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About the Editors

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FAMILY INVOLVEMENT IN EDUCATION

There is no single formula for parental involvement in educ programs because every family is different, and team members need to the best ap-proach for each family. Some parents want to maximize involvement in planning and program delivery. Others simply wan assurance that their child's education is in good hands, and once the confident of that, they prefer minimal interaction with their child's sc Most parents fall some-place between these two extremes. It is essenti teachers and other profes-sionals to understand the difference betwee level of family involvement and the quality of parenting. Parents that intensive involvement with their children's programs and those who minimal involvement can be great parents, and both can be poor or abusive parents.

The kind and amount of required interaction with families dep on a number of factors. Students with limited communication often re more home–school communication because they cannot share inform about their experiences. This is especially true for children who health challenges. For example, some parents need to closely monitor child's fluid intake on a daily basis.

Child-Centered, Family-Centered, and Family-Friendly Approaches

Child-centered education is tailored to a student's unique set of needs and ities and recognizes that children have individual rights independe their families. A high degree of individualization is required, whi consistent with a child-centered approach, because students with severe multiple dis-abilities differ greatly from one another and from other stude

Family-centered education shifts the primary intervention from child to the parents or caregivers. Educators teach them skills that they with their child. This approach is commonly employed in early interve programs and home-based education. It assumes that the best interes the child are also the best interests of the family as a whole. This is frequ but not always true. Sometimes the individual interests of the child different than the inter-ests of the parents, even in the best of fam Educators must remember that

their first responsibility is to their students, but they also need to recognize that a happy and healthy family is in the student's best interest. A family-friendly approach is one that attempts to put the student's needs first while considering the needs of the family as a whole.

Getting Acquainted with Families

Although law and policy generally focus on formal requirements to include family in meetings and obtain consent, just getting to know families and becoming comfortable with each other is extremely important. This helps to open and maintain lines of communication, and it makes formal interactions more productive as well as more pleasant for everyone involved. Table 2.1 contains questions to consider asking parents and families while getting acquainted.

Although all of the questions can be helpful, it is important not to bombard parents with too many questions at once. In addition, some questions may be too probing to ask before a basic level of comfort is established. For example, asking parents how they discipline their child when first meeting them is likely to be perceived as intrusive and produce defensiveness. In addition, it is better to address many of these topics in context. For instance, asking parents how they discipline a child while discussing how to handle some challenging behavior in school may be perceived as acknowledging the parents' expertise, whereas asking the same question out of context may be seen as checking up on the parents.

It is also important for educators to share information about themselves in the process of getting acquainted. Asking too many questions about others while not sharing anything about oneself can make people uncomfortable. Finding some common interests is also helpful. There are often natural opportunities to identify common interests. For example, a family member may mention that he or she traveled over the summer to a destination where

Table 2.1. Questions to ask parents and families to get acquainted

- What are your hopes and dreams for your child's future?
- Who are the members of the family?
- What works well with your child at home?
- What do you think are the most important things for us to know about your child?
- What is the best way for us to communicate with you?
- What were the best and worst aspects of your child's previous school experiences?
- Who are the family members that spend time with your child and participate in his or her care?
- What is considered respectful and disrespectful by the family?
- Who makes decisions affecting the children in the family?
- To whom does the family turn for support, assistance, and information?
- What are the family's values and customs?
- What are the family's child-rearing practices, forms of discipline, and expectations of children?
- What are the family's concerns and priorities related to their child with a disability?
- How can I learn more about the family's perspectives?
- What other health and community services does the family access for their child?

From Chen, D., Downing, J.E., & Peckham-Hardin, K.D. (2002). Working with families of diverse cultural and linguistic backgrounds: Considerations for culturally responsive positive behavior support. In J.M. Lucyshyn, G. Dunlap, & R.W. Albin (Eds.), *Families and positive behavior support: Addressing problem behaviors in family contexts* (p. 154). Baltimore, MD: Paul H. Brookes Publishing Co.; adapted by permission.

the teacher has also spent some time. Of course, the educator and parent always share a common interest in the student, and this is a great place to start. Educators can often engage parents by telling them about things they really like about the student or commenting on the student's possessions. For example, simple comments such as, "Sanjay has a beautiful smile" or "Where did you get that great lunchbox for Bonita?" can be great conversation starters.

