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Elements for Successful Parent-Professional Collaboration: The Fundamental Things Apply As Time Goes By

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Elements for Successful Parent-Professional Collaboration: The Fundamental Things Apply As Time Goes By

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Abstract

Abstract The Individuals with Disabilities Education Act (IDEA) mandates parent-professional collaboration. But difficulties between parent and professional collaboration seem to persist. These difficulties do not seem to be related to a lack of mutual respect or lack of good intentions. Perhaps difficulties exist because of a lack of common ground. Professionals' thinking is grounded in theory from personnel preparation and on-the-job experiences. Parents' thinking is grounded in personal experiences and information from professionals, other parents, technology, and media. This article describes a mother's and father's experiences over the past 25 years in a variety of settings as the parents of a child with severe disabilities and as special education professionals. They present their experiences in special education as parents and provide suggestions for parents and professionals to develop an effective collaborative relationship.

Keywords

Collaboration, parent involvement, family involvement, parent-professional collaboration

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We would like to thank our son, Tom. If it weren't for him we would not have had the array of experiences to share with other families and professionals. We would also like to thank Dr. Linda McCormick for her help in preparing the manuscript and Dr. Garnett Smith for his creative title..

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The Individuals with Disabilities Education Act (IDEA) mandates parent-professional collaboration. Collaboration, defined as working or acting together is a relatively straightforward concept. Why is it so difficult to accomplish where parents and professionals are concerned?

The difficulties surrounding collaboration in the educational arena do not seem to be related to lack of mutual respect or lack of good intentions. Our experiences over the past 25 years in a variety of settings as the parents of a child with severe disabilities and as special education professionals lead us to believe that parents and professionals sincerely respect one another and that they genuinely want an effective collaborative relationship.

The problem would seem to be lack of common ground. Parents and professionals have difficulty establishing a level of collaboration that will benefit the child because they are coming from very different places. Professionals' thinking is grounded in theory acquired from years of personnel preparation and accumulated experiences. The thinking of parents is grounded in personal experiences with their child and whatever information they have been able to glean from professionals, other parents, the internet, and the media.

We feel that our experiences as parents of a child with severe disabilities are fairly typical. Our son, Tom, was born in 1976. He began receiving special education services in 1977 in an infant program. Special education services ended in 1996 when he became 20 years old. We have also been professionals (teachers) in the field of special education for over ten years. We have experi-

enced collaboration as parents and as professionals. Some of our efforts at collaboration have been positive and some have been abysmal failures. The purpose of this article is to share our successes and our failures and provide suggestions. We hope that our suggestions can facilitate successful collaboration between parents and professionals (see Table 1).

Throughout the years we attended countless meetings with professionals regarding Tom's health and educational needs. The picture of exasperated professionals reviewing Tom's large files is one of our most vivid memories. For nearly 20 years our family was eligible for free lunches, low-income housing, and state funded medical plans. Tom received Social Security Supplemental Income (SSI) because of our family's low income. We remember waiting for hours at various departments of social services and the "looks" from others when using state medical cards or food stamps. Without Tom's teacher we wouldn't have known about SSI. She shared information regarding SSI to assist us economically and to ensure that he had medical coverage. She also informed us of our legal rights and helped us advocate for transportation and other resources.

Parents and professionals have difficulty establishing a level of collaboration.

Play It Again, Sam

Parents want information (Turnbull, Turnbull, Erwin, & Soodak, 2006) and they need it to be repeated over and over because they sometimes stop listening when a piece of information is especially painful or difficult to comprehend. It is important for parents to keep asking! Request that information be provided in language you can understand and continue asking until you have the informa-

tion you need. When it is difficult to directly ask for what you need, find a family member, friend, or agency who will intercede for you.

Professionals should not wait to be asked. They should provide assistance with advocacy, locating resources, and whatever other information the family requests regarding special education and the law (Turnbull, et al., 2006). This information must be provided in language family members can understand. Check to ensure that family members understand and can follow through. Be prepared to lend a sympathetic ear to parents, to listen to their stories and to respond to them with gentleness. Your primary responsibility is to discover how you will be able to assist not only the children with disabilities in your class, but their parents as well. Parents need to know that you are in their corner, that you will stand up for their child and seek what is best for the family.

