

PREFACE

The Families

We could not have written this book without the families whom we feature. They allowed us to enter their lives by telling us their stories. By telling their stories, they became our and our readers' teachers. They are forces for "the disability cause." But they are more than that: They are exemplars of all that is good, decent, generous, steadfast, and optimistic.

The Organization

Part I introduces the reader to the family systems theory. That theory undergirds our book because it not only explains the complexity of the lives of families affected by disability but it also simplifies our understanding of those families. Part II sketches the history of family-professional relationships and thereby provides the context for our discussion of today's relationships—what they are and what they should and can be. Part II also describes the two federal laws that govern special education services, emphasizing the special education law (Individuals with Disabilities Education Act). As the history chapter hints and the law chapter makes clear, disability is a civil rights issue, and IDEA is more than "just" a law about education: It is a law about equal opportunity for a full, enviable life. Part III introduces the seven principles that constitute the construct called partnership. It then emphasizes communication, one of the principles, and, in each of the following chapters, illustrates how educators should apply the principles. In a word, part III provides both theory (chapter 7) and practice (chapters 8 through 12); moreover, it does so in light of the family systems theory (part I) and consistent with the most recent stage of history and the law (part II).

Features of the Seventh Edition

The new edition retains the important aspects of the Sixth Edition in that it describes the family systems theory, the history and current status of policy, and the principles of partnership and their application by teachers and other professionals, plus cites of the most recent research, it also includes these features:

- To enhance affordability and portability the new edition is available as a Pearson eText. With the eText students can easily take and share notes, highlight, and search for key concepts.
- Each chapter begins by describing a student and the student's family and telling a short story about them in special education. Unlike previous editions, however, we do not provide the real names of the people in the stories. Nevertheless, you can be confident that the stories are based on fact. Only the names and places have been changed.
- In tribute to the extraordinary sacrifices military families make, chapters 7 and 8 tell about a family in the United States Marine Corps.
- In recognition of the multicultural nature of the United States, this edition features families from different ethnic and cultural origins. There are three Anglo-American

families—Robertson, in chapters 1 and 2; Turnbull, in chapters 5 and 6; and Brogdan, in chapters 7 and 8; an African-American family—Price, in chapters 3 and 4; an Hispanic-American family—Hernandez family, in chapters 9 and 10; and a Korean-American family—Park and Kim, in chapters 11 and 12.

- To give you a sense of the age diversity of students and families with whom you will be partners, this edition features a pre-school student—Steven Robertson, in chapters 1 and 2; a graduating secondary-school student—Leonard Price, in chapters 3 and 4; a man who spent his entire life in school in special education and graduated to integrated work and living—Jay Turnbull, in chapters 5 and 6; a child in elementary school—William Brogdan, in chapters 7 and 8; a secondary-school student—Maria Hernandez, in chapters 9 and 10; and an about-to-graduate student, Jisung Park, in chapters 11 and 12.

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PART

1

The Family Systems Perspective

The purpose of our book is to teach you how to be a partner with families who have members with a disability—especially those who are in special education!

As you will learn from chapters 1 through 4 and indeed the entire book, you can be an effective partner if you understand that families are systems. Whatever happens to one of the family members happens to all of them. A traditional metaphor to describe the family systems perspective is a mobile (Satir, 1972).

You will notice that the cover for our book includes an illustration of a mobile. That mobile has two purposes. First, it reminds you about what we said above: the family systems theory teaches us that whatever happens to one member of a family happens to all. Second, the mobile has seven elements, and

each has a name. These seven elements are the content of the family-professional partnership that this book teaches. You will encounter these seven elements in chapter 7 and then learn how to use them in chapters 8 through 12.

If you put one part of a mobile into action, you create motion in all of the other parts. That is how it is with families. The characteristics of family members (chapter 1), their ways of interacting with each other (chapter 2), the functions they perform for each other (chapter 3), and how they move through various stages of their lives (chapter 4) set the family system into motion, just like a mobile.

1 Family Characteristics



Steven, Ida, and John Robertson

"Steven is a rarity," says his mother, Ida. Consider the reason behind her statement.

Steven is 3¹/₂ years old. He is already a charmer of teenage girls and adults who cannot help but notice and then disregard his low muscle tone and speech limitations. What's the source of those limitations? A definitive answer was available only after he was a year old.

Until then, Ida wondered whether Steven's delays could have had anything to do with the fact that her older sister has an intellectual disability. Genetic testing and genetic counseling ruled out any connection between Ida, her sister, Steven's father, John—indeed, between any family member—and Steven.

But Steven's diagnosis and his parents' genetic workups did not occur until he was a year old. Would an earlier diagnosis have made any difference? Here, too, the answer is unclear. "I would have changed the way I interacted with Steven, but whether that would have made a difference, who knows," says Ida. "But I was clueless, a new mom. I had worked with preschoolers when I taught, but I had no experience with babies. I thought, 'Is it just me?' that Steven didn't

respond. When I made attempts to engage with him, it felt so unnatural and fake, but I didn't understand the real reason why. His low muscle tone and perhaps poor vision prevented him from engaging with me the way a typically developing baby would. He didn't respond, so of course it felt awkward making funny faces to what appeared to be an uninterested baby. If I had understood this, I would have attempted to engage him more."

Steven is not just a rarity. He also is a mystery. Why does he have this anomaly? And what difference does he make in his family? Undoubtedly, he makes a difference, but just how much of one is the still-to-be-answered puzzle.

Let's take a closer look at Steven's family. Both of his parents are university graduates. Financially successful in a large midwestern city, they grew tired of the fast-paced lifestyle and migrated to the West Coast.

Steven was born there, but the West Coast did not satisfy their taste. Free to live anywhere in the country, they chose the Southeast.

Once there, they realized that neither wanted to be a stay-at-home, full-time parent. That had nothing to do with Steven; each had a personality that would not be satisfied by that role. So, they enrolled Steven in a day-care center at a university-based child development research program.

Pleased with the program, they then enrolled him in its preschool. Both programs serve children with and without disabilities. Having taught preschoolers for a while, Ida became involved as a volunteer and

now is a part-time employee at the center. Steven has begun to affect her career. Not so with John.

Asked to characterize her family, Ida says it is a tightly knit extended family. Cousins feel more like brothers and sisters, and aunts feel like second mothers.

By contrast, John's parents are divorced and remarried, so there are two sets of grandparents, along with several great-grandparents. They too live far away from John and Ida.

How to sum up the Robertson family? By definition, John, Ida, and Steven are family by reason of marriage and blood. Their size is three; there are no immediately involved grandparents, uncles, or aunts. Their form is nuclear; they live together. Their cultural background is Anglo-American. Their socioeconomic status is mixed: They are highly educated, they were professionally and financially successful in two cities, but they live modestly now.

What This Chapter Will Offer You

The story about the Robertsons tells about the characteristics of their family as a whole. It tells about each family member as an individual and about Steven and his unique circumstances as a child with a disability. The Robertsons are our guides in this chapter. Here, you will learn about families' characteristics—the characteristics of a whole family, the characteristics of its individual members, and the unique circumstances that families present to professionals. At the end of the chapter, you will revisit the Robertsons and review what you learned about families' characteristics.

Introduction

Let's begin by acknowledging that families are like a mobile: whatever happens to one member affects all. Steven's disability undoubtedly affects his parents, but it does not have the same day-to-day effects on his grandparents. If they lived nearer Steven, it may affect them more than it does now. This matter of cause and effect—when one part of the mobile moves, it causes others to move—means that a family is a system: what happens to one part of the system (the family) affects the other parts (members).

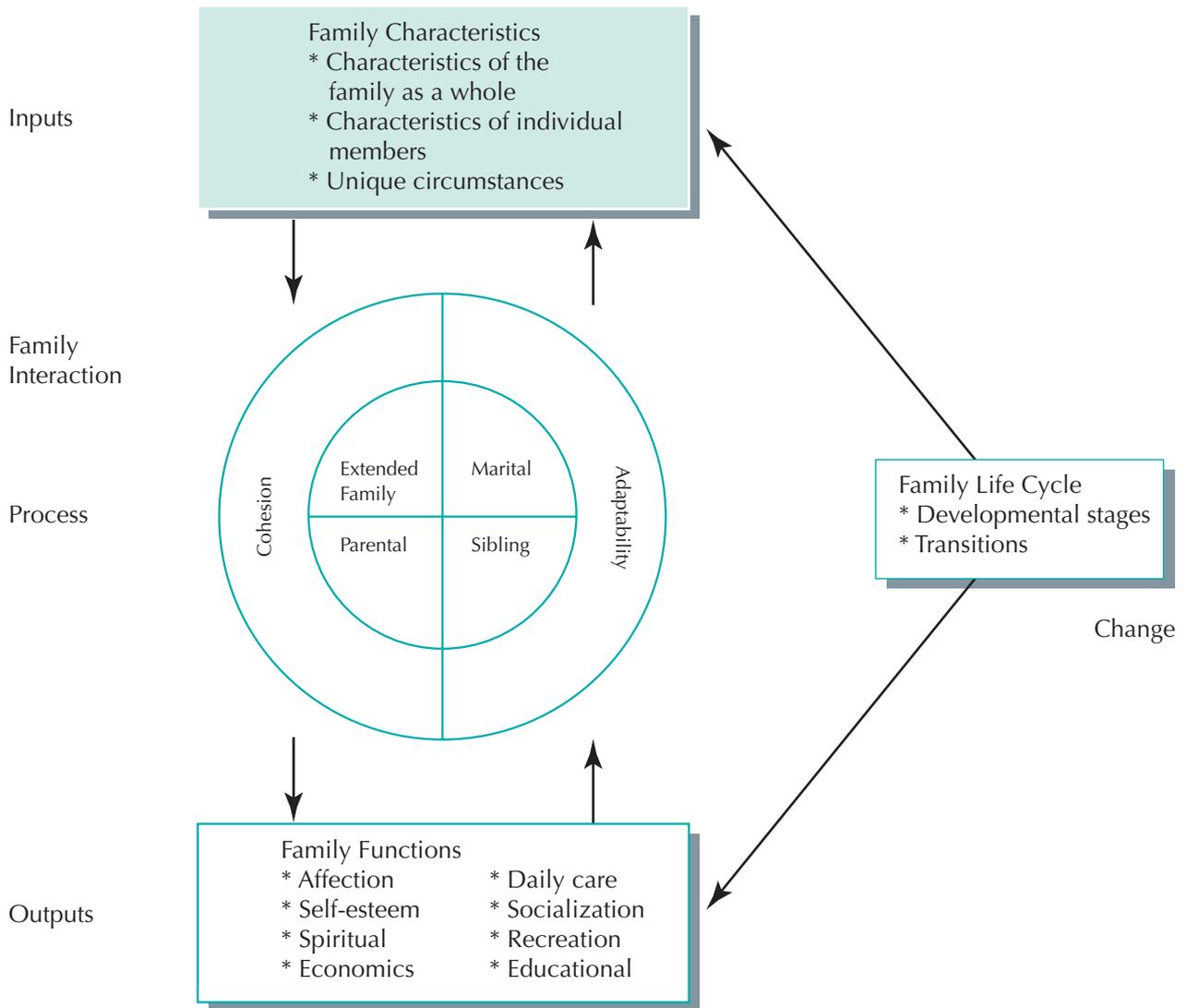
This chapter focuses on the first component of the family systems framework: the family's characteristics. Family characteristics are *inputs* into the family system. Figure 1.1 illustrates the family systems framework, highlighting family characteristics. These include

- the characteristics of the family as a whole,
- the characteristics of individual members, and
- the family's unique circumstances.

The characteristics of the family as a whole include its size and form, cultural background, socioeconomic level, and geographic location. In addition, each member of the family varies in individual characteristics related to exceptionality, coping styles, and health status. Finally, many families face unique circumstances such as economic hardships, homelessness, addiction to alcohol or drugs, abuse and neglect, exposure to violence and other fearful experiences, imprisonment, chronic illness, teenage parenting, and parenting with a disability. Every family is a distinct mixture of diverse characteristics.

Characteristics of the Family as a Whole

A family shares many characteristics as a single entity. Some of these characteristics are the family's size and form, cultural background, socioeconomic status, and geographic location.

FIGURE 1.1 Family systems framework: emphasis on family characteristics

Family: Definition, Size, and Form

Family Definition. Before discussing family size and form, let's think about a definition for the term *family*. The U.S. Census Bureau defines a family as consisting of two or more people (one of whom is the householder) related by birth, marriage, or adoption residing together (U.S. Census Bureau, 2011). Does this definition fit how you define your own family? Do all of your family members live in the same household? Are all the members of your family related by birth, marriage, or adoption?

The U.S. Census definition does not always fit our experiences with families. It may not fit yours, either. As a professional, you will encounter people who define *family* by including individuals who do not share the same household or are not related

by birth, marriage, or adoption. They are using a “functional definition”—describing a family according to whether people function as a family. That is our approach, too. Here is our definition:

Families include two or more people who regard themselves as a family and who carry out the functions that families typically perform. These people may or may not be related by blood or marriage and may or may not usually live together (Poston et al. 2003, p. 79).

Size and Form. Each family’s size and form depend on its own definition of family. Family size and form can be as exclusive as the Census Bureau’s definition or as inclusive as ours. Family size and form refer to the number of children, number of parents or caregivers, presence and number of stepparents or stepchildren, number of live-in family members who are unrelated by birth or marriage, and the involvement of the extended family.

Data from the 2010 U.S. Census reveal that approximately 19% of all people living in the United States had a disability. Approximately 8% of children under age 15 years have a disability (Brault, 2012). The child’s disability and health status, may change over time and can influence a family (Wei & Yu, 2012).

The impact of a child’s disability on the family can vary, depending on the family’s size and form. In large families, more people are often available to help with chores and specialized supports and resources needed by the child with a disability. Other children in the family can remind parents that their child with a disability is more like than unlike his or her brothers and sisters and that all children have various combinations of strengths and needs.

It is often assumed that a child with a disability creates severe strain in marriages. Some research does suggest that a child with a disability can increase marital stress (Meadan, Halle, & Ebata, 2010; O’Hare & Swick, 2012), but this is not always the case. Risdal and Singer (2004) analyzed all the research on marital adjustment in parents of children with disabilities and found that the research does not support the assumption that children with disabilities “cause severe family strain in almost all families” (p. 101). Neely-Barnes and Dia (2008) drew similar conclusions from the literature, noting that marital challenges do exist in some families but that many families find positive meaning in raising a child with a disability.

Having a child with a disability has had a positive influence on our marital relationship. . . . As a result of our child with a disability, my husband has become [*sic*] more considerate of me. . . . He now routinely shares housework with me to decrease some of my stress. (Huang, Ososkie, & Hsu, 2011, p. 222)

Families come in many shapes and sizes. You are certain to work with people whose parents are single as a result of death, separation, divorce, or choice. Although it is not the case for all single-parent households, many face economic challenges.

- Single female-headed families (31%) were more likely to live in poverty than single male-headed families (16%) or married households (6%) (DeNavas-Walt, Proctor, & Smith, 2012).
- Children living in female-headed households were four times as likely to live in poverty as compared to children in married households (Children’s Defense Fund, 2010).
- Roughly 69% of children living with a single parent were considered low income (Addy & Wight, 2012).

- Approximately 80% of all long-term poverty exists in single-parent families (Rector & Sheffield, 2011).
- African American children who are poor are considerably more likely than White or Hispanic children to live in a single-parent home (Seith & Kalof, 2011).
- According to recent data, there are almost 9 million women and children in the United States receiving WIC (Supplemental Nutrition Program for Women, Infants, and Children) (Children's Defense Fund, 2012).
- Single mother-headed families that include a child with a disability are significantly more likely to live in poverty than married households including a child with a disability or single mother-headed households that do not include a child with a disability (Parish, Rose, Swaine, Dababnah, & Mayra, 2012).

Economic challenges compound the usual challenges of being a single parent of a child with a disability.

I'm lonely. I don't have a partner, and it's hard to be a single mother when you have a child with autism. It's hard to be a single mother anyway, but when you have a child with special needs, it just, it's hard to get a break. (Nealy et al., 2012, p. 194)

Keep in mind that not all single-parent families struggle. Even two-parent families can struggle. In married households with children with and without disabilities:

- Almost 1 in 10 families living in rural and urban environments live in poverty (Mattingly & Bean, 2010).
- Approximately half of all children in married households, whether the household includes a child with a disability, are considered low income (Addy & Wight, 2012).

Family size and form often change over time. A different pattern of family size and form—more than two parents—exists when one or both parents in the original family have remarried or chosen to be with new partners. The new blended family may include children and extended family members from two or more previous marriages or relationships. Each blended family takes on their own form over time.

- Children may have to abide by different rules in two different households, adapt to two different lifestyles, or surrender the adult roles they may have assumed while their custodial parent was single.
- Stepparents may be uncertain about their authority, and children may regard their acceptance of a stepparent as a sign of disloyalty to their biological parent.
- Parents may not have the privacy or time to establish their new relationship because they have a ready-made family from the first day of their marriage or partnership.
- Negotiations among all the adults—the former and current spouses—may be necessary to resolve conflicts about the children and visitation schedules, discipline, lifestyle, and so on.
- On the positive side, a wide circle of interested family members may be able and willing to support each other and the member with the disability. As a result, a blended family can offer an expanded and rich pool of resources and support.