Educators often find it difficult to acknowledge and address their own limitations to parents, but it is usually important to do so. Teachers and other professionals are sometimes expected to be experts and know exactly how to address the needs of every student. In reality, they are often unsure about their own abilities and their students' needs. This uncertainty is often at its zenith when educators face the prospect of meeting the needs of students with severe and multiple disabilities. Many educators respond by trying to mask their uncertainty with feigned confidence, which can be counterproductive. It may raise unrealistic expectations in parents, make communication more difficult, and encourage parents to adopt a similar pretense of absolute confidence in their abilities.

Program Planning

Although most educators and many parents have strong views on what makes a good educational program, few consciously consider this fundamental question: What is the purpose of education? We might also ask ourselves: Does education serve the same purpose for every student? Although these questions may seem abstract and more philosophical than practical, the answers to these questions are critical to placement and program planning decisions. It will be difficult to agree on placement and planning decisions unless educators and parents share common ideas about the answers to these questions. Although their wording may differ, most educational theorists and philosophers agree on a simple basic purpose—the purpose of education is to prepare individuals for their adult roles in society. John Dewey, often recognized as the father of modern education, put it like this many years ago: "The purpose of education has always been to every one, in essence, the same—to give the young the things they need in order to develop in an orderly sequential way into members of society" (1933, p. 441).

This purpose has not changed over the centuries, but education has changed because society and the roles available to individuals have changed. Literacy, numeracy, and other skills that are commonly the focus of today's schools are not the ultimate goal, but rather can be seen as tools that equip a child for a potential future role. The exclusion of students with severe disabilities from public schooling in the past was simply a step toward the planned exclusion from participation in society. Exclusion sent the message that these children did not need to be prepared for a role in society because they would not be a part of it. Similarly, segregated educational placements prepare students with disabilities for isolated futures. Of course, it might be argued that

removing the student from the mainstream classroom of his or her same-aged peers would allow the teaching of some critical skills that will support enhanced reintegration into future environments, but this has not been well supported by outcomes from the last five decades of special education placements. For example, Myklebust (2013) found that students with similar levels of disability who were educated in regular classrooms with support services were more independent as adults than those educated in special education classes.

I can personally attest to the benefits of having a child with severe and multiple disabilities attend a general classroom. When my son Dave was 3 years old, he was enrolled in a special preschool for children with severe developmental impairments with a full complement of expert therapists. Parents attended along with their children, and no child in the class could walk yet. The first few classes were used to assess the students' skills, and then we were invited for a planning meeting, which did not go well for us. We were told that our son's impairments were too severe and that they would not be able to teach him to walk during that year, and therefore we were asked to leave the program. It was a shock, but we found an alternative within weeks. Dave was enrolled in a regular child care with a support worker. Dave was walking independently within just a few weeks, lining up holding hands with a partner at child care. He learned to walk because that is what he needed to do to take part in activities with the other kids his age. I cannot tell you whether he would have learned to do that if he had not been expelled from the special preschool. I really do not know, but Dave never went back to a special classroom, and he walked across the stage at his high school and university graduations.

The essential point of this personal story is that we have to formulate a vision of what we hope a student's future can be rather than a limited view of the child's capabilities in order to plan a meaningful education for any student, but particularly for a student with severe and multiple disabilities. This vision may not always be accurate, and it is likely to undergo numerous revisions as the student progresses through the years, but it is an essential starting point.

Educators must work with parents as partners in developing programs for students with special needs. This partnership is required by law, but educators need to recognize that this is much more than a legal requirement. Parents are an extremely valuable resource. Karten pointed out, "Sometimes parents and guardians are not the ones in denial; it is the interventions of educators or experts that deny parents as being experts, the ones who are most knowledgeable about their own child's strengths and needs" (2010, p. 308).

