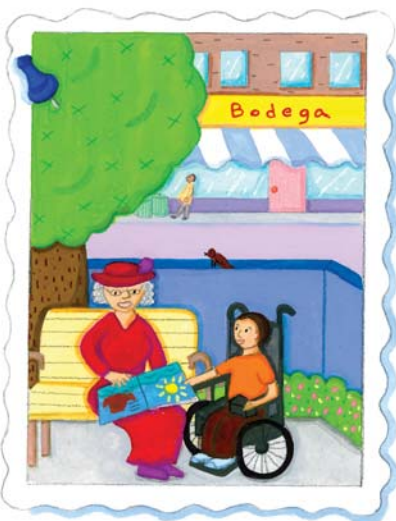


A Team Approach

Supporting Families of Children with Disabilities in Inclusive Programs

Louise A. Kaczmarek

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Since the first day she helped her son board the bus, Lakisha has worried. She hoped Spring Valley Preschool could give three-year-old Jeremy, who cannot speak or walk on his own, an opportunity to learn and interact with other children his age. Jeremy had been in an infant/toddler program for children with disabilities in which a developmental specialist and other therapists came to the home. Lakisha had enjoyed the trust and sharing with the developmental specialist; she looked forward to developing a similar relationship with one of the teachers or specialists at the preschool. Her son seems happy enough at day's end—maybe a little tired—but Lakisha has many questions: is Jeremy making friends? why are his clothes often messy? what is his day like? how are the new therapists? should she be following up with therapy techniques at home? She has called Spring Valley several times and left messages. The teacher called back once while Lakisha was still at work, but there has been no contact with Jeremy's early intervention consulting teacher; the program hadn't given families that number. Parent-teacher conferences will not happen until October. Lakisha is making a list of questions to take with her.

LAKISHA'S ANXIETIES ABOUT SENDING HER SON TO PRESCHOOL and her many questions are not uncommon in families who have young children with disabilities. Children with special needs are increasingly enrolled in inclusive community-based settings—child care centers, Head Start, and preschool programs (U.S. Department of Education 1999). Like other parents of these children, Lakisha faces certain issues not even considered by families with a typical child.

Preschools, of course, offer families of children with disabilities the routine support given to all families, but their needs often go further. These families sometimes require more or different types of support, just as children with disabilities often require more or different types of classroom support than their typical classmates.

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This article is intended for early childhood teachers and early intervention personnel serving children with special needs in community-based settings. While early care and education programs often stress creating learning environments in which all children belong, they also share the responsibility for creating a community in which all families belong. Although federal law mandates parental involvement in the special education process, such as in the development of the Individualized Education Program (IEP), there are additional strategies for supporting families of children with disabilities in inclusive settings that can be extremely useful. These strategies go beyond the requirements of the law to include deliberate, coordinated planning among early childhood and early intervention staff members, regular frequent communication between home and school, and the identification of useful community resources. This article focuses on these support strategies because when added to the mandates required by law, they can make a big difference in the lives of families of children with disabilities.



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Coordinated planning

Key to success in collaborating with families of young children with special needs is a commitment to coordinated planning and communication between teachers and early intervention staff. Only with teamwork can we reach out and support families.

Let's look at another scenario:

Two weeks before Marta's first day of preschool, Pine Hollow Center holds an orientation for new families. Rosa welcomes the invitation; she is a bit apprehensive about Marta's enrollment. Marta has cerebral palsy as a result of a stroke in utero. She is unable to walk independently and is delayed in other areas of development as well. On orientation night, Rosa meets Marta's preschool teacher, her assistant, the early intervention consulting teacher, and two therapists. She enjoys seeing the classroom and meeting other parents, including another mother whose child also had a disability and several families who also speak Spanish.

The families receive a Family Handbook with information about the program's general schedule, its approach to curriculum, a schedule of upcoming field trips, and general arrival/departure procedures. The handbook also includes an addendum from the early intervention program with the phone numbers and best times to call for all the personnel who will be supporting Marta's development and learning. Rosa leaves the meeting feeling welcomed and reassured. She is a little worried that Marta might not be able to maneuver her wheelchair into all of the activity centers available in the classroom and plans to call Kate, the early intervention consulting teacher, about that the next day. Overall, she feels welcomed by the staff and families and looks forward with excitement to Marta's first day in preschool.