As Tom's mother, I attended every IEP except one (a ride was late and a member of the IEP team called to say not to come as they were holding the meeting without me). The feelings of guilt and shame still haunt me. I attended every re-evaluation of eligibility. IEP meetings lasted a long time with many professionals whose names and titles I did not know. I could not concentrate as my other children were playing nearby and I had to be mindful of them while the professionals were talking. I remember wondering why the teacher had to write everything after the meeting while I waited to sign the papers.

As Tom's father, I recall attending a mere handful of his IEP meetings. Those meetings were generally held immediately after school. I was teaching school and simply could not leave my job and drive to an IEP meeting at a school that many times was

miles away from our home. Those meetings that I did attend were often held in clinical settings with lots of equipment but no other children in sight. At one meeting, a doctor I did not even know suggested that Tom discontinue the use of the prone stander since it was obvious he was not ever going to walk. At that point, my wife asked him if it were his son and not Tom, would he be making that suggestion.

Getting To Know You

Many times parents don't have child care (Salisbury & Dunst, 2000) and sometimes they need to bring their other children to meetings. Parents should inform professionals about their family and whatever restrictions they have. Introduce yourself to other team members and invite them to share how they know your child. During the meeting share stories that provide examples of your child's strengths. Create a picture of your child as you see him/her.

Professionals should ensure that parents are introduced to everyone who is present at the meeting. Introductions should be done informally to facilitate a welcoming environment where parents feel equal to each professional who is present. Explain each aspect of the meeting using language that is easily understood (Friend & Cook, 2003). Invite parents to share stories and provide suggestions about their child. Provide an opportunity for discussing the suggestions and allow parents to clarify. Say to yourself, "What would I want if this were my child."

We opened our home to mental health professionals, speech pathologists, physical therapists, occupational therapists, social workers, teachers, and educational assistants for home visits. We were grateful they would

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come see Tom in his home environment and meet other family members. We were able to talk more openly to professionals who came to our home. We could show them Tom's

room and share what he did at home and what we did for him. This was the best environment to share his strengths and needs and our dreams and fears.

Table 1. Suggestions for Parents and Professionals

| | Parents | Professionals |
|--|--|--|
| <i>Play It Again, Sam</i> | Keep asking for information that is understandable to you | Provide information that is understandable and assist with advocacy |
| <i>Getting To Know You</i> | Share with professionals about your family's/child's needs and strengths | Ensure all members know each other and their relationship to the family/child |
| <i>Welcome To My World</i> | Invite professionals to your home or suggest a familiar place for a meeting such as a community center | Ask if you could visit the family & child in the home. |
| <i>Tea for two</i> | Volunteer to help in your child's classroom and suggest activities, crafts, etc. you could manage | Open your classroom, welcome parents to visit and/or help |
| <i>Nobody Knows The Trouble I've Seen</i> | Share your feelings about assuming the role of teacher or therapist | Be responsive of parents fears assuming other roles |
| <i>The Times They Are A-Changin</i> | Be actively involved in the transition process. Visit the new placement with your child, meet the new teacher, and bring an artifact from her previous placement | Spend time with parents visiting the new placement with their child |
| <i>If You Don't Know Me By Now</i> | Showcase your child by sharing stories about your child's strengths and what you want him/her to learn | Focus on the child's strengths while acknowledging needs that are important to the parents |
| <i>Call Me, Don't Be Afraid, You Can Call Me</i> | Be available while engaging in stress relieving activities | Recognize the importance of respite and communicate with parents using communication form suggested by the parents |
| <i>Ac-cen-tchu-ate The Positive</i> | Ask about skills for your child and be open to suggestions while providing your suggestions | Explain the importance of a skill and provide informal opportunities for parents to share |
| <i>They Can't Take That Away From Me</i> | Keep your child as the focus while you share your expectations and express support | Acknowledge level of involvement chosen by parents, provide informal opportunities to share information, and reflect on own values and beliefs |

Welcome To My World

Parents might consider inviting their child's teachers and other professionals to see their child at home. If you are not comfortable opening your home recommend another place you would feel comfortable such as a community center or park. Discuss what your child does at home and what would help you and your child. For example, Tom would bite his shirt when he was agitated or bored. During a home visit I mentioned this to his teacher and emphasized how expensive it was to keep buying him new shirts. I hated to send him to school in a shirt with holes from his biting. Tom's teacher and I requested a behavioral expert. The behavioral expert came to our home and together we developed an intervention that would be used at school and at home. Having Tom's teacher and the behavioral expert come to our home was convenient for me. I felt very comfortable in my own home.

