

# THE DANCE OF PARTNERSHIP:

## Why do my feet hurt?

### Strengthening the parent-professional partnership

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There is no escaping it these days. "Partnership" is a recurrent buzzword in the fields of education, health, and human services. "Parents and professionals must be partners. Collaboration is the name of the game." This is the refrain sung by administrators, policy makers, direct service providers, and parents. Indeed, partnership is a noble goal and, on the surface, seems fairly reasonable to achieve. "Let us sit at this table together, create the best plan of action for three-year-old Sally---and *be* partners." Seems relatively easy. Yet, regardless of the hat you wear, you know that being partners is often challenging beyond words. At times, forming partnerships is *more* challenging than parenting my son, Micah, who has developmental disabilities. I did not anticipate that the partnering with professionals would be at times this hard.

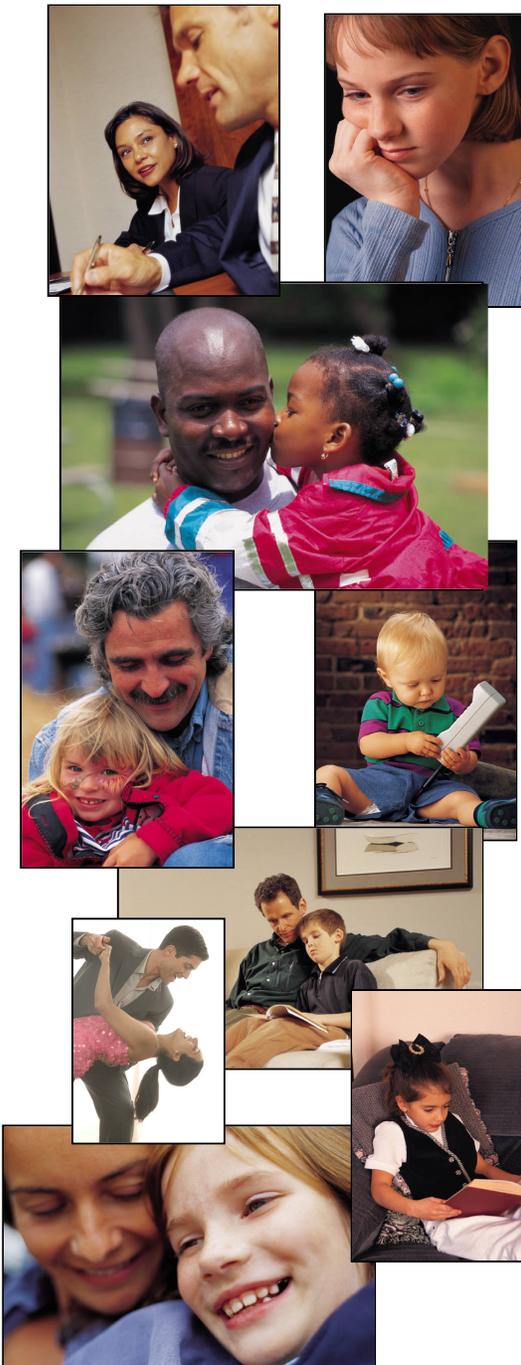
Several years ago, I began a journey to gain understanding about what complicates this partnership. My first step was to consult the dictionary for the definition of "partners." I found "*Either of two persons dancing together.*" (Webster's New World Dictionary, 1968). This image of dancing fit perfectly. Forming partnerships with the myriad of professionals who

have entered my life via Micah is like learning to dance. At first, my professional partners and I often do not glide together gracefully across the floor. Our movements feel stiff, awkward, and out of sync. We sometimes seem to be listening to different music with conflicting beats and rhythms. Our toes--and feelings--get stepped on as we try to maneuver around unspoken worries.

What is it that complicates this parent-professional partnership, this dance? Why do we often collide in our attempts to help our children and students reach their fullest potential? I have identified five distinct features, or dimensions, which both entangle and enhance our partnership dance. These ideas are based on my own personal experiences. My impressions on partnerships may not match those of all parents. However, the universality is found in the desire of all parents to have their uniqueness recognized and valued. The following is what I have learned about my partnership dances as Micah's mom.

#### **First Dimension — Choice: Do You Wanna dance?**

The first dimension pertains to choice. For most parents, this is



not a chosen relationship. In spite of the many gifts given to me by the scores of professionals I have met because of my son's disability, I would rather not know them under these circumstances. I would rather not have a child with a disability. I did not choose this.

On the other hand, most professionals made a very conscious choice to work with children. Many of you chose this work because of a strong sense of connection with these little people, and a passion for teaching. You anticipated that this work would give you some sense of meaning to your life and a sense of self-esteem and mastery, maybe not every day, but often. Many of you were drawn to make a difference in the lives of a child.