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Planning an Orientation to Help Families Understand Their Child's Program

Advantages

- Allows parents of children with disabilities to meet early intervention and classroom personnel as well as other parents of children with and without disabilities.
- Enables families to explore classroom layout, equipment, and materials.
- Informs families about curriculum, routines, activities, classroom procedures, and policies.
- Gives teachers and specialists an opportunity to learn family concerns and preferences.

Challenges

- Difficulty scheduling so that all parents and all early intervention and classroom staff can attend.
- Requires some extra preparation by staff before school actually starts.
- Overcoming language barriers.

Suggestions

- Prepare and pass out a Family Handbook; arrange for translations if necessary
- Include biographical sketches of staff in handbook.
- Prepare a family survey to find out concerns, communication needs and preferences, and volunteering interests.
- Provide phone numbers and best times to call for all members of the child's team.
- Find volunteers to serve as translators in families' home languages.

Follow-ups to Families Who Miss the Orientation

Phone Calls

- | | | |
|---|---|--|
| <ul style="list-style-type: none"> • Lets parents know they were missed. • Is a convenient form of communication. | <ul style="list-style-type: none"> • Some families may not have phones. • Could be problematic for families of limited English proficiency. | <ul style="list-style-type: none"> • Schedule another phone call if the time called is inconvenient for the family. • Send home printed materials distributed at the orientation before the call. • Use a translator if appropriate. • Keep call friendly and informal; encourage parents to talk and ask questions. |
|---|---|--|

Home Visits

- | | | |
|--|--|---|
| <ul style="list-style-type: none"> • Lets parents know they were missed. • Allows staff to learn more about a family and child than through other methods. | <ul style="list-style-type: none"> • May make some families feel ill at ease. • May be redundant if home visits are a routine part of the program. | <ul style="list-style-type: none"> • Offer options for meeting places other than the home. • Encourage parents to talk and ask questions; listen. |
|--|--|---|

Contrast Rosa's experience with Lakisha's. Although both mothers felt similar anxieties about preschool, many of Rosa's fears were allayed at orientation. Rosa got to meet both early intervention and preschool personnel, explore her daughter's classroom, hear about the curriculum and typical day, and converse with other parents. She left armed with a packet of information, including the phone numbers of all the preschool and early intervention professionals who would be providing services in Marta's program. (See "Planning an Orientation to Help Families Understand Their Child's Program.")

Such a successful meeting for families requires careful planning by preschool and early intervention personnel who serve different functions and often operate under different programs/agencies. Their team efforts demonstrate sensitivity to the needs of parents of children with disabilities and a willingness to provide coordinated joint support to the child and the family. Although not all collaborations will look exactly the same as this example, the underlying goal of any collaboration should be to make sure that parents have the information they need to understand the totality of their child's experiences in the preschool setting.

Establishing ongoing communication

After Marta's first day at preschool, Rosa can tell that her daughter has enjoyed the experience. Rosa is pleased, even though her daughter's new clothes are stained with paint and food. In Marta's bookbag is a communication notebook. In it, Eliza, the head teacher, explains that the book is for sending information back and forth between school and home and that the early intervention and preschool staff will frequently write in it to keep Rosa informed. Eliza describes Marta's first day and notes Marta playing particularly

well in the housekeeping area with another little girl. Eliza apologizes for the state of Marta's clothes; they forgot Marta's smock when it came time to paint. She suggests that Rosa send in an apron for Marta to wear at snack time. She encourages Rosa to write in the notebook, but also points out that phone calls or meetings can be scheduled, if Rosa prefers. Rosa writes back thanking Eliza for the report on Marta's first day. She indicates she will probably dress her daughter in older clothes—not an apron—so that Marta will not stand out from the other kids.

Marta's first day of preschool began in much the same way as Jeremy's. However, Marta and her mother were better prepared, thanks to the efforts of the teacher/specialist team. With the information Rosa received at orientation, she could talk to Marta about preschool, even show her photos of her teachers in the Family Handbook. The orientation and the resources from the meeting, along with the communi-

cation notebook, set the stage for regular and frequent open communication between school and home, a hallmark of successful partnerships between professionals and families (Dinnebeil, Hale, & Rule 1996; McWilliam, Tocci, & Harbin 1998).

The structure of classroom programs is not always conducive to easy communication. Teachers and other early intervention specialists must create an environment in which ongoing communication between home and school is valued. Many parents of children with disabilities need regular contact with their children's teachers and other service providers to monitor progress or an ongoing problem, inform each other of issues that arise, or seek information or advice (Soodak & Erwin 2000).



