

# CHAPTER 4

## COLLABORATING WITH AND SUPPORTING FAMILIES OF CHILDREN WITH ASD

### In this chapter, you will learn about:

- Strategies for creating effective partnerships with families built on trust, collaboration, and authentic caring.
- The theoretical framework for understanding parent–teacher partnerships, including family systems theory, Bronfenbrenner’s bioecological theory, and Vygotsky’s social-cultural theory.
- Sociocultural characteristics of families and their children with ASD such as divorce, single-parent households, remarriage, and blended families.
- Factors contributing to a family-centered approach that builds on the strengths of families.
- Addressing the needs of siblings.

### THE FAMILY AS A VALUABLE PARTNER

**The Individuals with Disabilities Education Act** (IDEA, 2004) mandates parent involvement in every phase of the special education process, including pre-referral, assessment, creating the educational plan, and monitoring progress. Parents of children with Autism Spectrum Disorder (ASD) are often assertive advocates who have overcome barriers to having their child identified as having ASD and have developed areas of expertise associated with ASD and their child (Stoner et al., 2005). The difficulty many parents report obtaining the initial diagnosis from medical professionals can impact their expectations about the teacher–parent relationship (Stoner et al.). Furthermore, ASD is a



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complex disorder with an unknown etiology that can add to the frustration parents often feel about understanding the disorder.

Partnering with families requires establishing a relationship built on trust. In addition, demonstrating competence, professionalism, and authentic caring require intentional skill development. Careful planning for conferences, inclusive practices during meetings, active listening skills, and conflict resolution skills are important for establishing trust and strengthening the family–school partnership.

An example of a promising practice for training teachers to collaborate with parents of children with ASD during educational planning is “the collaborative model for promoting competence and success”

(COMPASS; Ruble, Dalrymple, & McGrew, 2010). COMPASS is a teacher training intervention that supports teachers consulting with parents to target three goals that have been identified as deficit areas during assessment. Teaching strategies are identified based on the outcome of the prioritized goals. In a study of 35 special education teachers of children with ASD, teachers trained in the COMPASS model had significantly better individualized education program (IEP) goal attainment of target objectives than teachers of children with ASD not trained in the model (Ruble et al.). Furthermore, high treatment fidelity was reported in the COMPASS-trained group.

### ***Establishing Trust***

Trust is the backbone of an effective family–school partnership (Angell, Stoner, & Sheldon, 2009; Hoy & Tschannen-Moran, 1990; Turnbull, Turnbull, & Wehmeyer, 2007). Although parents and educators may have different belief systems and expectations about the partnership, trust provides a framework to investigate differences and develop shared goals (Angell et al.). However, parents of children with ASD may enter into the teacher–parent relationship distrustful of school personnel (Marcus, Kunce, & Schopler, 2005). Often they have experienced barriers to obtaining a diagnosis accessing services for their child

(Stoner et al., 2005). Furthermore, a child with ASD often presents unique and significant stressors to all family members, particularly mothers (Kuhn & Carter, 2006). In particular, research suggests that mothers of children with ASD experience significant stressors related to the pervasive nature of the disorder, lack of information about interventions and the course of the disorder, and challenging behaviors sometimes associated with ASD (Osborne & Reed, 2009; Phetrasuwan & Miles, 2009). In fact, parents of children with ASD may experience greater levels of stress than parents of children with other developmental disabilities or special health care needs (Schieve, Blumberg, Rice, Visser, & Boyle, 2009).

Angell, Stoner, and Sheldon (2009) identify barriers to a trusting relationship as including a lack of perceived competence (teachers appearing to lack knowledge about their child's disability), a school climate lacking acceptance and warmth toward children with disabilities and their families, barriers to receiving services, and problems with the multidisciplinary team. An overarching component of establishing trust is ongoing and effective communication. Angell and colleagues state, "The importance of communication in the development of trust cannot be overemphasized" (p. 167). They describe effective communication as honest, frequent, and immediate (communicating emerging concerns immediately).

**Table 4.1** Establishing Trust Within the Parent–School Partnership

- **Confidentiality**—Strive to maintain the family's confidentiality (Turnbull et al., 2007). Although personal family information can be important in documenting developmental history and other aspects of a child's functioning, be sure to honor a family's confidentiality to the greatest extent possible.
- **Reliability and Commitment**— Follow through with promises made to parents. Check to make sure that services and assessments have taken place within a reasonable time frame.
- **Communication**—Address problems as they arise, clearly clarify concerns and points made during interactions, practice good listening skills, and express yourself in a straightforward and candid manner (Angell et al., 2009; Hoy & Tschannen-Moran, 1990; Turnbull et al.).
- **Professional Competence**—Strive to learn about autism and interventions to address the child's identified needs. Investigate organizations, websites, books, or professionals with which you might consult or refer parent for additional information (Turnbull et al.). Parents perceive competent teachers as flexible and willing to try modifications or accommodations that may support their child (Angell et al.).

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**Table 4.1** (Continued)

- **Collaboration Within the School Team**—Trust in the school partnership is enhanced when parents perceive effective collaboration within the school multidisciplinary team (Angell et al.).
- **Equality and Respect**—Affirm that parents possess valuable knowledge and expertise about supporting their child (Angell et al.; Harte, 2009; Turnbull et al.). Make efforts to use inclusive language to encourage parents to voice concerns, contribute ideas, and share information.
- **Honor cultural differences**—Demonstrate sensitivity to cultural differences and reflect upon how the child’s beliefs and values may differ from your own (Dyches, Wilder, Sudweeks, Oblakor, & Algozzine, 2004; Summers et al., 2005; Turnbull et al.).

### **Authentic Caring**

Another significant component of trust is parents’ perception that teachers demonstrate **authentic caring**. Angell and colleagues (2009) define authentic caring as “actions and behaviors that parents identified as genuine, voluntary, child focused, and benefitting children or the parents themselves” (p. 166). Parents perceive teachers as demonstrating authentic caring when teachers go beyond what is required by the system and treat their child as an individual.

## **THEORETICAL FRAMEWORK FOR FAMILY-EDUCATOR PARTNERSHIPS**

As a teacher, understanding issues associated with families allows you to work more effectively with parents. Beliefs about child-rearing practices, disability, and interventions are a reflection of the family’s cultural experience. Recognizing a belief as a cultural difference, rather than an attitude of indifference, allows the teacher to encourage parents to become more involved in their child’s education.