Many children live with neither their adoptive nor biological parent. Over 400,000 children are in the foster care system (Children's Defense Fund, 2010, 2012). Approximately 2.7 million grandparents are raising their grandchildren, and almost 20% of them experience poverty (Children's Defense Fund, 2012).

Be sure to take into account how these families, as well as single-parent, cohabitating-partner, or remarried families, make decisions about a child's education. When the adults convene, they may engage in an amiable discussion about the child's best interests. Or they may create a family power struggle, requiring you or other professionals to mediate differences and state what you believe is best for the child. You may want to consult the school social worker or school counselor for suggestions on how to support the family in especially challenging situations.

Cultural Background

Cultural Considerations and Identity. Just as your own cultural background influences what you value, how you think, and how you behave, each family will also be highly influenced by their cultural backgrounds. If you accept this statement as a fact, then you may ask, "What does the word *culture* mean?"

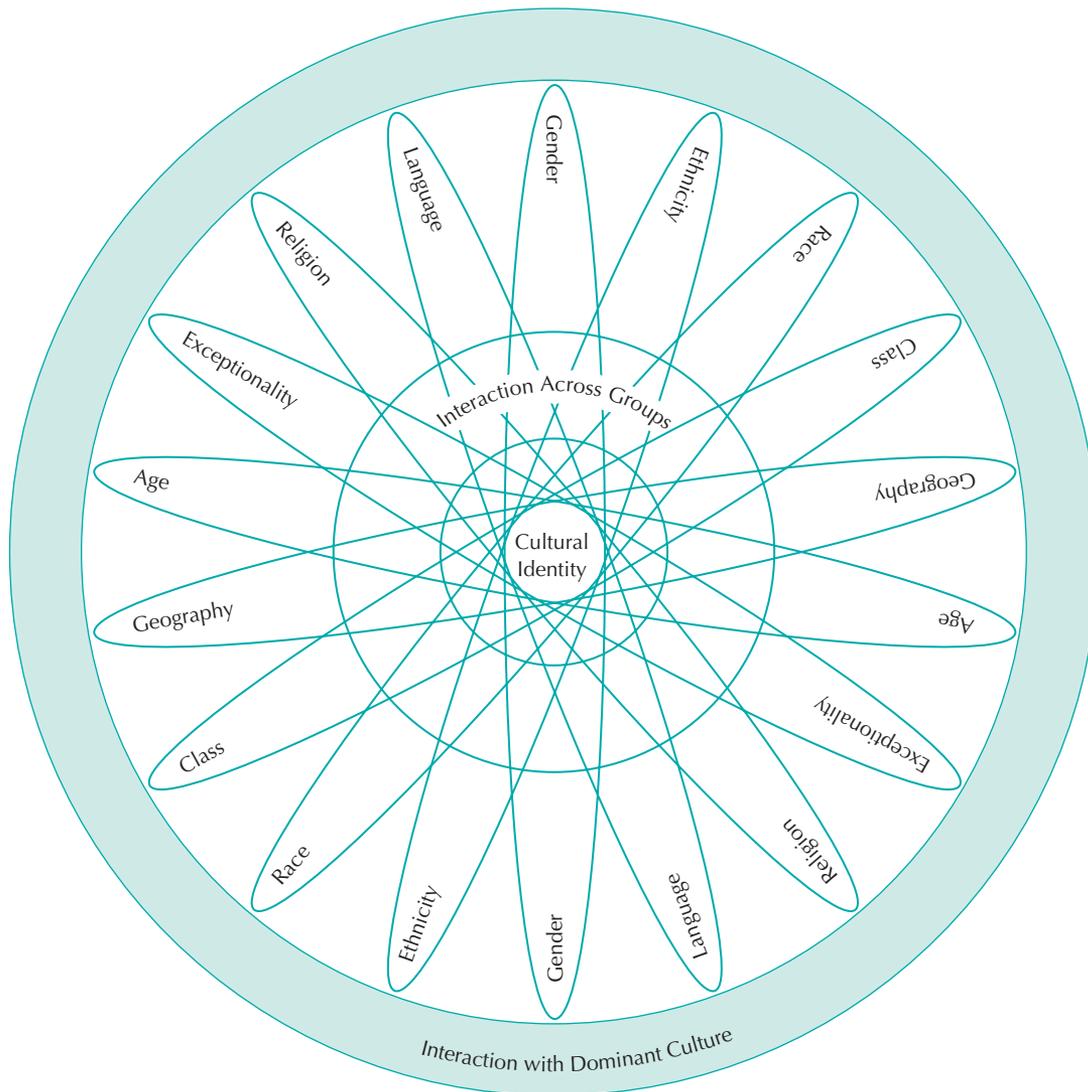
The term ***culture*** refers to the foundational values and beliefs that set the standards for how people perceive, interpret, and behave within their family, school, and community. Culture has traditionally been viewed through a limited lens with a focus on race, ethnicity, and national origin (Gollnick & Chinn, 2002). A broader perspective of culture emphasizes that culture is shaped by multiple factors, including but not limited to language, gender, geography, religion/spirituality, and experiences with disability.

This broader perspective approach suggests that culture is not only dynamic and continually changing but it is also personally and contextually determined. Under it, you will need to understand the experiences of each family and how they define their personal cultural identity. Each family is always developing new understandings and experiences (e.g., behavior, artifacts, and rituals) that enable members of the family to thrive (Rueda & Stillman, 2012). Indeed, "learning about one's own and others' cultures [is] a lifelong process—a journey with many destinations" (Lynch & Hanson, 2011, p. xv).

All of the factors that define a family's cultural identity are sometimes called *microcultures* or sociocultural influences (Gollnick & Chinn, 2002; Lynch & Hanson, 2011). Figure 1.2 illustrates several microcultures.

- *Spirituality and religion* influence beliefs, traditions, customs, and holidays that families value and thus the appropriateness of your communication with them concerning holiday events, schedules, and rituals.
- *Language* influences all aspects of communicating with families, especially when families do not speak English at all or with limited proficiency or are unable to read in English or any other language.
- *Gender identity* influences beliefs about the roles and ways that various family members should take in communicating with professionals.
- *Race* influences how discrimination may be experienced if families perceive they are not treated with equality or respect; negative experiences can foster skepticism about trusting others of a different race.
- *Ethnicity* influences whether people think they belong or whether they experience isolation or exclusion as outsiders in schools, particularly when they are of diverse ethnicity.
- *Age* influences the experiences family members have, as in the case of teenage mothers or grandparents who suddenly find themselves with parental responsibilities.
- *Geography* poses certain opportunities and barriers to partnerships, such as in rural settings when families live a long distance from school without public transportation.

FIGURE 1.2 Cultural identity shaped through microcultural groups



- *Socioeconomic status* influences the resources available to families and the extent to which their housing, daily living needs, medical care, well-being, and nutrition are adequate.
- *Education level* influences the types of jobs available and the personal experiences family members have with schools.
- *Disability* influences one's perspectives of cultural affiliations and the ways in which individuals or families identify themselves, such as in *Deaf culture*.
- *Migration and time of arrival* impacts on family adjustment of their experiences depending upon when and how arrival into this country occurred.

These “inside the family” characteristics shape a family’s beliefs, practices, and lifestyles and in turn how the family wants or can be a partner with professionals. But there are

“outside the family” influences such as the sociopolitical climate that can influence a family’s sense of comfort and safety if they live where discrimination, violence, distrust, and racism exist.

Your “take away” from learning about culture is simple:

- Make no assumptions.
- Consider that these microcultures may change over a family’s life span as the family develops new understandings and experiences (chapter 4).
- Treat all families as you would want to be treated.
- Treat families consistently with the law (chapter 6).
- Use best practices (chapters 7 through 12).

Racial/Ethnic Composition of Special Education. The National Center for Education Statistics reports that children with disabilities ages 3 through 21 constitute approximately 13% of the entire population of schoolchildren (Aud et al., 2012). As the cultural landscape of the United States continues to change, the White population, which represented about 80% of the total population in 1980, decreased to 66% in 2008 (Aud, Fox, & KewalRamani, 2010). This has led to changes in the demographic profile of students receiving special education services. Figure 1.3 sets out the percentages of students receiving special education services according to different racial/ethnic groups and categories of disability. Here are some notable findings:

- The largest disability category across all racial and ethnic groups is children with specific learning disabilities.
- There is disproportionate representation of some racial and ethnic populations in certain disability categories. For example, African American children are almost twice as likely to receive special education and related services under the label of intellectual disability than all other students. They are also more likely to be identified as having an emotional disturbance (U.S. Department of Education, 2011).
- American Indian/Alaska Native and Black (non-Hispanic) students (ages 6 through 12) are more likely to be identified as having a disability and served under IDEA than students in all other racial/ethnic groups combined (Aud et al., 2010).

What explains these data, particularly the data on the overrepresentation of students with disabilities from certain racial/ethnic groups? One explanation is that there has been a history of exclusion, disproportionality, and discrimination within special education against students with disabilities who are from culturally and linguistically diverse backgrounds and their families. Exclusion refers to barring or banishing a student from school; disproportionality refers to more students of a minority/diverse background in special education than the percentage of those students in the entire school population; and discrimination refers to denying equal opportunities to education solely on the basis of racial/ethnic group or disability.

Disproportionality and discrimination continue to affect school-age children (Fiedler et al., 2008; Harry & Klingner, 2006; McHatton, 2007; Sullivan, 2011; Sullivan & Artiles, 2011). Families who experience poverty often live in communities that lack resources for schools (National Research Council, 2002; Silverstein, Lamberto, DePeau, & Grossman, 2008).

- A higher percentage of African American, Latino, and American Indian/Alaskan Native students attend high poverty schools (Planty et al., 2009).

In a study of cultural beliefs and practices with families (Eberly, Joshi, & Konzal, 2007), one African American teacher noted,

As a Black child, I was told I was stupid by teachers. Sometimes teachers say some ignorant things to parents, and they don't even realize it. I didn't realize that my son was getting so many negative messages from that school. He came out thinking terrible stuff about Black people, and he's Black. (p. 17)

There is also the issue of underrepresentation for children from culturally and linguistically diverse backgrounds who need special education services. Young children are less

FIGURE 1.3 Disability distribution of students ages 6 through 21 receiving special education and related services under IDEA, Part B, by race/ethnicity: fall 2008

Disability	American/Indian Alaska Native	Asian/ Pacific Islander	Black (non- Hispanic)	Hispanic	White (non- Hispanic)
Specific learning disability	53.3	38.4	44.8	56.6	44.1
Speech or language impairments	16.3	26.2	14.4	18.6	20.2
Mental retardation	7.4	8.6	14.9	7.6	7.9
Emotional disturbance	8.0	4.4	11.0	4.9	7.9
Multiple disabilities	2.0	2.7	2.2	1.7	2.3
Hearing impairments	1.0	2.8	0.9	1.5	1.1
Orthopedic impairments	0.7	1.6	0.8	1.2	1.1
Other health impairments	6.4	5.8	6.9	4.7	10.1
Visual impairments	0.3	0.8	0.4	0.5	0.4
Autism	1.3	6.6	2.0	1.7	3.1
Deaf-blindness	!	0.1	!	!	!
Traumatic brain injury	0.4	0.4	0.3	0.3	0.4
Developmental delay	3.0	1.5	1.3	0.6	1.3
All disabilities ^a	100.0	100.0	100.0	100.0	100.0

Source: Office of Special Education and Rehabilitative Services, Office of Special Education Programs (2011). *30th annual report to Congress on the implementation of the Individuals with Disabilities Education Act, 2008*. Washington, DC: author.

^aTotal may not sum to 100 because of rounding.

likely to be represented in early intervention or early childhood special education if they are from lower socioeconomic status households or from families where English is not the primary language (Morgan, Farkas, Hillemeier, & Maczuga, 2012).

To address the issue of disproportionality within the special education system, Fiedler and colleagues (2008) suggest using a checklist to promote the use of culturally responsive practices school-wide and in inclusive classrooms—those in which students with and without disabilities are educated together. They suggested asking whether the principal has encouraged the faculty to have an attitude that all of the students are the staff's responsibilities and to discourage an attitude that some students are the responsibility of some, but not all, of the staff.

Immigration and Families with Limited English Proficiency. Immigration trends and the English proficiency of families and students strongly influence diversity in schools. As the following numbers suggest, the immigrant population in this country continues to grow, and many immigrant families face financial challenges.

- In 2010, data from the U.S. Census revealed that the legal and illegal immigrant population in the United States had reached its highest number at 40 million immigrants (Camarota, 2011).
- From 2000 to 2010, 14 million new immigrants settled in the United States, which represented the highest decade of immigration in this country (Camarota, 2011).
- In the United States 57% of immigrant-headed households that included a child under 18 years accessed at least one welfare program, in part because of low education levels. It is important to note this does not correspond to an unwillingness to work since 95% of these households with children did have at least one adult worker (Camarota, 2011).
- Approximately 61% of children of immigrant parents live in low-income environments, compared to 41% of children of native-born parents (Addy & Wight, 2012).

Specific to language, the number of school-age children for whom English is not the primary language continues to grow.

- The number of school-age children who spoke a language other than English at home almost doubled from almost 5% in 1980 to 11% in 2009 (Aud et al., 2011).
- Of the 2.7 million school-age children who spoke a language other than English at home, 73% spoke Spanish, 13% an Asian/Pacific Islander language, 10% an Indo-European language other than Spanish, and 4% another language (Aud et al., 2011).
- In 2010, there were approximately 4.7 million English language learners who attended public school in the United States (10%) compared to 3.7 million students (8%) in 2001 (Aud et al., 2012).

There are visible roadblocks in the educational system facing students and families from culturally and linguistically diverse backgrounds. “Racial disproportionality is not the only cultural challenge in special education; disproportionality is also associated with language proficiency” (Turnbull, Turnbull, & Wehmeyer, 2010b, p. 79). Although teachers may experience challenges when communicating with families for whom English is not a primary language, they can find creative ways of interacting. One Head Start teacher explained it this way:

The most frustrating part of my job is when a parent comes to either drop off or pick up [a child] and I cannot talk with them. So what we do in my classroom, I use the program Boardmaker . . . they [Boardmaker] have a picture for just about everything you can come up with and what's nice is you can set it to different languages and I have set it to Spanish. So if I have a picture out, I can go over and point to the picture or carry it with me. (Worthington et al., 2011, p. 56)

Many families of children with disabilities who have limited English proficiency identify communication as a barrier to developing trusting partnerships. Research with Latino parents has consistently suggested that challenges with communication because of limited English proficiency affect the extent to which educators provide appropriate supports and information to students and families (McHatton, 2007; Puig, 2012; Salas, 2004). Research with Chinese (Lai & Ishiyama, 2004; Lo, 2008) and Korean (Kim, Lee Youngsun, & Morningstar, 2007) families reached similar conclusions.

In addition to language proficiency, one overlooked issue is loss of language—the discontinued use of a native language. The “loss” phenomenon has affected Native American students and their families more than any other racial or cultural group (Turnbull et al., 2010b).

Clearly, many complex issues affect language proficiency and partnerships. Imagine a scenario in which one of your students is struggling with her school work. You know she speaks a language other than English at home, but she speaks English at school and you assume her family has some understanding of English. You also know, however, that her family recently settled from another country. You are eager to meet them. They arrive at the school for a parent night scheduled by the school. At parent night, you learn for the first time they do not understand or speak English and arrangements for an interpreter have not been made. What would you do? You might consider rescheduling a meeting and inviting an interpreter so you can start building a partnership with the family.

You will want to have a toolbox of different strategies. Some professionals will need to have access to interpreters or become multilingual (Al-Hassan & Gardner, 2002). A cultural mediator will also be helpful in building positive relationships with families. Cultural mediators “translate between the culture of the school environment and the child’s family in order to enhance understanding, share information and create a relationship that supports families as full participants in the assessment process, and delivering educational services” (Colorado Department of Education Special Education Services Unit, 2011). You will also want to:

- Honor cultural diversity by working to develop your own cultural competence. Cultural competence extends far beyond merely using interpreters, although this is one helpful resource.
- Show respect for the cultural community in which the family belongs.
- When communicating with parents who do not speak English, do not use jargon and technical terminology (e.g., when referring to a particular assessment procedure or professional support service or device) unless absolutely necessary.
- When communicating through interpreters, limit your comments to a few sentences so there is ample time for the interpreter to translate your ideas to the family. Periodically check in with the family to determine that they understand your meaning and to determine the accuracy of the translation.
- Start with an introduction of all the participants, including the interpreter, at the beginning of the meeting and clarify each person’s roles, expectations, and the agenda for the meeting.
- Speak directly to and look at the family (not the interpreter) during a conversation.
- Know the difference between an interpreter, who translates one spoken language to another, and a translator, who translates written documents from one language to another.

