

Therapists I Have Known and (Mostly) Loved

Roberta L. Paikoff Holzmüller

This manuscript embeds the author's firsthand experiences with pediatric occupational therapy with her expertise as a developmental psychologist interested in families and their collaborations with service professionals. The author's own experiences are used to illustrate points made in literature regarding parent-professional collaborations, as well as points made in interviews of other parents of young children with special needs. It is hoped that the article can serve as a "starting off" point for discussions and partnership building between pediatric occupational therapists and the children and families they serve.

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Introduction

As a parent-to-be, and a developmental psychologist, I looked forward to watching my firstborn child "unfold" in all the ways I had learned from both my formal training and informal observations of friends' children.

Early in my first child's life, I felt all those things. I watched him become oriented to the world, smile socially, roll over, sit up, crawl, and walk. But it was talking that I most anticipated. Speech is the primary way parents derive access to their children's thoughts and emotions. Moreover, all the best "stories" that people tell about toddlers have some basis in their speech, be it cute mispronunciations, adorable sentence productions, grammatical errors or malapropisms, or simply the funny, yet astute things they say. I could hardly wait to tell one of those stories that illustrated my child's charm and intelligence.

Knowing the tremendous variability in the timing of early speech, I wasn't particularly concerned when my child was 13, 15, 18 months old, and not talking. When our pediatrician suggested that, if he did not talk by 18 months, we get a hearing test and a speech/language evaluation if hearing was normal, I assumed that we would be told our child was just a late talker.

At 21 months of age, our son, who was still not talking, underwent speech/language evaluation since his hearing was fine. Though I had concerns by then, it was both a surprise and shock when the speech pathologist underscored the "seriousness" of my son's delayed speech and recommended speech/language therapy, occupational therapy, and play therapy. These feelings were compounded when we received the written report of the speech/language evaluation, stating he had "moderate to severe" delays, and placing age ranges for a variety of his skills, most well below his chronological age of 2. The report, coming as they often do a number of months after the evaluation, served to further lower our spirits, as nothing we did with our child seemed to "move him forward."

When our first son reached 27 months, our second son was born, under extreme and traumatic circumstances (diffuse brain injury assumed due to hypoxia at or before birth). For us, this was a tremendous tragedy, compounded by his older brother's continued speech delay and lack of response to therapies. Like most mothers, I suspect, I entered parenthood with images and dreams of a fulfilling, interactive family life. Now, all I could think to myself was, "Will either of my children ever talk to me?"

At that point, our family's story looked to be setting itself on a course far different than I had anticipated. In response to these concerns, I turned to the professionals who were recommended to help us, and asked them to help me turn to relevant literature as well. This

Roberta L. Paikoff Holzmüller, PhD, is Associate Professor, University of Illinois at Chicago, Institute for Juvenile Research, Department of Psychiatry, 1747 West Roosevelt Street, Room 256, Chicago, Illinois 60612; birdy@uic.edu

article focuses on some of these experiences, particularly as relevant to our family's experiences with occupational therapy.

Narrative As a Context for Family and Therapy

Disability studies underscores the negative role that rehabilitation can have in the formation of personal identities (Giengreco, 1995; Gill, 1997; Goffman, 1963). Most of these observations are based on studies of adults with disabilities or adult reflections by persons with disabilities on their earlier experiences in rehabilitation. Long before children have readily retrievable memories, parents begin a process of narrating their children's identities (Bruner, 1990). Most parents begin expecting their child's story to be something along the line of the culturally normative narratives that characterize a good childhood leading into a good life.

The realization that one's child may not have the hoped for unfolding story is a difficult emotional reality for parents. Even more compelling is that parents must set about the complex task of charting an alternative story for the child, one that will eventually be taken over by the child as he or she matures, but for which parents of young children feel tremendous responsibility.

Professionals such as occupational therapists realize their responsibilities for supporting a child's development, for addressing and remediating, when possible, impairments, and for making environmental adaptations. However, I suspect they have less awareness of their potential impact on the unfolding story of the child's life, and ultimately on that child's identity.