Teachers are part of the interconnecting relationships of the child and the family. Let’s consider three theories that address these complex relationships to facilitate the parent–teacher partnership.

### **Family Systems Theory**

Each child in your class is part of a dynamic family system. All families are unique, and the characteristics of families change over time. Divorces, adoptions,

births, deaths, and other transitions impact every member of the family. A child with ASD may place additional demands on parents. Recognizing the family as a system may help you identify resources or supports to alleviate stressors. Identifying supports for a sibling struggling academically, respite care so parents can have a date night, or a parent support group to help parents connect with social opportunities can have positive outcomes for the child sitting in your classroom.

**Family systems theory** was developed to explain the dynamic nature of the family (Minuchin, 1974; Satir, 1988). Family roles, boundaries and rules are components of the family system that can impact the parent–teacher relationship (Christian, 2006). Family systems theory helps explain how different family members may play certain roles. For instance, older siblings may serve as caretaker, a family member may serve as the peacemaker to negotiate conflict, or one parent may be more likely to interact with school personnel. The child with ASD has a family role as well. Their role is part of the intricate and fluid balance of the family system. Family roles are influenced by the culture in which the family lives or has lived.

Some parents immediately express a willingness to collaborate with the school. Others seem to set up a barrier resisting collaboration. At times, closing boundaries can help families strengthen the family unit. Sometimes these



Although the classroom teacher is not expected to play the role of a family therapist, understanding family systems theory provides a framework for conceptualizing the child within the family unit.

### CHAPTER REFLECTION: Your Family System

When you were a child, did your parents ever change jobs, have to care for an ill family member, or go through a difficult time? Did you have a sibling who left home for college or needed extra support from your parents? Consider how stress

placed on one member of your family impacted your own family system. Did family rules and individual roles become more pronounced and boundaries more closed, or was your family open to outside support?

boundaries help families unite and support each other. However, sometimes-closed boundaries prevent families from getting the support they need (Goldenberg & Goldenberg, 1996).

Hecimovic and Greogory (2005) describe characteristics for being an effective partner and support for families of children with ASD. These characteristics include respecting the uniqueness of the family system and communicating confidence in family members; praising families when they experience accomplishments; demonstrating empathy and sensitivity when working with families struggling to find appropriate interventions and meet goals; and being future-oriented and optimistic about the future. Overall, creating a family-centered support system is critical. Each member of the family, and the family system itself, impacts the development of the child with ASD. Likewise, the child with ASD impacts all members of the family. Consequently, supports that buffer the resiliency of the family system and its members facilitate the development of individuals with ASD (Symon, 2001). These supports can be introduced by outside systems, such as schools.

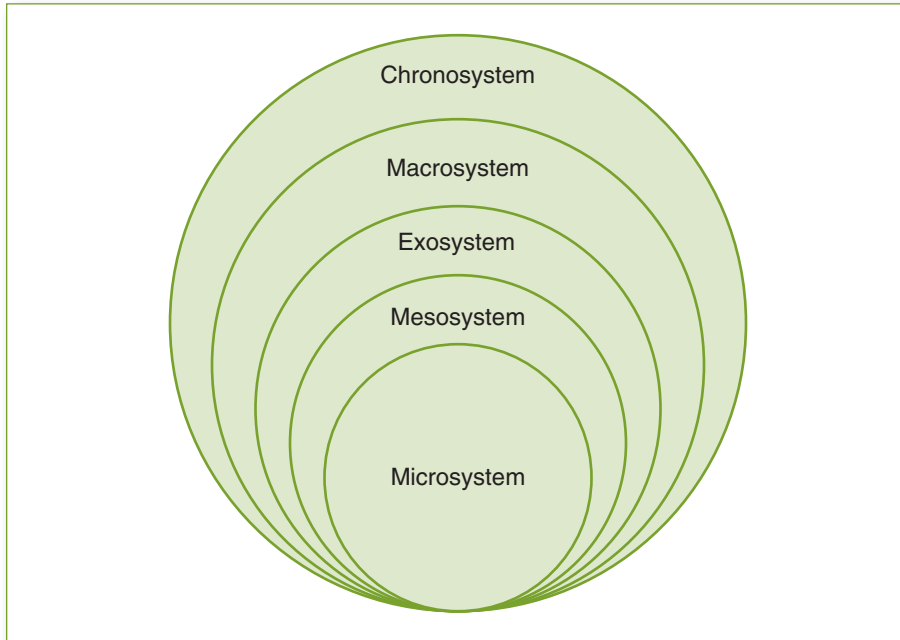
Supports to families can create opportunities for families to socialize and reduce isolation, attend meetings to participate in educational planning, and connect with advocacy groups to increase feeling empowered and optimistic. Integration of family-centered practices has been embedded into federal legislation guiding education of children with special needs.

### ***Bronfenbrenner's Bioecological Theory***

There are many other systems affecting the family. A framework for understanding these systems allows teachers a better understanding of the family and the interaction between family and school. The **bioecological theory** offers insight into developing special education interventions and strengthening the home-school partnership (Sontag, 1996). In fact, Bronfenbrenner advocated a family-centered approach to supporting children with special needs (Bronfenbrenner, 1975). Bronfenbrenner's bioecological systems theory (2004) describes nested levels in which the family system is nested, as depicted in Figure 4.1.

The level teachers might first consider is the **microsystem**, which involves day-to-day interactions. For example, a mother asks the teacher to work on independence in dressing at school. She describes morning battles involving picking out clothes and trying to get him to put them on. Her description of mother-son interaction is an example of a microsystem.

However, there is likely more to this story than meets the eye. Other systems may be impacting her concerns. For instance, difficulties getting dressed in the morning have resulted in the child being late to school many mornings. After

**Figure 4.1** Bronfenbrenner's Bioecological Systems Theory

several weeks of this, the school contacts the mother to let her know that her son has been excessively tardy to school. They inform her that if this pattern continues they will make a referral to social services. This relationship between the mother and the school represents a **mesosystem**, which is a relationship between microsystems (school and family). The school–family mesosystem impacts the urgency she feels in addressing her son's compliance and independence with getting dressed. If the teacher understood this additional level, she could speak with the principal and ask for some leniency as they worked together on the shared goal of increasing dressing behaviors in the morning routine.