Differences in Values. Language and communication issues are not the only factors that affect your relationships with families. Families’ values also shape their personal culture. Some families may adopt an *individualistic perspective*, and other families may adopt a *collective perspective*. Some families will have less confidence in *system-centered solutions* than in *relationship-centered solutions*.

Specific value orientations often are linked with certain racial or ethnic groups. For example, the values of collectivism have been ascribed more to Asian and Latino cultures than to European American culture. But be careful about making broad assumptions that link specific values with racial and ethnic categories. The demographics of the United States are changing rapidly and “the cultural values of young Americans are becoming more similar” (Vargas & Kimmelmeier, 2013, p. 209).

Individualism Versus Collectivism. The most dominant racial/ethnic microculture in the United States is European American. Generally, this microculture has valued individualism, self-reliance, early achievement of developmental milestones, and personal control over one’s own environment (Hanson, 2011; Harry, 2008).

This individualistic perspective is a fundamental premise of special education (Kalyanpur & Harry, 1999). As you will learn in chapter 6, federal policy requires that special education instruction focus on *individual* outcomes. Students with disabilities have individualized education programs that identify their current individual levels of performance and then specify future goals and objectives. Likewise, a state-of-the-art curriculum emphasizes self-determination—autonomy and decision making (Wehmeyer, 2002). Values will influence not only what the family wants for their child’s curriculum, but also whether the family chooses to be a partner actively engaged with professionals or to defer to professionals.

In contrast with the individualistic perspective, a *collectivist* perspective values the group more strongly than the individual (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Kalyanpur & Harry, 1999). Some scholars hold that, among African Americans, a group orientation is often valued over private gain (Goode, Jones, & Jackson, 2011; Logan, 2001; Willis, 2004). One African American immigrant father shared his thoughts about the community’s responsibility for children’s well-being:

In a childcare center, there are many people who are always keeping an eye on your child, and this is similar to what happens back home where every adult in a neighborhood is responsible for the well-being of the children in that neighborhood. (Obeng, 2007, p. 262)

Other scholars hold that, in Asian cultures, individuals are often expected to have family and clan, not individual members, as a central focus of their lives (Chan & Lee, 2004; Shogren, 2011). Similar expectations are thought to exist among Middle Eastern families (Sharifzadeh, 2011).

What is the relevance of individualism and collectivism for developing trusting partnerships with families? There are three implications—one affecting process, another affecting curriculum, and a third affecting the outcomes of education (Frankland et al., 2004).

- With respect to process, some families may regard individualized education programs as contradictory to their orientation of collective, cooperative, and mutually reciprocal priorities.
- With respect to curriculum, some families may not be interested in their child’s accomplishing developmental milestones or specific academic tasks if the accomplishment singles out their child for special attention, acclaim, or recognition.
- With respect to outcomes, some families may be far more interested in having their children learn skills for taking care of the home and elderly family members rather than acquiring skills to work in the private or public sectors of the economy, where productivity for profit or efficiency are the goals.

System-Centered Versus Relationship-Centered Approaches. Some families, often those from a European American culture, expect solutions for disability-related problems to be system based; that is, they expect solutions to be guided by federal and state policy and to be implemented at the state and local levels. It is no surprise that this value is

reflected in the legal underpinnings of special education (Lalvani, 2012; H. R. Turnbull & Turnbull, 1996; Zirpoli, Wieck, Hancox, & Skarnulis, 1994).

Members of many diverse racial/ethnic groups, however, regard personal relationships, not policies and procedures, as the bases of decision making (Lynch & Hanson, 2011; Shapiro, Monzo, Rueda, Gomez, & Blacher, 2004). For example, Alaska Native families who have a child with a disability told researchers that they wanted professionals to take time to understand their way of life (Ryan et al., 2006).

In the Inupiaq culture, family means parents, brothers, sisters, as well as extended family members, such as grandparents (often elders), uncles, aunts and cousins. Professionals are not merely working with a particular child and his or her parents; they are forming a relationship with all the people who are a part of the child's life. (p. 15)

Similarly, Native Hawaiian culture emphasizes relationships with other people but also with the community at large, the land, and the spiritual world (Mokuau & Tauili'i, 2011). And Native American cultures strongly prize relationships with nature, especially those that promote a sense of harmony (Joe & Malach, 2011).

What does this mean as you seek to develop partnerships with families? For one thing, the legal and bureaucratic referral and evaluation process to determine whether a student has a disability, and the educational implications of that finding and of individualizing special education services (chapters 9, 10, and 12), may be culturally uncomfortable or inappropriate for families who approach their child's education from a relationship orientation. So it seems wise for you to:

- Spend a significant amount of time establishing genuine relationships with families before you and the family begin making educational decisions. This has major implications for your time—a rare commodity for many professionals—and your willingness to establish personal familiarity as the basis for trust. Whereas many European American professionals and families may be eager “to get to the bottom line” in a meeting, many families from culturally diverse backgrounds may prefer to spend much more time, especially up-front time, on building relationships.
- Establish personal relationships with all family members and consider inviting the family to ask its own friends—those who are inside its circle of support—to collaborate with you and the family in making decisions about the child's education. Not all meetings between you and a family member need to be two-way; rather, the family's other trusted partners—members of the family's cultural communities and tribes—can make valuable contributions to the family-professional partnerships that you want to establish (Frankland et al., 2004; Zuniga, 2004).

We have discussed two ways that values may differ, but many other variations occur within and across microcultures and cultures (Kalyanpur & Harry, 1999; Lynch & Hanson, 2011; Zhang & Bennett, 2003). You will learn about other cultural variations in chapters 2 through 12.

Bear in mind that some assumptions you may make about families' values—about the values they “should” have because they are from specific cultures—may not always be accurate. Some families may display traits not strongly associated with their assumed cultural practices. We caution you against making assumptions about a family solely on the basis of certain microcultures and to recognize each family's cultural diversity as a valuable and essential resource.

Socioeconomic Status

A family's socioeconomic status (SES) includes its income, the level of family members' education, and the social status associated with the occupations of its wage earners. In

order to meet their most basic needs, families must earn an income that is approximately double the federal poverty level; families who earn less than this level are considered low income (Addy & Wight, 2012).

Many children and families living in the United States face economic hardships:

- Out of the more than 72 million children under age 18 living in this country, 32 million (44%) live in low-income households, defined as income two times below the federal poverty level. Another 21% of children and their families live in poverty (Addy & Wight, 2012).
- The number of children living in low-income families continues to increase and recently the percentage of low-income children under the age of 18 years exceeded that of adults (Addy & Wight, 2012).
- Almost 30% of children who live in low-income families have at least one parent who works full time and year-round (Addy & Wight, 2012).
- Poverty rates for young children have been steadily increasing with 49% of children under the age of 6 years living in low-income families and 25% living in poor families (Addy, Engelhardt, & Skinner, 2013).

Clearly, a family's financial situation will have a major impact on their lives. As you learned when reading about cultural diversity, a strong relationship exists between the identification of children as having a disability and some racial/ethnic groups. Poverty also affects this relationship. Children from racially/ethnically diverse backgrounds are much more likely to be members of families with low income. Of children living in the United States under the age of 18 years:

- Black, American Indian, and Hispanic children represent a disproportionate number of children identified as low income. These groups collectively comprise more than half (54%) of low-income children. They are also more than twice as likely to live in a low-income family compared to White and Asian children (Addy & Wight, 2012).
- The rates of children living in poverty are 64% among children who are Black and 63% among Latino children compared to only 32% among Caucasian children (Addy et al., 2013).
- Although there are 406 billionaires in this country, a child is born into poverty every 32 seconds, and children are the poorest age group in the United States (Children's Defense Fund, 2010).
- The poverty rate is even higher for families who have children with disabilities (Fujiura & Yamaki, 2000; Wang, 2005).

Poverty and economic vulnerability typically do not occur in isolation; they are associated with a number of other demographic characteristics, including race/ethnicity, parents' education and employment, and family structure (e.g., single- or two-parent families or grandparent head of household) (Addy et al., 2013). For example, parents who have lower levels of education are at greater risk for living in poverty. About 85% of children whose parents have less than a high school diploma live in low-income families, and 65% of children whose parents have only a high school degree are low income (Addy & Wight, 2012). The number of children a family has can have an impact on parents' employment. For many parents, it is not possible to work and also take care of their children with and without disabilities. For others, working, parenting, and being partners with their children's teachers present a triple whammy. There are, however, teachers and parents from diverse or economically challenged backgrounds who establish partnerships and, in doing so, make parenting and working more manageable, as you will read in the Change Agents Build Capacity box.



CHANGE AGENTS BUILD CAPACITY

Jessica Hannebaum—The White Church Approach

White Church Elementary School in Kansas City, Kansas, begins every school year with “family advocacy days.” Consider that title. It’s not just a new name for “teacher-parent conferences.” It’s a signal that the entire faculty will advocate for not just the child but also the child’s family.

That’s certainly how Jessica Hannebaum worked with the families of two third graders who had significant behavioral challenges. The children were from families that differed by race and socioeconomic status. What made the families more like than unlike each other was their children’s extreme noncompliant behavior and the fact that each child used prescribed medication to help stabilize their moods and behaviors.

Recognizing that the parents of each child were well-educated professionals, she communicated often and directly, holding “Student Improvement Team (SIT) meetings” every four to six weeks, sending home daily “behavior logs,” and asking them if she and they agreed on priorities for their children. By making that inquiry, she demonstrated that she regarded them as equals—as people who knew about their children and could contribute to their education.

Although she was in her first year as a teacher, she proved her professional competence at the SIT meetings by quoting her mother, a special education teacher with over 20 years’ experience: “Begin each day with a positive outlook because every day starts with a clean slate.” Then she proved her competence by developing and making clear her policies, curriculum, interventions, and expectations. And, finally, she earned their respect by

saying, “I will do my best to help your child succeed in the classroom through behavior plans, but it takes your child’s and your cooperation outside the classroom to truly make an impact.”

To prove she was committed to the children and their parents, she spent extra time before and after school with the children and their parents. “I wanted to give extra attention to the students and prove to the parents I was committed to helping their children succeed.” She then added: “That’s how I gained their trust.” Of course, it’s also how she built the children’s and parents’ capacities to overcome very challenging student behavior.

Take Action!

- **Bring the parents into the child’s education** (as Jessica does). Parents and children have their own interactions at home; a child’s behavior at school is not always identical to his or her behavior at home.
- **As a rule,**
 - pay attention to how you communicate;
 - encourage your colleagues to create a school-based culture of advocacy;
 - prove you are professionally competent by using evidence-based approaches to resolve behavior challenges;
 - respect the child and his or her parents by talking about expectations and outcomes;
 - take the extra step to prove your commitment; and
 - expect their trust.

The impact of family income occurs not only at the student and family level but also at the school level. Schools are often characterized as low SES or high SES schools; as you will learn in chapter 6, the federal No Child Left Behind Act characterizes low SES schools as Title 1 or struggling schools. The National Research Council (2002) reports that

- Schools with a high concentration of children from low-income backgrounds have lower per-student expenditures and fewer experienced, well-trained teachers than schools with a higher concentration of children from middle-income and upper-middle-income backgrounds.
- Parent advocacy is less likely to occur in schools with a high concentration of students from low-income backgrounds.

In every relationship with families, including those from low-income backgrounds, we encourage you to demonstrate respect, be nonjudgmental, and recognize their unique

strengths and important contributions. In chapter 8, you will learn more about communicating with families, including those who experience poverty; in chapter 10, you will also learn how to help families connect with community agencies that can assist them in meeting their basic needs.

Of course, you also will want to be careful about making assumptions about families who experience poverty. You may hear that families at lower SES levels are less interested in educational partnerships. As a professional, you may find that to be true, for some families, even as it sometimes is for families who do not experience poverty. And you may find it not to be true about others.

In our experience, a family's SES is not a reliable indicator of its motivation or knowledge/skills to develop family-professional partnerships. Your role as a professional is to encourage predictable, nonjudgmental, and trusting partnerships that convey to all families regardless of SES that you respect them and recognize their strengths.

Geographic Location

As a result of the rapid growth of technology and increased mobility in most segments of society, regional differences are receding. But some regional patterns persist: Southern hospitality, Yankee stoicism, Midwestern conformity, and Western independence remain attributes of many families (McGill & Pearce, 1996). More than that, rural and urban factors significantly influence service delivery and family life (Butera, 2005; Darling & Gallagher, 2004; Ridgley & Hallam, 2006).

- According to the U.S. Census Bureau, more families in rural areas have a member with a disability than do families not living in rural areas (Brault, 2011).
- More students with disabilities receive special education services in rural school districts than do students in urban or large town districts (U.S. Department of Education, 2007).

It is often difficult for educators to provide appropriate services in the least restrictive environment when students are geographically far apart. Many school districts create consolidated (jointly operated) special education programs and transport students to them rather than dispersing the specialists across the school district's entire widespread area. Distance impedes opportunities for teachers and families to enter into face-to-face partnerships. Life in a rural environment also hinders the recruitment and retention of highly qualified teachers and other specialists.

For many families, just accessing the necessary services and supports can create hardships. In a study on low-income families from rural areas (Ridgley & Hallam, 2006), one mother noted, "We have mostly what we need, except when [our car broke down]. Our car messed up on us" (p. 137). Another family from the same study indicated challenges getting her daughter to the cardiologist, explaining that the family had to "come up with the gas money to get her to the doctor" (p. 137). Another family had to rely on bus service to get to a faraway city to see a specialist but often did not have the \$5 bus fare to get there. Other families don't have the funds to put a healthy meal on the table.

It is not necessarily that I am buying quality, I am buying what fits in my budget and it's cheap and it is in my budget, because I have got to stretch what dollars I have got.

It is not like convenience all in one store—it is where the coupons are. We start at Shaw's . . . then we cross the road to Save-A-Lot and then we stop at Mountain's Market, because the milk and the sandwich meat are cheapest there. (Yousefian, Leighton, Fox, & Hartley, 2011)

On the other hand, rural areas can often receive and provide social support through informal networks such as neighbors, churches, and civic/social organizations. Also, some formal systems are innovative: Some school districts use video- and teleconferencing to link teachers, specialists, and parents.

Urban areas have their own set of challenges and resources. The percentage of students receiving free or reduced-price lunches is highest in urban schools (35%) compared to suburban schools (24%) and rural schools (8%) (Association for Career and Technical Education, 2012). Among families living in urban areas, 22% are raising a child with a disability, compared to 13% of all families in nonurban areas (Wang, 2005). Also, families who lived in an urban area and had a member with a disability were more likely to live in poverty than families without a member with a disability. It is sometimes difficult to evaluate whether urban students have a disability, given the complex interactions of poverty, race/ethnicity, and limited English proficiency.

Urban school districts often struggle to recruit and retain qualified personnel, especially those skilled in working with families from diverse or minority backgrounds. Listen to high school urban students describe their experience:

Nikki said, “They don’t give us a math teacher for math.” Marcus said, “They’ll give you a security guard.” . . . Roland said, “There was a substitute that was calling us stupid . . . That was the third or fourth time this happened too.” (Taines, 2011, p. 423)

Further, living in a complex, energy-filled urban environment can make parent-professional partnerships difficult to create.

Jonathan Kozol, the well-respected advocate and activist on public education, visited 60 urban public schools for his book, *Shame of a Nation*, and concluded that conditions for inner-city children had actually grown worse since the Supreme Court’s ruling in 1954 in *Brown v. Board of Education*. It is not just urban education that is facing enormous challenges. Our country’s relatively low spending for children’s education continues to be dramatic and alarming. Consider what Marian Wright Edelman of the Children’s Defense Fund (2010) noted regarding our nation’s education:

The greatest threat to America’s national security comes from no enemy within but from our failure to protect, invest in, and educate all of our children who make up all of our futures. . . . In 2008, the highest-paid American CEO took home over \$100 million, an amount equal to the salaries of 2,028 elementary school teachers, or 3,827 Head Start teachers, or 5,275 child care workers . . . This fiscal year, the Department of Defense is scheduled to spend a total of \$683.7 billion [which calculates to] \$29,679.13 a second. Just one second of defense spending is more than a Head Start teacher earns in a year. (p. v–vi)

Although urban areas face complex challenges, they also may offer valuable resources for families. These include a wide variety of accessible and affordable services, a large and established system of public transportation, and culturally and linguistically diverse specialists and services.

Military families, migrant farm workers, construction workers, corporate executives, and others have jobs that require them to relocate frequently. How can you minimize the worries that often accompany a family’s relocation?

- Communicate with and secure records from the student’s previous school.
- Avoid asking routine family and medical history questions that are in previous school records except when the information you need is not in the records or when (and if) families want to retell their story.

- Offer relocated families a tour of the school their child will attend, describe its programs, and introduce the family and student to the staff and other families in the program.
- When working with families who have immigrated into the United States, determine their English proficiency and, if their English is limited, what their native language is and how an interpreter or other supports can be used to facilitate communication.
- Work to facilitate a smooth relocation for the family.

