

Understanding Family Perspectives

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CASE STUDY

Mrs. Logan is a new special education teacher in your district. She is excited to work with children who have ASD, and she feels she will bond well with the families she will serve. Prior to the first day of school, she sent a letter to parents introducing herself and inviting parents to meet after school to discuss strategies for collaborating to best meet the various needs of her students. Mrs. Logan thought it best to be brief in her letter, so she simply provided a few sentences about herself and one last comment, “Feel free to stop by after school sometime to discuss how we can collaborate.”

At the end of that first day of school, not one family member stopped by her office for a meeting. Mrs. Logan was quite surprised that no one responded to her invitation. Several weeks went by, and still no one expressed an interest in collaborating with her in educating children with ASD. Mrs. Logan remembered learning in her teacher preparation program about the importance of partnering with families of children with ASD, and she wholeheartedly supported the rationale for doing so. She was keenly aware of how collaboration with family members helps support children’s development, both academically and socially, and was anxious to get started with those important partnerships.

As time went on, she grew disenchanted with the notion of school–family collaboration. The families’ apparent unwillingness to partner with her cultivated a growing frustration. She knew collaboration was beneficial for her students, but for some reason, her students’ parents didn’t seem to support such a partnership.

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LEARNER OBJECTIVES

After reading this chapter, the learner should be able to do the following:

- Provide rationale for partnering with families to educate children with ASD.
- Describe what families want in a school–family partnership and the related implications for establishing such partnerships.
- Describe the family’s experience of stress associated with raising a child with ASD.
- Examine how culture influences family perspectives and describe how educators can participate in culturally responsive collaboration.

“Listening is a magnetic and strange thing, a creative force. The friends who listen to us are the ones we move toward. When we are listened to, it creates us, makes us unfold and expand.”

—KARL A. MENNINGER

INTRODUCTION

The Importance of Family Partnerships

Partnerships are important for several reasons. The Individuals with Disabilities Education Improvement Act (IDEA, 2006) mandates parent–professional collaboration. Interpersonal collaboration is “a style for direct interaction between at least two co-equal parties voluntarily engaged in shared decision-making as they work toward a common goal” (Friend & Cook, 2010). That common goal is to help our students reach their highest potential.

Collaborating with the family members of your students is one of your primary responsibilities as a special educator. Legally, parents are considered a part of the IEP team, and concerns of the parent must be considered in IEP decision-making. Beyond the legal requirements, research advocates that when parents operate as partners in the special education process, there are benefits to students’ academic and social progress (Bacon & Causton-Theoharis, 2013; Dabkowski, 2004; Friend & Borsuck, 2009).

IMPORTANCE OF PARTNERING WITH FAMILIES OF STUDENTS WITH ASD

The importance of parent participation in the education of children with autism spectrum disorders (ASD) is well documented, with research linking parent involvement to positive outcomes such as improved academic and social skills (Benson, Karlof & Siperstein, 2008; Moes & Frea, 2002), as well as enhanced family well-being (Koegel, Bimbela, & Schriebman 1996; Renty & Roeyers, 2005). It is widely acknowledged that parent involvement in the education of children with ASD is considered a critical *best practice* (Benson et al., 2008; Moes & Frea, 2002; National Research Council, 2001). There is a considerable body of research promoting the benefits of parent involvement in the education of students with autism.

Parental involvement may be important for students on the autism spectrum due to the nature of the disability and the core deficits in language acquisition and social competency. The severity of the disability can affect the child’s ability to communicate, which, in turn, necessitates collaboration between parents and teachers in children’s educational planning and implementation (Bachner, Carmel, Lubetzky, Heiman, & Galil, 2006). Because students with autism might have difficulty expressing themselves verbally, it is critical that primary caregivers and teachers keep an open channel of communication to promote students’ best interests (Hebel & Persitz, 2014; Stoner et al., 2005). One parent in Stoner et al.’s research lamented that she could never know enough about what was going on at school because although she could ask her child, “he is not going to tell me. Not specifically. And that is the frustrating part for me” (Stoner et al., 2005, p. 46).

Additionally, parents are often well educated about ASD and their child, and they are therefore able to serve as a great resource to schools. Parents of children with ASD

often engage in an intense process of self-education when their child receives a diagnosis. It is quite likely that parents have acquired such extensive knowledge about ASD that they can be on near-equal footing with the education professionals in terms of their knowledge base (Benson et al., 2008). Schools would do well to capitalize on such rich resources and engage in sharing information between partners for maximum benefits to children's academic and social development.

