2

Fostering Family–Professional Partnerships

Ann P. Turnbull
Co-founder, Beach Center on Disability, University of Kansas, Emerita
H. Rutherford Turnbull
Co-founder, Beach Center on Disability, University of Kansas, Emeritus
Kathleen Kyzar
Texas Christian University
Nina Zuna
The Meadows Center for Preventing Educational Risk
The University of Texas at Austin

Introducing the Campbells: An African-American Family

Please note: Both families presented in this chapter are fictional; any similarity to one real family's circumstances is purely coincidental.

Loretta Campbell is determined that her son Jamal, 13, will be included in all school activities with his classmates who do not have disabilities. Her determination, however, encounters obstacles. "It has not always been easy to make inclusion happen." Hard going? Yes. Late-night emails and frequent telephone calls to Jamal's teachers prove how hard it is.

Transition exacerbates the challenge. Jamal has just entered middle school. At a time when nearly all students are acutely self-conscious and socially sensitive, Jamal's autism and intellectual disability inhibit his ability to establish friendships easily. But this has not stopped him from being curious about the many subjects that interest his peers, such as the nearby Dallas Cowboys football team.

Has Ms. Campbell's insistence on inclusion been worth the effort? Yes. Jamal enjoys the routine of going to school, and, with the support of his peers, he has just mastered finding his own way to all six of his classes in his middle school. He spends 80% of his day in general education classrooms and the remaining 20% in a resource room with other special education students to complete unfinished assignments and to develop self-management skills.

Ms. Campbell didn't want to send all the emails and make all the telephone calls. She had to. Jamal's teachers in elementary school and his new teachers in middle school were concerned about the academic challenges that middle school would present for Jamal. Many of them urged her to consider having Jamal spend the majority of his time in a resource room and then reassess his readiness for full inclusion at a later date. Admittedly, Ms. Campbell shared those concerns. Jamal has had difficulty with transitions, has been slow to establish friendships, and has exhibited behavior problems when faced with increased academic demands. However, she remembered how successful he had been in a fully inclusive elementary school when he had peer mentors who shared similar interests. Ms. Campbell trusted her instincts and advocated for Jamal's inclusion in all aspects of middle school. Nine months have passed and Jamal's success has exceeded everyone's expectations. While on spring break, Jamal indicated that he would rather be at school than at home! Ms. Campbell is pleased with the progress that Jamal has made and is justifiably satisfied with her advocacy for his inclusion.

But she's worn out: "This is hard work; I am tired both physically and emotionally from convincing teachers to do what I feel is right for my son. I don't think that they understand everything my family has gone through in addition to my long work hours and caring for three children as a single mom. To tell you the truth, I am not sure that I will be able to keep up this level of advocacy. I am also very concerned about Jamal's life after high school. I want him to have the same opportunities that he has now, but I just can't think that far into the future right now. Planning one year in advance is as much as I can handle at this moment."

Just what has her family "gone through"? Ms. Campbell has two other children, Shelia, 17, and Donnell, 15. Jamal's father left the household when Jamal was only 7 years old, and his brother and sister were 10 and 12. She has relied on her mother, Sandra (or Ma Ma Sandy as her grandchildren affectionately call her), and close friends for support. Ms. Campbell's father battled liver cancer for a year and died during Jamal's last year in elementary school; grieving and advocacy are not exactly compatible—each sapped her energy and neither allowed much room for the other. The older children, while sad, are coping; however, Jamal is demonstrating increased behavioral challenges as he struggles to understand the passing of his grandfather. Ma Ma Sandy remains stoic, but is beginning to show signs of depression, mourning the loss of her husband. Indeed, this past year has been quite challenging for the Campbell family; however, with the support of friends and extended family, they are managing.

Introducing the Gonzalezes: A Hispanic-American Family

Coming to America! Those three words tell the life stories of nearly everyone in this country, at least at some point in our ancestry. Almost all of us are immigrants, some of us more recent than others.

Coming to America meant economic opportunity for the Gonzalez family. Manuel came here from Mexico, leaving his wife Lucille and two children, Isabella, seven, and Maria, six, behind. Here, he worked as a migrant farmer until he became a citizen. His citizenship assured, he sought more permanent work and now has a job with a company that builds new homes in Wichita, Kansas. With citizenship and a good job in hand, Manuel brought Lucille, Isabella, and Maria to Wichita. Why Wichita? Because Lucille's sister, brother-in-law, and niece live there and they encouraged Lucille and Manuel to join them. At last, the family is together again. At least most of the family is together. Manuel's and Lucille's parents and most other family members still live in Mexico. "We aren't entirely a family until all of us are in one place, together," laments Manuel.

Coming to America also meant educational opportunity, especially for Isabella. She had insufficient oxygen when she was born and was diagnosed at birth as having cerebral palsy. She later acquired two other diagnoses: epilepsy and severe intellectual disability.

Although some general education programs and schools for children without disabilities in Mexico are beginning to accommodate children with disabilities, they are mostly for children with more mild disabilities. Isabella was rejected for admission to a regular school; its faculty regarded her disability as being too significant for them to address. Instead, she received most of her services from a specialized school and from medical personnel. After arriving in Wichita two years ago, Isabella has attended a public elementary school in a life skills classroom for children with disabilities. In this school she has some opportunities for inclusion in a few classes (e.g., art, music) with her peers without disabilities.

Isabella loves to be around other children and attends several classes (e.g., music, art, physical education) with her peers without disabilities, but Mr. and Mrs. Gonzalez wish that there were more opportunities for her to be included in a variety of school activities; they understand that it is important for her teachers to emphasize academic training for all students, but they want more social opportunities for their daughter. They have asked themselves, why don't the teachers recognize that Isabella enjoys being with children who don't have disabilities? Why can't the teachers help Isabella develop more of her social skills? And why do they leave it up to Mrs. Gonzalez to make sure that Isabella has opportunities to be with children without disabilities in her neighborhood and church?

Coming to America meant even more than employment and educational opportunities. It meant adjusting to a new culture, a new language, and a new lexicon of school terminology. In their native culture, Mr. and Mrs. Gonzalez had learned to defer to educators. Here, deference is not so much the norm; partnership and advocacy are. In Mexico, the school terminology was different from what it is here; there's "special-education speak," as Mr. Gonzalez put it—and he speaks English better than Lucille, having been here longer.

But language remains a barrier, especially now that Isabella is beginning to have more frequent seizures. On a daily basis she has petit-mal seizures (i.e., frequent eye blinks and mouth tremors) that last only a few seconds. Mr. and Mrs. Gonzalez worry about whether Isabella's teachers even notice these slight and frequently repeated seizures, much less appreciate the toll that they take on her body. At other times, she has grand-mal seizures that are so severe that her whole body trembles and she gets caught in the straps of her wheelchair. Mr. and Mrs. Gonzalez are concerned that the school is not properly addressing her needs or, worse yet, no one will see her when the big seizures occur. Speaking in Spanish, Mrs. Gonzalez explains the challenge: "There is not a translator every time I just want to pick up the phone and talk to her teacher or tell her on Monday morning how her weekend had been. We always have to schedule for a translator."

TWO FAMILIES AND TWO WINDOWS FOR UNDERSTANDING FAMILIES IN SPECIAL EDUCATION

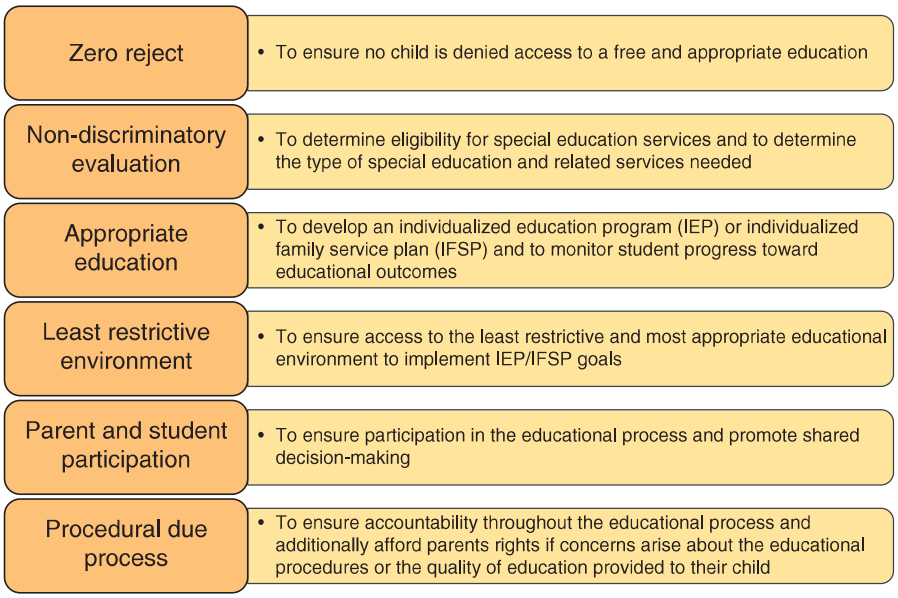
The Campbell and the Gonzalez families offer us two windows for understanding the relationship between special education for students with severe disabilities and the nature of family life. The first window lets us look at the law governing special education and relationships between educators and parents. The second window lets us consider the family systems perspective, a framework through which professionals can understand families' preferences, strengths, and needs.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT: PARENTAL RIGHTS AND RESPONSIBILITIES

One of the purposes of the Individuals with Disabilities Education Act (IDEA) has always been to create a combined federal, state, and local system that would provide all students with disabilities a free appropriate public education (FAPE) in the least restrictive environment. To secure that outcome, Congress created a framework within which educators and the parents of children with disabilities can be partners. The U.S. Supreme Court, in *Schaffer v. Weast* (2005), has said that the

Watch "Introduction to Special Education" at www.youtube.com/watch?v=MCdR2vA1g20.

FIGURE 2–1
Process for Implementing IDEA's Six Principles in Educational Decision-Making



"cooperative process . . . between parents and schools" is at the core of IDEA. In this chapter, we discuss that "cooperative process" by examining the partnership as it can exist under the six principles of IDEA (Turnbull, Stowe, & Huerta, 2007). For the sake of brevity, we use the word *parent* to refer to the parents and other family members that IDEA covers, unless we indicate otherwise. We also use the acronym *LEA* to refer to local educational agencies and *SEA* to refer to state educational agencies.

IDEA's Six Principles

Figure 2–1 illustrates IDEA's six principles and provides a brief definition of each principle. These principles are zero reject, non-discriminatory evaluation, appropriate education, least restrictive environment, parent and student participation in shared decision-making, and procedural due process. In this chapter, we have focused on the partnership that parents and professionals can create under IDEA.