Occupational therapy literature reflects a growing interest in understanding the narratives of persons with disabilities (Helfrich, Kielhofner, & Mattingly, 1994; Jonsson, Josephsson, & Kielhofner, 2000; Mattingly, 1991) and in using narratively oriented assessments (Mallinson, Kielhofner, & Mattingly, 1996) to better understand clients. Some authors also have argued that the therapy process can help the client achieve a viable narrative (Clark, 1993; Goldstein, Kielhofner, & Paul-Ward, 2004; Helfrich & Kielhofner, 1994). These are all sound arguments and can be easily extrapolated to the situation where the

"client" is the small child and his or her parents are co-involved in the process of "story making."

In this paper, my aim is to describe our encounters with occupational therapists and the impact that these had on the unfolding narratives surrounding my two children. In particular, I will focus on three issues in the development of family-professional relationships: (1) assessments and evaluations; (2) ongoing communication in a treating relationship; and (3) formal communications in annual meetings. My goal is to incorporate ways in which healthy family-professional relationships can resist or overcome many of the concerns raised in disability literature regarding potential negative effects of the treating process on children and family's identity and narrative development (Kielhofner, 2005).

Instilling Hope in the Narrative

The parents of a child with a potential or identified disability live with various levels of fear that their child's story will have an unhappy course. Each new bit of information provided by medical and rehabilitation professionals has the potential to affect the story for better or worse. In our family's experience, one of the most important things any therapist can do is to interject hope into the story as did an occupational therapist who evaluated my younger child in the hospital. She told me simply, "You watch him. You do not compare him to anyone else, you simply watch him for continued growth. If you see progress you're happy. If you see stagnation, you seek additional professional help." This was simple and useful advice at a time when so little was certain. It also served to provide an opening for an optimistic future story that was so needed at the time. Such simple words of hope allow parents to construct a positive alternative narrative to one of a life-long struggle.

Communication and Story Making

Our experiences with our children in occupational therapy serve to illustrate both some of the very finest and some of the more troubling moments of parent-professional communication that affected our

children's narratives. In what follows I will use them to illustrate some key principles of parent-professional communication and collaboration.

Some of these principles are derived from Turnbull and Turnbull's 2001 text, *Families, Professionals, and Exceptionality: Collaborating for Empowerment* (4th edition) and from Rosenbaum, King, Law, King, & Evans' (1998) conceptual framework for Family-Centered Service. Both sets of authors cite the importance of the parent-professional relationship in setting up a productive way to work with children and families (Rosenbaum et al.; Turnbull & Turnbull, 2001). In the following sections, I hope to illustrate these issues with examples from my own experience and from conversations with other parents of special needs preschoolers.¹

Developing a Relationship

Developing a relationship begins at initial evaluation, but can be particularly difficult since the evaluator is often put in the position of delivering "bad news" to the family about the child's status. When the initial evaluator will also ultimately become the therapist, the initial evaluation is the place for the family and therapist to begin the development of a trusting and honest relationship. Where the evaluator will not become the therapist, the evaluation and assessment process is often the family's first exposure to professionals in a given area, and represents an opportunity to promote trust and honesty in future treatment relationships. In both instances, then, the scene is set for how the story of therapy might unfold. As pointed out by Helfrich and Kielhofner (1994), the therapist should remember that he or she is entering into a story already in progress and, for better or ill, becomes a character in that story.

Moreover, a positive relationship is fostered when the evaluation process (and later therapy) is designed to be a collaboration between the therapist, the parents, and the child to achieve a narrative that the family wants. The sections that follow will elaborate many factors that influence that relationship. The first is how information is generated and shared in the therapy process.