Family Voices 2.1

"Consider us the expert on our child. We are valuable members of the educational team. Make time to invite us to be involved in problem solving and decision-making on a regular basis."

The focus of this book is on the responsibilities of professionals to facilitate and ensure collaborative partnerships in the education of students who have ASD. This chapter offers insights from parents' perspectives about what is working and not working related to the education of children with autism. A school-family relationship that is based on mutual understanding of each other's perspectives and realities provides the foundation for meaningful collaboration. It is of primary importance that teachers and school staff have an understanding of the family's perspective—what they experience in living with a child with ASD, what additional sources of stress they encounter, and what they want from a school-family partnership.

YOUR ROLE AS AN EDUCATOR IN PARTNERING WITH FAMILIES

Special education literature discusses at great length what parents want in a school-family partnership; the extent to which we, as educators, meet those needs has a significant influence on whether the partnership is successful. Parents place value on receiving information from educators, family-focused perspectives, cultural responsiveness, and equal opportunities to participate in decision-making. They want professionals to show genuine respect for their children, have the training and skills necessary to successfully support their children's appropriate behaviors, continually search for new knowledge and resources to update their skills, be willing to go the extra mile for their children to address their needs, and be committed to the whole family (Park & Turnbull, 2002). Families also value active parent-teacher communication, a full understanding of their child's abilities, and embracing a family-centered perspective (Hebel & Persitz, 2014). Parents want to feel that they are listened to, valued, and respected (Paige-Smith & Rix, 2006).

T.I.P. – Theory Into Practice 2.1

STOP AND THINK

Why do you think families of children with ASD would want to be involved in their child's education?

DEMONSTRATE RESPECT FOR CHILDREN

Families in Park and Turnbull's (2002) research said that they trust professionals who show genuine respect for children and treat them with dignity. Treating children with dignity, according to the families in Park and Turnbull (2002), means that professionals recognize and value children's humanity rather than focusing only on their problem behavior or other challenges. They behave in ways that are not degrading to children. They see the positive side of children, and they choose to focus on the child's strengths and preferences.

Park and Turnbull (2002) described professionals who maintained positive attitudes toward children as capable of "(a) identifying and valuing unique things about the child, (b) believing in the child's capability to learn, and (c) having a vision for the child's future accomplishments" (p. 119). For participants in Blue-Banning, Summers, Frankland, Nelson, and Beegle's (2004) research, respect meant valuing the child as a person rather than as a diagnosis or a disability label. One parent commented, "If they perceive someone as being less than human then they are going to treat that someone as an object. I want my son to feel like he belongs to the human race, like there's a place for him, like he fits in" (Blue-Banning et al., 2004, p. 179).

MAINTAIN A FAMILY-CENTERED PERSPECTIVE

Family-centered practices are characterized by placing an emphasis on family strengths, encouraging family choice in decision-making (Blue-Banning et al., 2004), and willingness to go the extra mile in their commitment to the whole family (Park & Turnbull, 2002). Educators who "go the extra mile" tend to do more than is required, and they sacrifice their personal time to improve children's development (Park & Turnbull, 2002). Educators who limit their services to a restricted view of time and responsibility, never going beyond the required workday to assist families, leave families disappointed (Park & Turnbull, 2002). Researchers have learned that school personnel should go above and beyond the call of duty, by reaching out to the family

outside the scope of school hours, by spending time outside of class with the child, by addressing the child's emotional needs where possible, and by providing personal contact information (Burke, 2012).

A commitment to the whole family, according to Park and Turnbull (2002), means that professionals naturally established and maintained relationships with families, learned about the child's home life, became acquainted with other family members, came to know the needs of the whole family, and responded to those needs as much as they could. Professionals who are flexible, regard their work as "more than a job," regard the child and family as "more than a case," encourage the child and family, and who are accessible to the child and family demonstrate their commitment to partnering with the whole family (Blue-Banning et al., 2004).

COMMUNICATE WITH FAMILIES

An important first step in establishing good communication is to be a good listener. We cannot underestimate the power of listening. Educators might believe that it is important to provide information to families, and they are not wrong. However, taking the time to hear and truly understand the family's perspective is critical. To prevent communication breakdowns, a special educator should practice empathetic listening. *Merriam-Webster* defines empathy as "the feeling that you understand and share another person's experiences and emotions; the ability to share someone else's feelings." It is "the action of understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another of either the past or present without having the feelings, thoughts, and experience fully communicated in an objectively explicit manner" ("Empathy," n.d.). Families of children with ASD want to know they are heard, first and foremost.