Zero reject is a rule that requires educators to offer FAPE to all age-eligible students with disabilities. It's a principle that is easy to understand: *All* means all. The type or severity of the student's disability is irrelevant. *All* includes Jamal and Isabella; their multiple disabilities do not result in exclusion but instead underscore the need for them to have the appropriate supports to have a meaningful education.

IDEA connects the zero-reject principle to parental rights and responsibilities in several ways. The first relates to the ages of the children. Under IDEA's early intervention provisions (referred to as Part C of IDEA), infants or toddlers (ages birth through two) may receive services designed to develop their capacities, minimize their potential for developmental delays, and enhance their families' capacities to work with their children.

> *When Jamal was 26 months old, he seemed to lose what little language he had and began to engage in odd behaviors such as lining up all of the coins in their change jar and spinning forks on the kitchen floor. He promptly was referred to early intervention, identified as having autism, and began receiving IDEA Part C services when he was 28 months old. These services ended when he was 36 months old. He then was evaluated and qualified for services under Part B of IDEA at the age of three.*

The second connection relates to older students and their right to a free education. Part B serves children ages 3–21 who have any one of 10 types of disabilities and need special education and related services to progress in the general education

curriculum. Part B services are free; Part C services might be free or low cost, depending on a family's income. *Free* means that neither the Campbells nor the Gonzalezes may be required to use private insurance benefits to pay for their children's education. They may use their insurance benefits to pay for services that their children need but that the schools do not provide (typically, medical services).

Mr. Gonzalez has health insurance for his family through his employer, but he, like other families, wants to use his insurance benefits only when absolutely necessary. But Isabella's seizures are occurring more often and are more significant; her seizures affect her education and he may have to pay physicians for services that he cannot get free from her teachers.

A third connection is related to school-imposed discipline.

Jamal has recently begun to engage in increased challenging behavior. While most of his behavior is self-injurious (e.g., hitting and pinching himself), he has been sent home on several occasions for aggressive behavior towards his peers (e.g., lunging, pushing, and hitting), causing his mother, a single parent, to leave work each time that the school called about his behavior.

Just what do the discipline provisions mean for Jamal? Under IDEA, an LEA has the authority to remove a child with a disability who violates a code of student conduct from the child's current placement to an appropriate interim alternative educational setting or another setting, or suspend the child for not more than 10 school days. At the same time, IDEA also protects the child's right to an education by giving the child's LEA the option of providing services during the 10-day period. So, Jamal could be out of school for up to 10 days for a school-code infraction, which would mean 10 days of lost income for the family.

If the LEA removes the child for more than 10 school days or changes the child's placement as a form of discipline, the LEA must (a) continue to provide special education and related services, (b) conduct a functional behavior assessment and develop and implement (or modify and implement) a (new or existing) behavioral intervention program designed to address the behavior for which the LEA has disciplined the child, and (c) determine whether the child's behavior (for which the child is being disciplined) is a manifestation of the child's disability (20 U.S.C. § 1415(k)).

Non-discriminatory evaluation is a rule that requires educators to eliminate bias on the basis of a student's language, culture, or other traits as they (a) determine whether the student has a disability and (b) specify what kind of special education and related services the student should receive if the student has a disability.

Educators and parents alike have the right to request an initial evaluation of a student. If educators want to evaluate a student, whether for an initial evaluation or for a re-evaluation, they must secure the consent of the student's parents. Parents may consent or refuse to consent. If the school has taken reasonable measures to secure parental consent and if the parents have failed to respond, the school may try to persuade the parents to consent by using mediation or another method of resolving disputes (i.e., procedural due process) or it may simply decline to conduct an initial evaluation. In that event, the school is not required to provide special education and is not liable if it does not because the parents have opted out of special education.

In partnering with families to conduct evaluations, educators have responsibilities such as providing notice of evaluations and ensuring that assessments are not culturally biased and are valid and reliable. However, not all evaluations are done by a student's educators. Parents such as Ms. Campbell and Mr. and Mrs. Gonzalez have a right to secure (at their own expense) an independent evaluation—one done by qualified professionals not employed by the student's school district—and to require that the school's evaluation team consider it. Parents also may recover the cost of an independent evaluation from the LEA if the LEA's evaluation is not appropriate according to a due process hearing officer or court or if the reevaluation was ordered by a due

process hearing officer or court. This means that team evaluations may not be completely influenced by only LEA members.

As much as their culture teaches them to defer to educators, Mr. and Mrs. Gonzalez may want to secure an independent evaluation for Isabella if they believe the school failed to properly assess her needs and strengths in her native language, as IDEA requires, or if the school does not have a specialist physician (such as a neurologist) to evaluate her to determine the causes of, and interventions for, her seizures.

Appropriate education is a rule that requires educators to comply with all IDEA processes and thereby benefit the student (*Board of Education of the Hendrick Hudson Central School District v. Rowley*, 1982). The linchpin for an appropriate education is the student's IFSP (for infants and toddlers, from birth to age 3) or individualized educational program (IEP) (for students aged 3–21). When developing an IFSP and IEP, the team should consider the evaluation data, the strengths of the child, and the concerns of the parents, in addition to the academic, developmental, behavioral, and functional needs of the child. The IEP may be revised as often as necessary, but is typically revised annually. Figure 2–2 displays the required content for an IEP. For students, like Jamal and Isabella, who take alternate assessments (see Chapter 3), their IEP must include short-term objectives. These objectives are typically used as benchmarks to gauge progress toward meeting the annual goals. Students have a right to related services

FIGURE 2–2
Required Contents of Individualized Educational Plan (IEP)

The IEP is a written statement for each student, ages 3–21. Whenever it is developed or revised, it must contain the following statements:

1. The student's present levels of academic achievement and functional performance, including
   - how the student's disability affects the student's involvement and progress in the general curriculum (for students 6–21)
   - how a preschooler's disability affects the child's participation in appropriate activities (for children 3–5)
   - a description of the benchmarks or short-term objectives for students who take alternate assessments that are aligned to alternate achievement standards
2. Measurable annual goals, including academic and functional goals, designed to
   - meet each of the student's needs resulting from the disability in order to enable the student to be involved in and make progress in the general curriculum
   - meet each student's other educational needs that result from the disability
3. How the student's progress toward annual goals will be measured and when periodic reports on the student's progress on, and meeting of, annual goals will be provided
4. The special education and related services and supplementary aids and services, based on peer-reviewed research to the extent practicable, that will be provided to the student or on the student's behalf, and the program modifications or supports for school personnel that will be provided for the student to
   - advance appropriately toward attaining the annual goals
   - be involved in and make progress in the general curriculum and participate in extracurricular and other nonacademic activities
   - be educated and participate in those three types of activities with other students with disabilities and with students who do not have disabilities
5. An explanation of the extent, if any, to which the student will not participate with students who do not have disabilities in the regular class and in extracurricular and other nonacademic activities
6. Any individual appropriate accommodations that are necessary to measure the student's academic and functional performance on state- and districtwide assessments; if the IEP team determines that the student will not participate in a regular state- or districtwide assessment or any part of an assessment, an explanation of why the student cannot participate and the particular alternate assessment that the team selects as appropriate for the student
7. The projected date for beginning the special education, related services and supplemental aids and services, and modifications and the anticipated frequency, location, and duration of each
8. Beginning no later than the first IEP that will be in effect after the student turns 16, and then updated annually, a transition plan that must include
   - measurable postsecondary goals based on appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills
   - A statement of transition services, including courses of study, needed to assist the student to reach those postsecondary goals
   - Beginning no later than 1 year before the student reaches the age of majority under state law (usually at age 18), a statement that the student has been informed of those rights under IDEA that will transfer to the student from the parents when the student comes of age

(From Turnbull, Ann; Turnbull, H. Rutherford; Wehmeyer, Michael L., *Exceptional Lives: Special Education in Today's Schools,* 6th ed., © 2010, p. 53. Reprinted and electronically reproduced by permission of Pearson Education, Inc., Upper Saddle River, NJ.)

(e.g., speech therapy, occupational therapy, physical therapy, music therapy, assistive technology) if, like Jamal and Isabella, the services are necessary to ensure that the student receives FAPE. While students may receive related services to ensure FAPE, families may also benefit from related services. Related services specifically for families could include family training, counseling, and home visits (e.g., PBS training for Ms. Campbell); parent counseling and training; or social work services. There are also important IEP considerations for older students. When students turn 16, their IEPs must describe appropriate, measurable postsecondary school goals and transition services to prepare them for future education, employment, and independent living, as appropriate.

IDEA's IFSP and IEP requirements enable families and professionals to work together as partners in planning and implementing the student's appropriate education. A LEA must take certain steps to ensure that one or both of the student's parents are members of any group (including the IEP team) that makes decisions on the child's educational placement. These steps include advance notice of the meeting, mutually convenient scheduling of the meeting (taking into account Mr. Gonzalez's long working hours), and arranging for interpreters for parents who are deaf or non-English speaking, such as Mrs. Gonzalez. If a parent cannot attend the meeting, he or she may participate through video conferencing or telephone conference calls, again with interpreters as needed.

The LEA may have an IEP meeting without a student's parents only when it can document that it attempted unsuccessfully to have them participate. The documentation should include detailed records of telephone calls, copies of letters to and from the parents, and the results of any visits to the parents' homes or places of work.

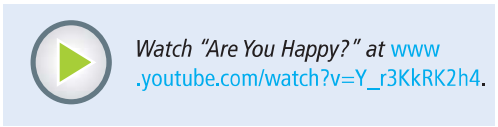
Parents may invite other family members or other individuals knowledgeable about their child to attend the IFSP and IEP team meetings. The parents' supportive allies can offer information that helps the entire team with additional information.

> *Ms. Campbell's mother has attended meetings in the past, as has Jamal's brother, Donnell. Ms. Campbell said that "having other children at a meeting can be very enlightening. Plus, I think it's helpful to hear their opinions because, a lot of times, they come up with better ideas on how to solve a problem with Jamal than the adults do."*

The presence of a large number of school personnel at meetings can also be overwhelming for the family. A large number may also be inefficient for a school. IDEA allows for an otherwise required member of the IEP team to be excused if the parent and school agree that the member's attendance is not necessary. The excused members may submit written recommendations for the IEP.

Educators should be cautious about their own "excused absences." School efficiency is one thing; student outcomes are quite another and are far more important. Schools must also consider the impression that an absence might convey. Might Ms. Campbell or the Gonzalez family regard an absence as a lack of concern or dedication to their child?

Least restrictive environment is a rule that, to the maximum extent appropriate, each child with a disability will be educated with children who do not have disabilities—that is, in the regular educational environment. This presumption favoring inclusion enables Jamal and Isabella to have greater access to their peers without disabilities to enhance social skills (which the Gonzalez family specifically indicated was a high priority for Isabella) and for both Isabella and Jamal to be exposed to the same general education curriculum as their peers without disabilities (albeit with accommodations and modifications as specified in their IEP).