Furthermore, recent changes in the father's employment require him to travel more frequently. Thus, the father is now less available to help in the morning. The father's work is an example of an **exosystem**, or social setting not immediately impacting the child but influencing relationships. This additional information helps explain why the mother had not brought up these concerns earlier in the school year and why they are so pressing now.

In public schools, federal financial support is directly tied to student attendance. In these tough economic times, schools may feel pressure to come down hard on excessive absences and tardiness. In this case, the school's reaction to a child being

tardy to school is influenced by a **macrosystem**, which is an institution or aspect of the greater culture that influences the microsystem. Helping the parents understand why the school is threatening to refer them to social services might ease feelings of persecution or distrust, and encourage the parents to meet with the principal to talk about this problem and set realistic goals. For instance, it might be acceptable to allow the child to come to school by 9:00 a.m. for 2 weeks while the teacher and parents work together with the child on dressing skills.

The last system in Bronfenbrenner's theory is the **chronosystem**, which describes the impact of sociohistorical changes over time. The mother may have become increasingly aware that parents can raise concerns about her child's educational goals because of increased awareness from autism advocacy groups and changes in special education laws over time. Furthermore, it is currently recognized that autism is a neurobiological disorder and that parents do not cause their child to have ASD. Thus, the time period in which one lives also impacts family decisions.

### **Vygotsky's Social-Cultural Theory**

**Vygotsky's social-cultural theory** (1962) considers the impact of culture on learning and overall development. This theory has gained increasing popularity in education because, unlike many other theories of learning and development, it takes into account the cultural context of learning. Vygotsky (1962) believed that learning takes place within the context of relationships. Cultural tools for transmitting knowledge, such as writing, mathematics, music, and storytelling, are passed down through generations.

Vygotsky believed that learning is most effective when it takes place within a child's **zone of proximal development**. This zone captures a point at which the child can almost master a skill alone, but still requires some support. Adults who know the child well can **scaffold** an activity so that support is slowly reduced as the child gets closer to mastery (Rogoff, 1990). This is a useful concept for developing educational goals.

You might wonder if such a theory applies to a child who has weaknesses in social communication and low motivation for engaging in social relationships. Although children with ASD might not learn the same as other children, they are still impacted by the culture in which they live. For instance, the sequence of behaviors embedded in morning routines is intricately related to culture (get dressed, eat breakfast, brush teeth). An adult who knows a child's preferences and skill level is able to enhance learning by creating mediated learning opportunities. In fact, some interventions developed for children with ASD are based on social-cultural theory, such as floortime and other play-based therapies (Greenspan & Wieder, 1998; discussed in Chapter 10).



An awareness of how a child plays and how parents interact with the child during play can facilitate learning in the classroom. For instance, in a survey of 748 parents of children with ASD conducted by the National Autistic Society (2007), parents reported gains in basic academic skills when Thomas the Train pictures, toys, and stories were used to teach concepts such as colors and numbers. Parents reported using Thomas & Friends to develop language, social skills, and emotional regulation. Parents also provided mediated learning experiences to help their children with ASD develop parallel play (side-by-side play) with siblings using Thomas trains.

### CHAPTER REFLECTION: Sandra Humphreys, a Parent-to-Parent Leader

Sandra is a Navigator Team Leader for her county. The statewide Navigator Team Project is managed by Parent to Parent of Georgia, the state's Parent Training and Information Center that is a federally funded program authorized under part D of IDEA. Sandra and her team have helped develop programs that provide monthly support meetings for parents of children with ASD and other disabilities, group outings for families, recreational programming such as "Challenger Sports" for children with special needs, and hosted trainings for families navigating the public school system's special education programs. She now works with Parent to Parent developing new teams in other counties throughout the state.

**Author:** *How did you get involved with Parent to Parent?*

**Sandra:** I began just advocating for my own daughter. When I retired, my daughter was 8,

and I wanted to volunteer somewhere. I had been that isolated mom, focusing all my attention around my daughter, Emmie. Now I work systematically to help all children, which also helps my daughter. By volunteering my time to lead a Navigator Team, I have learned even the smallest effort can make big differences for many children.

**Author:** *What are some of the concerns that parents express at the monthly brainstorming meetings?*

**Sandra:** Our earliest goals were to address core issues such as the need for child care, recreation for our kids in the community, social needs of families and children, and parent educators to help understand

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special education routines and laws. The top three goals continue to be (1) recreation, (2) socialization, and (3) education.

**Author:** *Describe the challenges you face in your role as leader of this parent-led support program?*

**Sandra:** Getting the word out to families that we are here and gaining their trust. It has been most difficult involving our underserved populations in the community. We would like to find a Spanish-speaking outreach worker and to have more African American families participate in our program.

**Author:** *What advice could you give to teachers working with parents?*

**Sandra:** When a parent speaks up with a question or comment, it is probably a bigger deal than you think! Many parents are afraid to voice their concerns or questions, so really pay attention to what they are asking or saying. Encourage parents to keep a journal of changes in medical or therapy regimens and to give all service providers a copy of the summary. Parents don't always know how to be good historians, and those working with their children often depend on them for background information. Encourage parents to attend support groups or workshops or join Navigator Team and become active in making changes that will support their child.

## **SOCIOCULTURAL CHARACTERISTICS OF FAMILIES AND THEIR CHILDREN WITH ASD**

### ***The Impact of ASD on the Family System***

Children with ASD are not only students in a classroom, but members of a family. Every family is different, and understanding the sociocultural characteristics of a family is important in effectively collaborating with parents. Both

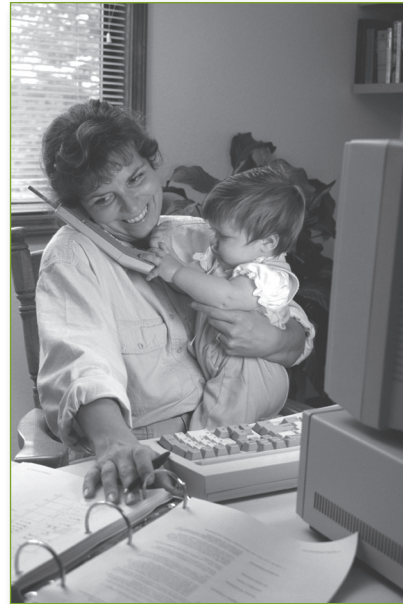
family systems theory and Bronfenbrenner's theories predict that difficulties experienced by one member of the family will impact the entire family system.

