

Understanding Individualswith Disabilities

CHAPTER OBJECTIVES

After studying this chapter, the reader should be able to

- 1 Recognize the reality that each individual with a disability is unique and has a unique history of family and life experiences;
- 2 Appreciate the importance of others, namely parents, siblings, peers, and teachers, in helping the individual with a disability to adjust and be successful in the school setting;
- 3 Appreciate the importance of a positive professional–parent collaboration in delivering special education;
- 4 Identify various activities that teachers can use to help students without disabilities increase their sensitivity to their peers who have disabilities;
- 5 Compare and contrast the effects of a mild versus severe disability on the adjustment of the individual with the disability, as well as the adjustment of the person's family;
- 6 List and discuss various strategies employed by parents to accept and integrate a child with a disability into the family;
- 7 Identify and explain the response commonly experienced by parents upon learning that their child has a disability;
- 8 Analyze the impact of a child with a disability on the organizational structure of the family: and
- 9 Identify the cornerstone that trust has in working with families. Describe the components of communication and the attributes of trust that embellish a positive partnership.

For teachers working with children and youth with disabilities, the understanding of the individual and the disability is imperative for the collaborative work required in the educational setting. The federal educational mandate, IDEA 2004, assumes a collaborative relationship between the school and the parents of children with disabilities. The Beach Center on Disability (2004) has conducted research on the interpersonal relationships required of parents and professionals to provide positive collaborative work in the delivery of special education services (Blue-Banning et al., 2004; Nelson, Summers, & Turnbull, 2004; Summers et al., 2004; Wang et al., 2004). Their work shows that despite the decades of mandated services to individuals

with disabilities and the spirit of the law to collaborate, the collaboration has been a difficult process for parents and professionals. This chapter discusses the unique aspects of the individual with a disability within the context of the skills that the physical education teacher will need in order to advocate for such a student. Collaboration with families is imperative in this success.

To understand the person with a disability is to understand that each person is unique, with a unique biological make-up and history that includes the home environment, parenting, and life experiences (e.g., Bronfenbrenner & Crouter, 1983) (Figure 4.1a and b). For parents of a child with a disability, "respecting their child" means that



Figure 4.1a A child with a disability is a unique person with a unique family and developmental history.



Figure 4.1b Parents of children with disabilities want professionals to respect their child.

professionals value their child as an individual rather than a disability label (Blue-Banning et al., 2004). As one parent reports, "If they perceive someone as being less than human then they are going to treat that someone as an object . . . I want [my son] to . . . feel like he belongs to the human race, like there's a place for him, like he fits in" (p. 197)

There is much in the child development literature regarding the interactive influence of nature and nurture (e.g., Rutter & Taylor, 2002). This means that a person's genetic factors and environment (family, parenting, home,

school, etc.) interact and have a profound influence on how an individual matures. Consequently, it is an "it depends" answer when someone attempts to explain how an individual will develop (Bronfenbrenner & Crouter, 1983). Therefore, it is difficult to describe exactly which factors are shared by all people with disabilities. Although some research has described this, it should be taken as a general guide and must be filtered through the current thinking of the interaction of the uniqueness of the individual and his unique life.

Teachers participating in Individualized Educational Plan (IEP) meetings and in the ongoing communication with parents within an educational setting require information on how to communicate with families. The following chapter discusses general information regarding adjustments followed by specific information on the current thinking on the collaborative family and professional partnership.

Factors Affecting Adjustment

Satisfactory solutions are achieved through the process of adjustment, a term used to describe the changes an individual undergoes in order to adapt to the environment. Adjustment begins at the moment of birth and is a continuous process throughout life. Certain innate factors, that are the result of inheritance, influence the kind of adjustment that is made in response to the stimuli of the environment. These factors are intelligence, physical appearance, temperament, and degree of disability.

Intelligence

By recognizing that child behavior is influenced by a number of factors, in general, the degree of native intelligence can influence the amount and quality of the direction and control of behavior. In many cases, a child with an intelligence within the mean/average of an intellectual quotient (IQ) is potentially better able to direct and control his or her personal behavior. Yet in reality the family situation and the functional skill the student has will also influences what is "intelligence." Certain life situations and experiences can overwhelm a student. IQ makes a contribution but today it is seen within a context. As a physical educator one has to be aware of the contribution that the student's IQ makes in addition to family support, personality, and opportunity to be physically active. Regarding family support, An and Hodge (2013) found in an phenomenological inquiry that parents of children with a disability felt that they had a role in advocacy for their child in physical education. They felt that they needed to be able to see the big picture of their child's engagement in physical education and to collaborate in partnerships with physical educators. They reported that this collaboration (between home and school) was not well established but they desired it and felt it would benefit their child.

Physical Appearance

Physical appearance is an important factor in the development of behavior tendencies because of the responses of others to physical characteristics such as body build, facial features, and obvious deformities. We are aware that even such slight deviations as more-than-average height or weight can cause others to respond with a certain amount of teasing or even ridicule. Greater deviations from typical cause more intense responses, even to the extent of casting the one who deviates in an inferior social role. Child development research in school settings validates that children who are perceived as attractive are treated more positively by teachers and other adults than children who are not.

Temperament

Behavioral tendencies are also influenced by what is generally called temperament. There are many different theoretical approaches to temperament. The work of Rothbart and colleagues represents a good fit for the developing child, as emphasized in earlier chapters. Here, the expression of the child's temperament is the result of the child's own unique genetic heritage, the environment in which the child is being raised, and the child's past and present experiences (e.g., Rothbart, 1989; Rothbart, Ahadi, & Hershey, 1994). Temperamental features such as fearfulness or impulsivity contribute both to how the child expresses his or her emotions and how parent—child interactions occur.