The presumption may be set aside when the student's needs are so great that, even with related services and with supplementary aids and services, educators conclude that the child cannot be educated satisfactorily in the regular educational environment. When setting aside the presumption, educators may place a student into one of several settings along a continuum of services, including resource rooms, special education classes, separate schools, and institutions and hospitals. Jamal and Isabella benefit

from the presumption, Jamal more so than Isabella. Jamal has received the majority of his academic instruction in the same classrooms as peers who do not have disabilities, albeit through an adapted curriculum and with the benefit of a paraprofessional.

Not all schools fully embrace inclusion; the reasons provided may vary. A few reasons may include philosophical differences among professionals on the issue, professionals' limited knowledge of how to successfully implement inclusive practices, limited resources, district allocation of resources only to specialized schools or only to a few schools in the district, and untrained general education teachers. Inclusion does not occur naturally. A group of researchers examining one highly effective inclusive elementary school revealed six key themes: (a) The needs of all students were met; (b) high quality instruction was provided to all students; (c) professional development opportunities were available; (d) administrators flexibly used resources and maintained a rigid schedule; (e) shared decision-making was utilized, allowing teacher autonomy for classroom decisions; and (f) data-based decision-making was a priority (McLeskey, Waldron, & Redd, 2014, p. 63).

Inclusion benefits the student with a disability and peers who do not have disabilities (Hunt & McDonnell, 2007). Regardless of their inclusion in the academic program, Jamal and Isabella have the right to participate in all other school activities, such as field trips, assemblies, social occasions, and after-school programs, often with the support of peers who volunteer to be in their circles of friends.

> *Isabella's health-related needs are a legitimate factor to consider with respect to her inclusion in general education classes. But what prevents her from participating in some extracurricular or other school events? Only her teachers' failure to understand that, at home, Mrs. Gonzalez arranges for Isabella's peers without disabilities to be part of the Gonzalez family. If this can happen at home, Mrs. Gonzalez wonders why it can't happen more at school.*

Similarly, infants and toddlers in early intervention programs must receive services in "natural environments," namely, those in which peers without disabilities participate, to the extent appropriate for the child. Natural environments are (a) the child's home, (b) full- or part-time participation in preschool programs operated by public agencies (e.g., Head Start), (c) segregated private schools (in which there are only children with disabilities) or integrated private schools (in which there are children with and without disabilities), and (d) classes in general education elementary schools (with children who do not have disabilities).

The natural-environments rule values the child's needs more than the child's placement. The natural-environments rule is a rebuttable presumption (i.e., it is assumed that states will provide early intervention services, supports, and programs in natural environments; however, states have the option to justify otherwise) similar to the LRE rule for children of ages 3–21 and is interpreted and applied in the same manner as that rule. LRE is a continuum of placements; while inclusion is the presumption, the team has the option to justify a different placement (e.g., one that is not in an inclusive environment) if the team decides another setting is a more appropriate placement for the provision of educational services.

Parent and student participation in shared decision-making is the fifth of IDEA's six principles. IDEA has consistently supported the notion that children's education can be made more effective by strengthening the parents' roles and responsibilities. We have described the ways in which parents may participate in their child's non-discriminatory evaluation, IEP development, and least restrictive setting planning. There are, however, still other ways for parents to participate as partners with educators.

Parents have the right to have access to their children's school records and to limit the distribution of those records to only those persons who have "a need to know." They also have the right to access the school district's general records about special education, such as the records that show how many students receive special education services and the amount of money that the district receives and spends on special

education. Obviously, they do not have the right to see other students' records. In addition, parents generally have the right to see the state's special education plan, receive public notice of hearings on the plan, and comment on the plan. They are entitled to serve on the state advisory council on special education, and parents must constitute the majority of the council's membership. Finally, parents of infants and toddlers are entitled to serve on the state's interagency coordinating council on early intervention and must constitute a majority of the membership of the council.

Most of all, however, parents have a right to participate in evaluation and IEP team meetings, and their children, whatever their age and however challenging their disabilities may be, also have a right to be members of the IEP team "whenever appropriate." When is it appropriate? Basically, whenever parents and educators decide that it is. However, IDEA specifies, at least by the age of 16, students must be invited as participants in their IEP meeting if transition planning and postschool outcomes are discussed.

To increase student participation in decision-making, educators can assist their students in (a) developing a portfolio of their work and information about their goals; (b) preparing a PowerPoint presentation about their needs, preferences, and goals; or (c) developing a recordable storybook about their achievements and their ideas about future goals to pursue. Research-based strategies are available to assist educators with facilitating IEP participation for students with disabilities (Cease-Cook, Test, & Scroggins, 2013; Griffin, 2011; Woods, Martin, & Humphrey, 2013) and teaching students self-advocacy skills (Hart & Brehm, 2013). Jamal's mother intuitively felt his participation in his IEP meetings was important, even though he was younger than the IDEA-required age of 16. It is critical that educators be open to parents' suggestions (even if not required by law); this builds trust and stronger family–school partnerships.

Jamal has been included in general education classrooms with his peers for the past several years; however, only recently, with his transition to middle school, were Jamal's opinions solicited. This was so because his mother stated that she would like for him to attend his IEP meeting to have a chance to ask questions and give his opinions about his transition from elementary to middle school. While his role was minimal at this IEP meeting, his first ever, he was able to share what it meant for him to "work and have fun" with his friends. Ms. Campbell was very proud of the advocacy role her son played at such a young age. Jamal practiced his "IEP speech" at home with his mother and siblings using his communication board.

It is essential for other IEP team members to listen with respect to the student's contributions, ask questions, and incorporate the contributions as collaborative decisions are made. A student's mere presence at a meeting can allow educators and parents to emphasize the student's strengths, instead of simply describing the student's needs; Jamal's presence prompted educators to consider his strengths.

Ensuring parents' full participation in educational decision-making might require additional effort, especially with parents from culturally and linguistically diverse backgrounds or whose culture does not place much value on a child's opinions. Cultural values strongly influence who families consider to be appropriate decision makers and the extent of autonomy that might be extended to someone who is not yet an adult.

Having Isabella participate and express her own desires about her education is a new experience for them. Mr. Gonzalez states, "We typically make the decisions for all of our children because we know what is in their best interests—we've been through the hardships. We know what the world expects and we have an obligation to guide our children in these ways."

Procedural due process is a technique whereby parents and educators may hold each other accountable for assuring that the student receives a free appropriate public education. One element of accountability involves parental consent to the initial evaluation, a re-evaluation, and the student's placement into special education. Without parental consent, educators have only limited options with respect to the child's education.

To ensure that parents are adequately informed in order to give consent, IDEA requires educators to give two types of notice to parents. The first notice is a "notice of action." Educators must give parents a notice before they take any action to change or refuse to change a student's identification (his or her classification as having a disability), evaluation, placement, or provision of a free appropriate public education. The second notice is a "rights notice"—basically, a notice regarding the parents' and student's rights to due process and procedural safeguards. Both notices must be written in language that the general public can understand. If the parents do not speak English, the educators must take steps to ensure that the notice is translated into the parents' native language, the parents understand the content of the notice, and there is written evidence that the requirements related to language and understanding have been met.

It is best for Isabella's teachers to be sure to provide her parents with a notice in both English and Spanish; Mr. Gonzalez does well with English, but Mrs. Gonzalez does not.

What if parents are dissatisfied with the educational services that educators are providing their child? They have several options. They may file a complaint with the state education agency; they may file a complaint with the U.S. Department of Education, Office of Civil Rights; or they may file a request for a due process hearing (a mini-trial to determine whether the educators are acting consistently with IDEA and providing a free appropriate public education to the student).

If the parents choose to exercise their due process hearing rights, they (or the attorney representing them) must notify their child's local education agency and state education agency, and include in the notice (a) their child's name and residence, and the name of the school that their child attends; (b) the nature of the problem with their child and the facts related to that problem (i.e., the action that the LEA proposes to take); and (c) how to resolve the problem.

A parent may not bring a complaint or sue an LEA for an alleged violation that occurred two years before the time the parent files the complaint. The two-year rule is known as a *statute of limitations* and requires a parent to act promptly so that the facts about the complaint will be "fresh" and the remedy, if any, will address the present needs of the child. The due process hearing is like a civil trial, with both the parents and the LEA having the right to be represented by lawyers and to produce evidence. The losing party may appeal to a state-level hearing officer and then to the courts. If the parents prevail (win), they may recover the fees that they paid to their lawyers.

Unfortunately, research indicates that many parents are dissatisfied with some aspect of their child's educational program. In a national, random sample survey of parents of students with disabilities, 31% of the parents of students with severe disabilities reported that they had considered suing the school or had threatened to sue because of their disappointment in the quality of the services provided to their child (Johnson, Duffett, Farkas, & Wilson, 2002). More than twice as many parents of students with severe disabilities indicated their consideration of suing than did parents of students with mild disabilities.

Summary of the Six Principles

Through each of its six principles, IDEA strengthens parents' rights. Five principles (zero reject, non-discriminatory evaluation, appropriate education, least restrictive environment, and parent and student participation in shared decision-making) establish a framework within which parents acquire rights in order to affect their children's education; the due process principle establishes a mechanism by which parents can hold the LEA accountable for complying with IDEA.

Assisting Families to Advocate: Parent Training and Information Resource Centers

To advocate for informed decisions about their children's education, families need current information about their child's disability, special education policy, and

evidenced-based practices. In this section, we will highlight two educational resources specifically created to meet the informational needs of families: Parent Training and Information Centers (PTI) and Community Parent Resource Centers (CPRC).

The PTI is an extensive national resource network for parents. Currently, there are 73 not-for-profit PTIs funded by the U.S. Department of Special Education, Office of Special Education and Rehabilitative Services. Each state has at least one PTI, and some states have two or more. Typically, PTIs are directed by parents of children with disabilities, and under IDEA, the majority of the staff must be parents. The purpose of PTIs is to prepare parents to be effective advocates in educational decision-making. They provide a broad range of workshops, conferences, other training opportunities, and even one-to-one assistance to families. Many have IDEA information in languages other than English and have staff who are from diverse cultural and linguistic groups.

Community Parent Resource Centers (CPRCs) are resources especially for traditionally underserved families. They are in communities that are characterized by cultural and linguistic diversity. CPRCs focus on parents with low incomes, parents of children who are English-language learners, parents who live in "empowerment zones" (federally designated urban areas that are eligible for additional federal assistance), and parents who have disabilities. CPRCs offer intensive, culturally relevant support to families. Currently, the U.S. Department of Education funds approximately 30 CPRCs.

Two national technical assistance centers supplement the PTIs and CRPCs. They are the Center for Parent Information and Resources (CPIR) and the Native American Parent Technical Assistance Center (NAPTAC). On the website of the CPIR (**www.parentcenterhub.org**), you can find many helpful resources, including a list of the names, addresses, and contact information for all of the PTIs and CPRCs by region (**www.parentcenterhub.org/ptacs/**).