In describing family characteristics, we have emphasized how families are the same yet different. Their size and forms, cultural backgrounds, socioeconomic levels, and geographic locations each present unique challenges. We cautioned that you should not make assumptions about families based solely on their characteristics. And we pointed out the constant and underlying common themes in your effort to build partnerships with them:

- respect their values;
- try to understand the many issues they face, in addition to their child's disability;
- be creative as you try to capitalize on their strengths and resources; and
- be open to forming partnerships that address their greatest expectations.

Characteristics of Individual Members

The commonality and diversity of families persist when we take into account the individual characteristics of each member of the family. These personal characteristics include the child's disability and each family member's skills in managing life, mental and physical health, communication, and motivation. These characteristics can either strengthen or challenge the family as a whole. They can affect the family's response to disability in one of its members and the family's inclination and ability to be partners with professionals. Let's now address the characteristics of the child's disability and the life management skills of family members.

Characteristics of a Child's Disability

The family as a whole and each of its members respond to a family member's characteristics related to a disability. These characteristics include (1) the nature of the disability (e.g., is the student visually impaired?) and (2) the extent or degree of the disability (e.g., what types and intensities of support will the student need over time?).

Nature of the Disability. The nature of the disability influences the family's response to it. For example, the families of children who have medically complex needs often have to adapt their routines to provide continuous care. But families may experience challenges that are not necessarily related to the child but rather the demands related to taking care of the entire family. Over 40% of families taking care of a member with an intellectual or developmental disability reported unmet needs for activities such as arranging time outside of the home for errands or doctor appointments, managing finances, and managing the household (Anderson, Larson, & Wuorio, 2011). Families may have unique needs for illness-specific information, equipment, and financial assistance.

- Children with hearing impairments may need communication accommodations that may include interpreters or equipment such as special telephones and captioned television (Jackson & Turnbull, 2011).

- Families of children with emotional disorders, attention-deficit/hyperactivity disorder, head injury, and autism often seek information related to the child's problem behavior and appropriate responses to it (Baker et al., 2003; Fidler, Hodapp, & Dykens, 2000; Hastings & Brown, 2002; Stein, Efron, Schiff, & Glanzman, 2002).
- Families of children with autism may want emotional support and support with coping, relationships, and financial matters (Meadan, Halle, & Ebata, 2010; Nealy, O'Hare, Powers, & Swick, 2012).

Regardless of the type of disability, if the child has a problem behavior or the parents perceive children's behavior as challenging, the family undoubtedly will benefit if you or another professional can help minimize the problem behavior and teach their child appropriate behavior (Fenning, Baker, Baker, & Crnic, 2007; Turnbull & Ruef, 1997).

I had to quit my job. So I have a Master's degree and I'm delivering newspapers so that I'm available [for my son] because there are behavior issues. The school will call me by 1:00 on any given afternoon and I will pick him up. (Goudie, Havercamp, Ranbom, & Jamieson, 2010)

There is no clear-cut evidence that the particular nature of the disability alone predicts how parents, siblings, or extended family will respond and adapt to the disability (Blacher & Hatton, 2001). Regardless of the nature of the child's disability, each child creates unique circumstances.

If you assume that a disability invariably burdens a family, you would be wrong. Children and youth with disabilities continue to make their own positive contributions to their families (Durà-Vilà, Dein, & Hodes, 2010; Hastings, Thomas, & Delwiche, 2002; King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009; A. Turnbull, Turnbull, & Wehmeyer, 2010a; H. R. Turnbull & Turnbull, 1978). Indeed, many families have affirmed that their children with disabilities are sources of happiness and fulfillment. Moreover, they have reported stress and well-being levels similar to those of adults in the general population.

In a study examining mothers' experiences about having a child with Down syndrome, Lalvani (2008) suggests that mothers often resist society's negative messages about disability, insisting they are not totally overwhelmed and never have any fun because of their child.

Extent and Age of Onset of the Disability. The extent of the person's disability does not, in and of itself, always cause the greatest impact on a family. The extent and when the child acquired the disability—the age of onset—are often highly related. For example, the diagnosis of a severe disability in a newborn requires the parents to deal immediately with what typically is an unexpected shock. When, however, a disability such as an emotional disorder or a learning disability manifests itself later in a child's life, the parents may feel a sense of relief—the diagnosis may affirm that they have been justified to be concerned about their child, although this can vary from family to family as well.

Families may have to cope with a complex set of mixed emotions. Some families of a child with a learning disability, for example, may be confused and frustrated upon learning that their child, who appears capable in so many ways, indeed has a disability (Shapiro, Church, & Lewis, 2002). Others may be relieved to learn that there are reasons for the problems they have observed in their child and yet feel guilty for not identifying their child's disability earlier.

Another factor can be the gradualness or suddenness of onset. Often the families of children with learning disabilities have a gradual awareness that the child has unique needs. A very different circumstance occurs with a sudden onset such as a head injury resulting from an accident. In that circumstance, families are thrust immediately into the world of trauma and rehabilitation units and often receive highly ambiguous prognoses (Michaud, Semel-Concepción, Duhaime, & Lazar, 2002). These families often have to make a series of ongoing readjustments as their child's characteristics fluctuate.

Severe disabilities or exceptional and early-blooming talent are often more apparent than less severe disabilities or average or latent talent. An obvious disability may enable family members to accommodate readily to the child's unique needs; however, it may stigmatize the entire family and result in their social rejection. Mothers of children with Down syndrome reject societal reactions to and assumptions about the pain, struggle, and hardship associated with a child with a disability and suggested that life was more similar to families without children with disabilities (Lalvani, 2011).

Mothers also reported surprising negative reactions from their doctors upon birth such as, "This is a tragic day," "My heart is breaking," and "You really need to go home and think about how this could negatively affect the daughter you have now . . . and how it is going to affect your life." Instead mothers rejected these and other negative and biased perceptions of having a child with a disability.

I think my life is more rich than I would have imagined at that particular day. I always felt that we had excellent opportunities but it's more enriched. . . . And it's great. I always felt as if our life was going to be good. I never felt like it was going to be this good. (Lalvani, 2011, p. 286)

A family may develop a definitive understanding of the child's support needs when their child has a severe disability because the disability is more noticeable. When, however, a child has a milder disability, a family may feel confused since the child may not "look" like he or she has a disability. Also, a family may find its hopes change over time as the child progresses or falls back.

The nature of the student's disability and the age of onset greatly influence when a student receives special education services and the type of services schools provide. As you develop partnerships with families, we encourage you to

- be sensitive to how students' individual characteristics shape families' priorities, resources, and concerns;
- highlight the student's strengths and preferences, to prevent the child's disability from obscuring these and other characteristics; and
- take time to listen to family stories to understand the influence the child's disability may have had on the family.

Life Management Skills

The term *life management skills* refers to the techniques that people use to solve their problems (Scorgie, Wilgosh, & McDonald, 1999). Olson et al. (1983) identified five life management skills, and subsequent researchers have validated those findings:

1. *Reframing*: changing how you think about a situation in order to emphasize its positive aspects over its negative ones (Hastings & Taunt, 2002; Lin, 2000).

- “Picking up the pieces of our life’s puzzle and reworking it into a different” picture (Bailey, Skinner, & Sparkman, 2003).
2. *Passive or positive appraisal*: setting aside your worries (Thompson, Hiebert-Murphy, & Trute, 2013).

“I try not to worry about where Eric will get a job after he graduates from high school. I try not to think about what his adult life will be. It works best for me to just take a day at a time. There is no use getting all upset over something that is years away” (Poston & Turnbull, 2004).
 3. *Spiritual and/or religious support*: deriving comfort and guidance from your spiritual beliefs (Poston & Turnbull, 2004; Rallison & Raffin-Bouchal, 2013; Skinner, Correa, Skinner, & Bailey, 2001).

“We are told that love conquers all. This is so, even death. But faith makes bearable the otherwise unbearable” (Turnbull et al., 2010a, p. 37).
 4. *Social support*: receiving practical and emotional assistance from your friends and family members (Brown, Anand, Fung, Isaacs, & Baum, 2003; Kyzar, Turnbull, Summers, & Gómez, 2012).

“My parents—especially my mom—are supportive. Both of them have taken the time to learn more about the diagnosis, which I think has helped in their acceptance of it” (Hutton & Caron, 2005, p. 187).
 5. *Professional support*: receiving assistance from professionals and agencies (Romer, Richardson, Nahom, Aigbe, & Porter, 2002; Soodak & Erwin, 2000; Zions, Zions, Harrison, & Bellinger, 2003).

“I mean, I was like ‘information!’ I couldn’t get enough . . . just anything, everything . . . You find something, your first help . . . whatever it was that [makes you go] ‘Oh thank God, somebody can talk to me,’” (Resch et al., 2010).

We want to add a caveat about the term *life management strategies*. The professional literature typically uses the term *coping strategies* instead of *life management strategies*. Families, however, talk about coping less often than professionals. Also, *coping* typically refers to dealing with a crisis situation; many family challenges, however, occur daily and weekly (Scorgie et al., 1999). The words you use in your work—your professional terminology—can be barriers to your partnerships with families.

- Use terms that do not stigmatize families or suggest that they or their children “suffer” from some kind of pathology or that coping always is a heroic act, though in fact it sometimes is.
- Personalize strategies to match individual family member support needs. Family members vary in the number of life management strategies they use and in the quality or effectiveness of each strategy (Bailey et al., 1999; Lin, 2000; Scorgie et al., 1999). Within the same family, some members may have strong life management capabilities, and others may need much more support because their own capabilities have not yet developed fully.
- Think of life management capacity metaphorically. For each member of the family, “The end of the rope is the end of the rope, regardless of how long the rope is” (Avis, 1985, p. 197). Individual family members have ropes of differing lengths.
- Avoid judging one family member in relation to another or wondering why one finds a situation so problematic that another finds so benign. Remember, the length of everyone’s rope varies and depends on all the situations they are handling in their life. As a partner, regard yourself as a “rope lengthener,” supporting everyone involved (families, professionals, friends, and community citizens) so that they will increase their capacity to address and resolve their priority concerns.

In a nutshell, there are numerous influences that will have an impact on individual family members in different ways and these attributes should be taken into consideration when building partnerships with families of children with disabilities. You will want to be aware of the child's disability, including the nature, extent, and onset of the disability, as well as life management or coping strategies since family members will likely respond to these attributes in their own personal way.

Unique Circumstances

Families face challenges over and above a child's disability. Indeed, the presence of a disability may not be the family's most significant challenge. A family may experience addiction to alcohol or drugs, abuse and neglect, exposure to violence and other fearful experiences, imprisonment, and chronic illness. We use the term *unique circumstances* to refer to the experiences or conditions, separate from the disability, that are also influencing how family members interact (chapter 2), carry out their functions (chapter 3), and change across the life cycle (chapter 4). In this section, we will address some—homelessness, parenting with a disability, and teenage parents.

Homelessness

Earlier in this chapter you learned that poverty is closely associated with single female-headed households and students receiving special education services (Children's Defense Fund, 2012; Fujiura & Yamaki, 2000; Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008). Here are some additional facts about poverty:

- Each year over 1.6 million children experience having no place to live. The United States has the dubious distinction of the largest number of homeless women and children in the world among all the industrialized nations (National Center on Family Homelessness, 2011).
- Children are the fastest growing group of the nation's homeless population. More than 1.3 million children are homeless and 40% of the homeless population are families of young children (National Law Center on Homelessness and Poverty, 2009).
- Becoming homeless can often affect families who have not been living in poverty. As Gargiulo (2006) notes, "some economically advantaged families may also confront a loss of housing. A medical crisis, job termination or unexpected bills could easily push a family into homelessness" (p. 358).

There are many other reasons why families experience homelessness, including loss of income source, domestic violence, and emotional or physical crises.

Over the past three decades, Americans have invested tens of billions of dollars to prevent, reduce and end homelessness. In spite of these efforts and investments, homelessness continues to worsen. . . . the frustration that Americans are feeling toward homelessness is being misplaced toward the un-housed, rather than the systems that have failed both the housed and the homeless. . . . [resulting in] crimes of hate against the homeless (National Coalition for the Homeless, 2012, p. 1).

Children who are homeless often move from shelter to shelter, disrupting their school attendance (Institute for Children and Poverty, 2001). One study reported that approximately one half of children who are homeless have developmental delays compared to 16% of children who experience poverty but who have stable housing (Kelly, Buehlman, & Caldwell, 2000). These children also experience emotional and behavioral



MY VOICE

On Being Homeless, Latina, and a Single Parent

. . . and you are sitting there and it's like your whole world is flashing right before your eyes and you say things that you don't mean to say and you try to say them in a proper way, but it just don't come out that way. I walked out there crying, literally, eating my tears because here I have no money, am homeless, and I knew [my child] needed to be stable, somehow. And it took me so long to get where I am now, and if I didn't go back and talk to the head supervisor of the program and give him a piece of my mind, I wouldn't have gotten my section eight [subsidized housing]. They literally treat you like you're garbage. I'm not the first one to come out of that office crying. I've seen women come out of that place crying . . .

Take Action!

- **Consider accompanying mothers** such as this one to the welfare office to support them.
- **If you do accompany them**, you will demonstrate that you respect them and are willing to advocate for them. Respect and advocacy are two of the seven elements of an effective partnership, as you will learn in chapter 7.
- **If you cannot accompany them**, refer them to a school social-services professional who might accompany them or refer them to agencies or people who would.

Source: Excerpted from McHatton (2007, pp. 243–244).

problems three to four times more frequently than children in the general school population. Homeless children often face health hazards, emotional stress, and dirty and overcrowded living conditions; each may increase the risk that the child will not receive special education services (Jackson, 2004).

Developing partnerships with parents who are homeless poses unique challenges, but these are not insurmountable. A highly successful program in Tennessee provides training to parents, after-school tutoring at shelters, convenient and safe places where students can play, clothing, and school supplies (Davey, Penuel, Allison-Tant, & Rosner, 2000). Read one single mother's perspective about being homeless in the My Voice box. As a teacher, you might wonder how you will ever find the time to be an advocate, start a new program, or meet the unique needs of families who are homeless. Here are some strategies:

- Consider who among your professional colleagues could best address these special challenges.
- Begin by enlisting the help of school counselors (Strawser, Markos, Yamaguchi, & Higgins, 2000) and school social workers (Markward & Biros, 2001).

Parents with Disabilities

People with disabilities may choose to become parents. Of course, parents who have disabilities also have strengths, just as their children who have disabilities have strengths. Often the disability itself does not interfere with how the family functions. The disability may actually enhance the parent's understanding of the child as, for example, when deaf parents raise deaf children (Jackson, Traub, & Turnbull, 2008). "In many ways they could not be happier than they are now . . . what to others might seem a world of terrible isolation is in fact a world of contentment with its own vibrant language and culture" (Hewitt, 2000, p. 138).

It is estimated that there are between 4.1 and 9 million parents who have disabilities. Part of the reason for this wide discrepancy stems from multiple data sources and different

ways of defining disability. Approximately 4.1 million parents with disabilities have children under age 18 living at home with them (Kaye, 2012).

When a parent has a physical disability, the effects on your relationship with him or her primarily involve such logistics as providing accessible meeting rooms or perhaps communicating through the most accessible and convenient means. But logistics are only one issue. Typically, more women than men with intellectual disability are parents, and typically these parents tend to have two to three children. Holburn and colleagues (2001) reached the following conclusions (based on their comprehensive review of the research on parents with intellectual disability):

- Approximately one quarter of the children of parents with an intellectual disability will have an intellectual disability. When both parents have an intellectual disability, the risk doubles.
- Challenges in parenting tend to increase as children get older.
- Mothers with intellectual disability rarely abuse their children; most mothers with intellectual disability provide adequate care, although some may unintentionally neglect their children without supports.
- A parent's competence is influenced by his or her background and current life circumstances; particular strengths, needs, and future plans; and style of interacting with his or her children.
- The most successful programs for increasing parenting skills are home based, long term, and based on a partnership between the parent and a professional in which the professional teaches the parent how to plan and make decisions.
- Parents with intellectual disability often have other challenges, such as unemployment or underemployment, substandard housing, inadequate health care, and problems with money management.

Grown children who had been raised by at least one parent with an intellectual disability generally demonstrate resilience as adults (Booth & Booth, 2000). The availability of friends and family to assist the parent with intellectual disability is a key factor in achieving positive outcomes. The children have a close emotional bond with their parents, but a lack of services and supports often contributes to challenges and limitations experienced by the family.

To increase the likelihood of successful parenting by adults with intellectual disability, support programs have broken down each step of a child-care task and created line drawings illustrating each of the steps of the task analysis, manuals written at a the third-grade reading level or below, or audiotapes of the manuals. These programs also include home visits to facilitate parents' implementing the training materials. When these steps have been used, parents with intellectual disability learned 96% of the child-care skills they were taught and maintained 80% of those skills after the study ended (Feldman, 2004).

Teenage Parents

In the United States, over 9% of births and 20% of all nonmarital births were to female teens in 2010. Out of children born to females under the age of 20, approximately 88% were to unmarried teenagers (Solomon-Fears, 2012).