Let's look at this issue of choice using this dance image. Here you are, the professional, eagerly awaiting your new dance partner. Your arms are stretched out inviting us, parents, to enter your world of interventions, appointments, activities, forms, and (maybe) hope. You beckon us into your brightly decorated offices and classroom. "Please come in and see what is here. I'm excited to share these toys and opportunities. Welcome."

We, as parents, having not chosen this dance, are usually not as eager to join you. We may approach you not with open arms but with tightly folded ones clutched to our chest. Sometimes, it is as if our backs are turned to your welcoming arms, eliminating all

opportunities for engagement. We may feel reluctant, ambivalent, and often unwilling. For one thing, if we choose to join you, we have to acknowledge that our child has special needs. We have to acknowledge that we are entering your world--one that is initially unfamiliar and frightening. Entering into our partnership with you demands that we let go of our dreams and begin to build new ones. So we may not appear too eager or too willingly to join you in this partnership dance.

To your open, welcoming arms, we parents may appear arrogant, withdrawn, hostile, uninvolved, or defensive. Some might refer to us as being "in denial." It is easy to see how you, as the professional might personalize our distancing attitude we seem to project with our folded arms and defensive posture. You may find yourself silently crying out to us, "I'm only trying to be helpful!"

I recall the story of one mother whose young son was unable to walk. The idea of a wheelchair was introduced to the family. A freshly graduated social worker met this mother at her home eager to take her to select her son's first brand-new wheelchair. The mother hardly shared the worker's enthusiasm. To the mother, this was another shattering of a dream. She wanted to be selecting a tricycle for her son, not a wheelchair.



One of your tasks as a professional is to not personalize our distancing attitude, and to understand, that in most cases, our reluctance to connect with you and your program is not about *YOU*, but rather about the situation and circumstances forced upon us, our families, and our child. Your acceptance and sensitivity toward our worries and fears help to relax our tightly folded arms. When you can see our ambivalence from our side of this partnership dance, then maybe you're less likely to be offended by our unintended, and sometimes challenging, dispositions. You maybe able to see that our lack of enthusiasm for one more meeting, one more phone call, one more form, one more test, one more transition is less about *YOU* and more about our worries and uncertainties.

### **Second Dimension — Forced Intimacy: *Too Close for Comfort***

The second dimension unique to our partnership deals with intimacy. Because we are sitting with you during one of the most painful and confusing times of our life, we feel thrust into an uninvited and awkward closeness with you. We sit before you at one of our most vulnerable times. You enter our hearts. You hear our guilt and shame. You listen to our inadequacies. You are stung by our salty tears. You are witness to our pain. We may welcome the tender support and practical interventions, but the nature of the circumstances forces an immediate intimacy that is

awkward. At times, it is as if we are forced into a slam-dance popular among the younger generation a few years ago.

Most relationships evolve gradually over time. In this unique parent-professional partnership dance, we often are forced into an instant closeness bringing us nose-to-nose with strangers long before there is a

foundation of trust to cushion the strong feelings. I'm struck by the fact that we parents sometimes cry in front of people whose last names we don't know. Our unexpected display of our feelings of sadness, rage, or frustration sometimes makes it hard to return to your office. We're not sure what you think of us and our strong emotions.

Many of us are rather awkward with feelings in general. In many of our relationships we try to avoid expressing and acknowledging them. I refer to feelings as the "F" word in partnerships--something to avoid at all costs. Consider Jeff, a friend of mine. Jeff's four-year-old daughter had an immune deficiency problem and was struggling to stay alive. The family teetered on the edge of life and death on a daily basis, sometimes on a moment-to-moment basis. One night Jeff decided to spend the evening at home away from the hospital, now his daughter's home. He hoped for a good night's sleep, but was rudely disturbed by a haunting dream in which his daughter died. Her death felt so real to him that he traveled to

the hospital in the middle of the night hoping to be reassured by her warm, rhythmic breathing. He maneuvered his way through New York City's night traffic, rushed through the hospital's long hallways, shoved open his daughter's door and knelt down close to her soft cheeks. He

burst into sobs as he felt her warm, reassuring breaths on his face.

A nurse observed Jeff's unexpected arrival and later

sat next to him offering supportive words. She commented that she was surprised to see this strong reaction from him as she had grown accustomed to his consistent positive attitude. "Jeff, I didn't know you felt this way." She remarked. Jeff looked at her and responded, "I always feel that way. It's just that I can't walk around falling apart all the time."