Educators should ensure that parents are aware of these resources and encourage parents to contact their state PTI, as well as the CPIR, to learn about training opportunities and obtain printed information developed specifically for families. For example, the PATH program in Texas is the PTI that would serve the Campbell family. There are only two CPRCs in Texas and neither one is close to the Campbell family. In this situation, several schools might work with the closest CPRC to develop a central resource center in one of the schools to house training materials, books, videos, and contact information for other community resources (e.g., the social security office, mental health centers, employment centers, drug treatment centers, safe shelters). Schools could also assist families with developing a local support group to meet the needs of families who face additional challenges related to poverty or a child's specific disability (e.g., autism or Down syndrome). One of the best ways that schools and professionals can advocate for families is to demonstrate that they care about the unique concerns and needs of families by inviting them to their school and making resources readily available to them.

In this section, we have shared two specific resources for assisting parents, and assisting teachers in assisting parents, to become stronger educational advocates for their children. The next section presents families' educational concerns within family systems perspective.

A FAMILY SYSTEMS PERSPECTIVE

A system is a "set(s) of elements standing in inter-relation among themselves and with the environment" (Bertalanffy, 1975, p. 159). Systems theory assumes that a system can be understood only as a whole. Systems theory has been applied to family sociology and family therapy in terms of how families interact as a whole system. Prior to the family systems approach within the field of special education, educators were concerned primarily about the education of the child within the context of the school

setting (i.e., what happens between the hours of 8:00 a.m. and 3:00 p.m.). Instead, family systems theory encourages educators to think about the child within the context of the whole family and how each family member interacts with and affects all other family members across multiple settings. When educators understand a student's life within multiple contexts (e.g., school, home, community), multiple roles (e.g., child, sibling, grandchild, nephew), and multiple interactions (e.g., child–parent, child–grandparent, child–sibling), they can develop more meaningful educational programs.

Watch "Abigail Branson Not Limited by Spina Bifida" at www.youtube.com/watch?v=PqUDdxm-qSA.

Raising a child with a disability can be stressful at times (Brobst, Clopton, & Hendrick, 2009; Guralnick, Hammond, Neville, & Connor, 2008), and research has indicated that severity of disability is negatively associated with both mothers' and fathers' satisfaction with family quality of life (Wang et al., 2004). That is, the more severe the disability, the less satisfied families are with their quality of life. However, Wang and colleagues noted that "severity" is a term that is not universally well defined; they recommended that, rather than broadly examining "severity," future studies consider the impact of more specific characteristics of disabilities. Turnbull, Summers, Lee, and Kyzar (2007) conducted a systematic review of the literature related to family outcomes for families of children with intellectual and developmental disabilities, and found that, across studies, behavior problems predicted lower family well-being, adaptation, and family functioning whereas family support (informal and formal) was positively associated with these outcomes (e.g., well-being, adaptation). Educators need to understand how the child with a disability affects all family members (e.g., siblings, grandparents, aunts, uncles), understanding both positive contributions and stressors. The Campbell and Gonzalez families help us understand the positive experiences families have, for example

> *Jamal and his older brother Donnell have a tradition of eating chicken wings and drinking Root Beer floats every time they watch the Dallas Cowboys play on TV. Jamal loves his brother very much, although he has yet to speak these words; however, the bond between these two brothers is obvious.*
>
> *The Gonzalez family practices Roman Catholicism. Isabella loves to attend church; it is the one place where she seems to be most happy, moving to the music and chanting along with the responsorial prayers in her own special way.*

However, the Campbell family is not without challenges.

> *When Jamal's routine is disrupted, his screams and self-abusive hits are almost unbearable for all family members to witness. They all generally know how to intervene to help Jamal communicate, but sometimes it can be very stressful, particularly when these behaviors occur in public places.*

Similarly, the Gonzalez family also faces some challenges.

> *They are often frightened by Isabella's seizures. They have continued to intensify as she ages despite her being on numerous medications. Both Mr. and Mrs. Gonzalez are afraid that something might happen to her when she is sleeping so they have often traded off nights to watch her sleep when she is having frequent seizures. This has left them exhausted the next day.*

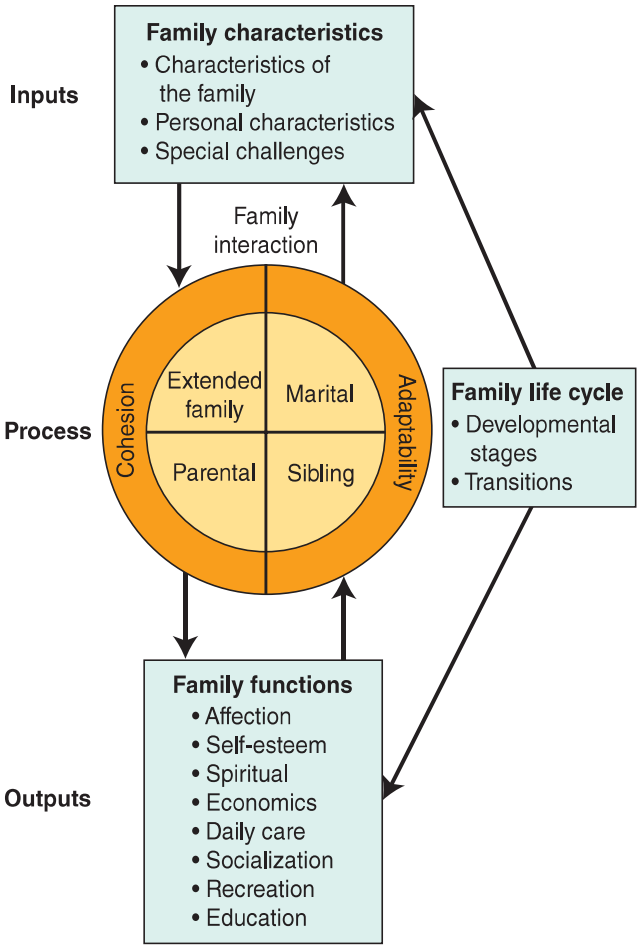
Educators need to be aware of situations that can be stressors for families. Indeed, the Campbell family would benefit from information on behavioral support and in developing behavioral interventions for Jamal, particularly for crisis situations that occur in public places. The Gonzalez family might appreciate information about obtaining on-call respite care to assist with nighttime support when Isabella's seizures are severe. Both the Campbell and Gonzalez families have multiple needs, but their teachers would not have known about these needs unless they learned from families how the child affects the entire family. They can learn if they (a) listen intently and

utilize empathy to acknowledge parents' concerns, (b) ask open-ended questions, (c) take notes during the conversation, (d) utilize the notes to summarize parents' concerns, and (e) develop a first step to address the concern (McNaughten, Hamlin, McCarthy, Head-Reeves, & Schreiner, 2008).

As we continue to explore family systems theory, consider the following question: Who is the consumer of your services? In the past, the student has been viewed as the sole consumer. The family systems approach, however, identifies the entire family as the consumer of services. This approach also seeks to have a much broader view instead of education or skill development only. Figure 2–3 depicts the family systems framework that we will be discussing in the remainder of this chapter. The components of the framework and their interrelationships within the family system are as follows:

1. *Family characteristics* describe the entire family as a unit (e.g., size and form, cultural background, socioeconomic status, geographic location), the family's personal characteristics (e.g., health, coping styles), and the family's special challenges (e.g., poverty, abuse). These characteristics are the underlying input to the system that shapes the way in which the family interacts.
2. *Family interaction* is the hub of the system; that is, the process of interaction among individual family members and subsystems (i.e., marital, parental, extended family, and sibling). Subsystem interactions are influenced by, and in turn influence, what family members do to respond to individual and collective family needs.
3. *Family functions* are the output of the interactional system. On the basis of its characteristics (the input), the family interacts (the process) to produce responses that fulfill family affection, self-esteem, spiritual, economic, daily care, socialization, recreation, and educational needs.
4. *Family life cycle* introduces the element of change into the family system. As the family moves through time, developmental and non-developmental changes alter the family's characteristics and needs; these, in turn, produce changes in the ways that the family interacts.

FIGURE 2–3
Family Systems Framework



(From Turnbull, A. P., Summers, J. A., & Brotherson, M. J. (1984). *Working with families with disabled members: A family systems approach* (p. 60). Lawrence: University of Kansas, Kansas Affiliated Facility. Adapted by permission.)

The family systems framework enables educators to recognize each family's complexity and uniqueness. Each family is composed of so many attributes that it can interact in an almost endless variety of ways. A family is not a static entity; it is constantly changing and also resists change. As a result, families and educators may have different views about educational goals and how to partner in order to develop these goals. The following sections briefly address each of the four components outlined in Figure 2–3 and highlight issues relevant to special educators. For a more comprehensive description of these elements, see Turnbull, Turnbull, Erwin, Soodak, & Shogren (2015).

Family Characteristics

Professionals often may be impressed by the increasingly diverse students and families in their schools. This diversity greatly influences not only how

professionals interact with the child in the school setting but also how professionals understand the child's effect on a family and a family's responses to meeting their child's needs. For practitioners to effectively educate their students, they need to understand and respond to various family characteristics. We focus on three types of family characteristics: (a) the characteristics of the family as a whole, (b) the personal characteristics of each family member, and (c) the characteristics of the special challenges that a family faces.

The Characteristics of the Family

Families vary in areas such as size, form (e.g., dual vs. single parents, original vs. blended family), culture, socioeconomic status, and geographic location. Obviously, although the Campbell and Gonzalez families have much in common, they also differ from each other in many ways. For example, there are many more Gonzalez family members than Campbell family members who reside in their respective households. In this section, we focus on culture as illustrative of variations in family characteristics.

Culture provides a framework through which individuals and families form a sense of group identity (Gollnick & Chinn, 2012). It involves many considerations, including race, ethnicity, geographical location, religion, income, sexual orientation, gender, disability, and occupation. People often equate culture with race or ethnicity, but culture is a much broader concept. For example, the Campbell family is African American, and in some states large proportions of African Americans reside in poorer, inner-city neighborhoods. By contrast, the Gonzalez family is of a different race and has a different cultural heritage; the Gonzalezes are Hispanic, specifically, Mexican. However, the Gonzalez and Campbell families both have limited incomes; each family lives in an inner-city neighborhood and shares the concern of increased crime and illegal drugs where they live.

The two families have different cultures. Ms. Campbell and her family are devout Baptists, while the Gonzalez family is Roman Catholic, attending mass in their native language of Spanish. Each has strong ties to their extended family; however, the Gonzalez family includes several members of their extended family in one household. These cultural differences can be substantial, but they are by no means bound to be so, especially when families and practitioners work together to share and understand how culture infuses their everyday lives.