Incorporating and Respecting Information From Families

Given the nature and logistics of clinical evaluation, developmental checklists and assessments designed to provide quick snapshots of a child are perhaps a necessity. From a parent's perspective, however, such assessments can convey the message the child is being appraised to determine whether he or she is a "cookie-cutter kid." Such assessments tend to be fault-finding in the sense that they emphasize deviations from developmental and functional norms. As a developmental psychologist, I certainly understood the value of standardized assessments and the data they can yield. As a parent, I found that they do little to reveal the unique strengths of my children. Moreover they neither reflect nor positively augment the child or family's narrative. More recent experience with occupational therapy colleagues developing a child self-report (Keller, Kafkes, & Kielhofner, in press-a, in press-b) provided quite another experience. Using assessments that provide the child or family an opportunity to identify their own view of strengths and weaknesses goes a long way in augmenting the usual standardized assessments of functional capacity. When these assessments are just as formal and given just as much weight as the other standardized assessments an important message is sent about what kind of information matters.

A related issue that arises during initial evaluations (and will be discussed further below regarding ongoing communications as well) is the degree to which and the method by which information from the family and the child is distilled and used in reports. In my own experience, information about how representative my child's behavior is on the given day, or how different or similar things are in the clinic setting compared to my home, are often given lip service whereas the formal evaluation in the clinic is assumed to be real indicator of the child's status.

Understandably, professionals wish to draw conclusions from standardized measures and observations. However, if parents provide specific examples or rationales for behavior seen, it is equally important to

address this information when reports are generated.

In occupational therapy, as in many other fields of health or mental health services, professionals have become increasingly aware of cultural differences that may contribute to variations in vocabulary, routines, and other factors that impact the skills and occupations of preschoolers and toddlers (Mattingly & Lawlor, 1998). In addition to the macro levels that we are all familiar with, it can be important to consider some of the "micro" levels as well. For example, at an evaluation of our older child, much was made of his lack of familiarity with having hair combed, but relatively little was made of my comment that my child was still bald, and had never had his hair combed! In this case, the therapist might have gotten more accurate information by asking about an alternative caretaking activity in order to assess my son's familiarity with family routines. In fact, it appears good assessment practice to ask first what caretaking activities a child may be familiar with rather than relying on the items provided on a given evaluative checklist.

Sharing Information

Occupational therapists walk a fine line in providing feedback to parents. They must appropriately address parental concerns while not stepping over that line into conjecture or pathologizing of the child. Often, this might involve laying out the full range of assessment or intervention possibilities, without emphasizing or omitting any. In this way, parents can do their own research and begin the process of informing themselves regarding possible issues for their child.

Providing accurate and realistic information often means letting families know when there are many possibilities and no clear answer. This may be challenging especially when families are eager for a prognostic diagnosis or label to inform their own ambiguous knowledge. Nonetheless, many families will benefit most when the occupational therapist is frank about the unknowns as it pertains to the child's developmental course. The fact that there is no certain outcome leaves the narrative open

for a number of possibilities, allowing families to consider the multiple ways that the story can unfold, and perhaps preparing them to cope with how the story does go.

As noted earlier, complimenting this realistic information with hope can be critical to a family. The comment that provided our family with the most hope for our older child came from a friend who is a speech-language pathologist. I ran into her at a department store while shopping with my older child. Upon hearing about his speech delay and the choices and questions we were facing, she said, "I always tell parents of children who are not talking that there is simply no way for me to distinguish between a child who is a late talker and a child who is going to go on and have more severe developmental difficulties. So, I recommend seeking service early as a precaution." Neither the speech-language pathologist nor the occupational therapist who initially evaluated our child said anything like that.

In fact, the occupational therapist, when I pressed her for explanations, simply said, "There is something wrong with his brain. That's why he's like this." At the time, I found this comment quite devastating, especially in light of the brain injury of my younger child (of which this therapist was well aware). It never occurred to me to further question what this meant, or what was the basis for this comment. In retrospect, it appears that this therapist was both trying to respond to my pressing her for a definitive answer, and wanted to underscore my son's problem in order to make sure we would take on her recommended course of therapy.

As much as therapists may feel responsibility to press for therapy that they believe will achieve the best functional outcome for the child, it's simply not the job of the professional to make a family "see the light." It is, however, the job of the professional to present the data on the child, be open to all their possible significance, and recognize the uncertain meaning of the data for how the child's life will unfold.