There is a significant body of research describing high stress levels of families that have children with special needs, particularly when families include children with ASD. In fact, families of children with ASD appear to experience a greater degree of stress than families of children with other types of special needs (Bouma & Schweitzer, 1990; Higgins, Bailey, & Pearce, 2005; Weiss, 2002). There are likely many factors contributing to this high level of family stress associated with ASD, including difficulties getting the initial diagnosis, lack of consensus about the cause and prognosis, uneven profile of skills, pervasive nature of the disorder, tremendous out-of-pocket expenses for treatment, and lack of integrated support services to address ASD.

When extra demands are placed on parents, multiple systems are impacted within and outside the family. Sometimes the stresses associated with raising a child with ASD interact with other characteristics of the spousal relationship resulting in marital discord. Marital discord is common in all types of families, but is exacerbated by additional stress to the family system. As parents have less time to devote to each other and themselves, issues such as family roles, resource limitations, and frustration are heightened.

### ***Families of Divorce***

The rate of divorce among families with children with ASD is not clear (Freedman et al., 2010; Hartley et al., 2010). Regardless of the frequency, marital stress and divorce introduces significant changes into all members of the family at many different levels (Rivers & Stoneman, 2003). Family changes associated with divorce may be particularly confusing and disturbing to a child with ASD. It is important that parents are able to put aside their differences to coparent and negotiate what is best for the children. For instance, visitation routines



There is a significant body of research describing high stress levels of families that have children with special needs, particularly when families include children with ASD. The many demands placed on families are exacerbated by lack of resources.

need to be strictly followed to introduce a level of predictability and stability into the noncustodial parent–child relationship. Likewise, a predictable pattern of activities during scheduled visitation may help provide comfort and smooth the transition.

### ***Single-Parent Households***

Children with disabilities more likely to live in single-parent household, primarily raised by their mother (Fujiura & Yamaki, 2000). Single-mother households, in particular, are more likely to live in poverty than other types of households (Fields, 2003). Most often, when parents divorce, the mother ends up with custody of the children. When families divorce, financial and emotional resources for addressing family needs are often significantly reduced (Boyd & Bee, 2010). In fact, in single-mother households the family income drops an average of 40% to 50% following a divorce (Bradbury & Katz, 2002).

When raising a child with ASD, cohabitating parents often decide to embrace traditional division of labor roles to address the intense caregiving responsibilities (Gray, 2002). Mothers returning to work following a divorce may find child care difficult to coordinate. Children with ASD may require specialized child care, which tends to be both expensive and difficult to find (Parish et al., 2008). Even mothers working prior to a divorce are likely to experience additional child care needs following divorce. Fathers with child custody are likely to experience similar difficulties. Often, single-parent families rely on extended family, particularly grandparents, for support with child care. Teachers can encourage the custodial parent to involve extended family members playing a key role in the child’s care in educational meetings and planning.

### ***Remarriage and Blended Families***

Some parents decide to remarry. These new blended families introduce stepparents and sometimes stepsiblings into the family. With so many changes introduced into the family, all the children are likely to need extra time with their biological parents and extra patience and love as they adjust to their new family. These changes are likely to be especially hard for a child with ASD. Social stories might be a helpful strategy for creating a scripted, visual, and concrete story explaining the sequence of events that take place in the new family environment (social stories are discussed in Chapter 10). Consultation with the custodian parent would be helpful in capturing the routines altered by the new family such as dinnertime, bedtime, and getting ready for school in the morning. Teachers

may consider asking the custodial parent if the stepparent might be included in meetings and goal planning. In any case, teachers should encourage stepparents to contact the school if they have specific questions about ASD.

The addition of stepsiblings provides increased opportunity for socialization. However, stepsiblings need to be provided with age-appropriate information about ASD, and rules about engagement for play, sharing personal items, arrangement of things in the house, and so on. Parents might be encouraged to lay down ground rules about how to prevent and address challenging behaviors for the family. It is especially important that a typically developing sibling (sibling without ASD) not be thrust into the position of caretaker and defender of her sibling with ASD. Siblings may find support from a sibling group for biological siblings and stepsiblings through local autism support chapters. Supports for siblings are discussed more later in the chapter.

There are many other types of family arrangements, and every family is unique. Taking time to understand the unique issues and changing dynamics of a child’s family will help you better support the child in the classroom. Table 4.2 provides tips for working with all types of families experiencing transition or hardship.

**Table 4.2** Supporting Children With ASD and Their Families During Significant Transitions

Sensitivity and support for the child with ASD in the classroom
Children in your classroom may need a “grace period” when these new transition occur, with somewhat lowered expectations.
Divorce or remarriage of parents may negatively impact the ability to focus and perform in the classroom setting for any child. However, the classroom routines are likely to be the one place of consistency in the child’s life. Thus, a sensitive approach to continuing with educational goals is desired.
Social stories may be helpful in providing structure for understanding new home routines such as visiting the noncustodial parents or getting ready for school without the help of the other parent. Social stories are discussed in Chapter 10.
A functional behavior assessment (FBA) may also be helpful in determining what triggers new challenging behaviors, and the consequences of the behaviors to create behavior plans that helps the child manage behavioral difficulties at school. The FBA and related behavior management strategies are discussed in more detail in Chapter 7.