To gain insight into the importance of culture, Mrs. Gonzalez describes a difference of opinion that she had with Isabella's teacher concerning an IEP goal that the teacher recommended for Isabella.

> *In their recent conference, Isabella's teacher explained that she will soon start a unit on families. Mrs. Gonzalez was thrilled, and shared that in their culture, young children often affectionately call their aunts and uncles* tía *and* tío*, the Spanish words for aunt and uncle, respectively. Isabella's sister, who does not have a disability, knows English but still does not use the English words aunt and uncle. Since English is taught in school, Isabella's teacher expressed that she was unsure about whether teaching Isabella some Spanish words would be appropriate. Mrs. Gonzalez further suggested that by introducing the Spanish words first, she would not only be honoring Isabella's cultural heritage, but would also allow the other children in Isabella's classroom to appreciate her culture.*

Culture influences marriage ceremonies, religious beliefs and practices, rites of passage (e.g., a bar or bat mitzvah), holiday celebrations, holy day observations, rituals surrounding death and burial, a person's perception of his or her relationship to the world, political beliefs, attitudes toward independence and work, and, in general, parenting practices (e.g., the extent to which it is appropriate for children and youth to be self-determining). Although you need to be aware of cultural differences, you also need to be careful not to stereotype families on the basis of this awareness. To say that all people of color, in comparison to European Americans, value family unity

and permanence, interdependence, and protectiveness is contrary to the real-life experiences of many individuals in these groups. Always strive to enhance cultural self-awareness and cultural competence so that you can, in turn, create partnerships with families that are respectful of their cultural values (Lynch & Hanson, 2011), as well as respectful of their individual family characteristics.

Personal Characteristics

The characteristics of a child's disability include many factors, such as the nature of the disability, the extent or degree of the disability, the time of onset, and future prognosis. A child with medically complex needs often requires a family to make adaptations in daily routines, such as providing ongoing assistance, purchasing special equipment, and interacting frequently with medical personnel (Kuo, Cohen, Agrawal, Berry, & Casey, 2011). Specific disabilities also have their own unique challenges. Families of young children with autism experience challenges accessing services following diagnosis, which increases parental stress (Braddock & Twyman, 2014). A child with a later onset of disability (e.g., disability caused by an accident during his or her school years) can cause major family readjustments (Cavallo & Kay, 2011).

Regardless of the particular nature of the disability, children and youth also provide a broad array of positive contributions to their families, including greater valuing of the family and increased family closeness, appreciation of new opportunities such as advocacy, and becoming more aware of others' strengths (King, Zwaigenbaum, Bates, Baxter, & Rosenbaum, 2012). Thus, for professionals to understand the impact of a child with a severe disability, they will need to understand both the child's demands on the family and the child's contributions to the family.

According to Ms. Campbell, "Jamal has contributed to the family by teaching his older siblings about responsibility, compassion, and patience." Grandma Sandy particularly likes Jamal's smile, his inquisitiveness, and infectious laughter. Ms. Campbell enjoys the times when Jamal shows affection and the connection between them is obvious. Thus, while the family experiences challenges related to caring for Jamal, they also experience joy from their relationships with him. And just as Jamal has affected his family positively, Isabella's love of music unites the Gonzalez family, particularly during church services.

Special Challenges

The final aspect of family characteristics relates to the special challenges that families face. Families face many challenges other than a child's exceptionality, from less extreme ones (e.g., moving to a new community, changing jobs, or having a new baby) to more extreme challenges (e.g., the death of a family member, which happened in the Campbell family). Additional special challenges include substance abuse, exposure to violence, having a family member who is incarcerated, having teenage parents, having parents with an intellectual disability, and living in poverty.

For example, poverty challenges many families, especially those whose children have disabilities (Hughes & Fanion, 2014). Families that live in poverty are more likely to be in poor health; have less access to health care services; and have babies who are born with a low birth weight, which is linked to later disability. Furthermore, ethnicity continues to be a distinguishing characteristic that determines who lives in poverty. Poverty can also have an impact on families' experiences with accessing community resources and their interactions with service providers (Parish, Thomas, Rose, Kilany, & Shattuck, 2012). Silverstein and colleagues (2008) set out to examine low-income parents' experiences with adversity and stress, but during their qualitative interviews they realized that many of these parents also talked about their struggles with navigating community and social service systems and interacting with professionals whose job it was to help them.

Ms. Campbell only occasionally receives child support payments and is too tired to fight the system or her ex-husband to collect these dollars regularly.

The Gonzalez family is on and off of welfare benefits, depending on Mr. Gonzalez's ability to stay employed in the housing construction business. For the past few years, the housing market has been in a slump, forcing them to once again collect welfare benefits, including food stamps to obtain groceries.

Many families indicate that receiving information about their child with a disability and about family issues is their number one need. To address families' special challenges, it would be helpful for educators to develop a community resource file by working closely with other school professionals (e.g., social worker, nurse, psychologist, music therapist) so that they are prepared to respond to families' information and resource needs. This file will also be helpful when planning for family and disability resource fairs at your school. Grant and Ray (2010) suggest that resources be arranged by topical area (e.g., physical/medical needs) and provide enough detail so that families can determine whether the resource will be helpful. For example, the entry should include the name of the resource, the contact information, the purpose of the resources, and helpful notes.

Family Interaction

The family is a unit of interaction. Each family member is affected by the child's disability, and the child is affected by each family member. The goal of educators should be to form a partnership with multiple family members who have an interest in supporting the child's education, including mother, father, siblings, and extended family members. Family–professional partnerships typically are mother–professional relationships. But *mother* and *family* are not synonymous terms. The members of some families are related by blood or marriage, whereas others are related by preference (e.g., a close family friend who is regarded as a family member).

Any interaction with the child or other member ripples throughout the entire family. A home visit can be a very positive experience, or it can create family stress because of the perception of having one's privacy violated or because of the need to alter the family's schedule of activities or responsibilities. Even a seemingly simple request such as asking parents to follow through on instructional programs at home can strengthen their relationship with their child, but it may also create major tension.

Just how much time does Ms. Campbell have for being a "follow-through" educator for Jamal, given that she is a single working mother also raising his two older siblings?

The time required for Mr. and Mrs. Gonzalez to address Isabella's disability-related needs is extensive. However, Mr. Gonzalez works long hours in construction and is physically tired at the end of the day. As a result, Mrs. Gonzalez maintains the home, cuts the lawn, and has learned to do minor repairs in the home. Each works long hours to make ends meet.

What support does either family have to be highly involved parents, assuming that the family wants to perform that role? Lack of support can cause tensions between parent and child. These can spill over into a marriage; sibling interactions; and interactions with extended family, neighbors, bosses, and co-workers. Interaction with any member of the system has implications for all members. From the perspective of family interaction, two major concepts are critical: (a) family subsystems and (b) family cohesion and adaptability in order to maintain balance.

Family Subsystems

The family systems framework highlights four major subsystems within traditional nuclear families:

1. Marital subsystem—marital partner interactions
2. Parental subsystem—parent and child interactions
3. Sibling subsystem—child and child interactions

4. Extended family subsystem—entire family or individual member interactions with relatives, friends, neighbors, and professionals

Variations in subsystems exist in many families, such as single parents, stepparents, families with one child or many children, families with extensive extrafamilial subsystems (such as the Gonzalez family), and families that consist of people who are not related by blood or marriage to each other but who perform the same roles as people who are related by blood and marriage. We will highlight information on marital and sibling subsystems.

Marital Subsystem

There is a common assumption that children with disabilities—particularly severe disabilities—place their parents at greater risk for serious marital problems. Risdal and Singer (2004) conducted a metasynthesis of 13 studies on marital adjustment in the families of children with and without disabilities. They found that families of children with disabilities experienced a small negative impact on marital adjustment in comparison to families of children without disabilities. These authors suggest that this is a positive finding given that the literature has tended to report that "children with disabilities cause severe family strain in almost all families" (Risdal & Singer, 2004, p. 101).

Raising a child with a disability can be stressful, although it does not necessarily imply that serious marital problems will occur (Brobst, Clopton, & Hendrick, 2009; Urbano & Hodapp, 2007). While Brobst and colleagues (2009) found that parents who have children with autism experience more parental stress and a higher intensity of child behavior problems than parents of children who do not have developmental disorders, they also found that respect for one's spouse was the most significant predictor of relationship satisfaction for both couples of children with and without disabilities, over and above variables such as parental stress or the level of the child's disability. What we do know is that a strong marriage makes a big difference in the family's overall quality of life. At the same time, it is also important to remember that many single parents also experience strong family well-being (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015). Ms. Campbell is one of those families, as evidenced by her close ties to her own mother and her siblings, particularly her brother, who is a father figure for her children.

Research has demonstrated better ways to reduce parental stress in families who have children with significant disabilities (Wang & Singer, in press). Kyzar, Turnbull, Summers, and Gómez (2012) conducted a systematic review of the literature examining the relationship of family support to family outcomes; support, largely defined as informal/social support, was consistently negatively correlated with stress and positively correlated with family quality of life, family functioning, and family satisfaction. Further research has documented the impact of family support not only on family stress but also on child outcomes such as reduced problem behavior (Carta, Lefever, Bigelow, Borkowski, & Warren, 2013; Neece, 2014).

Providing parental support by sharing information and resources, such as helping the Campbell family implement positive behavioral support strategies at home and in community settings, is one way to let families know that you care about their well-being outside of the classroom. Even a short note to the parent to share positive news about the child may be just the thing that a parent needs to hear after a long day at work.

> *Mrs. Gonzalez says, "Knowing that my little Isabella is happy at school eases my mind at home; I worry, you know, that no one will like her and she will be so sad. Just reading in her communication book that she smiled a lot at lunchtime makes my day!"*

Professionals can also support families' marital well-being by listening and responding to parents' preferences for the support that they themselves need in caring for their son or daughter. For example, when Mrs. Gonzalez indicates that there is stress

because of the long hours that her husband is working, Isabella's teacher might ask the social worker to contact the Gonzalez family occasionally to check on their need for respite care.

Finally, professionals should be respectful of alternative family lifestyles. Parents of children with severe disabilities, similar to those of children without disabilities, may be in same-sex relationships. Same-sex relationships may occur in families in which parents have been in heterosexual relationships, had children, and then have taken those children into same-sex partnerships, legal unions, or marriages. Some children in same-sex marriages are adopted or are born through in vitro fertilization. There are many steps that you can take to welcome children from these families into schools and to welcome their parents as well. Some suggestions from Lamme and Lamme (2002) include providing electronic and library resources on diverse families, including same-sex parents, and promoting a respectful school environment.