In addition to laying out the range of possibilities with regard to diagnoses and short-term or long-term prognoses, therapists involved in initial feedback or ongoing

communication can find themselves in the role of providing families with the places to procure services and get help. In the United States, based on current public policies, families have the choice of seeking services through early intervention (usually state-based) and school district programs, through private services, or through some combination. Depending upon the state, the school district, the nature of the child and family's need, and the particular circumstances of the family in terms of health care and insurance coverage, families may make any one of these choices.

Therapists who are the "point of contact" for a family may have a tremendous influence on the information families receive about potential services and how that information is "filtered." For example, some parents I spoke with were never made aware of options in the public sector. In our case, although each private professional we approached mentioned these options, they were discussed as an afterthought, with the tacit assumption that this was not something we would want or prefer, and with qualifying information (e.g., "You can use the state early intervention services, but they are very new, and we do not know how long the waiting period will be, plus you will not have a choice of your therapist."). In fact, there are regulations about how long the waiting period can last, and there is the possibility of some choice in our state's system.

The communications we received appeared to be based on tacit assumptions about our family's income, insurance coverage, and "what we would want" given our educational levels and background. However well-intentioned such assumptions are they are not as empowering to families as giving complete information and letting the family decide.

There are often good reasons to seek both private and public sector services. Moreover, what families can expect to receive as services from these alternative providers can be very different. For example, school-based services have the particular goal of preparing a child for success in a school setting whereas private services may be much more flexible in setting personal goals that have more to do with a family set-

ting, or success in other key play or leisure contexts. For example, tricycle peddling and bike riding are terrific leisure skills to work on with a young child. However, they are not essential for success on the playground. Therefore, they would not be likely to be covered in a school-based program, but could be very appropriate for a private therapeutic setting. Consequently, it is extremely helpful when therapists dispassionately clarify for families all the possible treatment options, and settings, so that parents can choose what mix of services is most appropriate, depending upon their child and their circumstances.

Minimizing Jargon

Although professional terms have a clear and important role to play in socialization and communication among professionals, they can seriously impair communication with families. Both written and oral communication suffer when parents do not have a complete understanding of how professional terms translate into children's behavior. This is particularly true in formal meetings, where jargon can serve to subtly reinforce parents' view that they are "not in charge" (Turnbull & Turnbull, 2001). There are important ways that therapists can help parents navigate jargon.

For instance, I have found it helpful to go over feedback one-on-one with professionals, particularly at times when a large group meeting or a formal written evaluation is coming. Although I have always found professionals willing to accommodate this request, none ever initiated it. It would be very helpful to parents if therapists provided advance information to prepare them for what will be discussed in team meetings. In many cases, such information could be easily provided over the phone or via e-mail, and does not have to be time-consuming. Additionally, the mysteriousness of jargon can be minimized by linking terms to everyday behavior on an ongoing basis. In the end, therapists may need to use jargon to communicate effectively with their professional colleagues, but they also have a responsibility to make this information intelligible to families.

Limiting Pronouncements

In ongoing treatment relationships, therapists have a responsibility to provide accurate information to parents about a child's levels of functioning and progress being made. I believe they also have a responsibility to focus on the future in a probabilistic manner, and to limit specific pronouncements regarding future capabilities or presumed abilities. I can recall at least one significant "mispronouncement" made regarding each of my children.

In the case of my older child several professionals told me that my child would have difficulty in school on multiple levels, including sitting still at circle time and recognizing emotions. Later, at school conferences I learned that he did not have these problems, and, if anything, was particularly sophisticated in recognizing and understanding the emotions of others (perhaps accounting for his intense dislike of one occupational therapist's approach of exaggerating emotions to "help him regulate"). With my younger child, a physical therapist assured us that he would not be walking for "a while," probably about 6 months. Imagine her surprise when, 2 weeks later, my child walked across the room and into therapy ahead of her. I have had therapists tell me the same thing in relation to both my children: "I have never seen a child improve like yours." This suggests that professionals should clearly couch any predictions in probabilistic terms. Indeed, developmental theory suggests that dramatic changes in children should not be all that surprising.