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Table 4.2 (Continued)

<b>Communication with both parents</b>
Keep the channels of communication between school and parents open for both parents.
If one parent has sole custody of the child, request permission from that parent to communicate with the noncustodial parent. Include both parents in meetings and decision making when appropriate.
Share information about parent support groups so parents do not feel alone.
Be a resource for information by recommending books, websites, workshops, and referrals to other agencies for support.
<b>Supports for siblings and stepsiblings</b>
Assist parents in locating siblings support groups.
Help parents identify age-appropriate information about ASD for new stepsiblings.
With parent permission, consult with the siblings' classroom teachers to help them be aware of the new family transition and possible need for emotional support.
<b>Financial issues</b>
Single parents often experience a reduction in family income following a divorce. This can be especially devastating for a single mother who had been a stay-at-home mother to devote energy to the demands of child care. Teachers can be helpful in providing information about financial supports for which she may be eligible.
The school social worker is a good resource for helping parents understand how to apply for resources such as Medicaid, state children's health insurance programs, Supplemental Security Income (SSI), and Social Security Disability Income (SSDI).
The National Autism Association's Family First program offers resources for families experiencing marital stress, including small grants for marriage therapy.
The Helping Hands program of the National Autism Association also offers financial support to help defray costs of interventions for children with ASD for families experiencing significant financial hardship.
There may be additional sources within your state or local community. Local autism support groups may have more information about these supports.
<b>Respite care</b>
Encourage parents to learn about available <b>respite care</b> (a short-term child care service) and take advantage of it. They will be better parents to all of their children when they are able to take care of themselves and nurture other relationships.
Finding respite care can be time consuming and may not all meet the needs of the family. However, encourage parents to investigate available resources. Look for services that offer flexibility.
The United Cerebral Palsy association offers a "Respitivity" program that includes families with children who have developmental disabilities. The Respitivity program offers respite care as well as hospitality support, such as a 24-hour getaway, including hotel and meals donated by local businesses in the community. Availability of the Respitivity program likely differs from state to state, but it is worth looking into!

### What can the teacher do to help?

Generally teachers are not trained family therapist and should not work outside their boundaries of knowledge or training. However, recognition of a significant family transition that has taken place and empathy for the ramifications of these transitions can go a long way. The following are suggestions for supporting children and families that have had significant family transitions.

## EMPOWERING FAMILIES OF CHILDREN WITH ASD

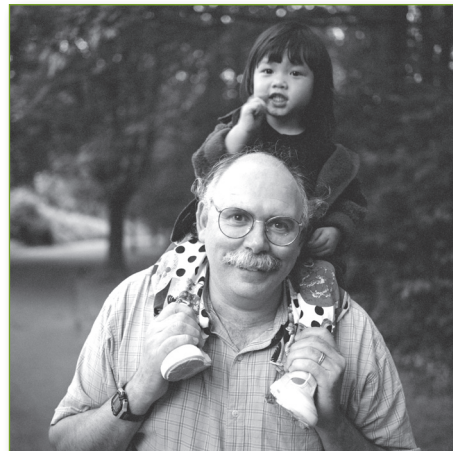
There is much research documenting the profound degree of caregiver stress associated with parenting a child with ASD (i.e., Gray, 2005; Hastings et al., 2005; Phelps, McCammon, Wuensch, & Golden, 2009). In fact, research indicates that caregivers of children with ASD experience greater degrees of stress than parents caring for children with other types of disabilities (Abbeduto et al., 2004; Grey, 2002; Schieve et al., 2007). However, despite experiencing a significant degree of caregiver stress, families have unique strengths that can be highlighted and integrated into educational planning. Identifying and building on family strengths and coping mechanisms can also be used to help parents cope with stress associated with caring for their child with ASD (Pottie & Ingram, 2008; Schieve et al.). When parents are empowered to cope with stress, identify their child's needs, and collaborate to plan for their child's education, there are significant benefits to the child's overall development (Dunst, 2002).

### Recognizing and Building on Strengths in the Family System

#### Extended family and friends

Although grandparents may not fully understand ASD, often they offer unconditional love, assist with child care, and provide empathy and friendship (Hillman, 2007; O'Brien & Daggert, 2006).

However, intergenerational conflicts sometimes arise when grandparents draw upon biases about people with disabilities that existed during



Grandparents are often a source of support and guidance for families. These supports can mitigate stressors associated with caring for the needs of a child with ASD.



their youth (O'Brien & Daggert, 2006). Grandparents may lack knowledge about the diagnosis and symptoms of ASD (Margetts, Le Courteur, & Croom, 2006; Sandler, 1998). Furthermore, grandparents and other extended family may not fully understand the emotional and physical toll that caring for a child with ASD has upon the entire nuclear family (Hillman, 2007). When grandparents are integrated into school activities, meetings, planning sessions, and information/training opportunities, they can provide invaluable supports for the child with ASD and the entire family.

In some instances, grandparents are the primary caregivers. Grandparents caring for a child with ASD may need extra support from the school and community. Financial limitations, difficulty accessing necessary supports, and considerations of who will care for their grandchild when they die have been identified as concerns of grandparents caring for children with disabilities (Janicky, McCallion, Grant-Griffin, & Kolomer, 2000).

### **Spirituality and the family's religious community**

Although public schools have the responsibility of separating matters of religion from public education, it can be helpful to recognize the support and strength some parents associate with their religion and religious community. Research indicates that some individuals find comfort in embracing their religion and spiritual practices during times of stress (Graham, Furr, Flowers, & Burke, 2001). In a study of 119 mothers of children with ASD, greater levels of maternal religious belief were associated with positive coping skill such as a higher self-esteem and a more optimistic life perspective (Ekas, Whitman, & Shivers, 2009). Furthermore, in a survey about the role of religion in families of children with autism, 66% of families reported personal prayer as a means of expressing their beliefs and seeking comfort (Coulthard & Fitzgerald, 1999). Some parents report experiencing a heightened sense of spirituality resulting from learning to cope with the day-to-day struggles associated with caring for their child with ASD (Ekas et al.).

### **Siblings**

There is conflicting research regarding the effect of growing up with a sibling with ASD (Quintero & McIntyre, 2010; Rivers & Stoneman, 2003). However, sibling relationships are likely to impact all siblings in significant ways.

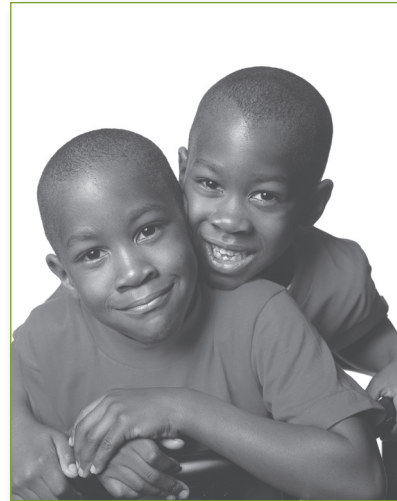


Typically developing siblings provide many benefits to their siblings with ASD. Siblings provide rich experiences with social interactions, model appropriate behaviors associated with play, provide companionship, and give opportunities to practice sharing (McHale, Sloan, & Simeonsson, 1986; Turnbull et al., 2006). In addition, siblings are likely to participate in some aspects of care for their sibling with ASD, with caregiving increasing as they age (Turnbull et al.). Siblings may act as a protector outside the home (Donnelly et al., 2000) and may provide their sibling with ASD inclusive social opportunities within the community to which they might not otherwise have access. Siblings may even take on the role of primary caregiver for their sibling with severe ASD when parents are no longer able to do so (Quintero & McIntyre, 2010).