Degree of Disability

Attention recently has been focused on the extent or degree of disability and its effect on adjustment. Although more research is needed in this area, some of the common assumptions of the past are now being seriously questioned. For instance, it was once widely accepted that the greater a person's disability, the more difficult it is for the individual to accept it or to achieve proper adjustment. Some have recently argued, however, that a person who is nearly "normal" in appearance and function may have a more difficult time adjusting than one who has a severe disability. Those who support this position postulate that an individual with a more severe disability recognizes that the disability is obvious to all and accepts his or her

position, whereas the individual with a mild disability may try to hide or deny the disability. Future research will help clarify this phenomenon. Until then it seems apparent that one should not assume that an individual that is mildly disabled will have fewer adjustment problems than those who are severely disabled.

Social-Environmental Influence

A continual interplay exists between the conditions arising from the individual with a disability and the conditions of the social environment—the attitudes and responses of others. Society tends to react in definite ways to any deviation from the norm. Sometimes the reaction is one of ridicule, curiosity, or maudlin sympathy; in the case of those close to the person with a disability, the reaction is often one of indulgence or overprotectiveness. The combined reactions of those in the social environment toward the one who deviates mentally or physically from the norm greatly influence that individual's adjustment. The responses of parents, peers, siblings, and teachers can significantly contribute toward a favorable social environment for the student with a disability.

Parent Reaction

Raising a child is recognized by most as a rewarding but a difficult and challenging task. As reported by Glass (1983), few couples are prepared for the realities of parenthood and the birth of a first child can be "... one of the most significant and stressful life events experienced by individuals." The birth of the first and subsequent children affects the marital relationship, economic status, and social status of a couple in very significant ways, some of which may be viewed by the couple as positive or negative. Whatever negative aspects may occur, they are usually overshadowed by the excitement of the baby and the infant's first responses such as the first smile and first vocalizations.

In contrast, the experiences for parents can be devastating, particularly when the severity of the disability is apparent at birth. The birth of a child with a severely disabling condition places the parents in a very awkward position. While it is customary in our society to respond positively to the birth of an infant, society views the birth of an infant with a disability negatively. Awareness of society's perception adds stress to an already stressful situation for the parents and may interfere with the marital relationship. In addition, the parents may be faced with extra hospital and medical costs and in some cases extensive and

extended medical treatment and further bills. Given these stresses and the sudden time frame in which they occur, it is understandable that there are common reactions among parents to the initial impact of the birth of a child who is not considered typical at birth. Among the most frequently identified responses are shock, denial, and grief.

When the infant's disability is apparent at birth, the initial parent reaction may be overwhelming. The stage of shock is likely to encompass feelings of anxiety, guilt, numbness, confusion, helplessness, anger, and despair. Unfortunately, it is at this time that many parents fail to receive the support they need or, in some cases, fail to comprehend the assistance that is available. Some parents avoid family and friends because of their own shame and uncertainty, as well as others' reactions.

The response of some parents to the birth of a child with a disability is to deny that a problem exists. These parents frequently suggest that the apparent delay is just that, and as the child develops, the deficits will be outgrown. For some, the denial process will involve obtaining additional professional opinions, hoping to find confusion and disagreement among the "experts." Although many parents overcome the denial stage, a conscientious effort must be made to acknowledge that the parents are struggling and to be understanding and consistent with the information shared.

Parents of newborn children who are disabled experience grief for two reasons: first, there is grief associated with the loss of the expected typical child. Second, the parents need time to adjust to the child actually born to them. In this latter situation, some parents grieve because of their fear that their child will die. Grief can continue for some time after the baby is born.

Severe Disability

As children with disabilities grow and enter childhood and then adolescence, their parents continue to be faced with many adjustments. This is particularly so for parents of children with severe disabilities. The realization for some that their child will not achieve sufficient independence to leave home will require an alteration in the normal family life cycle. The nature of the impact relates to expectations, family reorganization, prolonged and intensive care, provision of services, and fear of the future. It is for these reasons that some families go through adjustments at different times, yet retain the view that their child is a unique and special part of their family.

In a culture that is very conscious of chronological age, it is understandable that parents of children with severe disabilities are reminded at selected intervals of the child's life that their youngster is less than perfect. These include the expected milestones such as walking at 14 months and riding a bike at age 5 as well as socially imposed norms

such as driving a car at age 16 and eventually leaving home. Many parents indicate that they are at a loss to really know what to expect. For this reason, many parents have found that observation of other children with the same disability as that of their child helps them form reasonable expectations. Joining parent groups also provides an opportunity to share information about development in light of the child's disability.

The presence of a child with a range of disability levels, but particularly individuals with severe disabilities, also has an impact on the family and its organizational pattern. In our society, parents normally formulate certain expectations for their children based on the order in which they are born. The parents' perception of the child changes as the youngster becomes older and assumes more responsibility within and outside the home. The organizational structure of the family with a child with a severe disability, however, is altered to accommodate the child's slower rate of development or very different rate of developmental patterns. In some families, the child with a severe disability is always perceived to be the youngest regardless of the child's age and order of birth.

Parents of children with severe disabilities recognize that many of the tasks associated with infancy, such as feeding, dressing, and diapers, are extended for a longer period of time or may remain indefinitely. The parenting responsibilities associated with infancy are never easy and may be overwhelming when there appears to be no end in sight. Age of the parents, too, becomes a factor as they reach middle age. The prolonged and intensive care needed by some children with disabilities requires additional time as well as physical and fiscal responsibility.