Families also want to receive information. Some have made recommendations that the school system provide families with training programs to improve their understanding of special education issues and take the initiative to encourage parental involvement. Families may be quite knowledgeable about the ASD characteristics their child manifests and may even be keenly aware of various intervention strategies, but it is also important for schools to provide ongoing information that may supplement or enhance what they have learned. Moreover, professionals should not wait to be asked before providing information, as some families could be reluctant to approach educators for any number of personal reasons.

The information that educators share with families should provide a balance of the child's strengths and weaknesses, rather than a strict focus on the deficits they observe. Some parents have felt dissatisfied with how schools sometimes focus on addressing students only by their deficits. For example, parents in Bacon and Causton-Theoharis's

(2013) research grew weary of hearing phrases such as, “This is what he did wrong today.” Focusing on deficits as the dominant discussion pattern tends to build walls rather than bridges in partnerships.

T.I.P. – Theory Into Practice 2.2

WEEKLY COMMUNICATION

One way you can communicate with families is to send weekly progress reports to which parents can respond. A sample note home is below:

Date: _____

Student's Name: _____

Overall rating of the day/week (please check):

Poor Fair Good Excellent

Things that went well in class this day/week:

1. _____

2. _____

3. _____

Things that could have gone better:

1. _____

2. _____

3. _____

Teacher's Signature: _____

Parent's suggestions and advice about things that could have gone better:

Parent's Signature: _____

Family Voices 2.2

“I love when teachers share the progress and ways I can support what they are doing at school in our home. We have a daily teacher–parent communication log that really helps, and I can call any time I have concerns. They allow me to call meetings as needed when I need help, and they allowed me to call on a trip to Disneyland when my son was having a hard time to give me advice. They are very supportive of our family as a whole.”

Take initiative. Parents want school professionals to initiate communication efforts. Parents in Stoner et al. (2005) and in other reports (Staples & Diliberto, 2010) placed high value on frequent open and honest communication. They expressed their desire to stay informed about their child’s achievements or to be made aware of any problems that teachers encounter so they could be more involved in finding solutions (Stoner et al., 2005). Professionals should not wait for parents to ask before providing the information that parents want (Sheehey & Sheehey, 2007).

Parent involvement tends to increase in response to teacher initiatives to involve them (Rodriguez, Blatz, & Elbaum, 2014). In fact, research shows that the most significant predictor of special education involvement is specific teacher invitations (Fishman & Nickerson, 2015; Rodriguez et al., 2014). The most influential practice to encourage parent participation in meetings and contributions to educational planning is specific and direct communication from the teacher (Fishman & Nickerson, 2015). Given the desire parents have to participate in their child’s education, it is a good idea for professionals to engage in purposeful recruitment of parents’ involvement and collaboration.

Communicate through multiple means. To maintain a positive school–parent partnership, multiple communications that occur in multiple settings over an extended period are necessary (deFur, 2012). A few simple ways to provide communication to parents include yearly conferences, weekly folders of student work, parent report card pick up, and regularly sent out newsletters (Burke, 2012). Another strategy might include a daily communication journal. Each entry includes a brief summary of the student’s performance for the day, as well as any possible IEP progress (Staples & Diliberto, 2010). Weekly communication can include newsletters, and monthly communications, such as telephone or personal communications, can show support for school–family collaboration.

Communication with families is a centerpiece of meaningful school–family collaboration. Create opportunities to share information with families and to receive information as well. Some ideas are to schedule regular meetings over coffee, communicate with teachers through daily notebook entries, or communicate through e-mail. Be respectful to avoid a “one size fits all families” approach; rather, tailor the avenues of communication to meet each family’s need (Stuart, Flis, & Renaldi, 2006).

T.I.P. – Theory Into Practice 2.3

IDEAS FOR COMMUNICATING WITH FAMILIES

1. Weekly folder of student work
2. Weekly or monthly newsletters
3. Daily communication on journal/notebook to exchange back and forth
4. Telephone call
5. E-mail notes
6. Online website families can access
7. Coffee with the teacher opportunities
8. Parent surveys
9. Invite them to share their perspective prior to an IEP meeting
10. Provide parent training sessions
11. “This is what I did well today” notes sent home to parents
12. Schedule family’s frequent visits to the classroom for informal observations

INVOLVE THE FAMILY IN DEVELOPING GOALS AND INTERVENTIONS

Families are more motivated to partner with professionals who implement families’ perspectives when developing IEPs (Hebel & Persitz, 2014). They view being consulted and “listened to” as essential elements of any educational plan (Paige-Smith & Rix, 2006). Parental satisfaction with the intervention plan is dependent upon the family’s feelings being listened to (Paige-Smith & Rix, 2006). Many times, parents are motivated to participate in IEP meetings and decision-making but feel that school personnel do not demonstrate their efforts to listen or value parental input (Burke, 2012). Parents are more willing to engage in the school’s efforts to educate children with ASD when they are made to feel their input is valued.