You as professionals have the opportunity to allow us our feelings, even to invite us to "fall apart" once in awhile in the presence of someone who understands and cares. Your compassion and non-judgmental attitude can be a gift that decreases our sense of isolation, softens our stress, and decreases the number of times we unintentionally step on toes!

### **Third dimension -- Identification of Partners: *Will the Real Partner(s) Please Come Forward?***

The third dimension to our partnership deals with identifying *who* is the partner on the family side. You as professionals often enter this work because you enjoy children; you are drawn to the "little people." Additionally your education and training emphasized the child, focusing on how to arrive at the proper diagnosis of and intervention for the child. Thus, you as the professional enter this dance ready to partner with the child. "Let's dance, little one. You are my partner. I'm ready to play with you and teach you. Let's begin together."

Parents, however, want and should be primary partners in this dance. I am reminded of the words of Kristen Birkmeier (1993), a physical therapist and national speaker, as she addressed an audience of early intervention therapists. She said, "Put the parents first, for it is their lives that have been changed. The child is who she is, and needs your expertise, but not without the active involvement of the parents who live with this child 24 hours a day."

"Thank you! Thank you!" I remember whispering under my breath as I listened to Kristen. I was recalling Micah's early childhood days when I took him to his every-Thursday speech therapy sessions. I would hand him over to the speech pathologist, but I found myself wishing I could hand *me* over to her as well. He needed to learn how to stimulate his oral motor muscles, but I needed to learn how to live with a child who did not have words or a familiar way

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to communicate his needs. Micah and I both needed to dance with our professional partner.

This rearranging of partners to include the parents is often awkward and new for the professional. It is a shift away from the “old ways” where the focus was primarily on the child to a more inclusive perspective which invites parents in on the work. For me, some of the most meaningful sessions with Micah’s therapists were the ones when the professionals momentarily put aside the big, green, bouncy ball and turned to me to ask, “What are you concerned about? What have we neglected to think about for Micah? How are *you* doing?” Those questions felt wonderful and truly engaged me in this partnership dance.

Another aspect to this third dimension deals with the sheer number of partners. Earlier I stated that the definition of partners was “either of two persons dancing together.” As we all know, we are not talking about a partnership of two when dealing with our child. On the parent’s side there may be two, but more likely there are others, including significant loved ones, siblings, extended family members, and friends. On the professional side, there’s the speech therapist, the occupational therapist, the physical therapist, the social worker, the teacher, the nurse, the paraprofessional, and on and on. I didn’t just give birth to Micah; I gave birth to an



entire ballroom. And at any time, any one of those partners can change faces, as the professionals move in and out of jobs or assignments. Sometimes we are dancing with more people than is manageable.

I am a strong proponent of meetings that include all members of the team. It is in this setting that the creative problem solving is invigorating and reassuring. At our recent school meeting to plan for my son, one teacher learned from another teacher ways to involve his peers in assisting Micah with written assignments. Then, the speech therapist offered suggestions about new software to enhance his participation and we, his parents, reminded the team about the importance of using current events to engage Micah in the class discussions. The partnership dance was working!

Not all meetings of the entire team flow this evenly, however.

Negotiation with two people can be challenging, but with eight, nine or ten it can feel cumbersome and unproductive. Sometimes it makes sense to meet with only two or three members, especially when the issues are volatile or complicated. Most of us talk more freely and risk sharing our worries when we work with fewer people.

There are times when a large square dance is needed and other times when dancing

cheek-to-cheek makes all the sense in the world. All partners do not need to be at every dance, at every meeting.

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Knowing which meetings should be small and which

should involve the entire team is another way to reduce the amount of times that toes get stepped on. *Sometimes more is not better.*

#### **Fourth Dimension — Role Expectations: *Who’s Leading This Dance?***

The fourth dimension is the lack of clarity to our distinct roles; that is, who is leading this partnership dance. Historically, based on the medical model, the professionals were viewed as the experts. They lead this dance. They gave the direction to the dance and decided on the music. Now we hear more talk about parents being the experts. “Parents know their child best.” In many ways, I agree with this approach. My husband and I do know a tremendous amount about Micah, especially now that we’ve been his parents for 16 years. We know what grabs his attention---politics and sports. We know he often repeats himself when he wants to keep your attention and doesn’t know what else to say. We know that he needs coaching about ways to engage his peers. We know that he has an exquisite ability to read people’s moods and respond with compassion and insight.