The nature of the disability will require the provision of services beyond those normally provided for children without disabilities. In addition to medical costs, some children with disabilities will require the assistance of other specialists including physical and occupational therapists, speech and language specialists, vocational trainers, and counselors. Parents will need assistance in identifying the services needed and finding appropriate service providers. Obtaining the necessary medical assistance can also be a challenge. Many parents experience frustration when attempting to find medical specialists such as dentists, ophthalmologists, and audiologists who are comfortable in treating a child or adolescent with a severe disability.

Perhaps the major impact facing parents of a child with a severe disability is the fear of the future. This fear response is heightened as the child grows and the parents are faced with concerns about their own health and provisions for their son or daughter after their death. Alternative placements, including group homes and institutions, place additional stress on the parents and the major decisions

that confront them. It is not surprising that parents of children with severe disabilities experience greater parent burnout and more isolation than other parents. Divorce rates for parents of children with severe disabilities have been reported to be twice that of the national average.

Mild Disability

Although research exists concerning parents of children with severe disabilities, little information is available concerning parents of children with mild disabilities. There is some evidence to suggest that the parent—child relationship for the child with a mild disability may be more disturbed than that of the youngster with a severe disability. The impact felt by the family may be attributed to several factors including identification, type of disability, cause of the disability, and treatment.

Unlike the child with a severe disability, the child with a mild disability may not be discovered until preschool, kindergarten, or early elementary school. This discovery may come as a surprise to parents or it may serve as an affirmation of their own concern about the child's development. Parent response, therefore, may range from anger to relief. One of the advantages of later identification is that the family has formed a close tie to the child and the child has been accepted as a member of the family without labels.

The type of disability is also an important factor in determining the impact of a child with a mild disability on parents. In general, society tends to be more accepting of visible disabilities such as physical and sensory impairments and less accepting of hidden disabilities such as learning and emotional impairments. The use of labels is normally difficult to accept and may generate various defense mechanisms. Children with learning disabilities create unique problems for the parents as they struggle to understand the nature of this disability and its implications.

Many parents are concerned with the cause of the disability. This can be a very frustrating search because for several of the major learning disorders, including learning disabilities, intellectual disability, and emotional disturbances, (although there are levels of impairment) the exact or precise cause is usually unknown. Some parents believe that they are the cause of their child's disability. They may go to extremes in their thinking regarding this, associating some event (dropping the child, for example) as the probable cause. Some may believe that the cause is due to their own use and misuse of alcohol or stimulants. And of course some of these parents are just not able to comprehend their child's emotional disturbance. In other cases such as adoption, emotional disturbance of a child is a shock and very hard to manage. For many of these parents adjustment does not follow the pattern of parents of children with mild disabilities.

The impact of raising a child with a mild disability can be lessened for many parents if they know that treatment, including education, is available to assist their child. In this respect, parent groups have become essential in assisting new parents to interpret professional recommendations, retrieve information, and secure needed services. The impact of raising a child with a mild disability can be minimized if quality services, including education, provided by caring professionals are available (Blue-Manning et al., 2004).

Family Dynamics

Given the previous text, it should not be surprising to note that families with children with special needs are more likely to be overprotective of the child with special needs, have an imbalance in the amount of support provided by primary caregivers, and have marital relationships that become subordinate to parental roles.

Although the challenges associated with raising a child with a disability are significant, many parents find genuine joy and satisfaction in raising their child. Some parents employ coping strategies to assist them in their relationship with their youngster. For example, some parents learn to accept their child with a disability by altering their expectations. Instead of continually comparing their youngster to selected developmental scales, they begin to accept and appreciate the individual progress made by their child. Parents also learn to cope by seeking solutions to the problems their children are encountering. The emphasis is not on fixing or correcting the child but instead focuses on a healthy concern that the youngster should receive the best treatment and education possible. Some parents find it helpful to learn as much as they can about their child's disability and in a sense become an authority regarding the condition. In some instances, the interest of the parent has led to formal education and a profession in a related area. Lindemann and Lindemann (1988) suggest that the key to raising a child with a disability is for each member of the family to maintain some personal identity, activities, and interests. If this is done, the final result will be a family in which the presence of the child with a disability, brother or sister, will enrich the lives of all.

There are, of course, some coping patterns that are more negative in their effects on the child. Some parents may choose to overprotect their children in an effort to insulate and isolate the youngster from situations that entail risk and possible failure. Withdrawal is a strategy some parents employ to avoid discussions about their children as well as situations in which the child's presence might lead to questions or comments from others including friends, family, and strangers.

Sibling Reaction

In recent years, additional attention has focused on the reaction and needs of siblings of individuals with disabilities. Not surprisingly, the reaction of many siblings to their brother or sister is determined to a large extent by the reaction of their parents. Young children, in particular, usually follow the example set by their parents. During the teen years, the need to be accepted and liked by others is very important. Teenagers strive to be part of the norm and to be accepted. Having a sibling with a disability is different and may lead to embarrassment if their friends make insensitive remarks. Some young people avoid confrontations by not bringing their friends home and by avoiding family outings to public places.

Guilt, too, is a reaction experienced by many siblings. They experience guilt because they are not disabled. Fear is also a reaction of many siblings of children with disabilities. Younger siblings may fear that they, too, will become disabled. Older siblings may fear that someday they will become the parent of a child with a disability or that they will be expected to care for their brother or sister after the death of the parents.

Resentment sometimes appears to be a reaction of siblings. This may be attributed to several factors, including neglect because of the excessive amount of time the parents seem to spend with the sibling who is disabled. Some siblings resent the amount of time that they are asked to contribute to the care of the child with a disability. Young people, too, may see their sibling with a disability as a drain on the financial resources of the family, which seems to interfere with the family's ability to buy selected items.