Facilitating effective family–school partnerships requires that we be family-centered or family-driven. Being family-driven refers to approaches to interventions in which goals are established in true partnership with families, combined with the understanding that the family has expert knowledge, gained from experience or training, and they are therefore entitled and expected to contribute the effective interventions for their children in partnership with trained educators who also possess great knowledge about strategies for academic and social development (Bacon & Causton-Theoharis, 2013; Osher & Osher, 2002). When educators include families in decision-making, (rather than simply *telling* them what they must do, and recognizing that when a family understands and agrees with the intervention plan, they are better able to carry out the responsibilities assigned to them) it is beneficial to our students (Osher & Osher, 2002).

Empowering parents means equipping them with the knowledge and skills that will help optimize their child’s academic and social development. Researchers

recommend that schools work to meet the need for parental self-education by providing training and information concerning related services to parents (Stoner et al., 2005). It is equally important for service professionals to foster ongoing communication with parents, to recognize and value their expertise, and to provide support to parents (Hughes, Valle-Riestra, & Arguelles, 2008; Renty & Roeyers, 2005; Sawyer, 2015; Stoner et al., 2005).

BUILD TRUST

Schools should also communicate to parents that they are trusted. Trust refers to having confidence in another person's word, judgment, and actions and believing that the trusted person will act in the best interest of the person who trusts him or her (Turnbull & Turnbull, 2015). A sense of distrust is a considerable barrier influencing parents' interactions with school personnel. Participants in Stoner et al.'s (2005) study placed high value on establishing trust. Moreover, a lack of open, honest communication between home and school fostered mistrust in Stoner et al.'s (2005) research.

Building trust with parents involves taking children's and parent's best interest to heart. It means being reliable and making sure parents can depend on you to come through for them consistently. Demonstrate competence, showing your ability to perform the tasks required by your position. Remain honest, showing integrity and speaking truthfully to others. Finally, be open, and welcome communication, sharing necessary information with the people it affects (Tschannen-Moran, 2004). Parents need to know that you are qualified, fair, dependable, and have their child's best interests at heart (Bryk & Schneider, 2004).

T.I.P. – Theory Into Practice 2.4

HOW TO BUILD TRUST

1. Communicate with families—relationships improve when you nurture them. Volunteer information. Don't wait to be asked to give up information that is important to them.
2. Be honest—if you tell the truth, even when it's to say you don't know something about ASD, parents will trust you. Always be honest. Don't claim to know everything about everything. Say, "I don't know" when you really don't know.
3. Show respect—respect the family's time by never being late to a meeting and by demonstrating effective listening skills during the meeting. Start and end meetings on time.
4. Ask open-ended questions—learn more about parents and be interested in their answers. Open-ended questions give parents the opportunity to tell you about themselves and their child. Ask more questions based on the answers you get.

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5. Have your parents' best interest in mind—parents know when you are looking out for them and for their child and when you are looking out for yourself.
6. Listen attentively—show the other person that you've listened carefully. Paraphrase what was said; giving the information back to the parents in your own words is a great way to show you were listening and to demonstrate your understanding.
7. Don't be defensive—when parents have a question or concern about something, take the time to listen to everything they have to say before you react. Many times it comes down to miscommunication or misconceptions. Don't be afraid to clear up any issues, but do it with a tone that is calm and professional. Listening is just as powerful as explaining your side. Sometimes the frustration is not with you. . . . Parents simply just need to vent.
8. Take time to explain—when families are confused, be patient, and take time to help them understand, whether it is about an intervention strategy you are suggesting or an activity you are asking parents to implement at home.
9. Take responsibility—when something does not go as planned and it's your fault, take responsibility right away, and focus on the next steps. Families will trust a teacher who owns up to her or his mistakes.
10. Take what is being said seriously—don't dismiss another person's comments or challenges as being small or less serious than your own issues. Just listen. Whatever families are going through or dealing with is serious to them, and you should treat it as such.
11. Empathize—acknowledge the feelings behind what is being said, and show empathy. Families will trust you more when they feel that you understand them.
12. Be accessible—when families know they can gain access to you, it builds trust.
13. Stay up to date—remain updated on current best practices for educating students with ASD; with current events in the news, even if they're controversial; and with new ideas for collaborating with families. Always work to improve your skills and competencies to work with students who have ASD.
14. Go ABCD (above and beyond the call of duty)—take time to get to know parents and their child, make phone calls home, spend time outside of class with families and their child, and so forth. Let them know you truly care about them.