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Communication with parents of typical children often occurs when children are brought to school by their parents. These brief face-to-face exchanges serve to update families and staff about noteworthy events, activities, and concerns. Even for parents who drop off and pick up their children with disabilities, these informal exchanges are sufficient most of the time. However, parents whose children are transported to school by bus do not have these daily communication opportunities and others may require more in-depth communication than can be conveyed at arrival and dismissal. Further, pertinent personnel are not always present when a parent arrives to drop off or pick up a child. In such cases, alternative forms of communication are necessary.

Early intervention and preschool personnel should talk with families to determine what strategies will work best for coordinating their services to a child and keeping the parents informed.

Early intervention and preschool personnel should talk with families to determine what strategies will work best for coordinating their services to a child and keeping the parents informed. Potential communication strategies include notebook exchanges, telephone calls, conferences, e-mails, or home visits (see “Modes of Ongoing Communication”). Families should have an opportunity to express their preferences. This gesture lets families know that ongoing communication is a valued and expected part of their children’s preschool experience. A coordinated effort between both preschool and early intervention staff members is invaluable in developing a joint communication system.

Linking families to community resources

Rosa arrives early for her parent-teacher conference so she can browse the Parent Resource Lending Library. She had heard about the library at the orientation, but because of her work schedule and Marta taking the bus to school, Rosa had not had a chance to take a look. Now she needs a sitter for Marta while she attends an upcoming church event. Because Marta can be a challenge at bedtime, Rosa wants someone with experience, preferably with children with disabilities. In the resource literature, Rosa notices a notebook assembled by the early intervention and classroom staff. In one pocket are pamphlets from three respite care agencies. Rosa is perusing them when Eliza approaches to welcome her. After they join Kate, Marta’s early intervention consulting teacher, for the conference, Eliza mentions that perhaps Kate could look into potential funding for respite care.

As they talk further, Rosa says she’d been thinking about what the future holds for Marta: when she enters elementary school, during adolescence, and throughout adulthood. Rosa knows some people with severe disabilities hold jobs and live in group homes or even independently. Kate tells her about an area support group for parents of children with disabilities that might be a source of information on the functional potential of children with disabilities as they grow older. Rosa asks for the phone number and e-mail address.

Through the use of the preschool’s small resource library and in her interactions with Eliza and Kate, Rosa acquired information helpful to her and her family. Gathering information about community resources and parenting issues (such as TV watching or sleeping challenges) is often part of the support that early childhood centers provide to families. Classroom libraries, the public library, newsletters, and speakers can all inform families about resources (see “Strategies for Accessing Community Resources”). In addition to the usual topics of interest to all families of young children (such as recreational programs, special fairs and activities, child care resources, library information, government-supported programs), families of children with disabilities may be interested in parent support groups, disability-related organizations, respite

care services, advocacy and other policy-making groups, specialized clinics and disability-related medical programs, and groups supporting siblings of children with special needs.

Probably the easiest way for programs to provide information is to collect pamphlets and other materials from local, state, and national resources.

Probably the easiest way for programs to provide information is to collect pamphlets and other materials from local, state, and national resources. In addition, the Internet is an incredible source of information for families and programs alike. For families who have computer access, the program can collect a list of useful Web site addresses for the resource library. If there is a computer available in classroom, invite families to peruse bookmarked sites. (See “Online Resources for Families” for sites of particular interest to families of children with disabilities.) For families without computer access, print out selected Web pages to keep on file; update the information periodically.

Connecting within the program

The parents of children with disabilities are a particularly valuable classroom source of information and emotional support (Santelli et al. 1997; Santelli, Poyadue, & Young 2001). They can direct new families to community resources, share their experiences, and offer advice on issues that they themselves have confronted. In addition to social events or orientations, programs can purposefully connect families. This usually takes a little preparation to avoid violating family confidentiality. Enlist the support of veteran families of children with disabilities to be potential mentors to incoming families of children with disabilities. When a new family arrives, offer to make such a connection. If the offer is accepted, then the program contacts the parent mentor who then calls the new family.

Connecting outside the program

Many communities have parent-to-parent networks and support groups. In some, parents meet and talk with each other regularly, often about a selected issue. Other groups connect an individual family with a mentor whose child has a similar disability. Many groups sponsor newsletters, activities for children, emergency hotlines, and support for siblings. Many national organizations offer Web pages, e-mail updates, chat rooms, and Listservs on children and families with disabilities. Library and Internet resources can open up a whole new world for many families. (See “Online Resources for Families.”)