Although many siblings have spoken very positively about life with a brother or sister with a disability, studies are mixed on the effects of being raised with a sibling with a disability. One thing does appear clear: Siblings of children who are disabled need information. They need to know about the sibling's disability and how to explain the disability to their friends. Young children need basic answers to questions such as, How did this happen? Will it happen to me? They also need support, encouragement, and reinforcement for their accomplishments. Finally, siblings of children with a disability need to be recognized without continual reference to their sibling who is disabled. Sensitive teachers can be very helpful in assisting the sibling to make a positive adjustment.

Peer Reaction

In recent years, more students with disabilities are receiving their instructional program in inclusive education. When students with disabilities are properly placed, they benefit from the opportunity to interact. Teachers have learned from experience that a favorable classroom environment requires that students become more sensitive to the needs of their fellow students. Even children with minor differences, such as those who are overweight or who wear glasses, find it embarrassing to be called names, such as "fat" or "foureyes." Obviously, to be labeled a "retard" or "deaf and dumb" can be devastating to a person attempting to secure a place in the educational mainstream. Such examples are not without support, as there is some evidence to suggest that students without disabilities have many misconceptions about their peers with disabilities.

The results of surveys provide clear direction for public schools and teachers. Acceptance of students with disabilities and the concept of integration are not enough. Schools must assist students without disabilities to improve their knowledge of disabling conditions and persons who have various diseases. To do otherwise may create a situation in which initial acceptance may lead to avoidance and rejection if understanding and expectations are not emphasized from the start. Direct contact is of critical importance in improving understanding between groups of people. In addition, planned educational experiences should be undertaken to assist students without disabilities to relate in a positive way to peers with disabilities (Figure 4.2). Later in this chapter, specific suggestions to help the teacher accomplish this goal are presented.

Teacher Reaction

A positive and accepting teacher attitude toward the student with a disability is essential for creating a favorable learning experience. The manner in which the teacher responds to the special student communicates much to the student and his or her peers. If the teacher appears apprehensive and fearful, it is likely that other students will follow this lead. Teachers, therefore, must analyze carefully their own attitudes toward those who are disabled. Some teachers have recognized that they, like many others, are afraid of the student with special needs. Other common responses include a tendency to underestimate the student's capabilities, to worry unnecessarily about liability, and to be sympathetic and overprotective. Teachers who recognize these feelings are in an excellent position to undertake special projects to improve their understanding. For instance, one can read about the etiology of the student's disability, observe other children with similar disabilities, talk with other teachers who have worked with the student, observe the student in various settings, develop a list of the student's abilities, and talk with the parents. As teachers become more familiar with the needs of students with disabilities, they will learn the subtle but important distinction between empathy and sympathy; the student needs understanding but not sorrow. Teachers will also learn to become more sensitive to view the student not as a disabled individual but as an individual who has a disability, with abilities that are far greater in number than his or her disabilities.

A number of investigators (Jansma & Schultz, 1982; Patrick, 1987; Rizzo, 1984; Rizzo & Vispoel, 1991, 1992; Rizzo & Wright, 1988; Rowe & Stutts, 1987; Stewart, 1988, 1990; Tripp, 1988) have analyzed various factors related to the attitude of physical educators toward teaching students with disabilities. Research findings suggest that the attitude of physical education teachers toward working with those students with disabilities can be improved if coursework and in-service experiences provide information about the nature of various disabilities. In addition, the attitude of teachers can be positively affected if teachers are provided supervised practicum experiences to work directly with students with disabilities. Innovative work by Rizzo and Vispoel (1991, 1992) highlights that the attitude of physical educators varies according to the type of disability. They have noted, for instance, that students with behavior disorders tend to be perceived less positively than individuals with learning disabilities or mental retardation (Rizzo & Vispoel, 1992). This suggests, therefore, that greater emphasis may need to be placed on selected skills (e.g., behavior management) to ensure that teachers feel adequately prepared and positive about providing services for all students.

Most important, teachers will come to appreciate the challenge of adapting games and activities so that the student with a disability will benefit from and appreciate the many positive experiences inherent in the physical education class.

There must be continuous interplay among parents, peers, and teachers to create a favorable social environment for the student with a disability. Teachers and parents, in particular, must communicate to ensure that the special student adjusts. Cooperative planning and frequent interaction help parents and teachers maximize the assistance available to the young person with a disability.

Family and Professional Partnerships

The recent emphasis on parent involvement in the education of children with disabilities was communicated clearly with the emphasis on the role of parents in both the IEP and the Individualized Family Service Plan (IFSP) IDEA 2004. This emphasis has generated new enthusiasm for the partnership that should exist between home and school in the education of all children, particularly those students with special needs. Parents of children with disabilities have communicated, too, that they want to be partners, need assistance, and want their input to be taken seriously (An & Hodge, 2013). For future physical educators, this means that additional opportunities to meet and work with parents of children with disabilities should be given top priority. Future educators must also provide information and be receptive. The expectations of teachers were nicely summarized by one parent who reported, "... Let us process our grief over the fact that our children are not perfect. Give us information about our children's disabilities. And give us cautious 'optimism.' Let us know the potential range of limitations their disabilities may present, but let us also know what these special children may also be able to do. Allow us faith and belief in the future. And you professionals, 'just be human' " (Royeen, 1992, pp. 66-67). According to the research, it is important that professionals fulfill not only the "letter of the law" but also the spirit (Blue-Banning et al., 2004).