Parenting programs aimed at teenage mothers may be delivered in a group or on a one-to-one basis. They also vary in intensity and duration (Barlow & Coren, 2000; Barlow & Stewart-Brown, 2000; Coren, Barlow, & Stewart-Brown, 2003). Programs are offered in schools, homes, health clinics, and family support centers.

Overall, researchers conclude that parent programs for teenage mothers have produced positive changes in both parent and child outcomes. The most typical programs

appear to be group-based and offered over a 12- to 16-week span. Researchers speculate that a group setting enables teenage mothers to benefit from peer perspectives and support. A concern in many programs is the high dropout rate, ranging from about one third to nearly one half.

Almost all of the literature related to teenage parents of children with disabilities focuses on mothers, and very little attention is given to teenage fathers (Coren et al., 2003). You will want to develop successful partnerships with both teenage parents of children with disabilities. Many strategies apply to both mothers and fathers. DeJong (2003) suggests several ways to build trust with teenage parents:

- Work to ensure consistency in the professionals interacting with young children so that teenage parents can experience consistency and have someone to communicate with on a regular basis.
- Address the teenage parent's individual needs and concerns by scheduling regular opportunities to communicate.
- Provide teenage parents with the power and choice to increase the likelihood that they have some control in their lives.
- Assist teenage parents in practicing and managing their responsibilities to support them in developing more independence.
- Help teenage parents make plans and set goals to foster their child's enhanced development and well-being.
- Provide opportunities for teenage parents to be reflective, to enhance the likelihood that they learn to be sensitive, responsive caregivers.

We encourage you to read first-person accounts written by teenage mothers. Excellent sources include Gill (1997), Leff and Walizer (1992), Miller (1994), and Rose and Gallup (1998).

What will preschool, elementary, middle, and secondary school and then adulthood be like for Steven Robertson?

How will Ida and John and the Robertson "family mobile" move over time? How will their family interactions, the functions they perform for each other, and how they move through the various stages of their lives change over time? These questions beg an answer, one that awaits the future. There have been plenty of questions for the Robertson family in the past, and each has been answered. So the only safe answer for questions about the future is to let the future unfold as the past has unfolded, bit by bit. As it does, a family's views about disability and special education will shape and be shaped by events that the family can control and by some that the family cannot control.

Think about John and Ida's perspective of Steven's disability. How is this similar and different from the perspective you might hold as a professional?

When John discovered just how rare Steven's chromosomal abnormality was, he said, "We hit the

Revisiting Steven, Ida, and John Robertson

lottery. No, I really mean that. We hit the lottery with this kid."

Ida concurs. "As Steven develops into this beautiful person, we adore every aspect of him. He wouldn't be the same without those little slips in his genetic code. Parents always talk about how fast their children grow up, and, oh, how to cherish those younger years while they last. Well, our son is developmentally delayed, so we feel like we get to have a little extra time in the moment. I again think about my sister, and how she never really went through those rebellious teenage years. How lucky would I be if Steven turns out to be the boy who always loves his mother! Being a parent of a child with special needs is challenging, but I'm not in a position to say that it's harder than parenting any other child. It's different, and my guess is there are pluses and minuses on both sides."

WHAT THIS CHAPTER HAS OFFERED YOU

Let's take a look at the Robertson family in light of what you learned in this chapter. You can characterize them according to a traditional definition (married and child by the married man and woman); their size (three in the immediate family); their cultural background (Anglo-American); their socioeconomic status (well educated and upper to middle income); and their geographic location (southeastern).

You know about Steven's disability and how his parents use life-management skills by getting early education

for him and regarding him as the lottery prize in their life. You know that they have a unique circumstance: Steven has a disability, but the family is not homeless or likely to be so. And neither of the parents has a disability. So much for the Robertsons' characteristics. Now, what about their interactions, which are the second part of the mobile known as family systems?

2

Family Interaction



Steven, Ida, and John Robertson

How Steven, Ida, and John handle these changes will depend in large part on how they relate to each other. And they already have a pattern. Are they affectionate? “Yes!!” Ida emphasizes her answer. Do she and John regard themselves positively? By all means. “We have plenty of self-esteem and confidence, especially John. He has no problems going against the norm.”

Are they spiritual? As children, they were raised in different churches. At university together, they were agnostics. Now, they are on a spiritual journey, arising from an interest in yoga and eastern religions. This journey has helped to shape their commitment to live in the moment. They hope to pass this message on to Steven.

What about their family’s economics? Both parents had high-salaried jobs. Now they live a modest lifestyle.

They have struggled to figure out daily care for Steven. They have gone back and forth on the division of labor between themselves, and they finally have settled on seeking outside help with child care and preschool.

They socialize with friends of their own age, but Steven is not social with children his own age; he tends to play alone and is more likely to engage with adults.

“We are homebodies,” Ida says when asked about her family’s recreation. Steven likes the community pool and the beach at nearby lake.

As for education, two university degrees speak for themselves: Education is a value they share. They also value this for Steven; the day-care and preschool

You have learned about family characteristics, as exemplified by the vignette about the Robertson family, in chapter 1. It’s now time to learn about family interactions, the second element of family systems theory, also looking to the Robertsons as an example.

Ida is candid about herself and her family. More than a decade after graduating from university, she and John have already passed through several stages of their lives. They were children, adolescents, college students, friends, and professionals, and now they are married and have their son, Steven. What were their developmental stages? That’s not hard to detect; just read the previous sentence. What were their big transitions? Home to university was one; from there to the workforce another; marriage still another; and parenthood the most recent one. When Steven leaves his current program, he and they will experience yet another transition. Steven will not be in the infant-toddler category any longer; he’ll be a preschooler. Change has been a constant in their lives; it is inevitable.

programs at the nearby university include children with and without disabilities and bring researchers and their evidence-based interventions together with caring practitioners.

Think of the Robertson family as a system with subsystems, each consisting of many different interactions.

Now you're thinking in the "family systems" way. That's a good way to think. Keep thinking that way, with special attention to family interactions.

What This Chapter Will Offer You

In this chapter, you will learn how to develop partnerships with families to support marital, parental, sibling, and extended family subsystems. Finally, you also will discover what cohesion and adaptability are and how they influence family well-being, just as the Robertsons' tight binds within one system (parent-child) and their ability to adapt (to Steven disability and his transitions from one service system to another) affect their family's well-being.

Family Systems Theory

When you begin to work with families, you will notice how families (perhaps like your own) create subsystems; are more or less cohesive; and adapt well, poorly, or not at all to changing life circumstances. Just remember to look at them as a baby in a crib looks up at a mobile: An inert mobile is not nearly as fascinating as one whose every part moves when one part is activated in response to whatever external forces make it move.

Imagine that baby in the crib. She looks up and sees a toy above her. It is a mobile. She reaches out, touches one arm, and watches, fascinated, as each piece moves, not just the one she touched.

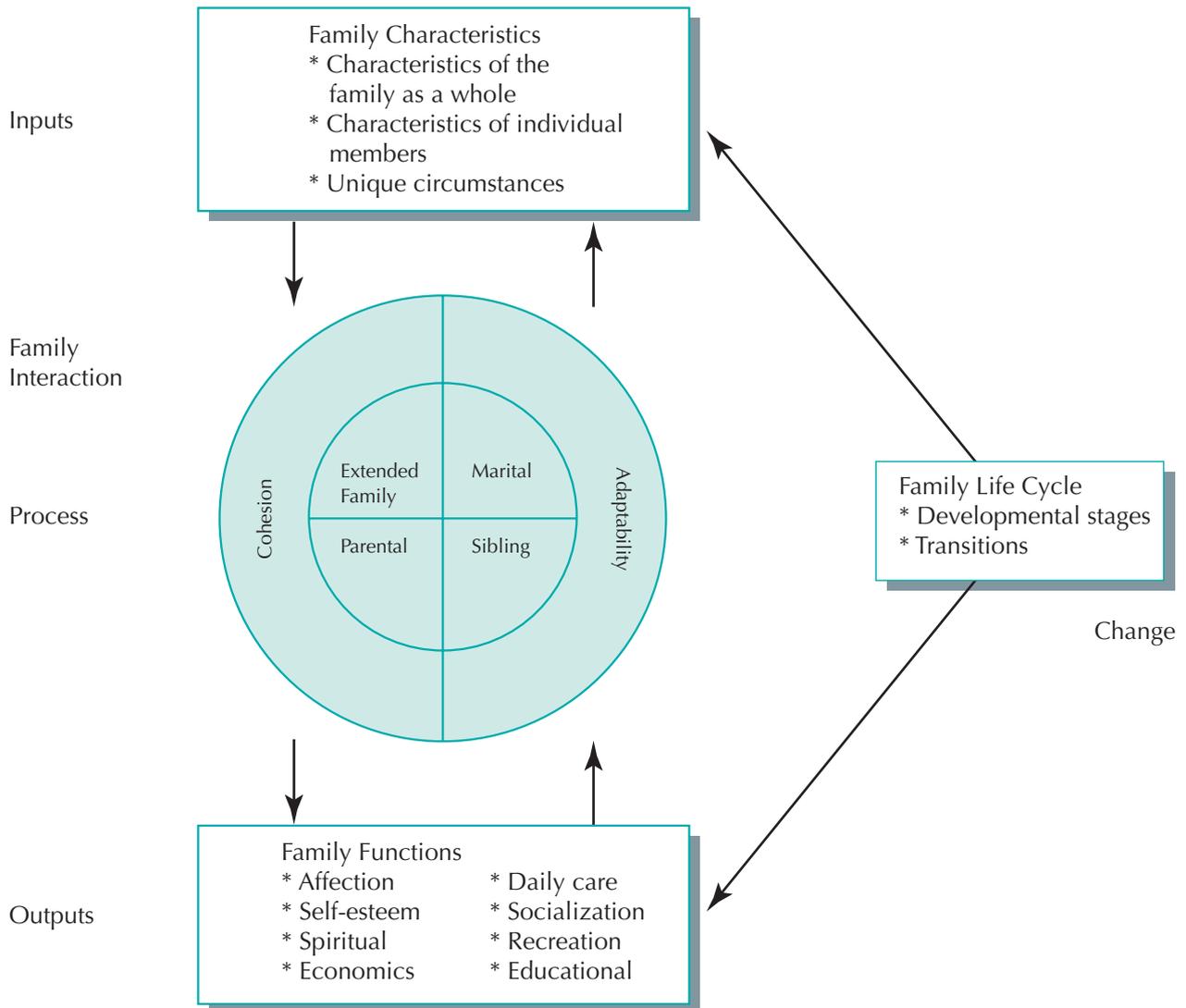
The baby has learned a lesson about mobiles, families, and systems. All pieces of the mobile are connected to each other, just as members of a family are connected to each other. What happens to one happens to all: that describes a "system."

Who are the all? And how is it useful to describe them and their relationships, their connections with each other, their "mobile-ness"? Family-theory literature gives us two frameworks to answer those questions.

One framework describes relationships according to the subsystems of a family. Thus, members are related through marriage and they interact with each other as spouses—this is Ida and John, forming the marital subsystem. Family members also are related and interact with each other as parents and children—this is Steven, Ida, and John, forming the parental subsystem. Brothers and sisters have relationships with each other; but since Steven is an only child, there is no sibling subsystem in the Robertson family. Grandparents, relatives, and friends have relationships with each other—this is Steven and Ida's parents and relatives, forming the extended family subsystem.

As we pointed out in chapter 1, the term *family* refers to two or more people who regard themselves as family and who perform some of the functions that families typically perform. Family, then, can be people who are not related by blood or marriage if they function as family members. To describe these four subsystems—marital, parental, sibling, and extended—does not, however, suffice to portray how family members relate and interact with each other. Two questions remain. First, are the family members "close" with each other—do they experience cohesion? Second, is the family adaptable? Can the family adapt to meet changing life circumstances, including the presence of a disability?

In this chapter you will learn about family members' interactions within the family and how the relationships within the family come into play as you develop partnerships with them. Here, as in chapter 1, we define *family* according to the functions that various people play.

FIGURE 2.1 Family systems framework: emphasis on family interaction

The family systems framework (the circle within Figure 2.1) shows four basic types of interactions or relationships—marital, parental, sibling, and extended family. We display the types of relationships in the inner quadrants of the framework and their qualities—cohesion and adaptability—in the outer ring.

Special educators, particularly early childhood special educators, have shifted from focusing primarily on the child or the parental subsystem (especially the mother and child subsystem) to focusing more broadly on the family as a whole (Carroll, 2013, p. 35; McWilliam, Snyder, Harbin, Porter, & Munn, 2000; Turnbull, Turbiville, & Turnbull, 2000). In making this shift, professionals have recognized that every member of a family differs from every other member (as the shapes hanging from the center of a mobile do), and any action related primarily to one member will rearrange the relationship of that person to all of the other family members.

There is more to be said. It is not just that the mobile is a useful way to think about families and their interactions. It is also that, whether they have children with disabilities or not, families are unique and complex. So, family systems theory provides a framework for understanding families. Family systems theory rests on three assumptions relevant to your partnership with families. These assumptions relate to

- the input/output configuration of systems,
- the concepts of wholeness and subsystems, and
- the role of boundaries in defining systems (Whitechurch & Constantine, 1993).

Input/Output

The first assumption of family systems theory is that family characteristics (chapter 1) are inputs into the system. The system then responds to these inputs, and the interaction produces outputs. Systems theory focuses on “what happens to the *input* as it is processed by the system on its way to becoming an *output*” (Broderick & Smith, 1979, p. 114, italics added).

Accordingly, and as Figure 2.1 shows, a family’s characteristics are the inputs into the family interaction. The family interaction occurs as families perform roles and interact with each other. The outputs of these roles and interactions are family functions. Thus, inputs interact with the system and produce outputs, and the outputs relate to how the family functions.

Wholeness and Subsystems

The second assumption of family systems theory is that the system is a whole, must be understood as a whole, and cannot be understood through only one or more of its parts, namely, its subsystems (Whitechurch & Constantine, 1993). Simply understanding the child with a disability does not mean that you will understand the family, yet understanding the family is necessary for understanding the child and what matters in her life.

You should focus on the aggregated inputs into the family and the resulting combined interactions within the family and with people outside it. Do not assume that one member, for example, the mother, “speaks for” all family members.

Boundaries

The third and last assumption in family systems theory is that boundaries exist between family members and subsystems and that boundaries result from the interaction of family members with each other and from the interaction of the family unit with outside influences. Boundaries also exist among family members on the one hand and the educators who work with their children on the other. These boundaries may often differ from those between family and friends, family and leaders of religious/spiritual communities, and other people with whom the family interacts, including professionals.

Families vary in the degree to which their boundaries are open or closed to educators or other nonmembers. Whether a family is more or less open affects how much the family will want to collaborate with educators or others. Some boundaries are porous; others are not. “You should keep in mind that any interaction with the child or other member ripples throughout the whole family” (Zuna, Turnbull, & Turnbull, 2011, p. 35).

The boundaries within a family also define its members’ roles with respect to each other. In some families, extended family members may take on the parents’ roles because the boundary between the two subsystems (extended family and parental) is open. In other families, grandparents may meet resistance when they make suggestions about child rearing. In those families, the boundary between parental and extended family subsystems is closed.

In this chapter, you will learn about family subsystems (marital, parental, sibling, and extended) and two “operating rules” of family systems and subsystems. We call these rules *cohesion* and *adaptability*.

Family Subsystems

Within the traditional nuclear family, there are four major subsystems (see Figure 2.1):

1. *Marital subsystem*: interactions among husband and wife or same-sex or domestic partners
2. *Parental subsystem*: interactions among parents or caregivers and their children
3. *Sibling subsystem*: interactions among children in a family
4. *Extended family subsystem*: interactions among members of the nuclear family, relatives, and others who are regarded as relatives

Interactions within one family will, of course, differ from those within another family; interactions also vary according to the subsystems within each family and the membership within each subsystem. For example, a family with only one child has no sibling subsystem. Similarly, a single parent does not have a formal marital subsystem but may have a partner who establishes the functional equivalent of a formal married system. What do you do when you work with families?

- Ask the student’s parent or parents to tell you about their family and listen carefully to the people they mention. These people are candidates for a partnership between yourself and the family.
- Ask the parent or parents about involving these extended family members, because the federal special education law grants rights to parents, not grandparents or uncles or aunts, to make decisions about the child’s education (see chapter 6).

Marital Subsystem

Interactions within the marital subsystem involve people who are married to each other or individuals who function as though they were married to each other. Whether married or not married but functioning as parents, all adults functioning as parents of a child with a disability are influenced by the child. The question is: How?

Impacts: Negative, Positive, and Mixed. Are marriages or partnerships strengthened, weakened, or unaffected by the presence of the child with a disability? As confusing as it seems, research says the answer to each of these questions is yes, as we noted in chapter 1.