At the same time, there is so much that we still don’t know and understand about him and his mind, especially as we face

his future as an adult. There are so many processes that are not clear to us. Our uncertainty was more prominent during his early childhood years. I was less likely to trust my “mother instinct.” During those early years, when professionals used that well-meaning but pat phrase “You are the expert, Ms. Fialka,” my mind would go as blank as a freshly cleaned chalkboard and I would shiver at my inability to say something profound or at least coherent. In the beginning I knew more about what he didn’t do, then what he could do. For me the use of the phrase “You are the expert” pulled me away from my familiar role of everyday-mom who giggled with Micah as we splashed in the bath tub, and instead shoved me behind the professional’s desk piled high with thick reports and foreign acronyms. “Expert? What do you mean by that?”

I prefer to move away from this idea of *expert* and in its place use the word *contributor*. Each dancer, professional and parent, contributes to the understanding of the child. Our unique contributions evolve and build on each other as we offer differing sides and perspectives about this child. There is the playground-side, the art class-side, the dinnertime-eating-side, the bouncing-on-daddy’s-knee-side. Each of our contributions is critical. Ann Hartman (1993) captured this spirit when she wrote to professionals, “We must relinquish the role of expert so that our clients’ narratives and experiences can be validated. . . . We do not discard our knowledge, we cease to privilege it, and we apply our knowledge with caution and humility, with the

recognition that it is one of many truths. . . .”

A square dance comes to mind as I see the partners circling in and around, over and through these many “truths,” relying on the hand of the next partner to guide us to the next place in our dance.

**Fifth Dimension — Differing Priorities: *Do You Hear What I Hear?***

The fifth dimension deals with priorities. Priorities for parents and professionals often differ. It is as if we each have on our own set of headphones and are listening to our own music with its own tune, words, and rhythm. There’s the mother-song, the father-song, the speech pathologist-song, the neurologist-song, and the teacher-song. Sometimes the only song we can momentarily agree on is “Hit the road Jack, and don’t you come back no more, no more!”

When Micah was about two years old, a teacher consultant made weekly visits to our home for “fun and therapy!” One beautiful spring day, we decided to play outdoors. As we moved to our back lawn, we saw our next door neighbor and her young daughter playing outside on their swing set. The teacher consultant, noticing that the little girl seemed to be about the same age as Micah commented, “It must be nice to have a playmate for Micah right next door.”

I understood her thinking, but offered my own experience.

“Some days it is pleasant.” I tentatively continued. “But more days than not, that sweet, unknowing girl is the constant reminder of what Micah can’t do, no matter how much exercising, and pushing and pulling of his low muscle tone arms and legs we do! Many days that innocent girl is a reminder of our lost dream.” The teacher consultant maintained her eye contact with me and respectfully acknowledged my perspective. “I never thought about it that way. I’m glad that you mentioned it to me. You helped me to see your world.” The teacher consultant, in essence, took off her professional-headphones, put on my parent-headphones and listened to my music and words. This interaction reminds me that as partnership-dancers we must be willing to take risks, offer our headphones to our partners and be willing to listen to each other’s music and experiences. We won’t be able to do it all of the time, but when we can, I believe we will be more effective in strengthening the parent professional partnership.

When the physical therapist suggests to a mother that she begin helping her child focus on proper hand-positioning of eating utensils, it is critical that the therapist also be mindful that this seemingly innocent recommendation may wreak havoc during the family meal time. When making new recommendations to families, one therapist asks the family a series of questions, “Now that I have suggested some new approaches at home, what have I missed? How will this change

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or disrupt your life? How will this complicate your daily living? What do I need to understand from your side as the parent?"

This type of questioning respectfully invites parents to share their music, their perspective so that recommendations can be relevant, practical, and manageable. This gives the message to parents that "I need your participation."

These five dimension--choice, forced intimacy, partnership roles, number of partners, and priorities--are present in all our dances, in all our parent-professional partnerships. When we are experiencing difficulties, when we step on each others

toes, when we feel we'd rather not be at this dance--at this meeting--then it is time to examine these five issues to determine which one might need to be further explored or addressed. The issue is not *will*

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these dimensions creep into our partnerships, because they obviously will. The issue is *are we willing* to recognize these dimensions and be courageous enough to discuss them and work on them together.

Maybe our theme song for our partnerships should at least begin with the refrain, "Getting to know you, getting to know all about you." I believe that if

parents and professionals are to be effective in creating marvelous opportunities for our children, then both sets of partners must carve out time to get to know each other's dreams, hopes, fears, constraints, and perspectives. We must take off our own sets of headphones and be willing to hear each other's music, with special attention to and inclusion of the parent's music and unique dance steps. To truly get to know the child, we must also get to know each other, not just as parents and professionals (more labels) but as people. This is hard work requiring patience, trust, and lots of getting to know each other, as well as ourselves. It is one of the most significant ways that we can make a difference in the lives of our children who are indeed the star dancers of this relationship.

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