Meetings with Parents

How parents are invited to program planning and other meetings to discuss their child's education is important (Browder & Spooner, 2011). A form letter notifying parents that the meeting will take place at a predetermined date may leave families with the impression that the school is doing the least possible to meet its legal obligations. Discussing upcoming meetings well ahead

of actual scheduling and asking about the family's scheduling preferences are more likely to make parental attendance possible and also communicate a more welcoming attitude.

The student should be present at and participate in the meeting whenever possible, and this should be made clear to the parent. If for some reason the student will not be attending or if it is left to the parent to determine if the student will attend, then this should also be discussed in advance. If the student will not be included in the planning meeting, then determine how student preferences will be assessed and incorporated into the plan.

Be clear that parents are welcome to bring others to the meeting, and encourage them to bring those who are involved in the student's care or learning. Some parents may also want to bring their infants or young children to the meeting rather than leave them with another caregiver. This may be particularly important to accommodate in some cultures in which infants remain with their mothers continually for their first year or even longer.

Be certain parents have a clear idea of how long the meeting can be expected to last. Many parents have work commitments or child care requirements that they need to consider in scheduling. If the meeting runs longer than the parent expects, then this can create a problem, and if the parent is worried about whether the meeting will run late, then he or she will likely be anxious and distracted. Conversely, a parent who is expecting a 2-hour meeting and finds that the meeting only lasts 20 minutes may also be upset.

Be clear about the purpose of the meeting. If the meeting is designated as a time to discuss goals, objectives, activities, and instructional methods, then these topics should be open for discussion for all. Parents are often told that they are being invited to the meeting for their input and discover that they are being asked to sign a previously prepared plan with little or no opportunity to provide real input. This scenario may result in some parents passively accepting the plan while feeling resentful, and others demanding that the planning process starts over with their input.

Starting the meeting on time or as close to being on time as possible is also important. Delays that keep parents waiting increase anxiety and send a message that the parents' time is considered unimportant. It is important that team members who have a role in the meeting actually attend and arrive in a timely manner. There may be times when an absence or late arrival of a team member is unavoidable, but these should be rare exceptions. Having team members drop in for a few minutes also communicates a lack of involvement and interest. In addition, it is inconsistent with the fundamental concept of collaborative teaming, which requires sharing and discussion of input rather than a collection of separate ideas from various team members.

If parents cannot attend meetings despite efforts to include them, then educators must seek other ways to obtain input that suit the family. For example, some families may want to jot down some of their ideas in a communication book, others might e-mail, whereas others might be able to take part in the meeting through a telephone or computer video link. In some cases, meeting

at the family home can be considered an alternative to a school-based meeting. For example, it may be important for all the team members in an early intervention program with a significant home-based component to visit the home. Some families may find meeting in their home to be intrusive, whereas others may be much more comfortable meeting in their home.

When parents do attend, take time to introduce everyone at the meeting to help parents feel at ease. Having name cards for all who are in attendance may be useful to parents, especially to parents who have not had the opportunity to get to know all the team members. If there are more than two or three team members who are new to them, then most parents will forget some of the names and positions of the individuals present and may be reluctant to ask questions or address them if they are unsure of their names.

Offering food or beverages can be helpful in making some parents feel more comfortable, but it is optional. If food or beverages are not offered to family members in attendance, then team members should not bring them to the meeting. For example, team members should not arrive at the meeting with their coffee mug in hand if coffee is not served at the meeting. Table 2.2. provides additional tips for planning meetings.

Resolving Disputes with Families

Differences of opinion and disputes can sometimes occur, even in the best relationships between educators and parents. When they do, it is important to seek a resolution that addresses the specific issue and restores the relationship between school and family. In most cases, it is desirable to resolve the issue without involving others. In some cases, it may be necessary to bring others into the discussion. For example, a parent may want the classroom assistant to bring a student down the block to an after-school child care at the end of the school day, but this might conflict with school policy. As a result, the principal may need to be part of the discussion. Table 2.3 lists tips for effectively addressing conflicts.

Communicating with Families

Starting in preschool, a communication book traveled back and forth between home and school in our son's backpack every day. A single notebook never lasted a whole school year, and some years we filled three or more. We added dedicated cell phones for emergency calls by junior high school, one in his backpack and the other with myself or his mom. The paper notebooks are now gone and our face-to-face, cell phone, and e-mail communications are supplemented with an electronic activity journal, a blog that ties Dave's activities to his program goals.