Sibling Subsystem

Some studies have found that brothers and sisters of siblings with disabilities have a higher incidence of emotional problems, lower self-esteem, and greater responsibility for household chores (Neely-Barnes & Graff, 2011; Mazaheri et al., 2013). However, research also suggests that there are many positive benefits to having a sibling with a disability, such as increased empathy, patience, social justice, and acceptance of differences (Dykens, 2005; Heller & Arnold, 2010; Stoneman, 2005).

The values that Ms. Campbell wants to pass on to her children include acceptance of differences and compassion for others. She is happy that Donnell and Shelia are learning these values through interactions with Jamal. Ms. Campbell speaks of the unconditional acceptance that Jamal's siblings show Jamal, saying,

> *It's just normal to them. This is who he is. I have always appreciated that in them. . . . They like to go in his room and watch movies—but they watch them with him, they don't ignore him. They all eat popcorn together. During football games, Jamal's brother, Donnell, will roughhouse with the NERF football; Jamal just breaks out in uncontrollable laughter. I think that's what I like the most—seeing them do things that typical siblings do.*

For Isabella's family, however, there is not only her younger sister but also her cousin, aunt, and uncle who live in the household with them. While this is temporary for now, until her uncle can find a job, they still function as one big family. In Isabella's eyes, it is as if she has two siblings.

A national resource for siblings is a program called Sibshops, which has the goal of providing information and emotional support for brothers and sisters. You can learn more about this program on their website (**www.siblingsupport.org**), as well as help parents locate a Sibshop near them. If your community does not sponsor Sibshops, you might consider collaborating with families, educators, adults with disabilities, and other community citizens to start a Sibshop program. Meyer and Vadasy (2007) have published a workbook on the steps for developing a Sibshop in your own community. An evaluation of the Sibshop program with school-age siblings found that siblings were able to talk more about the positive and negative aspects of having a brother or sister with a disability and they were able to identify more specifically how their sibling's disability affected their life in four areas: school, home, play, and the future (D'Arcy, Flynn, McCarthy, O'Connor, & Tierney, 2005). McCullough and Simon (2011) found that sibling support groups connected siblings to friends and mentors who had similar experiences. The siblings supported each other in advocating for their needs within the family.

An especially helpful way to become sensitive to sibling issues is to listen to sibling perspectives. Siblings can be invited to IEP conferences or to discussions with teachers or related service providers outside of the IEP conference. Another possibility for gaining information is to read the perspectives of siblings that are often provided in the newsletters of family organizations.

Establishing Balance: Cohesion and Flexibility

Family therapists have identified two dimensions in establishing balance in family relationships: cohesion and flexibility. Cohesion is the emotional bonding that family members have toward one another (Olson & Gorall, 2006). Balanced families (i.e., high cohesion and high flexibility) tend to experience greater satisfaction with their family system than unbalanced families (i.e., low cohesion and low flexibility) (Olson, Gorall, & Tiesel, 2007). Not only does family cohesion directly predict family satisfaction, but it also significantly alters the original relationship between family stress and family satisfaction (Lightsey & Sweeney, 2008). Thus, when families experience strong cohesion, stress is no longer a strong predictor of family satisfaction. Family cohesion mediates this relationship, acting like a buffer between the two.

So what can educators do to enhance family cohesion? One way that families can experience greater cohesion is to understand the value of each family member's contributions to the family's well-being and the importance of that person's insights in the family decision-making process. Educators could ask families to describe how certain programs would affect their family well-being and routines (e.g., positive behavior support, circle of friends). Educators could also enhance family cohesion by ensuring that all family members (e.g., Isabella's aunt, uncle, and cousin) are active participants in the decision-making process.

Because Isabella's aunt and uncle are also her godparents and would be responsible for her care if anything should happen to Mr. and Mrs. Gonzalez, including them in long-term planning, such as through a MAPS process (see Chapter 3), would be appropriate.

To help families experience a balanced life instead of one that is singularly focused on the child with the disability, you may connect them with community resources, refer them to professionals to address immediate concerns, and help their child build a social support network. Help families learn not only to rely on each other but also to reach out for supports to maintain balance in their lives. If you recall Ms. Campbell's comments in Jamal's opening vignette, she indicated that her body and mind are tired; she is unsure of how much longer she will be able to keep up her level of advocacy to ensure that Jamal continues to receive appropriate services.

Although she has support from her extended family, she still feels guilty about asking for assistance because she knows that everyone has his or her own life, too. When Ms. Campbell lost her dad, she kept a lot of her emotions in check so that she could support her mother. After all, her mother was also grieving from the loss of her husband, and Ms. Campbell did not want to burden her mother with additional stress.

How might educators support Ms. Campbell and her family during such a difficult time? A teacher might work with the school counselor to locate resources and books not only for Jamal but also for his siblings to help them cope with the death of a close family member. The educator also might refer the parent or siblings to virtual peer support groups on the internet, where the older siblings could talk with other peers who are coping with the death of a family member. Finally, the social worker might spend extra time with Jamal at school to help him use his communication board to express his feelings about the death of his grandfather and to develop a story about appropriate ways for dealing with his feelings.

Family flexibility is "the quality and expression of leadership and organization, role relationship rules and negotiations" (Olson, Gorall, & Tiesel, 2007, p. 2). Many families establish interaction patterns. For example, a mother may assume responsibility for bathing, dressing, feeding, and toileting a child with severe physical disabilities. This pattern may become so ingrained that she is unable to leave town for a vacation or a visit with extended family or even to have a break from these duties. If the mother is ill or an emergency arises, a family crisis related to parents' roles is likely to occur. One way to help families achieve successful interactions is to encourage them to develop an array of alternatives and options consistent with their cultural values.

For families who believe that it is too much trouble to teach others how to care for their children, you might be able to persuade people who are willing to provide caregiving to come to your classroom for tips from you on how they might best provide support. This would prevent parents from having to provide this orientation for those who might be able to help them.

Family Functions

Families exist to serve the individual and collective needs of their members. Attending to family functions is one way to characterize how families serve their needs. Figure 2–4 highlights these functions and some of the tasks performed by family members to meet them.

Family functions are not independent of one another. One function may facilitate another function, such as when a family member's participation in recreational activities leads to increased socialization and increased self-esteem from mastering a new hobby. On the other hand, one function may impede progress in another function area. For example, economic hardship may affect a family's ability to meet routine care needs (e.g., nutrition, transportation, health care), in turn impinging on a parents' or child's self-esteem.

A son or daughter with a disability can affect a family in negative, neutral, and positive ways. In the next two sections, we highlight the effects on the economic and socialization functions of families. For a thorough discussion of all family functions, see Turnbull, Turnbull, Erwin, Soodak, and Shogren (2015).

Economic Needs

All families must have income and a way to spend the money earned to meet food, clothing, shelter, and other needs. The presence of a son or daughter with a severe disability can create excess expenses (Parish, Rose, & Swaine, 2010). Some of the devices and services for a child with a severe disability may include adaptive feeding utensils; special clothing; lift-equipped vans; bathroom adaptations, such as support and safety bars; ongoing medications required for seizures and other physiological or psychological needs; and adaptive mobility devices, such as walkers and crutches. Many of these devices also require ongoing servicing and periodic replacement. Even families fortunate enough to have the best health insurance coverage find that the cost of buying and maintaining many adaptive devices and medical services is not fully covered. Mrs. Gonzalez comments,

> *Isabella will be nine years old soon, and we feel that she would be a good candidate for a power wheelchair; however, our insurance company will only pay for a manual chair, even with multiple requests and notes from her doctor. We desperately want her to keep up with her friends at school and a power chair would give her more independence. We know that she has the determination to learn to use a power chair, but we struggle to pay our bills some months, and purchasing a power chair is only an option for rich people.*

The economic impact on families varies with the nature and extent of the child's disability and, of course, with the family's own resources. Because Mr. Gonzalez works in housing construction, when the housing market is good, the Gonzalez family feels secure; however, these past few years have been quite difficult. The costs associated with providing for the needs of one family member can limit the funds available for the other family members. Parents and other family members may forgo

FIGURE 2–4
Family Functions and Tasks

1. *Affection:* Developing intimate personal relationships, expressing sexuality, giving and receiving nurturance and love, and expressing emotions
2. *Self-esteem:* Establishing self-identity and self-image, identifying personal strengths and weaknesses, and enhancing belonging and acceptance
3. *Economic support:* Generating income and handling family finances, paying bills, earning allowances, and handling insurance matters
4. *Daily care:* Purchasing food, preparing meals, providing health care, maintaining the home, providing transportation, and taking general safety measures
5. *Socialization:* Fostering individual and collective friendships, developing social skills, and engaging in social activities
6. *Recreation:* Developing and participating in hobbies or clubs, setting aside everyday demands, and going on vacations
7. *Education:* Participating in school-related activities, continuing education for adults, doing homework, providing for career development, and developing a work ethic

attending to their own needs in order to afford services for the child with a severe disability. Family members may become resentful, particularly siblings who might not understand the financial responsibilities of maintaining a household. Parents may know that a child could benefit from the purchase of a special piece of equipment and not be able to afford it, like the power wheelchair for Isabella.

The presence of a family member with a disability may prevent parents from obtaining employment because of the level of care and supervision required. Employment outside of the home for mothers of children with disabilities may help mitigate stress and depression (Morris, 2014). In 2012, it was estimated that more than 46.5 million families live in poverty, which represents about 15% of the U.S. population (DeNavas-Walt, Proctor, & Smith, 2013). The largest source of support for families whose members have disabilities is Title XIX of the Social Security Act, Home and Community-Based Services (HCBS) (Braddock et al., 2013). HCBS funding enables families to exercise control over how HCBS funds are spent. Studies consistently report that families who receive HCBS funding have high levels of satisfaction and an increase in quality of life (Heller, Factor, Hsieh, & Hahn, 1998; Timberlake, Leutz, Warfield, & Chiri, 2013). Understanding how to help families access HCBS funding to pay for items such as respite care, personal attendants, therapies, and adaptive medical equipment can help alleviate some of the financial burdens associated with raising a child with a disability. Both the Gonzalez and Campbell families would benefit from respite services through Medicaid HCBS, and Isabella might be able to obtain a power wheelchair. In addition, they should go to the websites of their Parent Training and Information Centers to find out about the state family support resources available, as well as any other programs that provide financial resources to families. The local Social Security Office can provide information about eligibility criteria for receiving Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Consider identifying appropriate community contacts and providing parents with the names and telephone numbers of persons to contact regarding estate planning, disability benefits, or family subsidies, and encouraging parents who have been successful in obtaining financial resources or who have completed financial planning to provide assistance to other parents who have financial questions (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015).

Socialization Needs

Often, professionals tend to focus on developing academic and behavioral skills for their students. However, parents are often disappointed that their sons and daughters with severe disabilities have limited friendships. Children with disabilities, like Jamal, have social impairments that severely affect their ability to develop meaningful friendships. Including socialization goals on students' IEPs is one way to address this need. An increasing number of studies guide educators toward effective teaching methods (Koegel, Kuriakose, Singh, & Koegel, 2012; Stichter, O'Connor, Herzog, Lierheimer, & McGhee, 2012). For example, peer models could help Jamal increase his social initiations and social responses.