Family Voices 2.3

"Teachers don't think to include me as much as I would like. Teachers don't have as much education about ASD as I do. Many teachers hold the view that parents should 'just be parents' instead of empowering them to be meaningful partners in the educational process."

DEVELOP YOUR OWN CULTURAL AWARENESS

Professionals serving children with autism and their families must be sensitive to cultural differences. Parents come into partnerships with varied cultural beliefs, understandings, perceptions, and ways of interacting, and those varied backgrounds and experiences must be understood and respected by school personnel if we wish to form effective partnerships. DeFur (2012) asserts that service providers who wish to develop a trusting relationship with families must respect one another, avoid being judgmental, and engage in cultural responsiveness. Also be aware that cultural differences may impose communication barriers and impede the development of parental collaboration with service providers (Hebel & Persitz, 2014). We must work toward building bridges rather than widening the barriers between partners.

Some of the potential cultural differences that will be explored in this section include (1) differing ways of interpreting disabilities; (2) variations in societal perceptions; (3) ways in which families rely on different sources of family support; (4) differing beliefs about the causes of disabilities; and (5) differing viewpoints about the best strategies for intervention.

Interpretation of disability. Culture plays a role in the way parents interpret their child's disability. Parents of different cultures may have differing views of normalcy and different views of the causes and labels related to disabilities, or they may not have a clear understanding of how their child's disability affects his or her learning. Labels such as autism might not exist in the parents' native culture (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Tincani, Travers, & Boutot, 2009). Some behaviors associated with a disability may be misinterpreted as a willful lack of cooperation rather than a genuine impairment in some cultures (Mandell & Novak, 2005; Tincani et al., 2009). "Unfortunately, educators may be inclined to dismiss differing views toward disability as evidence that families are 'in denial' about their child's condition" (Tincani et al., 2009, p. 85).

Interpretations of social behavior can differ among cultures. For example, in some Nigerian families, as is the case in some other cultures, giving direct eye contact is considered rude and therefore unexpected (Perepa, 2014). When teachers continue teaching children from culturally diverse communities to give eye contact, they are, in fact, violating the family's cultural norms. In some Asian cultures, children may avoid eye contact with adults and respond to a teacher's questions by being silent, out of respect for the adults (Perepa, 2014). "If teachers are unaware of such differences they could be mislabeling the children or teaching them culturally inappropriate skills" (Perepa, 2014, p. 315).

Societal perceptions. Cultural traditions, values, and beliefs can shape the way a society views disability. People from many backgrounds perceive autism as a source of disappointment, annoyance, shame, or worse. The stigma attached to a disability may look different depending on cultural background. For some cultural groups, having a child with a disability may carry implications of shame about one's failure as a parent. For example, having a child with a disability in Korea means that the parents have

failed to establish their credibility as effective parents (Kim, 2012). Parents, especially mothers, are often blamed for their child's disability in Korean culture, and it is perceived as a shameful family situation. Some cultures maintain the belief that "bad" mothers who are depressed and withdrawn caused the child to become autistic, rather than considering the possibility that dealing with the hardships of having an autistic child may have facilitated the mother's depression (Grinker, 2007). Many times, a parent's competence is called into question.

In some cultures, the family's name is dishonored when they have a child with a disability (Grinker, 2007). In those families, siblings will often avoid talking about their autistic sibling to friends and strangers to prevent "losing face" or receiving pity (Kwang Hwang & Charnley 2010). Parents may deal with the stigma surrounding autism by choosing to take their autistic child out of the house as little as possible and ultimately remain isolated from society (Kwang Hwang & Charnley, 2010). A great deal of shame and loneliness are associated with a family's inability to escape the cultural belief system, as they feel forced to keep a "secret" life at home (Kwang Hwang & Charnley, 2010). The stigma associated with autism in some cultures is so intense that many families will remain isolated and thereby avoid a diagnosis.

Treatments. A family's culture shapes their beliefs regarding the best course of treatment or intervention. For example, some families might believe that autism is a curable condition and may therefore follow a course of treatment designed to cure the disorder, or they may pursue other nontraditional forms of intervention (Mandell & Novak, 2005). A family that believes their child's autism is the result of biological variables may seek medical treatments specific to that cause while those who believe the cause was environmental may seek behaviorally based interventions (Ravindran & Myers, 2012). Some parents are convinced that if they find the right intervention and use it faithfully, their child will be cured of the condition (Ravindran & Myers, 2012). We must be sensitive to the beliefs of the cultures represented by our students.