Communication between educators and families can take place in various venues and utilize several different modes. Notebooks, commonly called communication books, that travel back and forth between home and school have been an essential part of communication for decades. They are still a very

Table 2.2. Tips for planning meetings

- If you are not well acquainted with the families, then take time to get to know them before the meeting.
- Find out who makes the decisions in the family regarding the child's education.
- Ask parents if they have any questions before the formal planning process begins.
- Let parents know that the most important role they have is parenting.
- Ask families whether they feel like they can take on an additional role in programming at home. Many families are delighted to take on an active role in programming, but many others are already stretched to their limits with work and caregiving responsibilities.
- Explain to families that their involvement in their child's educational program is invaluable and will result in learning experiences that benefit the child. Teachers need information about the child's strengths, interests, abilities, and needs and the family's preferences, goals, and concerns about the child. Because children spend more time with their families than with teachers, much of a child's learning will occur out of school, so parents need specific strategies and resources to promote the child's learning.
- Assist families in learning about the educational system by providing information about the services and programs in the school district, the families' rights, and the requirements of the individualized education program (IEP) process.
- Provide information in a format (e.g., individual discussion; print, video, or Internet resources) best suited to the individual family.
- Ask families what they would like to learn that is related to their child's education (e.g., assistive technology, augmentative and alternative communication devices or methods, positive behavior interventions and supports) or other topics of interest. Teachers may offer information on selected topics in a variety of formats (e.g., group meetings; video, print, or Internet resources) based on a family's needs and preferences.
- Prepare the family for the IEP meeting by discussing the agenda; explaining procedures; reviewing assessments; and asking about the family's goals, concerns, and questions about the child's education.
- Arrange for interpreters if needed, plan the meeting with the interpreter, and find out about culturally respectful ways of communicating with families and encouraging their participation in meetings. Ask parents if they want to help choose the interpreter. This can avoid the situation in which an interpreter may be linguistically qualified but culturally unacceptable to the family.
- Encourage a parent to bring a friend, relative, or representative to the meeting or event if he or she would be more comfortable.
- Create a welcoming atmosphere by providing a comfortable setting for the meeting, offering some refreshments, making introductions, having time for small talk, and having an open conversation about the issues being discussed.
- Recognize that some families may not be able to attend meetings despite your best efforts. Nevertheless, make sure that these families understand their legal rights and the educational options for their child. Let these parents know that they are missed and that you understand their particular situation. Continue to keep in touch through home–school journals, and call once in a while to find out how they are doing.

From Chen, D., & Miles, C. (2004). Working with families. In F.P. Orelove, D. Sobsey, & R.K. Silberman (Eds.), *Educating children with multiple disabilities: A collaborative approach* (pp. 31–66). Baltimore, MD: Paul H. Brookes Publishing Co.; Adapted with permission.

good option for many families. They allow parents to let the educators know about relevant events from home and educators to let family members know about relevant events from school. For example, a student's parent may want the school to know that his or her child had a rough night and little sleep, or the teacher may want the family to know that the student seemed uncomfortable and refused most of his or her lunch at school. Some days may require extensive entries, whereas others may be as simple as, "Sheena had a great day, lots of smiles. Send more flexistraws. –B.H." Other days may require much longer and more complex entries.

Daily notes back and forth in the communication book represent a simple and reliable way to report these events. Some basic rules to ensure that communication books are effective include the following:

- There should be at least one note from school and at least one from home each day, even if the note briefly states, "Good day, nothing unusual."

