabilities and adults with disabilities cannot avoid interacting with professionals. Professionals have needed expertise in educational methods, medical and surgical treatment, and other areas of importance to these populations. Realistically, because not all professionals will have disabilities themselves, would a parent not want her child to be taught by someone who, although not disabled, understood the disability experience as well as possible? Would a person with a disability not want to be seen by a medical provider who valued that person's life?

Because consumer-professional interactions are inevitable in the world of disability, collaborative relationships are highly desirable. Thus, to the greatest extent possible, professionals should be trained to understand the social world of the service user. Adults with disabilities and parents of children with disabilities need to serve as teachers in training programs for future professionals; and professionals need to interact with these individuals in home and community settings, not just in clinical or medical contexts. As such collaborative efforts increase, research will be needed to assess their effectiveness in bringing about real social change.

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