The impact of having a sibling with ASD on the typically developing sibling is complex and dependent on many factors, including severity of the ASD, individual characteristics, family supports, and degree of marital conflict between parents (Ferraioli & Harris, 2010).

Living with a sibling with ASD may promote development of interpersonal skills, nurturing skills (Howlin & Yates, 1990), and positive self-concept (Macks & Reeve, 2007). Furthermore, these early experiences may contribute to a desire to help others overcome adversity reflected in future career choices (Ferraioli & Harris, 2010). Siblings of children with ASD may also feel like a valued member of the family, as they are counted on to perform certain care duties for their siblings.

However, these positive experiences may come at a cost. Siblings of children with ASD may receive less parental attention and other family resources that are concentrated to meet the demands of caring for the sibling with ASD (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004) and may be exposed to significant levels of family stress (Henderson & Vanderberg, 1992). As they approach adolescence and increasingly value conformity to their peer groups, siblings of children with ASD may be embarrassed by the unusual behavior of their sibling and resent not being able to have friends spend the night or join in family activities (Ferraioli & Harris, 2010). In addition, they may feel burdened by caregiving demands and worry about how they might continue to care for their sibling when their parents are gone.



Siblings of children with ASD often benefit from support to address conflicting feelings and emotions they may have about their sibling with ASD.

## Addressing Needs of Siblings of Children With ASD

### Age-appropriate education and information about ASD

It is important to recognize each sibling as a unique individual with strengths as well as needs (O'Brien & Daggert, 2006). Sometimes siblings of children with ASD lack information or have misinformation about their sibling's behaviors, the cause of ASD, and other aspects of ASD. For instance, young children may not understand the stereotyped and repetitive behaviors, and may become frustrated when they are rejected during play (Ferraioli & Harris, 2010). Likewise, opportunities to learn effective means of communication and social engagement with their siblings with ASD can help empower typically developing siblings (O'Brien & Daggert).

### Social Support

Another source of sibling stress is feeling alienated from peers who they may perceive as not understanding the day-to-day experience of living with a sibling with ASD (Kaminsky & Dewey, 2002). Social support is important for all members of the family. Family support groups can help connect children and teens with peers who understand what it is like to have a sibling with ASD. The "Chapter Reflection: Sib Shops" box describes a program that connects children with siblings who have developmental disabilities with social support.

#### CHAPTER REFLECTION: Sib Shops

**Sib Shops**, created by Don Meyers and conducted all over the country, provide a forum for siblings of children with disabilities to connect with their peers and discuss meaningful topics such as feeling embarrassed by a sibling's behaviors and concerns about their sibling's long-term care needs. These events are described as fun programs that include games, cooking, and other recreational

activities where kids can socialize with peers who also have siblings with disabilities. In addition, Sib Shops help parents and teachers better understand the needs of children and adolescents who have siblings with disabilities.

*For more information, visit Sibling Support Project website at [www.siblingsupport.org](http://www.siblingsupport.org).*

### Quality Time With Parents

Although it is important to include siblings with ASD in family activities, at times typically developing siblings may need some time alone with their parents. Respite care can allow parents to attend special events with their typically developing peer, without concerns about drawing attention away from their special day. Making time to focus on each child's needs is important to the entire family system.

### PARTNERING WITH FAMILIES FROM DIVERSE ETHNIC BACKGROUNDS

Every family should be considered as a unique system with individual strengths and needs. Thus, we must be careful to not stereotype families or family members based on ethnicity. However, families from cultural backgrounds different from the majority culture share some characteristics (Greder & Allen, 2007).

Table 4.4 highlights some important points to consider when working with families from diverse ethnic backgrounds. Educators are encouraged to learn as much as possible about individual families and their culture when partnering to support children.

Aspects of parenting beliefs and beliefs about disability are influenced by culture. For instance, families from collectivist orientations (such as many Latino and Asian cultures) may be less interested in independent skills, such as

**Table 4.3** Tips for Helping Parents Support Their Typically Developing Child

- Teach parents how to introduce topics such as feeling embarrassed about their sibling's behavior or concerns about protecting their sibling.
- Help the child feel secure and safe.
- Accept fears, anger, and frustrations as natural. Offer unconditional love and make time to spend with each child.
- Emphasize that each child's needs are important and each child is an individual.
- Make sure caregiving demands of typically developing child for child with ASD are age appropriate and not overwhelming.

Adapted from O'Brien and Daggert (2006).

**Table 4.4** Working Families From Diverse Backgrounds

- Recognize that families from cultural minorities straddle two worlds (known as biculturalism). They are members of their communities, yet retain a cultural identity that may not be understood or valued by the majority culture (Dauphinais, Charley, Robinson-Zañartu, Melroe, & Baas, 2009).
- Reflect upon the impact of historical power inequities. Institutionalized racism and inequity are a real part of family memories for many families from ethnic minority backgrounds (Blue-Banning et al., 2000; Harry, 1992). What appears to be disinterest in collaborating with the school, may actually be distrust of institutions, such as schools (Harry, 1992).
- Strive to understand roles of family members and extended family. Parents may defer to elders in the family, such as grandparents, in making important decisions.
- Make extra efforts to provide information in a language parents can understand. Inquire about literacy needs in private, rather than during conferences with a group of people. Parents cannot fully participate as partners in supporting their child if they do not have access to information (Klinger & Harry, 2006). Likewise, parents need to be able to communicate their questions, concerns, and wishes to the educational team.

dress oneself, and more interested in their child following appropriate social protocols in public settings or being accepted by their family (Blue-Banning, Turnbull, & Pereira, 2002). These factors should be taken into consideration during educational planning.