Table 2.3. Tips for effectively addressing conflicts between educators and parents

- Seek areas of agreement and focus on the child's needs and not on the school or the system.
- Find as much common ground as possible. For example, if you both can agree that you want what is best for the student, then you can start form there.
- Begin with the premise that most issues are negotiable and then problem-solve conflicts between family priorities and professional recommendations. Provide alternatives for suggestions.
- Remember that the ideal solution is the best interest of the student, not winning the dispute. Sometimes the family perspective may prevail because it is the best solution. Sometimes it may be better to allow families to prevail in order to preserve a positive relationship with the family.
- Although accommodating families is important, educators must place the student's best interests first.
- Make an effort to comment on positive aspects of the student and family, even when disagreement persists.
- Let the family know if there is a time limit for the discussion, and then do not watch the clock.
- Tailor your comments for the family's situation. For example, use the child's name and provide specific examples of the child's behaviors or activities.
- Explain acronyms and technical terms and use words that are easily understood, but do not talk down to families.
- Never dismiss the parents' concerns as denial or unrealistic expectations.
- Express a genuine interest in learning about the child (e.g., strengths, interests, needs, typical activities, home routine, social interactions) and understanding the family (e.g., composition, roles, responsibilities, activities).
- Invite the family to share their observations and concerns.
- Describe your understanding of the differences to be resolved.
- Communicate your concerns in a straightforward and nonjudgmental way, and ask the family for help.
- Admit that teachers do not have all of the answers. Share what you think, believe, and know, and identify what you do not know.
- Be prepared to genuinely consider the family's perspective.
- Evaluate the child's current performance and base recommendations on measurable outcomes.
- Look at the world from the family's perspective and accept the family's point of view.
- Discuss strategies to achieve objectives.
- Agree on and record who will do what, where, and when, and develop a written action plan.
- Identify a time for another discussion to obtain feedback from the family on what is working, what needs to be changed, and any results of the intervention strategies.

From Chen, D., & Miles, C. (2004). Working with families. In F.P. Orelove, D. Sobsey, & R.K. Silberman (Eds.), *Educating children with multiple disabilities: A collaborative approach* (pp. 31–66). Baltimore, MD: Paul H. Brookes Publishing Co.; Adapted by permission.

- One person from school and home should be responsible for reading the new entries each day.
- Entries should be legibly signed or initialed. If initials are used, then a list of names and initials should be provided so each reader knows who wrote each note.
- If abbreviations are used, then there needs to be a list of abbreviations someplace in the book to ensure that they are understood.
- Keep the book in a specified convenient place and make sure it goes back and forth with the student each day. For example, it might be kept in the student's school backpack or in a pouch on the back of the student's wheelchair.

The traditional communication books are sometimes being replaced with electronic alternatives because of the advent of smartphones and tablet computers. For example, some students with severe and multiple disabilities have tablet, notebook, or laptop computers that go back and forth between home

and school each day that are used as part of their educational programs. Many teachers, students, and family members have smartphones available, and students who are medically fragile may have dedicated cell phones that go back and forth with them to facilitate immediate contact with families or medical assistance in case of any emergency. Home and school computers with Internet access are also frequently available.

In some cases, electronic devices have advantages over the traditional notebooks for home–school communication. In other cases, a simple notebook may be the better alternative. A number of things may make electronic alternatives worth considering. Table 2.4 lists some considerations for choosing electronic or paper alternatives.

There are sometimes advantages in blending the use of electronic communication with the traditional communication book. Many parents and educators may find a simple communication notebook easier to use but want to supplement occasional entries with photographs that are electronically recorded and transmitted. For example:

> Lenny has been staring off into space and moving his head to the left several times during the day. We do not know if this is a seizure or something else (see video on his iPad). Have you seen this? Do you know what this is?

Numerous free and low-cost journaling and diary apps are available from the Apple App Store, Google Play, Microsoft, and other software companies and can be easily adapted for use as a communication book. Several companies (e.g., WordPress, Blogspot) provide platforms for free, private blogs that also can be used for communication books.