T.I.P. – Theory Into Practice 2.5

CULTURAL AWARENESS "ROLE-PLAY"

1. Get several class members to form a team.
2. As a team, select a cultural group, one that is not represented by any member of your team, that you would like to research.
3. Research the various cultural characteristics and their attitudes and beliefs about ASD or disabilities in general.
4. Develop a role-play scenario that demonstrates how you would handle the situation if it arose. Emphasize how various cultural factors influence your interactions in the role-play.
5. Select from the ideas that follow, or come up with your own scenario.

6. Demonstrate your role-play to your classmates.
7. As your classmates watch the presentation, ask them to identify and discuss the various cultural characteristics demonstrated in the role-play.

Role-Play Ideas

1. Imagine you are in an IEP meeting, and the teacher's role is to translate professional terminology into everyday language.
2. Imagine that the teacher has several concerns about a child in the class and

has requested a conference to discuss the concerns. The teacher has sent numerous notes home and has left several phone messages, but the parent has not responded to requests to meet.

3. Imagine that you are in a parent-teacher conference, and the family member becomes very emotional in response to something the teacher said.
4. Imagine you are in a parent-teacher conference, and the teacher's role is to explain a particular treatment approach or educational intervention to be implemented.

UNDERSTAND THE STRESS ASSOCIATED WITH RAISING A CHILD WITH ASD

It is important to highlight some of the issues facing parents of children with disabilities such as autism and become aware of the ideas and strategies we can use to support parents through those challenging times. Parents may feel shock, denial, disappointment, fear, sadness, grief, guilt, disbelief, anger, and many other emotions related to their experiences (Dukes & Smith, 2007; Haley, Hammond, Ingalls, & Marin, 2013), or they may feel none of these. We should seek to understand this range of emotions and offer any assistance possible as we work alongside them.

There are times in the lives of families with disabilities that can cause anxiety or stress. The diagnosis of a disability is a stressful event for parents (Dukes & Smith, 2007; Fiedler, Simpson, & Clark, 2007) and may even result in the experience of grief (Haley et al., 2013). As they live with the reality of caring for a child with autism, parents might feel the stress of coping with daily life (Dukes & Smith, 2007). The reality of bringing up a child with special needs can also put tremendous strain on parents and their relationship with one another. Research shows that a higher proportion of marriages fail due to the pressures they experience in raising a child with special needs (Dukes & Smith, 2007; Fiedler et al., 2007). Another concern of parents is that their child will experience peer rejection and failure to develop friendships (Fiedler et al., 2007).

Practitioners may not be in a position to help parents deal directly with their feelings; simply being welcoming and supportive to their children is often a great help to parents, “and there is a huge sense of relief when they realize that they are not alone. They have someone who is interested in their child’s needs and how they can be met and [is] willing to work alongside them to help their child reach their potential”

(Dukes & Smith, 2007, p. 100). Regardless of the degree to which families respond and adjust to the stress, it is important that educators demonstrate awareness, understanding, and compassion toward families and strive toward teamwork.

Family Voices 2.4

“Stress is something I’m all too familiar with. But isn’t every parent? Bathing, homework, meals, carpools . . . all the stressful things about being a parent are no different for any of us. Having a son with autism just adds another layer to the stress . . . but I wouldn’t trade it for anything. My son is an amazing human being with multiple talents and creativity, just like yours.”

UNDERSTAND THE SOURCES OF STRESS

It is clear that having a child with ASD can be associated with stress. “Once a child is diagnosed with ASD, challenges for the family continue to build and parental stress rises as parents strive to adapt to meeting the needs not only of their child diagnosed with ASD but also for the positive functioning of their family” (Hall & Graff, 2010, p. 189). The sources of stress that have been identified in the literature to be discussed in the following paragraphs will be grouped into three categories: managing the behaviors associated with ASD, a perceived lack of professional support, and public perceptions of ASD.

Managing behaviors associated with ASD. Challenging behaviors associated with autism are perhaps the most pervasive and enduring source of stress for families. Behavior problems such as noncompliance, conduct problems, and maladaptive social behavior have been linked to parenting stress in the literature (Lecavlier, Leone, & Wiltz, 2006; White, McMorris, Weiss, & Lunsy, 2012). Family stress is often linked to the social and communication deficits and problem behaviors associated with ASD (Jellett, Wood, Giallo, & Seymour, 2015; Johnson, Frenn, Feetham, & Simpson, 2011; Hayes & Watson, 2013; McStay, Trembath, & Dissanayake, 2014; Rao & Beidel, 2009). When their children have limited communication skills, mothers of children with autism tend to report higher stress levels (Pisula, 2011).