Popular belief assumes that a child with a disability has a negative impact on a marriage. Early research did suggest that the rate of divorce and marital disharmony was higher in marriages where there was a child or youth with a disability (Gath, 1977; Hodapp & Krasner, 1995; Murphy, 1982). As Helen Featherstone (1980), the parent of a child with a disability, noted: “A child’s handicap attacks the fabric of a marriage in four ways. It excites powerful emotions in both parents. It acts as a dispiriting symbol of shared failure. It reshapes the organization of the family. It creates fertile ground for conflict” (p. 91).

However, here is what later research shows about the impact of a child with a disability on couples:

- The divorce rate among couples is not necessarily higher when a family has a child with a disability (Freedman, Kalb, Zablotzky, & Stuart, 2012; Miodrag & Hodapp, 2011; Urbano & Hodapp, 2007).

- Higher degrees of marital well-being were experienced by mothers when they had positive perceptions of their child (Lichenbrock, Ekas, & Whitman, 2011).
- Some husbands and wives report higher levels of marital satisfaction resulting from their shared commitment to their child (Brobst, Clopton, & Hendrick, 2009; Risdal & Singer, 2004; Scorgie & Sobsey, 2000; Stoneman & Gavidia-Payne, 2006).

Even though some families do experience marital strain when they have a child with a disability, the “impact is small and much lower than would be expected given earlier assumptions about the supposed inevitability of damaging impacts of children with disabilities on family well-being” (Risdal & Singer, 2004, p. 101).

Thus, it appears that strain on marriages as a result of having a child with a disability has a much smaller effect than once thought—and is often influenced by other factors. Elsie Helsel (1985) reflected on the impact of her son, Robin, on her marriage:

Professionals are constantly probing and asking questions concerning how Robin’s constant presence and problems affect our marriage. Once again, there are pluses and minuses. From my point of view, Robin has added more strength than strain. My husband and I will not have a footloose, carefree, romantic retirement lifestyle, but we will have something else—the opportunity to feel needed. (pp. 85–86)

Helsel’s perspective is reflected in a later study and the quote from it:

I think our relationship became closer due to having a child with a disability. . . . My husband realized that I have spent most of my leisure time in caring for our child . . . Sometimes, I am really tired and don’t want to prepare dinner, so my husband takes us to a restaurant. (Huang, Ososkie, & Hsu, 2011, p. 221)

- Some early research has found no impact of having a child with a disability on the family system (Abbott & Meredith, 1986; Singer & Nixon, 1996; Young & Roonarine, 1994), and some later research suggests that family adjustment and family life with a child with a disability mirrors that of typical families (Lalvani, 2011; Thompson, Hiebert-Murphy, & Trute, 2013).
- Many mothers of children with Down syndrome have noted the positive transformation that occurred in their personal lives. One parent described feeling “more connected” with her spouse (Lalvani, 2008). Her statement reflects other research about the positive impact a child with a disability can have on a marriage (Green, 2007).
- Studies have found that women report greater marital satisfaction when their partners use more problem-focused strategies in dealing with stress associated with daily and routine challenges (Huang et al., 2011; Stoneman & Gavidia-Payne, 2006). (You will learn more about how families use coping and problem-solving strategies later in this chapter.)

Overall, you should remember that each family system is unique, and how a child with a disability affects the family system and the marital subsystem will vary based on family characteristics and interactions. Once again, we caution you: Make no assumptions about the effect of the child on the marital subsystem.

Marital Stability. A strong marriage affects a family’s overall well-being (Simmerman, Blacher, & Baker, 2001). One parent underscored the critical importance of marital stability to the family’s quality of life: “Your marriage is foundational to everything. It was our love that carried us through” (Scorgie & Sobsey, 2000, p. 202). Consider what the research suggests about marital stability:

- Although parents of children with autism did report greater parenting stress and lower relationship satisfaction than parents of children without autism, both groups

had similar perceptions of their partner's support, respect, and commitment to the marriage (Brobst et al., 2009).

- Marital satisfaction and conflict are similar for parents of typically developing children or children with disabilities (Parker, Mandleco, Roper, Freeborn, & Dyches, 2011).
- The marital quality of parents who have children with developmental disabilities can vary greatly. Some parents experience positive outcomes and others experience negative effect such as marital strain. (Hartley et al., 2010).

Within any marriage, each partner has specific needs and roles to fulfill for his or her partner (such as affection, socialization, and self-esteem). One parent notes that “parents don’t get to spend any time together . . . when you’re dealing with situations like at our house where it is chaos at times, and not because he is a bad child, not because we are bad parents” (Resch et al., 2010). It makes good sense to respect and support the marital relationship as you form partnerships with parents and partners. Figure 2.2 provides tips on how to support interactions between parents and their significant others. When you work with parents who seem to need support with respect to their marriage, you may support them if you:

- Suggest that they may consider engaging in marriage counseling to support them in maintaining their commitment to each other while also raising their child (Johnson, 2012).
- Ask whether they would like you to give them the names of any qualified professionals whose reputations you believe are good, and even whether they want you to make the referral on their behalf.

At the same time, a strong marriage is not the only way to achieve positive family outcomes. Many single parents of children with a disability also experience strong family well-being. If you are unsure how to proceed, you should discuss your perspective about the family with a school social worker or other counselor, withholding the name of the family and the student so as to ensure their privacy and earn trust in your ability to honor any confidentiality they have asked for or may expect to have. If you do consult with other qualified people, it is best to limit your request for help by asking for advice on how best to proceed; it is not advisable to ask them to intervene unless the family already has given you their permission to ask for intervention. In some cases, a social worker or counselor might take the lead and have an initial conversation with the family.

Parental Subsystem

The parental subsystem consists of interactions between parents or other couples acting as parents and their children. Couples can consist of biological, step, adoptive, or foster parents or domestic partners. Some couples stay married to each other, some never marry, some divorce, and some remarry.

FIGURE 2.2 Supporting interactions between parents and significant others

- Communicate with parents and ask them what preferences they have regarding how and when they communicate with you.
- Encourage parents to consider activities they may wish to engage in separate from their child or children.
- Ask parents what kinds of information or resources they would find most helpful. Make information available to them based on their preferences.
- Consider time and other implications of home-based educational activities on the needs of the parents to spend quality time together as a couple.
- Seek ways to offer flexible scheduling or other alternatives if a planned school activity or meeting conflicts with a couple's schedule.

Impacts on the Parental System. Just as with marital satisfaction, the impact of a child with a disability on the parental subsystem varies and is based on the family's characteristics.

- Some parents of children with disabilities report greater stress and more challenges than parents who do not have children with disabilities (Baker-Ericzén, Brookman-Fraze, & Stahmer, 2005; McMahon, Malesa, Yoder, & Stone, 2007; Olsson & Hwang, 2001; Warfield, Krauss, Hauser-Cram, Upshur, & Shonkoff, 1999).
- Other parents do not report differences in stress (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989; Harris & McHale, 1989; Thompson et al., 2013) or depression (Singer, 2004) levels.
- Parents of children with developmental disabilities often demonstrate a high degree of optimism (Carroll, 2013).

In this section, we will discuss issues associated with (1) foster parents, (2) adoptive parents, (3) gay and lesbian parents, (4) fathers, and (5) mothers.

Foster Parents. The word *foster* means to help someone develop. Foster parents take care of children who are not their biological children by providing a safe and welcoming home for them. As one foster parent noted, "He was in group care before coming here and labeled unadoptable, so naturally we adopted him" (Shannon & Tappan, 2011, p. 1471). Here are some facts you may not know about children in the foster care system in the United States. In 2011:

- There were 400,500 children in the foster care system.
- The number of children who entered foster care were close to the numbers of children who exited the system.
- Most children were in nonrelative foster homes (47%), more than a quarter of children were living with relatives (27%), and the remaining were in group homes, institutions, pre-adoptive or trial homes, or supervised independent living situations.
- About 1% of children ran away from their placement.
- About 45% of children spent less than one year in foster care.
- Close to half of children entering foster care were under the age of 5.
- Children in foster care were White (41%), Black or African American (27%), Hispanic (21%), and other race/ethnicity (11%) (U.S. Department of Health and Human Services, 2012).

Foster parents often have permanent or temporary custody of children who are in the care or custody of a state's child protection agency because they have been abused, neglected, or otherwise maltreated by their biological parents. Foster parents seem to be motivated precisely because of the child's circumstances. Foster parents do not have the same legal status as a child's biological parents or as parents who legally adopt a child. Their authority is limited by the state agency or by the order of the court that places a child into foster care. You should always determine the legal status of a foster parent before you rely on that person's authority with respect to the child's education.

Here are some questions to consider asking when establishing a partnership with foster parents and caregivers:

- How long has the child been in foster care?
- How many foster homes has the child been in since the first placement?
- How do the birth parents and foster parents communicate to one another about the child?
- What is the current visitation plan? (Lewis, 2011)

Keep in mind that other professionals probably will be working with the family so they may be able to share this information with you. You will also want to remember there are unique considerations when working with foster families and children with disabilities. These include locating accessible placement and service options to meet the child's individualized priorities, training and support for families as well as Child Protective Services workers, and coordinating and collaborating with other agencies (Shannon & Tappan, 2011).

What happens after foster care? Some children return to their birth families, some live with other relatives, and some are adopted. Generally speaking, however, their outcomes are troublesome:

- Approximately 25% of children in foster care are homeless and approximately 33% are on welfare 1 to 1.5 years after leaving foster care at age 18.
- Only 40% of youth in foster care had held a job for at least 1 year up to 4 years after leaving foster care (Child Welfare League of America, 2002).

We encourage you to make every effort to develop trusting partnerships with foster parents. Typically they are either left out of the educational decision-making process or included at only a superficial level (Altshuler, 1997). You will want to share with the foster parents the nature of the student's educational program, just as you would for parents who do not have foster children, and direct them to resources and support services, particularly if they have had limited experience with children with disabilities.

Adoptive Parents. Many parents choose to expand their families by adopting a child. Here are some facts about adoption in 2012 in the United States:

- About 70% of parents who choose adoption are married, 22% are single female, 5% are single male, and almost 2% are not married.
- Types of adoptions include private domestic adoptions (38%), foster care adoptions (37%), and international adoptions (25%).
- Almost 90% of parents of adopted children report they would definitely make the same decision to adopt again.
- About 40% of adopted children are transracial (U.S. Department of Health and Human Services, 2012).

Over time the research has consistently concluded that families who have adopted children with disabilities typically experience a high level of well-being (Denby, Alford, & Ayala, 2011; Glidden, 1989; Glidden, Kiphart, Willoughby, & Bush, 1993; Lazarus, Evans, Glidden, & Flaherty, 2002; Todis & Singer, 1991).

Actually, it's just the knowledge of giving a good home to a kid who hasn't had a real great life up to that point by no choice of their own . . . we thought we could be good parents, but it was so slow. We just had the belief that when it is meant to be it would be. (Denby et al., 2011, p. 1548)

There are more similarities than differences in the coping strategies used by adoptive and birth parents of children with developmental disabilities (Glidden, Billings, & Jobe, 2006). Lazarus and colleagues (2002) found that adjustment levels and short- and long-term positive outcomes were similar for transracial adoption (adopting a child of another race or ethnicity) and intraracial adoption (adopting a child from a similar race or ethnicity). They suggest that "ethnicity and race differences of parents and children do not generally diminish the positive outcomes reported by parents" (p. 21).

Gay and Lesbian Parents. Here is what we do know about gay and lesbian households in the United States:

- There are 594,000 same-gender parents, and, of them, 115,000 have children in the household (Lofquist, 2011).
- Estimates are that the number of children and youth in the United States who have gay parents ranges from 6 million to 12 million (Lamme & Lamme, 2003).
- Same-gender couples raise approximately 4% of all adopted children and 3% of foster children in the United States (Gates, Badgett, Macomber, & Chambers, 2007).

Children enter gay and lesbian families in many different ways, including through adoption, surrogacy, artificial insemination, foster parenting, and birth to parents previously in heterosexual relationships. Although the presence of families headed by same-gender partners continues to be more evident in our country, barriers still exist for gay or lesbian couples to become parents. Challenges faced by many same-gender couples include access to reproductive health care and discriminatory policies and practices in adoptive and foster care systems (Patterson & Riskind, 2010).

Although the research is scant, there exists a body of research indicating that children raised by gay and lesbian parents do not significantly differ from children raised by heterosexual parents with respect to their gender roles or social, behavioral, and emotional adjustment (Biblarz & Savci, 2010; Fitzgerald, 1999; Tasker, 1999). But they may have different experiences.

Same-gender parents expressed concern about the realities that their children may face in school and the community. For example, 73% of more than 100 gay and lesbian parents indicated that their most common concern was whether their children would be teased or bullied (Ray & Gregory, 2001). Sixty-two percent were concerned that there would be no discussion in the preschool or school curriculum about gay and lesbian families. The experiences reported by the 48 children in this study were particularly revealing. Bullying was a major problem. According to the students, bullying usually started around third grade and became harsher as students proceeded through middle and high school. Slightly less than half of the students had experienced bullying by sixth grade. Elementary students who were bullied generally sought teacher intervention, but many teachers did not take sufficient action to stop the bullying.

From seventh to twelfth grades, bullying was also common, although it seemed to subside in eleventh and twelfth grades. When bullying did occur, it escalated more than at the elementary level, as described by one girl: "I had apple cores and banana peels and rocks thrown at me every time I walked past them. 'Dyke, dyke, dyke' they'd call at me. I used to get very scared; very frightened" (Ray & Gregory, 2001, p. 32). High school students expressed disappointment that their teachers did not provide any kind of discipline for homophobic taunting. They also underscored the benefits of being raised in same-gender families, including having a greater appreciation of diversity and participating in events for gay and lesbian people such as gay pride events.

Finally, some research suggests that there are positive outcomes for children of same-gender marriages or partnerships. Gay and lesbian parents who adopt children are able to respond well to the responsibilities and tasks that are necessary for healthy family functioning (Enrich, Leung, Kindle, & Carter, 2005; Farr, Forssell, & Patterson, 2010). Beyond the research, there are powerful narratives, such as the one you will read in the My Voice box.

Figure 2.3 includes tips on how you can help create a respectful school environment for students who have gay or lesbian parents. These suggestions will assist you in creating strong partnerships with gay and lesbian parents.

Fathers. How do the experiences of fathers of children with disabilities compare to those of mothers? As you learned in chapter 1, many family characteristics influence how a family adjusts to having a child with a disability. One of those characteristics is the type of disability.

- Fathers (and mothers) of children with Down syndrome experience less stress from child-related factors than fathers of children whose disabilities are not associated with a particular etiology (Ricci & Hodapp, 2003).
- Fathers of children with autism report lower stress than mothers, although no difference was noted in stress between parents of children with Down syndrome and typically developing children (Dabrowska & Pisula, 2010).
- Fathers and mothers of children with Down syndrome and autism spectrum disorders held similar beliefs about having a child with a disability but differed in the strategies they used to meet their priorities (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009).
- Stress experienced by fathers of children with disabilities is strongly influenced by their partner's mental health including depression (Flippin & Crais, 2011; Hastings et al., 2005; Kayfritz, Gragg, & Robert Orr, 2010).
- Paternal stress is also influenced by personal and/or social acceptance of the child (Keller & Honig, 2004; McHatton, 2007; Saloviita, Italinna, & Leinonen, 2003).

The father-child relationship has many potentially positive outcomes for children and youth. Fathers positively influence their children's cognitive, personal-social, and gender-role-identification development (Grossman et al., 2002; Roggman, Boyce, Cook, Christiansen, & Jones, 2004). When fathers are involved with children at age 7, the children have better psychological adjustment in their teenage years (Flouri & Buchanan, 2003). Furthermore, when fathers are involved when their children are 16 years old, the youth have fewer psychological problems when they are in their 30s. Clearly, fathers' involvement provides psychological protection for their children.

There also is research about the fathers, not just their children:

- Fathers of children with and without developmental disabilities did not differ in the level of involvement with their children (Dyer, McBride, Santos, & Jeans, 2009).
- In terms of their own psychological well-being, the only difference between fathers of children with and without disabilities was that self-acceptance was higher for fathers who had children with disabilities (Boyras & Sayger, 2011).
- There was no difference in parental stress between fathers (and mothers) of children with Down syndrome and parents of typically developing children (Dabrowska & Pisula, 2010).
- Cognitive appraisal, the ability to interpret the events and experiences of one's life, can influence the stress related to parenting a child with disabilities and depression in both mothers and fathers (Carroll, 2013).

FIGURE 2.3 Creating a respectful school climate for gay and lesbian parents and their children

- Seek out experiences where you interact with people who have diverse sexual orientation, and enhance your own comfort level in being with others who are different from you.
- Just as you would celebrate Black, Hispanic, and women's history months, also celebrate Gay Pride week. Encourage parents and other community citizens who are gay to speak at an assembly, provide audiovisual resources about gay issues, and highlight famous gay and lesbian people (Walt Whitman, Oscar Wilde, Alexander the Great, Billie Jean King, Gertrude Stein) in the curriculum.
- Encourage students to do book reports and research projects on gay issues.
- Point out gender stereotypes in books and encourage students to recognize diversity within gender roles.
- At the middle and high school levels, encourage activism in combating harassment.
- Encourage students who appear to be the target of discrimination and harassment related to homophobic language to receive support from school counselors. Provide discipline to students who harass or bully others in a homophobic way.
- Find out about local support groups, and encourage students who are dealing with their own sexual orientation issues or those of their parents to consider attending these support groups.
- Display gay-affirmative symbols in the school such as rainbow stickers.