Professionals should take advantage of opportunities to visit their students at home (Salisbury & Dunst, 2000; Turnbull et al., 2006). Not all parents may feel comfortable having professionals in their homes but many would welcome the opportunity. Ask parents if you could visit the family in their home or another place of their choice. If home is not convenient recommend a place that is comfortable perhaps a community center or local park. Remember to be nonjudgmental regarding parents that may not want to open their homes to professionals. And remain nonjudgmental regarding what you see and hear in a student's home. Be culturally sensitive to the family when you visit. It is a privilege to be invited into a family's home. Leave your biases at the doorstep and show respect by adhering to cultural customs. For example, in

We were able to talk more openly to professionals who came to our home.

Hawaii we remove our shoes before entering a home.

As his mother I visited Tom's classroom frequently. I attended special assemblies and events. But I never felt comfortable in his classroom. I felt like an outsider. His classroom was busy with adults assisting children who required extensive support. I felt inadequate. I did not know how to engage or interact with Tom's peers. When Tom was at school it seemed he was in a different culture. His life was different at school. He "practiced" doing things we never did at home. The furniture and equipment seemed cold and mechanical. The professionals were very nice and welcoming. They were familiar with the equipment and with each child in their classroom. I thought about the classrooms of Tom's siblings and how the students and teachers welcomed me when I visited. I was comfortable assisting in those classrooms. But in Tom's classroom I stood, watched, and tried to smile. Not all parents feel inadequate working with their child or in their child's classroom but some may.

Tea For Two

Parents might want to volunteer to help in their child's class (Darch, Miao, & Shippen, 2004; Salisbury & Dunst, 2000). Parents should be able to provide suggestions regarding activities, crafts, equipment, etc. you feel you could manage and you know your child would enjoy. Get to know the other children in your child's class. Remember you are there to assist and to discover more about the world in which your child spends his day.

Professionals should help parents feel comfortable when they visit your classroom. Develop ways of including and assisting par-

ents who want to be involved in their child's school. Find ways to make your classrooms inviting to parents so they feel included and part of the school and classroom community. Introduce them to the students and staff. Have a small group activity a parent could lead such as reading a story or playing an audio taped story. Allow parents to help plan activities that interest them. Tom loved music and loud noises. Playing an adaptation of musical chairs with his peers in wheelchairs and standers would have been fun for me as well as Tom. And when he was an adolescent Metallica would have been his music of choice.

We worked with our son at home on stretching and strengthening as the physical therapist and occupational therapist recommended but we never felt comfortable giving him therapy. We felt inadequate and doubtful of our technique especially when it seemed the therapy was hurting him. We wanted to be the parents not the teachers or therapists.

We wrote goals and objectives for Tom while we went camping during the summer. These goals and objectives were given to his extended school year teacher to document that his IEP was being addressed when he was not physically at school. We felt more comfortable implementing those goals and objectives as they included skills relevant to family activities such as sitting upright in a beach chair for 10 minutes around the campfire or at the beach.

Nobody Knows The Trouble I've Seen

Parents should share with teachers and therapists feelings of reluctance towards assuming therapy responsibilities at home. Let your child's teachers and therapists know of activities your family enjoys at home and in

the community. Brainstorm ways to include physical and/or skill development in activities familiar to your family.

Professionals should be patient and understanding of those parents who aren't ready to accept the responsibility of being their child's therapist at home (Atheide & Livermore, 1987; Brazyk, 1989; Turnbull et al., 2006). If parents are willing to perform therapy at home ensure they are using proper techniques. Warn them about any possible discomfort their child might feel. Demonstrate the use of therapy during family activities. If parents or siblings engage in a particular recreational activity such as jogging or weight training demonstrate ways to include their child.