A key source of stress for parents of children with ASD is their child’s behavior. Maladaptive behaviors, such as physical aggression and screaming, for example, are behaviors that parents may find stressful to manage. Parents may feel helpless when their child’s responses to their attempts at calming him down are often unpredictable

and incomprehensible (Pisula, 2011). In turn, parents who feel unable to make changes in their child's behavior might feel as if they are in a constant state of crisis (Mount & Dillon, 2014).

Perceived lack of professional support. Parents of children with autism may perceive a lack of professional support. For example, parents have been especially frustrated with the delayed and drawn-out diagnosis process because children with autism may be assessed by more than four professionals before finally receiving a diagnosis (Pisula, 2011). Parents in Mount and Dillon (2014) reported their frustration related to the limited support or advice around coping strategies that were offered at diagnosis. Events leading up to and following a diagnosis of ASD can be overwhelming to families.

Insufficient knowledge of symptoms and a general lack of education among professionals are also cited as a source of stress for parents (Pisula, 2011). Parents expect professionals to have up-to-date knowledge of ASD and to direct the family in decision-making, but this is often not the case. Unfortunately, the accessibility of autism-specific services and professional support is unsatisfactory to a number of parents (Pisula, 2011). As a result, parents can feel they are “left alone to coordinate, advocate for, and make decisions about treatment,” and “they are overburdened with duties, sometimes feeling incompetent and anxious about whether they have made the right choice of intervention for their child” (Pisula, 2011, p. 91).

Public perceptions of ASD. Not only do parents of children with autism have to cope with the challenging behaviors associated with their child's ASD and the unsatisfactory experiences with professionals, but they must also bear the stigma society attaches to people with autism. Since the mid-20th century, parents have been blamed for causing their child's autism (Neely-Barnes, Hall, Roberts, & Graff, 2011). As awareness of autism has increased throughout the years, we would expect increasing acceptance and less blaming for causing the child's condition, yet parents still report the experiences of blame from extended family members and the public (Neely-Barnes et al., 2011). Regularly, we hear from parents in the literature of their experiences with being seen as “bad parents” (Neely-Barnes et al., 2011).

Often people interpret the behaviors associated with ASD as a sign of poor parenting or failure to discipline properly. Parents report feeling stigmatized and isolated as a result of people's misjudgments about the child's behavior (Mount & Dillon, 2014). Neely-Barnes et al. (2011) also considered that “constant stares and comments by people in public contribute to the higher levels of stress and depression experienced by parents” (p. 223), concluding that “further education of the general public is needed.”

T.I.P. – Theory Into Practice 2.6

RESOURCES FOR PARENTAL STRESS

A great resource for understanding the parental stress associated with raising a child with ASD is available from the Interactive Autism Network. The article “Relieving Parental Stress and Depression: How Helping Parents Helps Children” is available at http://iancommunity.org/cs/articles/parental_depression.

Look at this resource and others, and develop a plan for how you can be of help to parents of children with ASD.

Consider developing a list of resources to provide parents when the opportunity arises.

UNDERSTAND THE IMPACT OF STRESS ON THE FAMILY

Parental well-being. Parents of children with ASDs report higher levels of stress than parents of children without disabilities, and they are at increased risk for experiencing anxiety, depression, poorer quality of life, and fatigue. Compared with mothers of children who do not have disabilities, mothers of children with ASD reported higher levels of negative affect, significantly more days when they felt fatigued, more days with work intrusions, more time caring for their children, more time doing household chores, and less time on leisure activities (Smith et al., 2009). They also reported having more arguments and twice as many days with stress at home (Smith et al., 2009).

Researchers have suggested that attending to behavior problems associated with ASD increases the likelihood that parents would report depressive symptoms such as low mood and lack of enthusiasm and initiative (Jellett et al., 2015; Johnson et al., 2011). Others, such as Bromley, Hare, Davison, and Emerson (2004) and Rao and Beidel (2009), have shown that 50% of mothers of children with ASD reported immense psychological distress and that they experienced loss of their own social activities and disregard for their own autonomy and their career. Based on the multitude of stressors that parents of children with ASD report, the negative impact on parental well-being is of little surprise.