Moreover, it can be very important to couch predictions (which as pointed out earlier are all fodder for the child's future narrative) with equal emphasis on what might and what might not be possible. In this regard, when my younger son was still not verbal (under 1 year of age) and beginning to experience some obvious motor delays, an occupational therapist commented to me, "Although I think he will struggle with certain motor issues, it's clear he also has a lot of strengths, and will have some very positive ways of functioning too." What was helpful about this statement was that, although acknowledging

the obvious presence of some developmental concerns, it was probabilistic and hopeful, allowing us to consider a wide range of realistic future narrative possibilities for our son.

Involving Families in Treatment Planning

Among the most frustrating concerns for parents is not having adequate input into their child's therapeutic process. This became most problematic when priorities within our family diverged with therapists' goals. Therapists often convey the implicit message that the ideal parent is one who will "try anything" in the goal of improving their child. As a parent, I want what's best for my child! However, with two children and multiple goals for each child, as well as particular goals for our family as a whole, I must constantly weigh each new possible activity, therapy, or routine in light of the former concerns. Doing so sometimes put me at odds with what the therapist thought was best.

A good example occurred a couple of years ago, when one occupational therapist identified as a goal for my then 2-year-old, younger son to begin feeding himself. The therapist was very concerned about this self-help skill, and felt it was important for him to begin to feed himself at home, saying to me, "You are just going to have to push it. You have to insist on it." My response was to tell her about what was important to me about food and mealtimes in my family. I wanted her to understand that mealtimes are often the only times the four of us sit in one place for any length of time, and that what was most important for us about that time was that it be enjoyable. I told her that at this point, it was more important to my family to have a pleasant time and a chance to communicate with one another than to make mealtime a battle of wills.

What I most appreciated from our occupational therapist at that point was her willingness to "agree to disagree." Although I hadn't changed her mind about this issue, and she hadn't changed mine, we were able to move on and continue in our collaboration. And, at some point, I managed to get my younger child to feed himself in much

the same way as I had my older child, by being pleasantly distracted and not quite so available to feed him. Our family philosophy is that therapy works best when it frees parents up to be parents. Parents should incorporate ideas that make sense and work within their parenting style and family context.

Working As a Team

Teamwork is important for parents and treating providers, as well as between professionals. It is important for professionals to keep in mind that it can often feel overwhelming to parents to be involved in early intervention situations, particularly when children are more "involved," and multiple professionals are being seen. In the first 2 years of life, my younger child saw four different early intervention professionals (physical, occupational, developmental, and speech therapists) as well as medical and other consulting professionals. The number of therapeutic exercises we were "assigned" as homework became so numerous that at some point I began to chart them. The lowest number I ever charted was 10, and they topped out at 18. It's not that any one of these exercises was particularly time-consuming or demanding, but taken in concert, they were near impossible to coordinate.

Because I really understood the rationale for these exercises and they were clearly addressing areas where my child was experiencing delays (gross and fine motor development) we did our best to address them. Nonetheless it was extremely helpful when our occupational and physical therapists were willing to prioritize exercises when their sheer number seemed to be getting out of hand. In addition, our occupational therapist and physical therapist did some cotreatment, which was tremendously helpful both in terms of respecting our time, and in terms of minimizing the degree of overlap in the different "homework" assignments.

Teamwork can become even more important as children become older, when schools are involved. We have appreciated the willingness of school programs to meet our children's needs, and to promote appropriate goals, and respond to our parental concerns quite directly.

Open Communication and Negotiation About Intervention Options

One of the largest concerns that many parents have is knowing whether specific therapeutic strategies are likely to translate into improvements in their children's ability to function in developmentally relevant contexts like school and social interactions. Most of all, families want a story in which their children succeed in school, make friends, are part of a happy family life, and are progressing toward a happy adulthood.