We do not remember the first time Tom was assessed for special education. He had been referred by his neurologist to an infant program. The infant program was very family centered. And although we only took Tom to his infant program twice a week we felt very comfortable there. We watched and soothed him as the therapists worked with him. We spoke to other parents and we shared stories about our children. We were invited to join parent groups and participate in picnics and group gatherings where we celebrated our children's achievements. We knew the professionals who worked with him very well. They were interested in Tom and in his family. We did not want our son to leave the infant program when he turned three. At the time we did not understand his need for "academic" education with a special education teacher. We wanted him to continue with physical, occupational, and speech therapy. We did everything we could to prolong his placement in early intervention. And although Tom turned 3 years old

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in April he was allowed to stay in the early intervention program through the summer until school started in September. Tom eventually did transition to a special education preschool on a public school campus. It was not our neighborhood school. He traveled nearly 30 minutes to school by bus. It was not as easy for us to get to his school to see his classroom and teacher. But we did manage to visit several times each year. Tom remained at the same school with the same teacher throughout preschool and elementary school. When Tom transitioned to the junior high school we were very anxious. Each transition was difficult. We clung to the familiar. We knew the school personnel, policies, and environment. Change was challenging. It took Tom longer than us to adjust to new people and places. But inevitably the change provided different opportunities for learning that benefited Tom. We both needed to be challenged to accept new people, new environments, and new goals.

Professionals should focus on the strengths of the child and the goals the child has met.

The Times They Are A- Changin

Parents need to be involved in the transition process (Noonan & McCormick, 2006; Turnbull, et al., 2006). Parents should become familiar with the new campus and individuals who will be working with their child. Bring your child along to meet the teacher and staff prior to the transition. Share with your child's prospective teacher ideas that might ease your child's transition such as favorite toys/objects, methods for calming (e.g. music, rocking chair), and activities. Bring something from your child's previous classroom (e.g. pictures, favorite object) so there is something familiar to your child.

Professionals should realize that change can be difficult for parents and their

child. Include parents when planning each transition. Encourage the parents and child to visit the projected placement to meet professionals and other staff. Suggest they visit the class when other students are there as this might also ease the transition. Provide an opportunity for the parents, child, current professionals and prospective professionals to meet informally to share concerns and expectations. Assist in developing rapport with prospective professionals.

Initially we were impressed during Tom's re-evaluation meetings with the reports read by professionals. The assessment reports were very detailed and included much technical information regarding his IQ and adaptive behavior skills. Even though we did not al-

ways agree with the results of the various assessments we were amazed at the amount of time and expertise professionals demonstrated in conducting and analyzing the results of the assessments. Some of the information did not seem pertinent. What did it matter if his IQ was 20 and the

age equivalency of performing certain skills was 18 months? We knew he could do things an 18 month old could not do. He was able to unlock any door or cupboard he wanted. He could tune any radio to a station playing his favorite songs. Yes, he mouthed things but somehow he knew not to put certain things in his mouth. And as he became older it seemed his eligibility for special education continued to be based on these same assessments. It became painful to hear a report read and explained that although Tom was now 14 years old his IQ remained at 20. And in spite of his goals and objectives and numerous interventions he continued to perform (according to the assessments) at the developmental age of an 18 month old. We did not need to hear that

again. And we certainly did not need to be reminded that he could not tell stories to his friends, write a thank-you note, answer the telephone and take a message, take care of his personal needs, or help with household chores.

If You Don't Know Me By Now

Parents should realize that a review of assessment results is mandated by IDEA. You may have a voice as to which assessments should be administered for your child to continue eligibility for special education. Share stories about your child that highlight your child's strengths and accomplishments. Bring photos of your child showcasing achievements regardless of the amount of progress. Display work your child has accomplished at home. And include ideas of what you would like your child to learn.

Professionals should focus on the strengths of the child and goals that the child has met or is approaching rather than comparing the child with a typical child through norm-referenced assessments (Noonan & McCormick, 2006). Ensure that goals and objectives include those that will enable the child to function adequately at school and with the family at home and in the community (Salisbury & Dunst, 2000).

We are grateful for all the professionals who worked with Tom. We did not have the time or knowledge to obtain and coordinate services and resources. We were thankful there was a place for him to go during the day where he was safe. He was learning many skills he would not have learned at home. And although we anxiously anticipated his return home from school, we were also grateful for

the respite school provided.

Call Me, Don't Be Afraid, You Can Call Me

Parents, if possible, take some time while your child is in school to engage in an activity that relieves your physical and emotional stress. This might include exercising, yoga, meditating, reading, listening to music, etc. But be available in case of an emergency. If you feel you are not able to be the care coordinator provide the care coordinator with information regarding your need for services and resources. Appreciate those who work to support your child to reach his/her potential.