MY VOICE

Gay and Lesbian Partners—The Fears of Intolerance

When our daughter first started preschool, we were scared. We were in a somewhat unusual situation. My partner had been the one to officially adopt our daughter, even though we were both involved in the process every step of the way. And, while we had started the process of solidifying my legal rights, it was taking longer than we wanted it to. Plus, we had had some bad experiences; once my partner had been out of the country and our daughter needed a medical procedure and I could not consent for it. We spent a crazy night trying to coordinate legalities from opposite sides of the earth, while my daughter lay there just wanting her mommy to take care of her.

So when preschool was starting we were very, very anxious; we knew that both of us would need to be involved every step of the way because of our daughter's special needs. Even though we viewed ourselves as equal partners, would the school? Would we run into issues with them listening to my ideas? Would my partner have to bring everything to them? How could we handle that? Should we try to figure out some way to expedite the adoption process, even if it cost a great deal of money?

Luckily, our worst fears never materialized. We were both treated as full partners in our daughter's education. There were a few legal things we had to deal with—paperwork so I could pick her up and talk to the school about certain things—but the school facilitated all of this. And there was never a question about both of us being equal partners on her team. Now, as we transition to elementary school, the legal issues are taken care of, but we still worry about if we can re-create the level of trust and collaboration we had with the preschool program.

Take Action!

- **Get to know the roles that parents play in their child's life** and how you can support the roles and build trusting partnerships.
- **Become familiar with legal issues** you might need to be aware of and how you can build trusting partnerships with families.
- **Consider the vulnerabilities that a family may experience** and how you could help family members address them as you build partnerships.

Traditionally, fathers who are “present” and mindful when interacting with their children with intellectual disability are also more involved in the support and care of their child (MacDonald & Hastings, 2010). Rud Turnbull describes these daily care rituals and their effects:

We (my son Jay and I) were truly of one body, and not just in the seminal sense. These father-and-son rituals were our bonds of touch—wash and shave routine in the shower, dry him everywhere, de-wax his ears after the shower, or in the office between visits to our home; cut his fingernails, help him pull on socks, untie and retie his knotted shoes; button his shirt; tuck it in; make sure he has his wallet and keys; put on his watch—he held it out to me, always interrupting my dressing, always asking for everything to be in place and same order. Through giving him such varieties of care for forty-one years, I had become part of him, even as he, upon receiving my love, and giving me his, had become part of me not only in the biological way but also in the daily ways of ordinary life (Turnbull, 2011, p. 98).

Because fathers have been traditionally perceived as the less involved parent, professionals should make an extra effort to establish partnerships with them (Flippin & Crais, 2011; Frieman & Berkeley, 2002; Rump, 2002). Here are some strategies educators might use to reach out to fathers (Rump, 2002):

- Provide visible information about the importance of men in children's lives in mission statements, family handbooks, and family communications.

- Reach out and involve the father during family/child program intake. If a father is not present, inquire about him or other significant male figures in the child's life, and stress their important roles in the family.
- Talk with the father as well as the mother when telephoning a family at home.
- Ensure that program print materials communicate to men as well as women by monitoring the choices of paper color, graphics, topics, and language.

There can be a number of significant men in the lives of children who do not have a traditional father figure. Grandfathers and nonpaternal males such as male partners of mothers, teachers, men from religious communities, brothers, and neighbors can bring an important male presence into the lives of children. If you develop trusting partnerships with only one parent or with only one of several family members, it will probably fall short of being a true family partnership. Be inclusive; reach out to all parents and to all family members if you have permission to do so.

Mothers. Despite some research indicating that mothers usually find parenting their child with a disability burdensome, mothers often experience positive transformations and come to view their experience as mothers to be positive. This is especially true of mothers who have a child with Down syndrome (Lalvani, 2008, 2012).

Although the trend is for mothers and fathers to share parenting roles, mothers have traditionally assumed a larger part of the responsibility for family needs (Renwick, Brown, & Raphael, 1998; Simmerman et al., 2001; Traustadottir, 1995; Voydanoff & Donnelly, 1999). That fact, however, does not mean that mothers become depressed because of their duties.

- Approximately 68% of mothers of children with disabilities did not show elevated symptoms of depression (Singer, 2006). However, 18% of mothers of children without disabilities and 32% of mothers of children with disabilities scored over the cutoff for minor depression, suggesting that there is a far more pessimistic view of how mothers function when they have children with disabilities than their real-life experiences warrant.
- The quality of mother-child relationships did not predict maternal depression or challenging behavior in their child (Baker, Seltzer, & Greenberg, 2011).
- Stress experienced by mothers of children with disabilities has been associated with behavior challenges with their children (Hastings & Brown, 2002; Hastings et al., 2005; Saloviita et al., 2003).
- Maternal distress led to increased behavior challenges in children with intellectual disabilities, and the child's behavior challenges promoted maternal distress (Hastings, Daley, Burns, & Beck, 2006).
- The demands of taking care of their child resulted in maternal stress (Keller & Honig, 2004) as well as physical and health challenges (Magill-Evans, Darrah, & Galambos, 2011).
- Facilitating more effective father-child interactions can reduce maternal stress and optimize family coping (Flippin & Crais, 2011).

Mothers may also experience stress because they are unable to secure or hold onto a job due to their child's schedule or circumstances.

The reason I lost my job is that I couldn't get there on time [because of the struggles in the morning with my son] . . . In the last few years, with the stress of [my son who had emotional and behavior disabilities] and the divorce, I could not get there on time. (Scott, 2010, p. 686)

The number of children with disabilities in a family may also contribute to maternal stress. Mothers of children with autism and another child with a disability (other than

the child with autism) experienced more depressive symptoms and anxiety and lower family adaptability than mothers who had only their child with autism (Orsmond, Lin, & Seltzer, 2007).

It is important for you to recognize the sources of stress for mothers if you are intent on building a partnership with the family. Your early interactions with mothers and other family members are the foundations for your later relationships with them. Unfortunately, mothers' initial experiences with professionals are not always positive. Lalvani (2008) reported that mothers of young children with Down syndrome consistently received negative messages about having a child with a disability, most of which came from the medical community.

An earlier study that examined over 1,200 mothers of children with Down syndrome after the birth of their child (Skotko, 2005). The majority of mothers felt anxious or frightened after the diagnosis. Few if any positive aspects of Down syndrome were shared with mothers, and they reported receiving limited or no resources to support them. Read about policy responses to newborns with disabilities in the Change Agents box.

Latina mothers whose infants were in the neonatal intensive care unit reported they had higher levels of stress related to caregiving roles and communication than English-speaking mothers (Denny, Okamoto, Singer, Brenner, & Barkley, 2006), suggesting that limited opportunities for Spanish-speaking mothers to communicate in their native language may likely contribute to this stress.

There is growing interest about the impact of a child's disability in different cultural and ethnic groups (Harry, 2008; Kalyanpur & Harry, 2012; Zhang & Bennett, 2003). In mothers of children with autism spectrum disorders, African American mothers had lower levels of negativity about having a child with a disability than Caucasian mothers (Bishop, Richler, & Lord, 2007). Discovering how a family perceives the child's disability is an important part of understanding family interactions.

Sibling Subsystem

The sibling subsystem consists of the interactions between brothers and sisters. One of the most obvious interactions relates to socializing; brothers and sisters often provide the first peer relationships for each other. Through their interactions, brothers and sisters give each other opportunities to experience sharing, companionship, loyalty, rivalry, denial, and other feelings. As with all family relationships, the nature of the brother-sister bond is culturally rooted. Different cultures have different expectations for siblings. In many cultures, caretaking is a paramount role in the daily life of the family, and siblings' roles can reflect that expectation (Lynch & Hanson, 2011; Stoneman, 2005). Other influences that can shape sibling relationships are cultural identity, age, birth order, gender, and disability (Carroll, 2013; Hodapp, 2011; Lynch & Hanson, 2004).

Although siblings can be socialization agents (Gallagher et al., 2000; Tsao & McCabe, 2013) and even tutors (Tekin & Kircaali-Iftar, 2002) during their younger years, they often are increasingly responsible for providing care and coordinating services for their brother or sister with a significant disability. These roles increase as their parents age. Families whose members with a disability have lived with their parents well into adulthood indicate that siblings, especially sisters, tend to provide caregiving and companionship, especially when their parents are in the later stages of life (Burke, Taylor, Urbano, & Hodapp, 2012). Siblings naturally think about the future and how to care for their brother or sister. Providing early support to siblings is essential as they want to know about estate planning, negotiating the system, guardianship, and financial and legal implications (Arnold, Heller, & Kramer, 2012). Consider this sibling's perspective about her 17-year-old brother with cerebral palsy:

I think [Paul's] going to need a lot of support for living on his own . . . my hope is that he would call me and ask me for help. . . . When you get to be that age, you can't tell your parents everything. So, I'd be the one for him to call. (Marks, Matson, & Barraza, 2005, p. 210)

Brothers or sisters with a disability influence their siblings in many different ways (Blacher & Begum, 2011; Hodapp, Urbano, & Burke, 2010; Lardieri, Blacher, & Swanson, 2000). Siblings can derive many benefits from the relationship, including enhanced maturity, self-esteem, social competence, insight, tolerance, pride, vocational opportunities, advocacy, and loyalty. Others sometimes experience negative effects, including embarrassment, guilt, isolation, resentment, increased responsibility, and pressure to achieve. Still others regard having a brother or sister with a disability as a neutral experience. Younger children may not be able to fully realize the positive contributions of their older sibling who has a disability (Carroll, 2013).

Like all sibling relationships, positive and negative reactions can also occur simultaneously. There is no single definitive impact; impact depends on the size of the family, birth



CHANGE AGENTS BUILD CAPACITY

Build Capacity—Genes Are Destiny?

Genes are destiny. True? Yes, in some ways. No, in others.

Genes influence the biology of family members. A person's biology is inherent until medically altered; traits are passed down from a parent. But genes need not shape families' lives. Why? Because everyone's life is malleable and not just medically. Indeed, nothing has so changed the lives of most individuals with disabilities and their families as public policy and professional practice.

That's so because public policy reflects the past even as it is a beacon into the future. It's also so because professional practice reflects the past even as it equips a person and family for the future.

At least two different but similar policy statements have shaped the interactions of family members affected by disability, including those whose genetic characteristics appear in their children.

The Principles of Treatment of Disabled Infants, issued in 1983 by leading professional and medical associations in the fields of intellectual and physical disabilities, condemned the withholding or withdrawing of life-sustaining treatment from newborns with birth anomalies solely because they have disabilities. It presumed they have a moral and legal right to treatment and called on federal, state, and nonprofit agencies to support the babies and their parents. Congress codified the Principles when it amended the Child Abuse Prevention and Treatment Act. Interactions among family members that include withholding and withdrawing of life-sustaining medical procedures, food, and water now are disallowed. (Authors'

note: Rud Turnbull, a coauthor of this book, was one of the principal draftsmen of the Principles.)

The Principles of End-of-Life Treatment, adopted in 2006 by a large number of family-driven and professionally based disability organizations, tracked the "baby" Principles, condemned withholding and withdrawing life-sustaining treatment of any child and adult solely because of disability, and presumed in favor of treatment. Although these have not been adopted as part of federal law, some elements of them are in state guardianship and medical-practice laws, affecting family members' interactions with each other. (Authors' note: Rud Turnbull also was a member of the consortium of disability policy leaders who drafted these Principles.)

Take Action!

- **Consider carefully how family members interact with each other** and bear in mind that siblings often face difficult decisions and may appreciate your guidance so long as it is based on well-received principles about treating members who are at the edges of their lives.
- **Be respectful and nonjudgmental** when family members face hard decisions. Offer them support or, if you would feel more comfortable, refer them to individuals and agencies from which they can receive support.

order, gender, the nature of the disability, cultural beliefs, coping styles, and other unique circumstances occurring within the family.

It sometimes is falsely assumed that siblings of persons with disabilities have predominantly negative outcomes and experiences (Dykens, 2005; Hodapp, Glidden, & Kaiser, 2005; Stoneman, 2005), but two reviews of the research dispel that assumption (Meadan, Halle, & Ebata, 2010; Stoneman, 2005):

- Some siblings of children with disabilities experience positive outcomes (e.g., high levels of self-concept and social competence), and other siblings have no effect or some negative effects.
- There is no difference in self-esteem in siblings of children with and without disabilities.
- Most sibling relationships are positive, rich, and satisfying.
- Having a sibling with a disability does not cause pathology or maladaptation in children.
- Parents do tend to focus more attention to their children with disabilities than typical siblings.

Having a sibling with a disability is generally a positive experience. Of course, there can be many challenges just as in any family interaction. Here are two perspectives from siblings on the positive aspects of having a brother or sister with autism (Moysen & Roeyers, 2011):

Ivan knows . . . almost everything about animals or astronomy. During dinner he keeps on telling about it . . . So, I've learned a lot from him! (Eric, 10 years) (p. 48)

My brother can't get me mad . . . My parents told me he doesn't mean what he's saying and . . . it has improved. Where he first said: I hate you, he now only says: you're a silly moo! (Rebecca, 14 years) (p. 49)

Even given the positive outcomes and experiences associated with having a sibling with a disability, siblings may be interested in support or resources. Siblings of children with disabilities articulated their need for many different kinds of support including disability-related resources, caregiving information, and more formalized avenues for siblings to share information and support with other siblings (Arnold et al., 2012). There may also be specific life cycle stages where siblings want information or interactions with other siblings who have similar experiences.

Don Meyer, a national leader in creating support programs for siblings of children with disabilities, has created a model known as “Sibshops.” This program provides information, education, and peer support for brothers and sisters of children with disabilities and health needs. Sibshops offer recreational and fun opportunities that reflect a “commitment to the well-being of the family member most likely to have the longest-lasting relationship with the person with special needs” (Sibshops, 2013).

This program reflects a belief that brothers and sisters have much to offer one another—if they are given a chance. The Sibshops curriculum has been used throughout the world including the United States, Canada, England, Iceland, Japan, New Zealand, and Mexico. If your community does not sponsor Sibshops, you might collaborate with families, educators, people with disabilities, and other community citizens to start one.

Siblings can be helpful as social role models and in promoting the successful inclusion of their brother or sister with a disability (Gallagher et al., 2000; Tsao, Davenport, & Schmiege, 2012). Siblings offer valuable perspectives on how to include their brother or sister with a disability in school and other activities. The child with a disability often wants to emulate his or her brother or sister or at least be in the same school. Brothers and sisters can ensure that their sibling with a disability receives opportunities and encouragement at school and in community activities. Siblings can serve as a conduit of information between the school and their parents.

Because brothers and sisters carry out important roles within a family, it behooves professionals to include them in family partnerships. Read first-person narratives for additional insight into sibling perspectives (Meyer, 2009; Meyer & Vadasy, 2007).

Extended Family Subsystem

Think of each person in your extended family and then total how many there are. Reflect on the role that they have had in your life, beginning when you were a young child until the present. What factors have either increased or decreased their availability and support?

The Role of Culture. The answers to these questions may depend on your cultural background. Cultures tend to define the composition of extended family and the frequency of contact between the nuclear and extended families (Lynch & Hanson, 2011).

In many American Indian families, the child-rearing activities may rest with family members other than parents. In many instances, the grandparents are responsible for the children. Aunts and uncles also are likely to be involved, especially if the family resides on the reservation and not in an urban area (Joe & Malach, 2011, p. 123). Likewise, Latinos, as a whole, adhere to a collective sense of family, often resulting in extended family configurations that offer valuable support services (Vega, Hough, & Romero, 1983). Moreover, the godparent or *compadre* system offers support by adding to the family via marriage and the use of godparents at baptism, confirmation, and the *quinceañeras*, the coming-of-age celebrations for 15-year-old girls (Zuniga, 2004, p. 196).

Although many cultures value the support of extended family members, there is great diversity in the presence, frequency, and type of support that extended family members provide.

- Do not assume that every family from a culturally or linguistically diverse background gains support from extended family members.
- From the outset, ask parents to define which family members they want to involve as they work with you and other professionals. Only after they identify these extended family members should you try to identify culturally sensitive ways for including them in partnerships.

Grandparents. Grandparents can often provide a unique and important source of support, and yet there is limited information about their role and outcomes in families of children with disabilities. Here is what we do know about grandparents:

- Mothers of a child with moderate to profound intellectual disability describe the grandparents' role by suggesting that they received help with child care from grandparents (45%), received advice and encouragement (40%), received help with household tasks (16%), and received financial assistance (15%) (Heller, Hsieh, & Rowitz, 2000).
- There is a high level of involvement and support from grandparents in families with a child with a disability; grandparents often felt a sense of responsibility to maintain the quality of life and well-being of the child's family (Miller, Buys, & Woodbridge, 2012).
- Parents of children with a disability received less practical help with everyday tasks from grandparents than parents of children without disabilities; however, both groups received the same amount of emotional support (Heller et al., 2000).
- In single-parent families, grandparents were more likely to provide support and were more likely to provide weekly help to families of children with disabilities than were other relatives or friends (Green, 2001).
- There can be support as well as stress associated with grandparent presence (Hastings et al., 2005) because within the same family, grandparent support and conflict were associated with mothers' (but not fathers') stress.