Many times over parents have to consider how a particular therapeutic strategy might contribute to that story. The following example illustrates the complexity of this process. At different times, the sensory integration "brushing" program was recommended for both of my children. We seriously considered it as we did all treatment suggestions. After asking many questions and gathering our own information we decided that the program had some serious disadvantages that outweighed its potential advantages. First, it was tremendously time-consuming. Second, as a developmental psychologist I remained unconvinced that there was a clear connection between the program and the issues or goals for my children. Therapists who recommended the program patiently gave detailed explanations of the theories behind the program, but they could not provide either data or arguments that clearly showed a link between the changes in sensory systems or neural pathways and the specific behavioral or language goals we had for our children. I was not provided and could not find empirical evidence from controlled studies that this program produced outcomes. It was also unclear why this brushing program would be any better for my sons than play in the naturalistic situations where their bodies would be exposed to a variety of sensory input, such as various arts and crafts projects in a preschool setting. In the end, we opted out of the brushing program; once again, agreeing to disagree with our occupational therapist. Many months later and to my chagrin I found that the therapist had documented that "parents are noncompliant with treatment recommendations." I convinced this therapist to remove this phrase by reminding her that

our decision not to pursue a therapy was considerably different from a lack of effort. We may have seemed “noncompliant” to her but to us we were highly engaged in therapy and actively seeking the best information for our child.

This circumstance raises a number of important issues surrounding how therapists can best communicate information about treatment recommendations and options with parents. First of all, even if there are positive findings about treatment efficacy based on group studies, such evidence does not guarantee that the intervention tested will work for particular individuals. Communication regarding the implications of research for individuals should acknowledge this fact (Rosenbaum et al., 1998). Parents need to know that data about a sample or population can only be applied probabilistically to any one individual. The temptation and desire to attribute change to any one particular therapy or experience in a child is almost irresistible for parents and therapists alike. Nonetheless, it is impossible to pull apart, for any one child, what particular experiences have resulted in which changes, or what deleterious circumstances may have contributed to stagnation. Thus far, empirical research, although certainly giving us trends of improvement, has had little to say about the key questions facing the field of early intervention: Who benefits when, how, and why (Guralnick, 2000; Meisels & Shonkoff, 2000)? It is almost always the case that children will improve over time, no matter how severe their disability (Pakula & Palmer, 2000). These are realities that parents have a right to know.

As a parent who happens to be extremely well-versed in development, I have found the whole process of decision making and retrospective sense making surrounding our children’s services to be complex and indeterminate. I have my own theories about how changes have occurred for each of my children, but absolutely no idea whether or how specific experiences may have contributed to developmental changes in my children. Is it coincidence, for example, that my younger son started walking within a month of the tapering off of phenobarbital? Did my older son’s speech take off dramatically at 3

years of age because it was hardwired to do so, or because we found a speech therapist who he found particularly engaging, or because he was in preschool, or because our speech therapist came to our home instead of seeing him in a clinic setting, or because of some combination of these changes? For our children’s narrative what matters is not so much “why” these improvements have occurred, but rather that they have occurred. For expansion of our research and knowledge about our interventions, it is critical that we continue to work toward answering the “whys” of intervention effectiveness.

In my example of the brushing program above, the key factors in our choosing not to use it with either child were its time-consuming nature, the lack of clear links to functional behavior, and the lack of systematic data regarding its effectiveness. As with all family decisions about intervention, science (whatever its state of development) has to interface with the real lives and unfolding stories of families and children. Whenever specific programs or protocols have been suggested for my kids, I have always asked whether there are any data to support the program, or anything that I can read about it. Although I have sometimes been provided with readings, it is most often the case that a therapist will tell me that the program is relatively new and there are not much data either way, but that she has seen it “work with so many other children like your child.” It strikes me as critical that professionals be confident and comfortable with their ideas and recommendations, but that they simultaneously be very comfortable with the limitations of current knowledge. In fact, some well-placed “I don’t know” will make the conviction of statements uttered with more certainty even more convincing.

Therapists can be very helpful to parents in choosing between a range of options, and in making alternate choices over time. In the end, these choices will be based both on available evidence from research and on the individual trajectories, family, and other circumstances and contextual options available. Moreover, therapists need to be respectful of each family’s approach to the care of their child, whether it is implicit or explicit.