A significant change in federal education law since the mandate of PL 94-142 in 1975 has been the changing role of the parents. Parents have always been identified as significant in the process of delivery of special education services, but the reality was that they were typically overwhelmed by the numbers of educational staff and, at times, by the information presented in IEP, and later in IFSP, meetings. Parents have commented for decades on this reality. For many, the cry has been "Listen to me, I am this child's parent!" Parents have tried to explain to professionals that they do indeed know their child. Too often, professionals have acted as if this were not the case.

According to IDEA 2004, parents are involved in decision making and advocacy when they participate in the IEP development, give consent, have access to records, participate in hearings, and protect the confidentiality of student records. Under the special education law, parents serve as advocates for their child with a disability. Conducting extensive interviews with parents of children with disabilities to study Family Quality of Life (FQL), given this advocacy role, Wang and colleagues (2004) reported on parents' perceptions of their advocacy. One mother said, ". . . I feel that I am my son's greatest advocate. Because there is no one else that is going to speak up for my son but me." Another parent poignantly added, "... Who will listen for those who cannot hear? Who will have vision for those who cannot see? Who will speak for those who cannot speak? Who will stand up for those who cannot walk?"

Wang and colleagues studied 78 families of children with disabilities, 80% of whom had a child with moderate to severe disabilities, and found that improved partnerships between schools and parents were dependent on

- viewing family members as equal partners in the decision-making process,
- · respecting family values and beliefs,
- · listening to families nonjudgmentally,
- · recognizing family expertise about its own child,
- · communicating a child's strengths,
- · using words that families can easily understand,
- · being friendly,
- protecting family privacy, and
- avoiding conflict when family opinions differ.

A total of 137 families and 53 professionals were interviewed in a qualitative research study aimed at developing guidelines for successful family and professional partnerships (Blue-Banning et al., 2004). A profound point emphasized in the report was the need for a "common sense of ordinary decency" in creating positive partnerships. The study identified six themes of collaborative partnerships as well as indicators for each theme. Each theme was valued by both the professionals and the families as leading toward positive collaboration. A summary with sample indicators follows:

- 1. **Communication:** The quality is positive and the quantity is understandable.
 - a. Indicators: Being tactful, open; listening, coordinating information
- 2. **Commitment:** There is a shared sense of the importance of the child, the family, and the goals identified.
 - a. Indicators: Demonstrating commitment, flexibility, accessibility; the child is not "a case"

- 3. **Equality:** Equality is pervasive and all members feel equally powerful in influencing outcomes.
 - a. Indicators: Avoiding use of "clout"; validating others, fostering harmony
- 4. **Skills:** People are competent, fulfill their roles, and use recommended practice in their role.
 - a. Indicators: Expect child to progress, consider whole family and whole child, be willing to learn
- 5. **Trust:** A shared sense of assurance about reliability and dependability of members.
 - a. Indicators: Reliability, discretion, child is safe
- 6. **Respect:** Members exhibit esteem through their actions and communication.
 - a. Indicators: Valuing the child, being nonjudgmental, being courteous, avoid being intrusive

These findings are important for physical education professionals to understand and to adapt to their work with families when providing special physical education services to students with disabilities. Physical educators have unique opportunities to be positive about physical activity and the value it has for the life of the student with a disability. The trained special physical educator has much to offer each student and family. Oftentimes special physical educators must be advocate for the student in the school physical education program and must advocate with their colleagues in special education, administration, and in the community in which they live.

The Role of the Teacher

The environment of the individual with a disability does, as was suggested, play an important role in adjustment. Any disabling condition potentially reduces the social interaction between the person and his or her environment. Nevertheless, the help and understanding of those in the person's environment make a tremendous difference in the quality of the adjustment. No one develops a socially acceptable personality and becomes well adjusted entirely by personal efforts; individuals must have the help of family, friends, teachers, and classmates.

We are primarily concerned here with the role of teachers in promoting a positive environment for the wholesome personality development of the child with a disability. Any educational endeavor to help the child make a more satisfactory adjustment must include the promotion of better understanding among the children with whom the child with a disability comes in daily contact with in the classroom and on the playground. These children constitute the greater portion of the child's social environment.

In developing a favorable climate in the classroom for the acceptance of students with disabilities, the teacher may discuss with the students the reasons for liking and disliking certain people. The teacher might emphasize that performing to the best of one's ability is just as admirable and worthy of respect as being the most outstanding performer. Attention should be directed toward the concept that one does not have to excel in popular spectator sports such as football and basketball; success, according to one's ability, in an adapted game of beep baseball is of no less significance than success in the more common games.

Seven Principles of Partnership

In the work of Dr Ann Turnbull, the mother of a young man with autism, and her colleagues at the Beach Center at the University of Kansas, there are seven principles that guide partnership between families of individuals with disabilities and the professionals that educate their child. These include communication, professional competence, respect, commitment, equality, advocacy, and trust (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). They find that trust is the keystone in an arch of principles that locks all the other principles into place. On the one side of the arch, communication, professional competence, and respect are leaning in on trust. On the other side of the arch, commitment, equality, and advocacy press in on trust. Each of the components is backed up by research. When they describe these principles, it is a two-way street. The principles apply to the professionals and to the families. But they have a lot to say to the professionals. Here is a sample about communication that really resonates through the other principles and how trust is defined and implemented:

Communication: Friendly. It helps families when professionals are friendly. School professionals think that the parents want business-like manner. Parents reported a dislike for that approach preferring what they termed a "personal touch." Personal touch means being friendly. And instead of conducting interviews, conduct conversations.

Listen. Hear the family's language and use it in your conversations. "... convey genuine interest, understanding, and acceptance of the family's feelings and experiences" (p. 140).