> *One of Jamal's teachers noticed his keen interest in football so she contacted the parents of two students in Jamal's class, who also love sports, to ask if their children could be peer models for Jamal in a more formal way. After the parents and students gave consent, Jamal's teacher provided them with some training that included information about autism strategies they can use to increase Jamal's social interactions in a variety of school settings (e.g., classroom, lunch, class transitions).*

Carter and colleagues (2013) provide a step-by-step guide on how to expand the peer networks of students with severe disabilities in schools by implementing a peer buddy program. These steps include (a) soliciting support from administrator and faculty; (b) identifying students with disabilities and peers; (c) identifying school personnel to facilitate the peer buddy program; (d) determining network meeting logistics and holding meetings; and (e) encouraging social connections outside of meeting time,

reflection on the program, and maintenance of established peer network. Webster and Carter (2007) conducted an extensive review of studies examining social relationships and friendships in children with and without developmental disabilities, and concluded that while this is an under-investigated topic, there are several important findings to consider. One study in their review (Freeman & Kasari, 2002) investigated the characteristics and qualities of playmates of children with Down syndrome who were similar in chronological age and gender but did not have a disability, and found that the play was more responsive and interactive in the dyad of playmates in which age and gender were matched as compared to the play of dyads in which chronological age and gender were not matched. A second study in their review (Lee, Yoo, & Bak, 2003) reported that 33% of children without disabilities participating in the study indicated the opportunity to spend time with a peer with a disability as the most important factor in developing friendships. Additional responses from the peers regarding their perspectives of factors contributing to friendship formation included teacher encouragement to help and understand a child with a disability (17%), their willingness to teach or help a child with a disability (11%), and closer placement to a child with a disability (11%).

You should be cautious about peer relationships. What can seem like friendships for children with severe disabilities are really helping relationships (e.g., peer tutoring and monitoring of behavior). Despite research indicating that having peers in helping or academic support roles are useful ways to initiate friendships, you should evaluate whether the characteristics of true friendships are also present in these relationships. Friendships typically revolve around companionship (e.g., going places together, participating in school activities, engaging in sports and activities), emotional support (e.g., tending to feelings, expressing affection and caring, enhancing self-esteem), and instrumental support (e.g., providing information, practical help, or advocacy) (Turnbull, Blue-Banning, & Pereira, 2000). You also can encourage parents to consider how to foster friendship.

> *Mrs. Gonzalez has made it a point to invite children from their neighborhood to their house to spend time with Isabella and to develop a friendship with her. She teaches the children a few basic Spanish words so that they may connect with Isabella from her own cultural perspective.*

Not all parents have the time to orchestrate friendships for their child with a disability, as Mrs. Gonzalez does. Therefore, you should brainstorm about the many different settings and individuals who would be available to facilitate friendship development. A broad range of people can be friendship facilitators, including general and special education teachers, related service providers, paraprofessionals, family members, community citizens, and classmates. Many teachers have used the "Circle of Friends" approach with success for students with disabilities (Thousand, Villa, & Nevin, 2002). Circle of Friends (**http://www.circleofriends.org/**) is a social skills training approach used to encourage friendships between students with disabilities and their peers without disabilities. Approximately 80% of the studies included in a review of research about Circles of Friends showed an improvement in attitudes and acceptance, and a smaller number (19%) showed improvements in knowledge of people with disabilities (Lindsay & Edwards, 2013).

From a family systems perspective, it is important to recognize that although you may perceive friendships to be very important, families may have other priorities. In some situations, families may also believe that friendships are important but may have no unclaimed minutes in which to take on one more responsibility.

Family Life Cycle

Families differ in characteristics, and those differences influence interaction patterns that affect the family's ability to meet its functional needs. Each family changes as it goes through the stages and transitions of the family life cycle. Two dimensions of the family life cycle are (a) life-cycle stages and (b) life-cycle transitions.

Life-Cycle Stages

The family life cycle has been described as a series of developmental stages that are periods of time in which family functions are relatively stable (Carter & McGoldrick, 2005). Researchers and theorists disagree concerning the number of life-cycle stages that exist. Some have identified as many as 24 stages, although others have identified as few as 6 (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2015). The number is not as important as the tasks that families are responsible for accomplishing at each stage. Six of the stages are (a) birth and early childhood, (b) elementary school years, (c) adolescence, (d) early adulthood, (e) middle adulthood, and (f) aging.

Many tasks facing the families of adolescents are different from those facing the families of preschoolers, as the Campbell family illustrates. Now that Jamal is in middle school, he is also about to change physically and perhaps emotionally. The impending changes raise discomfiting issues. Who, for example, will teach him about the changes in his pubescent body and appropriate times for private moments? What roles are appropriate for educators with respect to his adult physical changes? In middle school, Jamal has many more teachers; luckily, he has two male teachers. How might they be included in educational planning meetings? How might Jamal's uncle also be included in these discussions? These are sensitive issues for both the school and the family, but they are life-cycle needs that must be addressed given Jamal's past inappropriate behavior in school.

Table 2–1 identifies possible parental issues encountered during the first four life-cycle stages, which are the stages in which families and educators have the most contact.

Inclusion. Although some families' tasks and issues tend to be stage specific, others permeate all stages. An example of the latter is advocating for inclusive experiences. Many families strongly favor inclusion and are the major advocates for their children in obtaining inclusive experiences starting during the early childhood stage and continuing throughout the life span (Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010).

For Ms. Campbell, inclusion is a very important issue. She continues to work hard to ensure that her son has the supports he needs in order to be included as much as possible with his peers without disabilities.

TABLE 2–1
Possible Parental Issues Encountered at Four Life-Cycle Stages

Life-Cycle Stage	Possible Parental Issues
Early childhood (ages 0–5)	Obtaining an accurate diagnosis Informing siblings and relatives Locating support services Clarifying a personal ideology to guide decisions
Elementary school (ages 6–12)	Establishing routines to carry out family functions Adjusting emotionally to implications of disability Clarifying issues of inclusive practices Participating in IEP conferences
Adolescence (ages 13–21)	Adjusting emotionally to possible chronicity of disability Identifying issues of emerging sexuality Addressing possible isolation and rejection by peers Planning for career and vocational development
Adulthood (from age 21)	Addressing the need for preferred living situations Adjusting emotionally to adult implications for intensive support Addressing the need for socialization opportunities outside the family Initiating career choice or vocational program

As inclusion advocates, families often invest tremendous energy at each stage to access experiences that enable their children to be in, and benefit from, typical settings. During *birth and early childhood,* these experiences could include attending neighborhood and community playgroups and child care, and participating in community recreation programs designed for young children. During the *elementary school years,* families might focus on their child attending neighborhood schools' general education programs, and taking advantage of typical extracurricular activities such as Scouts and community recreation programs. During *adolescence,* participating in extracurricular activities consistent with preferences, and enjoying friendships and dating are some examples. Finally, some inclusion efforts families may consider in *early adulthood* for their young adult are supported employment, developing a home of one's own, and participating in community activities consistent with one's preferences.

Families who commit themselves early to inclusion and advocate for inclusive experiences across the life span often spend a great amount of time and energy educating others, making logistical and support arrangements, and troubleshooting when special issues arise. Educators who strongly favor inclusion are also advocates; their advocacy takes place primarily at the school level, educating general education teachers and related service personnel about the importance of integrating specialized instruction into typical settings to ensure that their students have opportunities to access the general education curriculum.

Self-Determination Skills. A second pervasive issue across the life span is development of self-determination skills. Self-determination consists of the following four essential characteristics: self-realization, self-regulation, psychological empowerment, and autonomous actions (Wehmeyer, 2007). These skills help children and youth with severe disabilities live their lives according to their own personal values and preferences. Although the major emphasis within the special education field has been on development of self-determination skills at the adolescent level (Test, Fowler, Wood, Brewer, & Eddy, 2005), the foundation of self-determination starts during the early childhood stage and evolves throughout the entire life span (Wehmeyer, 2014).

Some educators and families may be unsure of how to enhance their child's self-determination skills, particularly when children are young. Shogren and Turnbull (2006) provide the following practical strategies: (a) Place artwork and photos at the child's eye level, (b) create a private area that the child can call his or her own, (c) use routines to ensure predictability and consistency, (d) have a childproof area that allows for safe exploration so that the child can develop a sense of control over the environment, (e) allow for age-appropriate risk taking, (f) be careful to not overprotect the child with disabilities relative to his or her siblings and peers, and (g) set up social and environmental reinforcers for appropriate behavior (Shogren & Turnbull, 2006).

From the earliest years, families and professionals must clarify their values and priorities related to self-determination and recognize that its development is a long-term life-cycle issue (Palmer, 2010; Palmer et al., 2013). Clarification is important now for the Campbell family and Jamal's teachers; his entry into middle school is a good time to discuss these matters, especially because Ms. Campbell is already concerned about Jamal's future after high school but is unsure of how to proceed in planning for the future. While IDEA requires transition planning to begin when Jamal is 16 years old, it is still not too early to ensure that Jamal's current curriculum and IEP goals are preparing him to lead a self-determined life after high school graduation.

Life-Cycle Transitions

Transitions represent the periods of change as families move from one developmental stage to another. These stages are similar to plateaus but transitions resemble peaks and valleys that divide those plateaus. Because transitional times prompt changes in expectations and often in service systems, they typically are the times that families identify as the most challenging (Rous, Hallam, Harbin, McCormick, & Jung, 2007;

Winn & Hay, 2009; Ytterhus, Wendelborg, & Lundeby, 2008). These transitions may involve movement from the intensive care nursery to the home and community, from early intervention to preschool, from preschool to kindergarten, from elementary to middle school (as for Jamal Campbell), from middle school to high school, and from high school into adulthood. Transition is not culturally neutral.

> *In Mexican culture, la quinceañera is the celebration of a girl's 15th birthday to mark her passage from young girl to womanhood. The celebration also takes place in conjunction with a religious ceremony in which the young girl renews her religious vows to the Catholic Church (Pizarro & Vera, 2001). While this celebration is still several years away for Isabella, her mother has already mentioned the significance of this event for all young girls in her culture and says that Isabella will celebrate this life event as well.*

Educators can incorporate these special events within instruction. Lychner (2008) is a music educator; he provides several examples of how to celebrate students' multicultural heritage, including important life-cycle transitions, within the context of the classroom using music as a medium. Another example is to use children's storybooks and journaling exercises. Numerous children's texts teach students about important cultural life-cycle transitions. One text, in particular, *Remembering My Roots and Living My Traditions,* is a story about two young siblings who travel to their home country, Mexico, for the summer. One dialogue between the siblings tells the story about their attendance at their cousin's *quinceañera*. When Isabella is older, her teachers might also invite Mrs. Gonzalez to the classroom to share her story about her own *quinceañera* celebration.