## SUMMARY

The family is a valuable partner working with educators and other team members to set goals, evaluate functioning, choose interventions, and plan for transitions. Establishing trust is key to creating and maintaining an effective family–school partnership. Trust is developed through ensuring confidentiality, being reliable and committed to following through with promises, engaging in good communication, demonstrating professional competence, integrating resources from the school team, treating parents equally and with respect, and honoring cultural differences. The family systems theory, Bronfenbrenner’s bioecological, and Vygotsky’s sociocultural theories provide theoretical framework for creating family-centered supports.

Teachers should learn about the family system to the extent possible. Characteristics such as low income, being a speaker of English as a second language, single-parent households, remarriage, and being a cultural or ethnic minority can place additional stressors on the

family. Families that have children with special needs, particularly ASD, may benefit from information in obtaining supports for siblings, information about financial supports, and respite care (including after school and summer). Educators are encouraged to learn as much as possible about the culture of families when partnering to support their child.

### TEACHING TIPS

- Incorporate a means of personal reflection into your weekly practice as an educator. For instance, in a journal consider the extent to which you were able to work toward building trust with the parents of children you support. Set goals for areas you need to strengthen, such as carrying through with promises made to families, effective communication with parents, professional competence (are there areas in which you could use additional training?), collaborating with the school team, demonstrating affirmation and respect for beliefs and preferences of parents, and honoring cultural differences.
- Work toward understanding the roles of family members and extended family. Make sure parents understand that they are welcome to invite extended family or friends to participate in IEP meetings and discussions.
- Determine if a parent requires information in a language other than English, or is unable to read, prior to a formal meeting such as an IEP. To the extent possible, ensure that parents have access to information about their child's progress, special education procedures, and so on, in the language and medium they can access.

### DISCUSSION AND REFLECTION QUESTIONS

1. How might you work toward building a partnership built on trust with parents who had a bad experience working with their child's previous teacher?
2. When you talk with the child's previous teacher, she informs you that the parents are angry and argumentative during meetings. She feels that the parents blame the school for their child's ASD. Consider what you might do in preparing for the conference to help the parents feel included and prepared for the meeting? What steps can you take during the meeting to diffuse conflict and address parental concerns, while also meeting the goals of the meeting? Finally, how can you follow up with parental concerns and issues raised during the meeting to continue to build parental trust?
3. You have a child in your class with a sibling with ASD. This child is academically successful, yet seems socially withdrawn. How might you go about providing support for the sibling and linking resources with the family?

## RECOMMENDED FURTHER READINGS AND INTERNET SOURCES

### Further Readings

- Carter, E. (2007). *Including people with disabilities in faith communities: A guide for service providers, families, and congregations*. Towson, MD: Paul H. Brookes.
- Turnbull, A., Turnbull, R., Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality. positive outcomes through partnership and trust* (5th ed.). Upper Saddle River, NJ: Pearson Prentice Hall.

### Internet Sources

- Family Support America—Provides resources and links to programs that are family-centered. <http://www.familysupportamerica.org>
- National Center for Culturally Responsive Educational Systems. [www.nccrest.org/publications/briefs.html](http://www.nccrest.org/publications/briefs.html)
- About.com: Autism—Provides websites linking resources about including people with autism in religious services within several different faiths. <http://autism.about.com/od/copingwithautism/p/spirituality.htm>
- Sibling Support Project. <http://www.siblingsupport.org>

## REFERENCES

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation, 109*, 237–254.
- Angell, M. E., Stoner, J. B., & Shelden, D. L. (2009). Trust in education professionals: Perspectives of mothers of children with disabilities. *Remedial and Special Education, 30*, 160–176.
- Blue-Banning, M. J., Turnbull, A. P., & Pereira, L. (2000). Group action planning as a support strategy for Hispanic families: Parent and professional perspectives. *Mental Retardation, 38*, 262–275.
- Blue-Banning, M. J., Turnbull, A. P., & Pereira, L. (2002). Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research & Practice for Persons with Severe Disabilities, 27*, 204–219.
- Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46*, 722–730.
- Boyd, H., & Bee, D. (2010). *Developing child* (12th ed.). Boston, MA: Pearson.
- Bradbury, K., & Katz, J. (2002). Are lifetime incomes growing more unequal? Looking at new evidence on family income mobility. *Regional Review, 12*, 2–5.
- Bronfenbrenner, U. (1975). *Influences on human development*. New York, NY: Holt.
- Bronfenbrenner, U. (2004). *Making human beings human: Bioecological perspectives on human development*. Thousand Oaks, CA: Sage.
- Coulthard, P., & Fitzgerald, M. (1999). God we trust? Organised religion and personal beliefs as resources and coping strategies, and their implications for health in parents

- with a child on the autistic spectrum. *Mental Health Religion and Culture*, 2, 19–33.
- Christian, L. G. (January, 2006). Understanding families: Applying family systems theory to early childhood practice. *Beyond the Journal. Young Children on the Web*. Retrieved from <http://www.naeyc.org/files/yc/file/200601/ChristianBTJ.pdf>.
- Dauphinais, P., Charley, E., Robinson-Zañartu, Melroe, O., & Baas, S. (2009). Home-school-community communication with indigenous american families. *Communiqué*, 37, 1–6.
- Donnelly, J. A., Bovee, J., Donnelly, S. J., Donnelly, J. R., Donnelly, L. K., Donnelly, J. R., . . . Callaghan, M. R. (2000). A family account of autism: Life with Jean-Paul. *Focus on Autism and Other Developmental Disabilities*, 15, 196–201.
- Dunst, C.J. (2002). Family centered practices: Birth through high school. *Journal of Special Education*, 36, 139–147.
- Dyches, T. T., Wilder, L. K., Sudweeks, R. R., Oblakor, F. O., & Algozzine, B. (2004). Multicultural issues in autism. *Journal of Autism and Developmental Disorders*, 34, 211–222.
- Ekas, N. V., Whitman, T. L., & Shivers, C. (2009). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 39, 706–719.
- Ferraioli, S. J., & Harris, S. (2010). The impact of autism on siblings. *Social Work in Mental Health*, 8, 41–53.
- Fields, J. (2003). *America's families and living arrangements: 2003*. Current Population Reports, P20-553. Washington, DC: U.S. Census Bureau.
- Freedman, B. H., Kalb, L., Zablotsky, B., & Stuart, E. (2010). *Relationship status among parents of children with autism spectrum disorders: A population-based study*. Paper presented at the International Meeting for Autism Research, Baltimore, MD.
- Fujiura, G., & Yamaki, K. (2000). Trends in demography of childhood poverty and disability. *Exceptional Children*, 66, 187–199.
- Goldenberg, I., & Goldenberg, H. (1996). *Family therapy: An overview* (5th ed.). Monterey, CA: Brooks.
- Graham, S., Furr, S., Flowers, C., & Burke, M. T. (2001). Religion and spiritual beliefs in coping with stress. *Counseling and Values*, 46, 2–13.
- Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, 27, 215–222.
- Greder, K. A., & Allen, W. D. (2007). Parenting in color. Perspectives on parenting. In B. S. Trask & R. R. Hamon (Eds.), *Cultural diversity and families* (pp. 118–133). Thousands Oaks, CA: Sage.
- Greenspan, S. I., Wieder, S., & Simons, R. (1998). *The child with special needs: Encouraging intellectual and emotional growth*. Reading, MA: Addison Wesley.
- Harry, B. (1992). Restructuring the participation of African-American parents in Special Education. *Exceptional Children*, 59, 123–131.
- Harte, H. A. (2009). What teachers can learn from mothers of children with autism. *Teaching Exceptional Children*, 42, 24–30.
- Hastings, R. P., Kovshoff, H., Ward, N. J., Espinosa, F., Brown, T., & Remington, B., (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disability*, 35, 635–644.
- Hecimovic, A., & Gregory, S. (2005). The evolving role, impact, and needs of families. In D. Zager (Ed.), *Autism spectrum disorders: Identification, education, and treatment* (3rd ed., pp. 111–142). Mahwah, NJ: Lawrence Erlbaum Associates.
- Henderson, D., & Vanderberg, B. (1992). Factors influencing adjustment in families of autistic children. *Psychological Reports*, 71, 167–171.
- Higgins, D., Bailey, S., & Pearce, J. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9, 125–137.