Be Clear. Use parent-friendly language. This is important when providing the results of assessments. Some families know more about special education and terms than others. Listen to them speak and adjust how information is passed to them. Avoid using technical terms.

Be Honest. Convey honest information with a sensitivity to the family reactions and avoid blaming them, pointing out strengths related to the family and the child.

Coordinate Information. Provide relevant and practical information. One parent of a child with autism explained that she never felt like she knew enough about what was going on. The mother recognized that her son couldn't communicate what happened at school that day. She wanted someone to coordinate the information not just provide it.

Trust. "Trust exists when people believe that the trusted person will act in the best interests of the person extending the trust and will make good faith efforts to keep their word" (p. 153). To create trust, Turnbull et al. report that trust is developed by professionals with families if they are reliable, use sound judgment, maintain confidentiality, and trust in themselves.

The Beach Center on Disability, which is directed by Dr Turnbull, has numerous state-of-the-art activities and publications (www.beachcenter.org). The language they use is respectful and comes from a depth of research and advocacy. For decades, the federal government (Office of Special Education and Rehabilitation (OSERS)) has supported and relied on the Center to conduct research and to package the materials for use across cultural settings.

Invite People with Disabilities to Speak to Students

All too frequently there is a tendency to generate good ideas and to develop plans of action without first involving those people who are affected by the decisions. People with



Figure 4.3 Teachers have a responsibility to help students appreciate the ability of their peers with a disability.

disabilities have much to offer in any discussion about the nature, severity, or effects of various impairments. Some people with disabilities feel very comfortable addressing groups and explaining such interesting information as the process blind people use to prepare a meal or to walk down a sidewalk. As one would expect, not all people with disabilities enjoy addressing large or even small groups. For this reason and because of the candidness of students' questions, the selection of speakers should be done carefully. Most professional advisory groups, such as the National Disability Sport Association and the local ARC (Association for Retarded Citizens), have lists of speakers who are qualified to address student groups and are interested in doing so. "Disability awareness" is a prominent part of school activities, as well as teacher preparation programs in special physical education (for activities see Disability Awareness, in Lieberman & Houston-Wilson, 2002).

Interview People with Disabilities

The interview is an activity suitable for older, more mature students. The specific assignment is to locate a person with a disability and then to ask a series of questions relative to the effects of the individual's disability on performance of daily living activities. The questions should be general, with the primary goal being to encourage interaction of people with and without disabilities. Most students who undertake this exercise find varied responses by people with disabilities to the interview process—some are enthusiastic, some agree reluctantly, and some firmly reply no.

Obtain Films and Books That Provide Information about People with Disabilities

Today many excellent resources are available at reasonable cost. For example, the humorous film What Do You Do When You See a Blind Person? may be obtained free or for a nominal charge from the State Commission for the Blind. Likewise, a School Alert Kit, which presents an enlightened discussion of epilepsy, may be obtained free by contacting the local chapter of the Epilepsy League of America. A partial list of books, films, and agencies of and for those with disabilities is found in Appendix II on the CD.

Obtain Appliances, Assistive Devices, and Equipment That Assist Persons with Disabilities to Function in Society

Opportunities for young people to explore the function and operation of wheelchairs, for instance, can prove to be a very interesting experience. With the help of individual Braille alphabet cards, supplied by the American Foundation for the Blind, students can be given basic lessons in reading and writing Braille. Older children can use these cards to create and decipher jokes written in Braille. Young children can use their pencil erasers to form Braille impressions on sheets of aluminum foil and then try to decipher each other's messages. Similar valuable and enjoyable experiences can be created to illustrate the use of other devices such as hearing aids, canes, and walkers.

Simulate Disabling Conditions

Individuals of all ages are intrigued with opportunities to experience what it might be like to be disabled. Although such activities never fully simulate a disability, they do provide additional understanding and serve as the basis for some quality discussions. A few simulation exercises that have successfully been used include the following:

- 1. Permitting students to serve as guides for their blind-folded classmates. For a demonstration of the correct procedure for serving as the sighted guide, the students should observe the film *What Do You Do When You See a Blind Person?*, which may be obtained from the State Commission for the Blind. Then, the students should attempt specific tasks while blindfolded, such as throwing a ball at a sound and identifying different objects by touch, and perform movement activities, such as hitting a ball and swinging a golf club. Finally, students should take turns assisting each other to perform the activities while simulating blindness.
- 2. Utilizing wheelchairs borrowed from hospitals and community agencies, permit students to have the experience of sitting in and operating a wheelchair. As with the simulation of visual impairments, encourage the participants to perform routine physical activities, such as shooting a basketball or serving a volleyball. Students should also be asked to use the washroom. Many young people find that this experience helps them become more appreciative of the skill and ease with which wheelchair users can move. Novice wheelchair users also quickly become aware of the frustrations that can be generated by the inaccessible architectural features found in many public buildings.
- 3. Students can also be asked to perform various tasks utilizing only one arm or leg. Assistive devices such as canes, walkers, and braces can be borrowed to allow opportunities to simulate disorders, such as amputations and cerebral palsy. Using a crutch instead of a foot to kick a ball provides the student with a different perspective concerning the ability of a peer. Swinging a bat with only one arm helps the nondisabled student appreciate the special skill and strength a student with an amputated arm must develop to participate in a

game of softball. Examples such as these in which students participate in a game or sport while simulating the loss of an arm or leg contribute to an awareness of the unique talents that individuals with disabilities develop.

Space does not permit discussion of other simulated experiences that can be undertaken. Those identified, however, do serve as examples that can be expanded or changed to fit the needs of various student groups.