Summary

Only by working together can early childhood and early intervention agencies provide the kind of coordinated, coherent support that best serves families of children with disabilities. We must recognize that some families in inclusive early childhood programs require more or different support than do families of typical children. With a shared and coordinated approach, developmentally appropriate programs can meet their needs.

Modes of Ongoing Communication

Advantages

Challenges

Suggestions

Classroom Visits

- Allows parents to see classroom in action.
- May provide opportunities for talking with personnel.
- Enables families to observe child's interactions with staff and other children.

- May not be convenient if child is transported by bus to school, if family transport is limited, or if work schedules conflict.
- Can be disruptive for some children.

- Consider making a videotape of child to send home as an alternative. (See Audio Recordings.)
- Follow up tape with a phone call or joint viewing opportunity.
- Ask for suggestions for making classroom visits and scheduling easier for parents and educators.

Newsletters

- Keeps families informed of ongoing events and changes.
- Educates families about childrearing, development practices, community events, and available classroom and community resources.

- May not reach families with limited literacy or English proficiency.
- Can be time consuming to produce.

- Try a quarterly newsletter: start of school; December; late February; May/June.
- Use simple publishing software.
- Ask for a volunteer parent to help.
- Include a Meet the Teacher column in each issue.

Communication Notebooks

- Informs families of child's progress, activities, and demeanor; upcoming events; other issues and concerns.
- Keeps staff informed about home progress, including health updates, emerging skills, family events.
- Encourages back and forth interaction, asking and respond to questions.
- Provides a forum for emotional support to families and staff.
- Provides a permanent ongoing record of the child, "snapshots of history."

- Reaching families with limited literacy or English proficiency.
- Some families may prefer more direct contact.
- May be inconvenient for some families.
- Reluctance of some families to write in the book, even though they may value the information.

- Use bound composition books or journals so the book stays intact.
- Date entries.
- Begin the book with an introduction and explanation of use.
- Stress that grammar and spelling are not an issue.
- Schedule a regular time to write in the books.
- Encourage use by all staff who serve the child.
- Do not get discouraged if parents don't respond; most will appreciate your efforts.

(cont'd on p. 8)

Modes of Ongoing Communication (cont'd)

Advantages	Challenges	Suggestions
Phone Calls		
<ul style="list-style-type: none"> • Is convenient form of communication. • More direct and interactive than handouts, other written communication, or recordings. 	<ul style="list-style-type: none"> • Problematic for families of limited English proficiency or for families who do not have phone service. • Offers less frequent communication than communication books. • May be difficult to schedule with busy family schedules. 	<ul style="list-style-type: none"> • Set up a regular calling schedule at mutually convenient times. • Provide families with numbers and best times to call. • Ask families for best times and locations to call them. • Strive for two-way communication, not just a professional report.
E-mail		
<ul style="list-style-type: none"> • Can be written at convenience of staff. • Delivery method independent of child 	<ul style="list-style-type: none"> • Internet not available to all families or staff. • Subject to technical problems. • May require a teacher's time outside of classroom day. 	<ul style="list-style-type: none"> • Exchange e-mail addresses in family survey. • Agree on an e-mail plan: how often, when, etc. • Find out how often families read e-mail.
Audio Recordings		
<ul style="list-style-type: none"> • Use an audiocassette for sending and receiving messages from home. • Faster than writing messages. • Includes more information than written communication (such as through intonation). • Might be useful for parents with limited literacy skills. 	<ul style="list-style-type: none"> • Requires technology (tape player) in home. • Listening to messages is more time-consuming than reading. • Does not provide a permanent record of information. 	<ul style="list-style-type: none"> • Find a quiet part of the classroom and schedule to record and listen to messages. • Ask a bilingual parent to translate.
Routine Conferences		
<ul style="list-style-type: none"> • Usually a standard part of many programs. • Offers an opportunity to discuss child's progress, program activities, and concerns of both parents or staff. • Often includes a written summary of child's progress or status. 	<ul style="list-style-type: none"> • Infrequent—usually held only once or twice per year. • May include only a limited number of early intervention and/or classroom personnel. 	<ul style="list-style-type: none"> • Encourage staff and families to schedule conferences as the need arises. • Celebrate accomplishments, don't just deal with concerns. • Hold at least one conference with teachers and specialists together for family. • Engage translators for families of limited English proficiency.