Table 2.4. Paper communication notebook versus electronic alternatives

Traditional paper home–school communication book	Electronic alternatives: e-mail, instant messaging, blog, apps, and so forth
Simple	May require set up and, for some users, learning new skills
Inexpensive	Requires equipment, but may use equipment already available
Only requires basic literacy	Requires some computer literacy
Primarily text, but pictures or additional documents can be attached	Can easily incorporate pictures, videos, and attachments
Goes back and forth with student	Can go back and forth with student, or devices already in school, home, and elsewhere can be used
Only available to one author or reader at a time	Can be available at multiple times and places to various people
Works for one communication from home and one from school on each school day	Can be available at all times to both home and school
Durable and lasting	May be subject to computer crashes or service interruptions
May be lost or misplaced	Messages and entries may be intentionally or accidentally deleted

In many cases, there are frequent opportunities for informal communication between educators and family members. The frequency of these opportunities varies substantially across families. For example, some parents may personally bring their children to school each morning and pick them up at the end of the school day, whereas other children come and go by bus, and their parents only come to school for specific meetings. Opportunities for informal communication are good times to build a positive relationship with families and share general information about how things are going at home and school. Informal interactions, however, cannot take the place of a more formal system of communication for sharing important information. Returning to the example of a parent dropping off or picking up his or her child, both the parent and educator are likely to be juggling a number of tasks at this time. A teacher may be trying to make sure that all of his or her students remember their coats and backpacks, get several students out to their bus, greet other parents who are picking up their children, and determine why one student has been upset while this conversation with a specific parent is taking place. The parent may be putting on the child's coat, repositioning the child in his or her wheelchair, or checking to make sure his or her child's backpack has everything that should be there. These do not typically make good times for sharing important information, and it may be necessary to let parents know that they may need to remind you later of something with an e-mail or note so you will not forget.

SIBLINGS

Many children with severe and multiple disabilities have brothers or sisters. Two or more children in the same family may have severe disabilities in a significant minority of cases. This may occur by mere chance, as a result of common genetic risk factors, or other common risk factors such as extreme prematurity in multiple births. The family faces greater challenges and is likely to require greater support when more than one child has a disability. More frequently, however, children with severe and multiple disabilities have typically developing brothers and sisters.

Considerable research has demonstrated some positive, some negative, and some mixed effects on siblings of children with disabilities. Positive effects on siblings include personal growth, a more mature perspective on life, increased sensitivity, improved family dynamics, greater social-emotional maturity, more socially responsible attitudes as adults, and a variety of others (Findler & Vardi, 2009). Reported negative effects include increased stress, risk for depression, anxiety, and risk for behavior problems (Stoneman, 2005). Research results often conflict regarding whether siblings of children with disabilities differ from other children on measures of emotional and behavioral well-being. One reason for the conflicting results appears to be related to whether the studies control adequately for other factors that affect well-being. A study using a large sample and adequate controls for other variables known to influence well-being (Emerson & Giallo, 2014) found that siblings of children

with disabilities fared slightly worse on measures of well-being than other children, without controlling for other variables. The difference was small, however, and most of the differences disappeared when other factors such as socioeconomic status and parental educational levels were controlled. This, as well as evidence from studies, indicates that the mere presence of a sibling with a disability does not harm children. Stoneman pointed out the following in her comprehensive review, "Many siblings thrive and benefit from having a sibling with a disability," but "it is also true that a few children seem to be harmed by the experience" (2005, p. 341). Why some siblings thrive while others experience difficulties is not entirely clear, but some factors have emerged.

Siblings also do better when parents are managing challenges well. The entire family is likely to suffer when parents are overwhelmed with challenges that they cannot manage. The parents and other adults may also act as models, and their children often display similar attitudes. So, if the parents and other adults express positive attitudes toward having a child with a disability in the family and how it affects their lives, then the sibling is likely to adopt similar attitudes. The level of a sibling's involvement in the life of the child with a disability also appears to be important. Placing too much responsibility on the sibling may be overwhelming and extremely stressful, but too little may also lead to difficulties. Because a large portion of parental activities are likely to be oriented around the child with a severe disability, leaving the sibling out of these activities can result in the sibling feeling isolated from the family. Siblings seem to do best when they are encouraged to take part at a level that is comfortable for them. Siblings also need to be acknowledged and respected for their contributions and need some time and attention of their own from their parents and others.

Educators can play a useful role by letting parents know that most siblings do fine, modeling positive attitudes, and acknowledging the contributions of siblings. If a sibling appears to be struggling emotionally, seems to be overwhelmed by stress or excessive responsibilities, or requests help, then he or she may require individual support. In many cases, if the sibling is experiencing difficulties, then it is a sign that the family as a whole needs more support.