Family functioning. Family functioning refers to the extent to which families communicate, manage daily life, and foster positive relationships (Jellett et al., 2015; Johnson et al., 2011). Evidence suggests that when there is a child with ASD, family functioning is often affected. There is greater strain on the family system, less participation in recreational activities, less connectedness, and a higher incidence of anxiety, as family life centers on the affected child (Jellett et al., 2015). Childcare demands,

feelings of not being a skilled parent, and lack of social support can significantly affect parental and family functioning (McStay et al., 2014; Rao & Beidel, 2009; Warfield, Chiri, Leutz, & Timberlake, 2014).

Parents also discuss the large amounts of time they must give to their child with ASD, leaving little time and energy for other siblings. A mother in Hall and Graff (2010) described the effect of autism on their family by saying that autism “takes over everything—your whole family . . . our entire family becomes consumed with it” (p. 195). Parents in Mount and Dillon (2014) reported their endless efforts to ensure that other siblings receive adequate parental attention and their constant need to justify the actions of their child with ASD to siblings. The stress associated with caring for a child with autism can have a negative impact on the child, the parent, and the entire family (Hutton & Caron, 2005).

Awareness of the contributors to the stress that families can experience may ultimately lead to targeted interventions that can support families and facilitate family functioning (Hayes & Watson, 2013; Jellett et al., 2015). Educators may also be in a better position to foster parent involvement when they can demonstrate acknowledgment of the demands of raising a child with ASD, the factors that contribute to their stress, and the effect of that stress on the family.

Tips for Partnering With Families

1. Know why establishing partnerships is important.
2. Demonstrate respect for children.
3. Maintain a family-centered perspective.
4. Take the initiative to communicate with families, regularly and through multiple means.
5. Listen with empathy.
6. Involve the family in developing goals and interventions.
7. Promote equality in decision-making.
8. Develop cultural awareness.
9. Understand the stress of raising a child with ASD. Know the potential causes and impact of that stress on families.

SUMMARY STATEMENTS

- Increased awareness of family perspectives is an important step in developing meaningful collaborative partnerships for the education of students with ASD.
- Educator dispositions that help facilitate meaningful school–family collaboration include demonstrating genuine respect for children, maintaining a family-centered perspective,

and responding to the needs of the child with professional competence.

- It is critical for schools to engage in ongoing communication with families, promote equality in the decision-making process, and to develop cultural awareness in order to form more effective partnerships with the families they serve.
- Managing the behaviors associated with ASD, a perceived lack of professional support, and public perceptions of ASD are the most common sources of stress reported by families who are raising a child with ASD.

WHAT WOULD YOU DO?

Look back at the case study about Mrs. Logan presented at the beginning of the chapter. Based on what you have read in this chapter and your own experiences, how would you respond to the following questions?

1. What are your first reactions to this situation? Has Mrs. Logan done anything wrong, or has she failed to do something that might be more inviting to parents?
2. If you were Mrs. Logan's principal, what advice would you give her? Give examples of the support you would offer her.
3. Other than the information provided in this case study, what additional information would you seek about the families of Mrs. Logan's students? How would that information help determine the kinds of support you could offer or the ways you would mentor her to facilitate parent involvement?
4. Assume that you identify a need for more *family-centered* practices. What are some strategies for parent involvement that you might help her put into place?

CHAPTER REFLECTION QUESTIONS

1. How does your understanding of the sources and effects of stress on a family that is raising a child with ASD impact how you will approach families in your efforts to collaborate?
2. How do educator dispositions affect family involvement in the education of students with ASD?
3. What can school professionals do proactively to facilitate meaningful school–family collaboration?
4. What are some ways in which cultural differences can create barriers to collaboration?

RECOMMENDED RESOURCES

Communicating With Families

- Pinterest. *Parent/teacher communication*. <https://www.pinterest.com/TheBigAWord/autism-parentstudentteacher-communication/>
- New Horizons. *How educators and support professionals can help families*. <http://education.jhu.edu/PD/newhorizons/Exceptional%20Learners/Autism/Articles/How%20Educators%20and%20Support%20Professionals%20Can%20Help%20Families/>

Cultural Awareness & Sensitivity

- <http://courses.unt.edu/Ennis-Cole/articles/File2.pdf>

- <https://www.pdx.edu/multicultural-topics-communication-sciences-disorders/autism-spectrum-disorder-cultural-implications-and-considerations>
- <http://www.worksupport.com/documents/culturallysensitive.pdf>

Family Stress

- <https://www.autismspeaks.org/news/news-item/ian-research-report-family-stress-%E2%80%94part-1>
- http://iancommunity.org/cs/articles/parental_depression
- <http://www.child-autism-parent-cafe.com/stress-on-families.html>

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