Strategies for Accessing Community Resources

Advantages

Challenges

Suggestions

Parent Resource Lending Library

- Contains items that reflect topics of interest to families.
- Includes national, state, regional, and local resources of interest to all families, not just those who have children with disabilities.
- Offers a variety of different kinds of materials: books, booklets, videotapes, audiotapes, training materials.
- Allows family members to browse at their leisure.
- Lets families know that you are there to support them as well as their children.

- Finding appropriate space.
- Keeping the library up-to-date.
- Setting up and maintaining a checkout system.
- Finding/creating identical resources in Spanish or other home languages.

- Brainstorm and compile initial resources through team effort; then assign one or more staff members to keep the library up-to-date.
- Ask families what information they are especially interested in.
- Make a basic list of contents that tells where items can be found in the collection.
- Include local resource directories.
- Collect pamphlets from agencies and programs in your area.
- Look for and collect information from agencies that serve specific ethnic or language communities.
- Collect and organize pamphlets in binders using pocket inserts, or house in file boxes or drawers.
- Post upcoming community events on bulletin boards, or send home information with children.
- At classroom computer station, bookmark addresses of useful Web sites.
- Print out information from Web sites or lists of URLs to add to library.

The Public Library

- Often has more resources and more up-to-date items than a center can acquire.
- Usually offers public access to the Internet.
- Has knowledgeable staff to assist family members in finding information.

- May not be easily accessible or convenient for some families.
- May not have resources available in other languages.

- Work with your local library in setting up a resource section for young children, including children with disabilities.
- Provide families with library hours of operation, resources available, and other information.
- Regularly visit the library to see what's new and available.

Parent Meetings

- Invite speakers from local resources.
- Conduct a resource fair with individuals from multiple agencies.

- Not always convenient for parents to attend.

- Advertise well, including personal invitations.
- Participate in a community resource fair and advertise that to families.
- Invite families and staff members other programs or centers to hear your speaker(s).

References

- Dinnebeil, L., L. Hale, & S. Rule. 1996. A qualitative analysis of parents' and service coordinators' descriptions of variables that influence collaborative relationships. *Topics in Early Childhood Special Education* 16 (3): 322-47.
- McWilliam, R., L. Tocci, & G. Harbin. 1998. Family-centered services: Service providers' discourse and behavior. *Topics in Early Childhood Special Education* 18 (4): 206-21.
- Santelli, B., F.S. Poyadue, & J.L. Young. 2001. *The parent to parent handbook: Connecting families of children with special needs*. Baltimore: Paul Brookes.
- Santelli, B., A. Turnbull, J. Marquis, & E. Lerner. 1997. Parent-to-parent programs: A resource for parents and professionals. *Journal of Early Intervention* 21: 73-83.
- Soodak, L.C., & E. J. Erwin. 2000. Valued member or tolerated participant? Parents' experiences in inclusive early childhood settings. *Journal of the Association for Persons with Severe Handicaps* 25: 29-41.
- U.S. Department of Education. 1999. *Twenty-first annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, D.C.: Author.

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Online Resources for Families

Directories of Parent-to-Parent Organizations by State

- Exceptional Parent Magazine**—
www.eparent.com/resources/directories/p2p.html
- The Waisman Center Family Village**—
www.familyvillage.wisc.edu/cof_p2p.htm
- Family Voices**—www.familyvoices.org/states.htm

Directories of National Organizations Focusing on Disabilities

- NICHCY Database of Disability Organizations (state and national)**—
www.nichcy.org/search.htm
- Exceptional Parent Magazine**—
www.eparent.com/resources/associations/associationlinks.htm

Listservs, Chatrooms, and Discussion Boards

- Developmental Disabilities Forum**—www.nwlancia.com//list.php?f=7
- The ARC of the United States**—
<http://thearc.org/wwwboard/wwwboard.html>
- ERIC**—<http://ericec.org/maillist.html>
- Waisman Center Family Village**—www.familyvillage.wisc.edu/coffee.htm

Comprehensive Disability-related Web Sites

- DRM Guide to Disability Resources on the Internet**—
www.disabilityresources.org/
- The Family Village**—www.familyvillage.wisc.edu
- National Information Center for Children and Youth with Disabilities**—
www.nichcy.org/
- Center for Disease Control and Prevention**—
www.cdc.gov/node.do/id/0900f3ec8000e01a