- Hillman, J. (2007). Grandparents of children with autism: A review with recommendations for education, practice, and policy. *Educational Gerontology, 33*, 512–527.
- Howlin, P., & Yates, P. (1990). A group for the siblings of children with autism. *Communication, 24*, 11–16.
- Hoy, W. K., & Tschannen-Moran, M. (1990). Five faces of trust: An empirical confirmation in urban elementary schools. *Journal of School Leadership, 9*, 184–208.
- Individuals with Disabilities Education Act, 20 U.S.C. §§ 1400 et seq (2004).
- Janicky, M. P., McCallion, P., Grant-Griffin, L., & Kolomer, S. R. (2000). Grandparent caregivers I: Characteristics of grandparents and the children with disabilities for whom they care. *Journal of Gerontological Social Work, 33*, 35–55.
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 43*, 225–232.
- Klingner, J., & Harry, B. (2006). The special education referral and decision-making process for English language learners: Child study team meetings and placement conferences. *Teachers College Record, 108*, 2247–2281.
- Kuhn, J., & Carter, A. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry, 76*, 564–575.
- Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders, 37*, 1060–1067.
- Marcus, L., Kunce, I., & Schopler, E. (2005). Working with families. In F. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 1055–1085). New York, NY: John Wiley & Sons.
- Margetts, J. K., Le Courteur, A., & Croom, S. (2006). Families in a state of flux: The experience of grandparents in autism spectrum disorder. *Child: Care, Health, and Development, 32*, 565–574.
- McHale, S. M., Sloan, J., & Simeonsson, R. J. (1986). Sibling relationships of children with autistic, mentally retarded, and non-handicapped brothers and sisters. *Journal of Autism and Developmental Disorders, 16*, 399–413.
- Minuchin, S. (1974). *Families and family therapy*. Cambridge, MA: Harvard University Press.
- The National Autistic Society. (2007). *Making connections. A report on the special relationship between children with autism and Thomas & Friends*. Retrieved from <http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=368&a=14021>.
- O'Brien, M., & Daggert, J. A. (2006). *Beyond the autism diagnosis. A professional's guide to helping families*. Baltimore, MD: Paul H. Brookes.
- Phelps, K.W., McCammon, S. L., Wuensch, K. L., & Golden, J. A. (2009). Enrichment, stress, and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual & Developmental Disability, 34*, 33–141.
- Phetrasuwan, S., & Miles, M. S. (2009). Parenting stress in mothers of children with autism spectrum disorders. *Journal for Specialists in Pediatric Nursing, 14*, 157–165.
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry, 45*(4), 855–865.
- Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology, 22*, 855–864.
- Quintero, N., & McIntyre, L. L. (2010). Sibling adjustment and maternal well-being: An examination of families with and without a child with an autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities, 25*, 37–46.
- Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism:



- Marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33, 383–394.
- Rogoff, B. (1990). *Apprenticeship in thinking: Cognitive development in social context*. New York, NY: Oxford University Press.
- Ruble, L. A., Dalrymple, N. J., & McGrew, J. H. (2010). The effects of consultation on individualized education program outcomes for young children with autism: The collaborative model for promoting competence and success. *Journal of Early Intervention*, 32, 286–301.
- Sandler, A. G. (1998). Positive adaption in parents of adults with disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 33, 123–130.
- Satir, V. (1988). *The new peoplemaking*. Palo Alto, CA: Science and Behavior Books.
- Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, 119, 114–121.
- Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M.E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities*, 20, 39–51.
- Summers, J. A., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. L. (2005). Measuring the quality of family-professional partnerships in special education. *Exceptional Children*, 72, 65–81.
- Symon, J. B. (2001). Parent education for Autism: Issues in providing services at a distance. *Journal of Positive Behavior Interventions*, 3(3), 160–174.
- Turnbull, A., Turnbull, R. Erwin, E., & Soodak, L. (2006). *Families, professionals, and exceptionality: Positive outcomes through partnership and trust* (5th ed.). Upper Saddle River, NJ: Pearson Prentice Hall.
- Turnbull, A., Turnbull, R., & Wehmeyer, M. L. (2007). *Exceptional lives. Special education in today's schools* (5th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.
- Turnbull, H. R., Wilcox, B. L., & Stowe, M. J. (2002). A brief overview of special education law with focus on autism. *Journal of Autism and Developmental Disorders*, 32, 479–493.
- Vygotsky, L. S. (1962). *Thought and language*. Cambridge MA: MIT Press.
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115–130.