Different cultures have various kinds of rituals that they consider important, such as baptism, first communion, bar or bat mitzvah, graduation, and voting. Because these rituals serve as symbols of ongoing development for the family, they help reorient family perspectives toward changes that are occurring throughout the transition. A special challenge for families who have a child with severe disabilities is that the child often does not have access to many of these rituals and therefore does not have the experience of transition. Educators can support families by encouraging and supporting the inclusion of their child in these rituals. (See Chapter 16 for a discussion of symbols of adulthood.)

Some families may believe that their children should not participate in certain family rituals because of their disability. For example, a mother may think that her child cannot benefit by having religious confirmation experiences. Perhaps you might convene parents whose children have been confirmed and parents who fear that the experience might be unrealistic for their child. Leaders in a religious community might not encourage parents because they may never have had the experience of including a person with a severe disability. Sharing resources with religious leaders or inviting them to the IEP meeting (of course, with parental consent) to learn about classroom adaptations might be a welcomed gesture to assist with adaptations in religious classes. Educators might also learn helpful tips from the religious leaders as well.

An excellent and inspiring example of a child's inclusion in religious confirmation experiences is the film documentary, *Praying with Lior* (**www.prayingwithlior.com**). This film chronicles the experiences of a child with Down syndrome during his bar mitzvah. On the website, educators will find a schedule for nationwide showings of this film. School districts and other organizations may also purchase the video for educational purposes to teach about inclusion and family dynamics. A key point is that many parents are led to believe that normal events are unrealistic for their children with disabilities. By telling them about other families' experiences, or referring them to books or web materials, you can help them abandon that notion.

There are many other ways that professionals can collaborate with families in enhancing successful transitions. Table 2–2 includes ideas for how professionals can help families improve their child's transitions.

TABLE 2–2
Approaches for Professionals to Enhance Successful Transitions

Early Childhood • Provide parents with resources and tips to assist with child separation anxiety (e.g., books parents can read to their child about the first day of school; leaving the child with others for short periods). • Provide information about various preschools in the community to assist parents with decision-making. • Encourage participation in "Parent to Parent" programs (**www.p2pusa.org**), in which veteran parents are matched in one-to-one relationships with parents who are just beginning the transition process.
Childhood • Provide parents with an overview of curricular options. • Ensure that IEP meetings provide an empowering context for family collaboration. • Encourage participation in "Parent to Parent" matches, workshops, or family support groups to discuss transitions with others.
Adolescence • Assist families and adolescents in identifying community leisure-time activities. • Incorporate into the IEP skills that will be needed in future career and vocational programs. • Visit or become familiar with a variety of career and living options.
Adulthood • Provide preferred information to families about guardianship, estate planning, wills, and trusts. • Assist family members in transferring responsibilities to the individual with the exceptionality, other family members, or service providers, as appropriate. • Assist the young adult or family members with career or vocational choices.

LEARNING OUTCOME SUMMARIES

2.01 Parent Rights and Responsibilities

Learning Outcome

Identify the connections between the six principles of the Individuals with Disabilities Education Act of 2004 and the rights and responsibilities of parents of students with disabilities.

Historically, family–professional partnerships have not been as positive and productive as they could have been. IDEA has established ground rules for both educational professionals and parents in their interactions with each other. Associated with each of the six major principles of the law—zero reject, non-discriminatory evaluation, appropriate education programs, least restrictive environment, parent and student participation in shared decision-making, and due process—are requirements for family–professional partnerships.

IDEA alone does not ensure collaboration among parents and professionals. Parents and educators alike must work within the guidelines to develop partnerships to meet families' individual needs and preferences. The preferred educational roles of the parents and other family members vary across families. Likewise, the level of involvement sought by different family members fluctuates.

2.02 Parent Training and Information Resource Centers

Learning Outcome

Explain the services provided by Parent Training and Information Centers and Community Parent Resource Centers.

Educators should assist families in becoming educational advocates to ensure that families are equal partners in making decisions about their children's education. To this end, Parent Training and Information Centers and Community Parent Resource Centers assist parents in learning the information necessary to meet their child's educational needs. It is important that educators seek out these training and information resource centers, and partner with the staff in addressing families' concerns, priorities, and needs.

2.03 Family Systems

Learning Outcome

Articulate the major elements of the family systems framework, and the implication of disability on each of these major elements.

Educators should view students within the broader context of family life. Student learning is not limited to skill development within the school context only; understanding the broader family system enables educators to provide services that meet the complex needs of today's students. Disability is an aspect of some families' characteristics that can add challenges but also many positive outcomes and experiences. A family systems perspective offers a framework for understanding the characteristics, interactions, functions, and life-cycle issues of families so that more effective service provision can be implemented.

SUGGESTED ACTIVITY: A TALE OF TWO FAMILIES

The Angelino Family

The Angelino family has five children and a sixth is on the way. The children are ages 14 (girl), 12 (boy), 10 (girl), 7 (boy), and 6 (girl). They all attend a nearby parochial school. Mr. Angelino owns a butcher shop that had been his father's and that was begun by his grandfather, who emigrated from Italy in 1904. The butcher shop at one time had upstairs living quarters for the family, but about 10 years ago the family moved into a large, Victorian-style house about a block away.

Mr. Angelino's youngest brother once came back from college with ideas about expanding the business and marketing the family's secret recipe for Italian sausage, but Mr. Angelino (the oldest son) decided against it because it would take too much time away from the family. He is fond of saying, "We are not rich, but we got a roof over our heads, food in our bellies, and each other. What more could we want?" This youngest brother is the only one in the family with a college education, and he is also the only one who scandalized the family by marrying a non-Catholic. Mr. Angelino uses his little brother as an example of the detrimental effects of "too much education."

Both Mr. and Mrs. Angelino come from large families; most of their brothers and sisters still live in the "Little Italy" section of this large eastern city. All grandparents are dead, with the exception of Mrs. Angelino's mother (Mama). Mama lives in the home with them and is very frail. One of Mrs. Angelino's brothers or sisters is sure to stop by nearly every day, bringing children, flowers, or food, for a visit with Mama. They often take Mama for rides or to their homes for short visits, depending on her health, and help with her basic care.

Life with the Angelinos can be described as a kind of happy chaos. Kids are always running in and out of the butcher shop, where the older brothers and male cousins are often assigned small tasks in return for a piece of salami or some other treat. The old house is always full of children—siblings and cousins—from teenagers to toddlers. Children are indulged until they reach age 9 or 10, at which time they are expected to begin taking responsibility, which is divided strictly along traditional gender-role lines. Child care, cooking, and cleaning are accomplished by the women—older sisters or cousins, aunts, or mothers. Evening meals are a social event. There is nearly always at least one extended family member or friend at the table, and everyone talks about the events of the day, sometimes all at once, except when Mr. Angelino has something to say, at which point everyone stops to listen. Mr. Angelino is obviously a very affectionate father, but he expects his word to be obeyed. Bedtimes, rules about talking at the table, curfews, and other rules are strictly enforced. This situation is beginning to cause conflict with the oldest daughter, who wants to date and spend more time with her friends from school. Mrs. Angelino is often sympathetic to her children's requests, but her husband has the final say.

All in all, life in the Angelino home is warm, close, and harmonious. Mrs. Angelino, as she approaches her eighth month of pregnancy with this last "surprise" child, shares her contentment with her priest: "I don't know what I have done to deserve so many blessings from the Good Lord."

The McNeil Family

Mr. and Mrs. McNeil have been married for two years, and she is expecting their first child. Mr. McNeil is the youngest partner in a prestigious law firm in a midwestern city.

Everyone considers him upwardly mobile and thinks that it is phenomenal that he achieved a partnership only five years out of law school. Mrs. McNeil has a degree in interior design. She worked full time for a while for a decorating firm in another city. After she married, Mrs. McNeil moved to this city, where she has a part-time, on-call job with an exclusive architectural firm. She has ambitions of starting her own business.

Mr. McNeil is an only child. His parents live on the East Coast. They are both successful in business—his father is a banker and his mother is a real estate broker. They have always demanded perfection from their son, and he seems to have lived up to their expectations. Mrs. McNeil has one younger sister. Her parents live on the West Coast. They are both professionals; her father is a college professor and her mother is a social worker. Mrs. McNeil's family has always been very close. She calls her parents about once a week, and the family occasionally has conference calls with the parents and the two siblings to decide some important issue or to relay some big news. Mrs. McNeil's parents place no demands on her except that she be true to herself. They often tell her how proud they are of her accomplishments.

Both sets of parents are experiencing grandparenthood for the first time with Mrs. McNeil's pregnancy. They are thrilled. It sometimes seems to the McNeils that their parents vie with each other over the gifts that they give them. The McNeils refuse the more extravagant gifts to make the point that they are indeed making it on their own, and they have discussed some strategies for disengaging themselves from so much contact with their parents.

The McNeils' avant-garde apartment is the scene of much entertaining with his law firm colleagues and her artistic friends and decorating clients. Although their social spheres overlap somewhat, each has separate groups of friends and pursues individual interests. They call this "giving each other space," and they consider it to be an important strength in their marriage. The McNeils believe strongly in supporting each other's careers and in sharing family responsibilities; they divide cooking and cleaning in a flexible manner, according to whoever has the time. They are also attending Lamaze classes together and are looking forward to sharing childbirth.

Exercise

The babies whom Mrs. Angelino and Mrs. McNeil are expecting will have severe cognitive and physical disabilities.

1. For both families, flash forward 5 years.
   a. It is January, more than halfway through the kindergarten school year, and the Angelinos are concerned that their son, Nico, is not benefiting from his education. He has not made progress toward his IEP goals and they have not seen much improvement in his academic or functional skills at home. With which IDEA principle does this issue most closely link, and what are the Angelinos' rights and responsibilities?
   b. It is the summer before kindergarten and the McNeils have found the perfect school for their daughter, Elle; however, the school has expressed their hesitation for including Elle in general education for most of the day. With which IDEA principle does this issue most closely link, and what are the McNeils' rights and responsibilities?
2. Explore information in your state/region regarding the availability of a Parent Training and Information Center and/or Community Parent Resource Center. What services are offered that you believe will be helpful to the Angelinos? What about the McNeils?
3. Use the family systems framework to predict the preferences, strengths, and needs of both families in terms of characteristics, interaction, function, and life cycle.
4. The Angelinos and the McNeils have different cultural values. How would you characterize the cultural values of each family? How do you think these cultural values influence what they consider to be appropriate self-determination for each of the parents (mother and father), as well as for their children with and without a disability? (Assume that the McNeils will have more children who do not have a disability.)