In our own family, my underlying theory of development has emphasized the importance of the “normal, kid-type” experiences, and I have sought to minimize aspects of early intervention and service provision that have felt artificial to me. For this reason, I have consciously gravitated to more group-based therapeutic and educational activities for my younger child, trying to create a balance between group activities that are therapeutic (where he is one of a group of children with motor or other developmental challenges) and inclusion-based (where he participates with typically developing children to the best of his ability, with assistance as needed). Another parent, who had a stronger theoretical predilection to the importance of one-on-one time (or a child with a more tentative personality or different developmental issues), might choose a very different path. Neither of these paths may be wrong, but they are certainly quite different. It is the job of therapists to be knowledgeable about child development change, and to be able to provide background data or theory on recommended therapies or techniques to parents. But in the end it is the family that lives with the unfolding story that therapy should impact and, thus, the family that must be empowered to be in charge of it.

Conclusion

Much has been written recently about the importance, more specifically, of developing approaches that are family-centered (Rosenbaum et al., 1998) or establish collaborations between parents and therapists or educators (Turnbull & Turnbull, 2001; Turnbull, Turbiville, & Turnbull, 2000). We’ve come a long way from prior generations where parents were encouraged to view children’s disabilities as pathological, and to work within an expert model where therapists know what’s best for children. Despite these important improvements there are still challenges that need to be addressed and acknowledged.

This paper aimed to illustrate some of the key issues raised in the literature from a personal perspective, illustrating places where therapist–parent communication has been invaluable toward meeting child and family goals, and other situations where, at

least from this parent's perspective, that has been less true. The discussion was framed in the larger context of the narrative process by which families seek to create stories for themselves and their members that are acceptable, sensible, and hopeful.

So it seems altogether appropriate to conclude with where our family story is now. Our older son, now 6 1/2 years of age, has speech clearly within developmental levels, and a vocabulary quite advanced in certain areas of interest. His adaptive functioning at school is fine, such that he is no longer eligible for school-based services. In our public school, he is at or above grade level in all areas, meeting standards across the board. His social abilities and friendships seem about average, no better and certainly no worse than those of his peers. Our younger child, now 4 years of age, ultimately received the diagnosis of cerebral palsy. He is able to walk and to talk, both with increasing fluency over time.

Is all this true because of the choices of services we made for them? We have no way of knowing for sure for it would be difficult, if not impossible, to assign causality to one or another therapy. What I can say is that I believe my older son would ultimately have met all the goals he is meeting right now, with or without the therapies, but that it might have taken him longer without the professional assistance he received. Knowing then what we know now, we might have waited but my guess is we would have continued to seek therapy. What parent is willing to chance further delays? With regard to my younger son, I believe the risks were so much greater that it was absolutely essential that he receive the services and consults that he did. It may be the case that he'd "be there" today anyway, but given the initial injury to the brain, it's a gamble I would never have taken.

Regardless of all these choices, all the second guessing, theorizing, and decision making that has gone on, as a developmentalist, I am well aware that my children have benefited first and foremost from what Urie Bronfenbrenner has called the essential need for young children: "Somebody's got to be crazy about that kid!" (Bronfenbrenner, 1979). My children have been blessed to have parents, an extended family, and a committed group of professionals and

friends, all of whom are crazy about them. Who could ask for anything more?

Well, there is that fantasy I shared at the outset. Happily, I have finally joined the league of parents with wonderful, "chatty" stories about both my children (most recently, my older child asking us whether a tornado was taller than the "Serious Tower" in Chicago, and my younger child asking, "Do butterflies eat butter?").▲

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Endnote

¹ As part of a larger project, four parents of special needs preschoolers were interviewed extensively regarding their own stories, and the ways in which professional relationships had been helpful or harmful to their unfolding lives raising a special needs child. Parents were recruited through advocacy groups for parents of children with special needs in the North Shore area of Chicago suburbs. These families were all white; no additional information regarding demographics was requested. Families told their stories in a relatively open manner, with a series of structured probes. Further information about these data are available from the author.

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