Essential to the entire process of simulation is the opportunity to hold discussions after the experiments. Questions that may be asked include, "How did it feel to be blindfolded?" "Was your guide helpful?" "Did people stare at you in your wheelchair?" "Were buildings difficult to enter?" Discussions about such questions are a must to help clarify young people's feelings and concerns. Not all of the answers are available, but the process should serve to make students more empathetic toward people with disabilities and should thus assist in the integration of children with disabilities into the mainstream of physical education. With empathy comes understanding and with understanding, the process of successful mainstreaming begins.

Reverse Mainstreaming—Reverse Inclusion

"Reverse mainstreaming" is a term that was used before "inclusion" replaced mainstreaming as more politically appropriate. Reverse inclusion is a process that is very helpful to many teachers who are preparing for the first time to introduce children with disabilities into a general education class by identifying a small number of select students without disabilities to serve as aides in a special physical education class. (These students must be trained to assist.) This reverse inclusion has many advantages. It allows students with disabilities the opportunity to benefit from peer interaction in a setting with which they are familiar as well as providing them with an opportunity to enhance their skill level before integrating into the regular class. Students without disabilities benefit from this arrangement, as it affords them the experience of interacting in an environment that is different from that to which they are accustomed. This new sensitivity will assist them to better comprehend the feelings students with disabilities have as they enter the general physical education class. Many teachers have found reverse mainstreaming helpful because it allows them to observe children with and

without disabilities interact. Discussion sessions should be held with both groups of students to respond to questions and concerns they may have. These sessions generate information that will assist the teacher to lay the foundation for successful integration of students with disabilities into inclusive physical education.

Its emphasis is on direct contact between children with and without disabilities, which is an effective mechanism to facilitate attitudinal change. It should be stressed, however, that these experiences are most beneficial with young children who are less likely to have developed fixed attitudinal responses to those who deviate from the norm. Initial efforts should also be structured and directed toward exposing students to individuals with mild and moderate disabilities before moving to those who are severely mentally retarded and emotionally disturbed.

The activities that have been described will do much to eliminate the wall of isolation with which many youngsters with disabilities have had to contend. Integrating those with disabilities may at first require additional planning time. Dividends, however, will be evident as youth with and without disabilities grow in their awareness and appreciation of individual differences. Inclusion offers hope that more children will learn to recognize others' abilities rather than their disabilities.

In addition to helping others understand and accept people with disabilities, an educational program should be directed toward helping these youngsters develop skills and abilities. In these ways, those with disabilities may overcome the fear, shame, and social inadequacies that cause them to seek refuge in escape, projection, and other unacceptable behavior. The special physical education program can make significant contributions to the total educational program by helping those with disabilities to develop better motor skills, improve body mechanics, increase physical fitness, and enhance body image. The special contributions of various kinds of physical education activities will be presented in the chapters dealing with the specific types of disabilities.

"There is no clear-cut evidence that the particular nature of the disability alone can predict how parents, siblings, or extended family will respond and adapt to the disability.... Each child and each disability creates unique circumstances, including the need to form partnerships with specialists and with other families similarly affected." (Turnbull et al., 2011, p. 17)

Selected Readings

- An, J., & Hodge, S. R. (2013). Exploring the meaning of parental involvement in physical education for students with developmental disabilities. *Adapted physical activity quarterly*, 29, 147–163.
- Auxter, D., & Pyfer, J. (1985). *Adapted physical education and recreation*. St. Louis, MO: Times Mirror/Mosby.
- Bardach, J. L. (1979). Psychological adjustment of handicapped individuals and their families. *Awareness papers*. Washington, DC: White House Conference on the Handicapped.
- Beach Center on Disability. (2004). University of Kansas. Retrieved from www. beachcenter.org.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. G. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children*, 70(2), 167–184.
- Bolton, B. (1976). *Psychology of deafness for rehabilitation counselors*. Baltimore, MD: University Park Press.
- Bronfenbrenner, U., & Crouter, A. C. (1983). The evolution of environmental models in developmental research. In P. H. Mussen (Ed.), *Handbook in child psychology* (Vol. 1, 4th ed., pp. 357–414). New York, NY: Wiley.
- Cruickshank, W. M. (Ed.). (1980). *Psychology of exceptional children and youth* (4th ed.). Englewood Cliffs, NJ: Prentice-Hall.
- Daniels-Mohring, D., & Lambie, R. (1993). Dysfunctional families of the student with special needs. *Focus on Exceptional Children*, 25(5), 65–67.
- DeLoach, C., & Greer, B. G. (1981). Adjustment to severe physical disability: A metamorphosis. New York, NY: McGraw-Hill.
- Dunn, J. M., & Boarman, A. M. (1979). A need: Better understanding of people with special needs. *Campfire leadership*, Winter, 6–9.
- Faerstein, L. M. (1981). Stress and coping in families of learning disabled children: A literature review. *Journal of Learning Disabilities*, 14(7), 420–423.
- Featherstone, H. (1980). A difference in the family. New York, NY: Penguin Books.
- Garrison, K. G., & Magoon, R. A. (1972). *Psychology: An interpretation of psychology and educational practices*. Columbus, OH: Charles E. Merrill.
- Gath, A. (1977). The impact of an abnormal child upon the parents. *American Journal of Psychiatry*, 130, 405–410.
- Glass, J. (1983). Pre-birth attitudes and adjustment to parenthood: When 'preparing for the worst' helps. *Family Relations*, 32(3), 377–386.
- Hardman, M. L., Drew, C. J., & Egan, M. W. (1984). *Human exceptionality*. Boston, MA: Allyn and Bacon.
- Jansma, P., & Schultz, B. (1982). Validation and use of a mainstreaming attitude inventory with physical educators. *American corrective therapy journal*, *36*, 150–158.
- Kirtley, D. D. (1975). *The psychology of blindness*. Chicago, IL: Nelson-Hall.
- Kübler-Ross, E. (1970). On death and dying. New York, NY: MacMillan.