A different kind of stress occurs when the child is diagnosed with a genetic condition (Bailey, Skinner, & Sparkman, 2003). Typically, parents receive genetic counseling and then must explain these findings to grandparents, uncles, aunts, or other members of their extended family. Parents who had children with the genetic condition known as Fragile X syndrome reported that either they or their spouse informed extended family members of the genetic test results. Approximately two thirds of the parents described this experience as either somewhat stressful or very stressful since extended family members needed to consider the meaning of the results for themselves. This was especially true for siblings of the parent who was the genetic carrier of the condition (Bailey et al., 2003).

Grandparents and other extended family members of children with disabilities need information and support to deal with their own feelings, issues related to their grandchild's behavior or development, and to know how to provide care for the rest of the family (Gallagher, Kresak, & Rhodes, 2010; Janicky, McCallion, Grant-Griffin, & Kolomer, 2000). Grandparents' or family members' ideas about people with disabilities may be more traditional than those of the child's parents. For example, a Latino mother of a young child with a disability might describe how her own mother would agree to make a *mandos* (bargain) related to her grandchild. She would promise the Virgin of Guadalupe (Mexico) that she would visit the basilica and wear the colors of the Virgin every day if the Virgin would heal her grandchild. But the child's own mother might also be quick to add that she herself does not subscribe to her mother's approach; the differences between them were more generational than spiritual.

Sometimes extended family members may share their negative perceptions about children with disabilities. Conversely, grandparents and other family members can be very helpful in dealing with the new reality of life with a child with a disability and recognize the positive outcomes as expressed by this grandparent:

Well, I think it's probably made the family stronger because you have to blend together to give each other support. It's really united the family. (Miller et al., 2012, p. 107)

Up until this point, we have focused on grandparents as part of the extended family; however, many grandparents assume the parenting role.

- There are more than 2,600,000 grandparents who are care providers for their grandchildren in the United States (Children's Defense Fund, 2012).
- Some of the reasons grandparents assume caregiver roles include teenage parents, unemployment, poverty, substance abuse, maternal incarceration, and child abuse and neglect (Janicky et al., 2000).
- Grandmothers reported that they participate in their grandchild's individualized education program (IEP). Many grandparents acknowledge the struggles of raising their grandchild with disabilities, but they also indicate that things get easier and much child progress is noted when they receive information and know what to do for the child (Gallagher et al., 2010).
- A comparison of grandparents who were raising a grandchild with a disability and those raising a child without a disability revealed that both groups were caring for an average of two children (Force, Botsford, Pisano, & Holbert, 2000). Although grandparents raising children with and without disabilities had many similarities, they also differed. Grandparents who had a child with a disability reported a greater need for help from schools, a greater need for transportation, and greater use of speech therapy services.

Grandparents clearly play an important role in a family's life. Figure 2.4 includes suggestions on providing information and resources that can assist extended family members to support the child and family.

Cohesion and Adaptability

You have just learned about the subsystems—the people who interact in the family. Now it is time to consider how they interact. You will learn about two elements of family interaction—cohesion and adaptability. Cohesion and adaptability in a family describe (1) the emotional bonding that members of family subsystems have and (2) the quality and nature of boundaries, organization, and negotiations among family subsystems (Olson, Gorall, & Tiesel, 2007).

The rules governing family interaction are unique to each family and are influenced by their culture. The families you interact with will vary in cohesion, adaptability, and what works for them (Lynch & Hanson, 2011).

Many of the early studies on families of children with disabilities have been conducted by European American researchers with European American research participants. Some professionals may mistakenly think that the level of cohesion and adaptability acceptable to European American families is the level to which all families should adhere. As you learned in chapter 1, however, culture and other characteristics significantly affect families, and you will want to honor these important considerations in developing partnerships.

Cohesion

You have already learned that certain boundaries serve as lines of demarcation between people inside and outside a subsystem. Boundaries and cohesion interact.

- Boundaries may be open or closed; that is, they may or may not be accessible to interaction with people outside the subsystem. From a European American perspective, subsystems are typically open enough to allow individual autonomy and closed enough to provide support for each family member (Summers, 1987).
- Boundaries also help define families' bonding relationships. Family members typically feel closer to each other than to those outside the family. This element of family bonding relates to cohesion (Olson, Sprenkle, & Russell, 1979).
- Family cohesion refers to family members' close emotional bonding with each other and to the level of independence they feel within the family system (Olson, 1988; 2011; Olson, Russell, & Sprenkle, 1980).
- Cohesion exists across a continuum, with high disengagement on one end and high enmeshment on the other.
- Some parents have noted that humor is a strategy for bringing cohesion to a family (Rieger, 2004; Rieger & McGrail, 2013).

One author used the physical metaphor of “the touching of hands” to describe cohesion in the family:

FIGURE 2.4 Assisting extended family members

- Provide parents with information to help them better understand the needs and reactions of extended family members.
- Provide parents with information about the disability, needs of children, and priorities of families that can be shared with extended family members.
- Encourage the development of grandparent or extended family member support groups. Those groups might be facilitated by school social workers, psychologists, PTA volunteers who are grandparents, or extended family members of a child with a disability.
- Find individuals in the community or at school who can be matched with an extended family member to share positive reflections and perspectives on life with a child with a disability.
- Encourage extended family member participation in IEP or IFSP conferences, classroom visits, school events, and family support programs.
- Provide library materials, community resources, or Internet sources for extended family members.

The dilemma is how to be close yet separate. When the fingers are intertwined, it at first feels secure and warm. Yet when one partner (or family member) tries to move, it is difficult at best. The squeezing pressure may even be painful. . . . The paradox of every relationship is how to touch and yet not hold on. (Carnes, 1981, pp. 70, 71)

Range of Cohesion. When families are highly cohesive, boundaries among their subsystems are blurred or weak (Minuchin & Fishman, 1981). For example, a mother of a child who is deaf and blind and has many physical care needs may delegate some of the responsibilities to an older daughter. The daughter may have fewer parent-child and sibling interactions because she has been drawn into the parental subsystem. Her own needs as a child and a sibling may be overlooked or subordinated.

The extent of cohesion may depend in part on each family's cultural beliefs. What may appear to be overprotection in one culture may be appropriate protection, nurturance, and affection in another. For example, Latino families may find it acceptable for preteens or even adolescents to sit on their mother's lap or for preschoolers to drink from a baby bottle long after European American parents would consider those actions inappropriate (Zuniga, 2011).

What happens when families have low degrees of cohesion, even to the point that children with disabilities are isolated from other family members? Limited interaction leaves children without the support, closeness, and assistance needed to develop independence. Low cohesion—sometimes called disengaged family interaction—can involve limited involvement of family members in each other's lives, few shared interests or friends, excessive privacy, and a great deal of time apart (Olson, 2011; Olson & Gorall, 2006; Olson et al., 2007). Few decisions are made with family input and involvement. For all family members, particularly the member with a disability, low cohesion can be both lonely and difficult.

Disengaged relationships can take place within and among subsystems (Olson & Gorall, 2006; Olson et al., 2007). For example, disengagement within a subsystem exists when a father denies the child's disability or withdraws from parental and marital interactions. Disengagement among subsystems occurs when the members of the extended family cannot accept the child and that part of the family subsystem is excluded from family celebrations.

Implications of Cohesion. Positive outcomes accrue for families when family cohesion is balanced (Boyras & Sayger, 2011; Gavidia-Payne & Stoneman, 1997; Lightsey & Sweeney, 2008; Margalit, Al-Yagon, & Kelitman, 2006; Olson, 2011; Olson et al., 2007). Cohesion is necessary for a family's well-being. "The level of harmony in the family seems to be the most crucial factor influencing stress" (Keller & Honig, 2004, p. 346). Parents value the increased family unity and closeness that often comes from having a child with a disability (Behr & Murphy, 1993; Lalvani, 2011; Stainton & Besser, 1998; Summers, Behr, & Turnbull, 1989; Turnbull, Guess, & Turnbull, 1988).

There are two reasons you should work with families to establish a comfortable level of cohesion.

- By recognizing the levels of cohesion between and within subsystems, you can create a context that supports the family as a whole to meet its needs as well as the child's (Zuna et al., 2011).
- By considering the degree of family cohesion, you can provide appropriate services and supports or refer the family to those services (Margalit et al., 2006; Taanila, Järvelin, & Kokkonen, 1999).

For example, you will know to ask whether a particular program encourages a culturally appropriate level of cohesion. Or you will be competent to make appropriate early education recommendations. Mothers who are highly involved in early childhood programs are

sometimes unintentionally reinforced for establishing highly cohesive relationships with their young children. They are encouraged to spend considerable time in the classroom, attend mothers' groups, provide home teaching, and transport children to various services (Turnbull et al., 2000). When they spend all this time with the child, what happens to their own needs and the needs of other family members? Obviously, you will want to be sensitive to the implications of your professional recommendations.

Adaptability

Adaptability refers to the family's ability to change in response to situational and developmental stress (Olson, 1988, 2011; Olson et al., 1980) and to the family's leadership, organization, and negotiations (Olson et al., 2007). As with a family's cohesion, adaptation is influenced by family values and cultural background. Adaptability can be viewed on a continuum. At one end are families who may be unable or unwilling to change in response to stress. At the other end are families who are constantly changing, so much so that they create significant confusion within the family system (Olson et al., 1979).

Ranges of Adaptability. At one end of the adaptability continuum, families demonstrate a high degree of control and structure, and their interactions involve many strictly enforced rules. These families firmly delineate the hierarchy of authority along with the roles that each person plays. In this structure, negotiating authority and roles is rare and usually intolerable. For example, consider a family with a son who sustains a brain injury and accompanying physical disability. If the child's mother was primarily responsible for meeting the child's needs, the added caregiving demands may be more than she can handle. Also, if the family is not comfortable with sharing responsibilities with persons outside of the family, the added demands can create stress for the mother as well as all other family members. Here is what the research says about adaptability in families with children with disabilities:

- There is a relationship between parental adaptation to their child's disability and the quality of relationships they have (Wade, Stancin, Taylor, Drotar, & Yeates, 2004).
- Families demonstrate positive adaptability when there is a balance between the stress and the coping strategies that are used (Manning, Wainwright, & Bennett, 2011).

For mothers of children with autism, adaptation takes time as they rearrange their homes and lives, and revisit their plans and dreams for the future.

You have to rearrange your life . . . there is no more spontaneous . . . everything is planned.
You can't just call anybody . . . it has to be people you trust and know how to handle him.
We do a lot of things here [at home] because we can't do them outside as a family (Lutz, Patterson, & Klein, 2012, p. 210).

Adaptation is a process rather than a one-time event for families.

Many families gradually adapt their power hierarchies to support their child or adolescent to become a self-determined adult. As you will learn in chapter 4, self-determination is culturally and individually rooted. Some families place great value on their children's increasing autonomy, whereas others emphasize family interdependence (Brotherson, Cook, Erwin, & Weigel, 2008; Kalyanpur & Harry, 1999; Shogren & Turnbull, 2006). You need to be sensitive to family and student preferences while negotiating the degree of student decision making that the family considers appropriate.

It is helpful to identify the person or persons who have primary control over family decisions and rules. For example, if you ask a mother to try a home-based language program but do not take into account the husband's decision-making power and possible rejection of your request, it is unlikely that the program will be effective. Indeed, if the mother carries

out the intervention against her husband's wishes, the program may create marital and parental conflict. You should examine how any recommendation for home-based programs will affect each family member. Work with the family to develop options consistent with its values, goals, and ability and willingness to adapt.

By contrast, other families demonstrate a low degree of control and structure. Their interactions often are characterized by few rules, and even these are seldom enforced. Promises and commitments are often not respected, and family members may learn that they cannot depend on one another. Frequently, there is no family leader, negotiations are endless, and roles are unclear and often changing.

Implications of Adaptability. Most families strike a balance between the high and low extremes of adaptability and flexibility (Olson et al., 1980). The ability to be flexible and to adapt to life changes contributes significantly to positive adjustment (Glidden et al., 2006; Lustig & Akey, 1999). Family members often value identifying a range of options when life changes occur and negotiating the best option for the family (adaptability and flexibility) while also maintaining a strong commitment to each other and the family (cohesion). However, "families who face competing demands may become less flexible in their ability to accommodate everyone's needs" (Orsmond et al., 2007, p. 265).

You can use any one or more of these effective ways to support those families who are dissatisfied with their current level of adaptability and flexibility.

- Use a strength-based approach that acknowledges the family's success with specific coping strategies. Consider using a "reframing" approach that allows families to view their situation from a more favorable and positive perspective (Manning et al., 2011).
- Help families plan for positive change. If possible, discuss schedule changes and transitions well in advance. Before approaching a family, ask yourself:
 - Is this change too sudden or radical for this family's current level of adaptability?
 - Does the family have the flexibility to handle the change given current family roles?
 - Would the student and family benefit from gradual transitions? When a student will be changing classrooms or school buildings, start with a gradual transition, one day a week, before making the complete transition. If a child needs to learn how to ride the bus, intermediate steps may be reassuring to the student and his or her family. Initially, the student may only ride part of the way or ride along with a friend or another family member. Also, invite the bus driver to be part of the planning team.
- Encourage families to examine various alternatives. Many families who lack flexibility and adaptability may not know how to examine alternatives (Shank & Turnbull, 1993; Summers, Templeton-McMann, & Fuger, 1997).
- Identify with families what they perceive to be helpful. Family adaptation can result when parents feel their needs are met, including the need to access information, seek answers, find support, or locate socialization or spirituality networks (Lutz et al., 2012). They may benefit from learning problem-solving skills, including sarcasm and humor:

The squeaky wheel gets the grease (laughs) . . . I said, "if you don't find placement for this kid I'm camping out in your office" . . . They probably all thought I was whacked. But you have to be that way. (Lutz et al., 2012, p. 260)

You will want to remember that family dynamics are complicated and often require highly specialized professionals to provide the most appropriate and personalized supports. You will want to work closely with other professionals. If a family may be interested in receiving services from the school counselor, school social worker, or other community professionals, collaborate with the school counselor or social worker on how to approach the family and suggest these alternatives. If a family asks you about possible resources, refer members to those resources.

The Robertson family has several subsystems. Within Steven's immediate family, there are three quite distinct individuals: a young boy with a disability and two university graduates pursuing different careers. Ida and John form the marital subsystem—and each has different characteristics and levels of adaptability, flexibility, and cohesion. Each parent is introverted—at least that's how Ida describes herself and John. And they have worked to adapt to having a child with a disability yet maintain cohesion within their marital subsystem.

Ida and John's relationship with Steven forms the parental subsystem. Ida and John are flexible in the roles they adopt as parents, sharing household responsibilities and using outside sources (e.g., day care and preschool) to meet Steven's needs. Since Steven is an only child, there is no sibling subsystem. In terms of the extended family subsystem, Ida and John's parents and stepparents in John's case and relatives are involved in their lives and play defined roles.

Revisiting Steven, Ida, and John Robertson

Remember, just like a mobile, what happens to one family member or in one family subsystem affects the entire family system. Changes will continue to happen in the Robertson family system as each member grows and develops. But is change just a temporal thing for the Robertson family—something that happens as time goes by? So far, yes.

The Robertsons' fundamental characteristics have not changed. Two of them are still and always will be well educated and bright. One—Steven—is an unknown at this point. True, he has a disability. But what does that mean for him, Ida, and John? There is no way to predict; we know only that he has a special challenge but we don't yet know what he will achieve in his life. Much will depend on how his parents, researchers, and practitioners become partners with each other.

WHAT THIS CHAPTER HAS OFFERED YOU

Are you ready to connect the content of this chapter to the Robertson family? If so, you know that you have been introduced to the family systems theory. You are familiar with the metaphor of a mobile: all of its pieces are connected, just as every member of a family is connected. Steven, Ida, and John are the parts of the Robertson mobile; what happens to one of them influences each of the others. You also learned about the Robertsons' subsystems—the marital one (Ida and John), the parental one (John's influence), and the extended family one (the grandparents). As you learned about these systems, you also learned the three basic assumptions that guide the family systems framework: input/output, wholeness, and

boundaries. As you also read, there are many factors that affect the parental subsystem; these factors include the positive outcomes and unique factors to consider when working with foster parents, adoptive parents, same gender parents, mothers, and fathers. Finally, you read how cohesion and adaptation in a family can lead to overall well-being, and you know that Ida and John are cohesive—they have a solid marriage—and adaptable, for they have learned that Steven, their “fluke” son, demands (and gets) nothing less than his parents' ability to be flexible in the many functions that they and other families perform. To learn about three functions, say “good-bye” to the Robertsons and “hello” to the Prices.