Professionals should recognize that for some families school provides an opportunity for respite. And that respite is a necessity in order for family members to maintain their physical and emotional well-being and healthy relationships (Collins & Collins, 2001; Singer, Irvin, Irvine, Hawkins, & Cooley, 1989; Westling & Fox, 2006). Communicate with parents regarding potential services and supports. Provide

daily feedback regarding their child's progress and incidentals that occur at school (Friend & Cook, 2003). Parents may not have the time to respond to written communications but most will appreciate hearing how their child is doing. Be mindful of parents who are linguistically and culturally diverse. You may need to communicate verbally using an interpreter (Friend & Cook, 2003; Turnbull et al., 2006).

We are appreciative of those dedicated professionals who worked so diligently with Tom during his many years in special education. He has many skills today that he would

Although we anxiously anticipated his return home from school, we were also grateful for the respite school provided.

not have had if they had not worked hard to teach him. There were times when his professional team members suggested we include teaching a specific skill that we doubted he would be capable of learning. We were unfamiliar with strategies such as applied behavior analysis, systematic instruction, functional assessments, and positive behavioral supports. We did know that our son loved music, knobs, buttons, and sounds. We wanted him to learn to use technology. We do not remember one skill that the professionals attempted to teach him that he did not learn. He may not have been able to perform the skill independently but he was able to partially perform the skill. He was introduced to technology and was somewhat successful in using it. His pocket talker allowed him to choose an item from the lunch menu. It also allowed him to say, “Hi” to his general education peers. We’re grateful for those skills despite the fact that we may not have initially understood their importance. Many of those skills are important for functioning in our family because our culture, for the most part, coincides with the Western culture that prevails in special education.

Tom’s transition to adult life seemed easier for him than us.

Ac-cent-chu-ate The Positive

Parents should ask professionals to explain the importance of a particular skill. It’s OK to provide your point of view. Be receptive and patient with the suggestions. You may be pleasantly surprised with the results.

Professionals should explain the importance and positive impact a skill will have for the student and for the family. Listen attentively and respond to parents’ questions, concerns, and suggestions. Provide informal opportunities for parents to discuss what is important and functional for their child not

just at school but at home and in the family’s community (Salisbury & Dunst, 2000).

A family’s ethnic culture and language may influence the parents’ attitude and relationship with professionals who work with their child (Kalyanpur & Harry, 1999). Not all families want to be involved. They may value the teacher as a professional and leave educational goals and instructional methods to the teachers. Some families may have extended family to assist them. Their child may socialize with “cousins” on a regular basis. School attendance and educational programming may not be important for a family whose post-school goals for their child with severe disabilities include working interdependently with family members and living with family. We knew that Tom would always live with his family at home. We thought about what would happen if we died or became unable to care for him but we hoped a sibling would step forward. We didn’t want to think about it. Our goal for Tom was not living and working independently. It was living.

They Can’t Take That Away From Me

Parents, try to be supportive of the professionals who work with your child. Share your expectations for your child. Recognize feelings of discouragement and anger. Keep your child as the focus of your interactions with professionals and staff. If your child cannot be present bring a picture or some memento to remind everyone.

Professionals should understand that parents choose their level of involvement (Salisbury & Dunst, 2000). That choice may be a reflection of cultural values. Reflect on your own culture, values, and beliefs regarding special education and disabilities (Chan, 1990). Become knowledgeable of the cultural

values and beliefs of your students' families (Chan, 1990). Take time to "talk story" getting to know your students' families by conversing informally with them. Be mindful that for some families having a child with a disability is extremely stressful and emotional (Turnbull et al., 2006). Feelings of grief, denial, anger, and acceptance can shift daily, even momentarily. Be understanding.

Our involvement in special education ended a few years ago. Tom's transition to adult life seemed easier for him than us. He seemed to appreciate not having to wake up early to catch the bus to get to school. He loved being home listening to his music. But for us the inadequate adult services we first received made us long for the days of special education. Eventually Tom was accepted into a "waiver" program that enabled us to hire someone as his personal assistant. We developed a schedule of activities at home and in the community that Tom and his assistant engaged in regularly. Tom's assistant was about his age. Together they "worked out," ate, went out, and listened to music. He became Tom's best friend. Tom graduated to adult life and that life was good!

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