- Lieberman, L. J., & Houston-Wilson, C. (2002). *Strategies for INCLUSION*. Champaign, IL: Human Kinetics.
- Lindemann, J. D., & Lindemann, S. J. (1988). *Growing up proud: A parent's guide to the psychological care of children with disabilities*. New York, NY: Warner Books.
- Lindgren, H. (1969). *Psychology of personal development*. New York, NY: American Book.
- Marion, R. L. (1981). *Educators, parents and exceptional children*. Rockville, MD: Aspen Systems.
- Miller, A. G., & Sullivan, J. V. (1982). *Teaching physical activities to impaired youth.* New York, NY: Wiley.
- Nelson, L. G. L., Summers, J. A., & Turnbull, A. P. (2004). Boundaries in family-professional relationships: Implications for special education. *Remedial and Special Education*, 25, 165–253.
- Patrick, G. (1987). Improving attitudes toward disabled persons. *Adapted Physical Activity Quarterly*, 4, 316–325.
- Rizzo, T. L. (1984). Attitudes of physical educators toward teaching handicapped pupils. *Adapted Physical Activity Quarterly*, 1, 263–274.
- Rizzo, T. L., & Vispoel, W. P. (1991). Physical educators' attributes and attitudes toward teaching students with handicaps. *Adapted Physical Activity Quarterly*, 8, 4–11.
- Rizzo, T. L., & Vispoel, W. P. (1992). Changing attitudes about teaching students with handicaps. *Adapted Physical Activity Quarterly*, 9, 54–63.
- Rizzo, T. L., & Wright, R. G. (1988). Selected attributes related to physical educators' attitudes toward teaching students with handicaps. *Mental retardation*, *26*, 307–309.
- Roberts, R. N., Rule, S., & Innocenti, M. (1998). Strengthening the family-professional partnership in services for young children. Baltimore, MD: Brookes.
- Robinson, N. M., & Robinson, H. B. (1976). *The mentally retarded child.* New York, NY: McGraw-Hill.
- Ross, A. O. (1964). *The exceptional child in the family.* New York, NY: Grune and Stratton.
- Rothbart, M. K. (1989). Temperament and development. In G. Kohnstamm, J. Bates, & M. K. Rothbart (Eds.), *Temperament in childhood* (pp. 187–248). Chichester, England: Wiley.
- Rothbart, M. K., Ahadi, S. A., & Hershey, K. I. (1994). Temperament and social behavior in childhood. *Merrill-Palmer Quarterly*, 40(1), 21–39.
- Rowe, J., & Stutts, R. M. (1987). Effects of practica type, experience and gender on attitudes of undergraduate physical education majors toward disabled persons. *Adapted Physical Activity Quarterly*, 4, 268–277.
- Royeen, C. B. (1992). A glimpse of the human experience: Parenting infants and toddlers who are disabled. *Infants and Young Children*, 5(2), 65–67.
- Rutter, M., & Taylor, E. (Eds.). (2002). *Child and adolescent psychiatry*. Oxford, England: Blackwell.
- Schulz, J. B. (1982). A parent views parent participation. *Exceptional Education Quarterly*, *3*(2), 17–24.

- Seligman, M. (1979). Strategies for helping parents of exceptional children. New York, NY: Free Press.
- Seligman, M. (1983). Siblings of handicapped persons. In M. Seligman (Ed.), *The family with a handicapped child.* New York, NY: Grune and Stratton.
- Sherrick, C. E., Swets, J. A., & Elliott, L. L. (1974). *Psychology and the handicapped child.* Washington, DC: U.S. Department of Health, Education, and Welfare.
- Shontz, F. C. (1980). Theories about the adjustment to having a disability. In W. M. Cruickshank (Ed.), *Psychology of exceptional children and youth* (4th ed.). Englewood Cliffs, NJ: Prentice-Hall.
- Stewart, C. G. (1988). Modification of student attitudes toward disabled peers. *Adapted physical activity quarterly*, 5, 44–48.
- Stewart, C. G. (1990). Effects of practica type in preservice adapted physical education curriculum on attitudes toward disabled populations. *Journal of Teaching in Physical Education*, 10, 76–83.
- Summers, J. A., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., & Nelson, L. G. L. (2004). Measuring the quality of family-professional partnerships in special education services. *Exceptional Children*, 72, 65–82.

- Tew, B. J., Payne, H., & Lawrence, K. M. (1974). Must a family with a handicapped child be a handicapped family? *Developmental Medicine and Child Neurology*, 16, 95–98.
- Tripp, A. (1988). Comparison of attitudes of regular and adapted physical educators toward disabled individuals. *Perceptual and Motor Skills*, 66, 425–426.
- Turnbull, A. P., & Brotherson, J. J. (1984). *Assisting parents in future planning*. Papers presented at the CEC 62nd Annual Conference, Washington, DC.
- Turnbull, A., Turnbull, R., Erwin, E. J., Soodak, L. E., & Shogren, K. (2011). Families, professionals, and exceptionality: Positive outcomes through partnerships and trust (6th ed.). Upper Saddle River, NJ: Pearson.
- Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. (2004). Parent's perceptions of advocacy activities and their impact on family quality of life. Research and Practice for Persons with Severe Disabilities, 29(2), 144–155.
- Zuk, G. H. (1962). The cultural dilemma and spiritual crisis of the family with a handicapped child. *Exceptional Children*, 28(8), 405–408.

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