Striving for Therapeutic Relationships: Parent-Provider Communication in the Developmental Treatment Setting

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The purpose of this grounded theory study is to develop a beginning substantive theory that explains the communication process between parents of children receiving center-based services for developmental delays and disabilities and the professional providers of those services. Communication is defined broadly as including both content and relationship dimensions. Twenty parents and 14 providers described their experience of communication with one another. The core phenomenon constructed from the data was striving for therapeutic relationships within a context of uncertainty. Both parents and providers operated in a context of uncertainty regarding the child and his or her development and prospects for the future as well as their expectations of each other. Both parents and providers used strategies of balancing, reading the cues, questioning, managing uncertainty, and managing the sessions. The outcomes were relationships that were valued by the extent to which they were perceived as therapeutic to parents and child.

Keywords: *parent-provider relationship; developmental disability; early intervention; communication; uncertainty*

Developmental disability is a generic term, used since the late 1960s to describe clinical conditions that cause disability, begin early in life, and require supportive services (Pope & Tarlov, 1991). Once an initial concern has been raised about a child's development and a recommendation for intervention made, services are provided in some type of early intervention program. These programs vary according to the locale and type of agency and can include services from one or more disciplines in either a home- or center-based program. Services begin as early as a delay or problem is diagnosed and may continue until the child reaches age 3 and becomes eligible for services through the local school district. Some children

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continue to receive supplemental therapy services through early intervention programs even after transition to public school. The interventions are generally provided to only one child at a time and last from 30 to 50 minutes one or more times a week, allowing a significant amount of time for parent-provider interaction and development of their relationship over an extended period. Despite much published work on what is seen as desirable or undesirable in terms of personal characteristics of parents and providers or best practices in early intervention, little is known about how parents and providers actually experience and manage their ongoing relationships. The purpose of this study was to explore from both sides the experience of parent-provider communication in the context of early intervention, focusing on the central question, What is it like for parents and providers to communicate with one another in developmental treatment settings?

The need for information is crucial to parents of children with developmental delays and generally includes information about normal child development, the child's special needs, how to help the child at home, and other services available for the child in the community (Bailey, Blasco, & Simeonsson, 1992; Meeropol, 1991; Sloper & Turner, 1992; Summers et al., 1990; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989). Although parents want information, such information about the child's present function and future prognosis is often threatening. Parents want to hear positive things about their child and their parenting and be able to maintain hope in the future (Strauss & Munton, 1985), creating a tension between wanting and not wanting to know, with some knowledge creating fear and anxiety.

This parental need for information parallels the provider's desire to share information. Implementation of Public Law 99-457, Education of the Handicapped Amendments, in 1986 has led to mandated family-focused care, centered on collaborative relationships and implemented through the Individualized Family Service Plan (IFSP) (McGonigel & Garland, 1988). The family must be involved as much as possible, and the needs and wishes of the family rather than a prescriptive focus on child change must drive intervention practices.

Responding to this mandate, most investigations of early intervention practices tend to focus on identifying the characteristics of a family-centered approach or determining whether particular programs meet the preidentified characteristics of family centeredness. Flexibility was the primary program characteristic identified by both parents and service coordinators as promoting collaboration with families in an investigation of early intervention program practices by Dinnebeil, Hale, and Rule (1999). Families valued flexible options in scheduling and in how services were delivered. Flexible program policies contributed to staff's being able to offer individualized options to parents. Examination of parent and provider preferences regarding the IFSP process through focus groups and interviews (Minke & Scott, 1995; Summers et al., 1990) indicate that interpersonal relationships and provider sensitivity to families are very important to both parents and providers. Investigations to identify those personal characteristics parents and service coordinators see as supporting or interfering with collaboration (Dinnebeil et al., 1996; McWilliam, Tocci, & Harbin, 1998) indicate the importance of a philosophy of family rather than only a child orientation, a positive attitude toward the family, sensitivity and responsiveness to family needs and concerns, and skills and knowledge regarding child development and interventions. Parent participants in one study (Knafl, Breitmayer, Gallo, & Zoeller, 1992) advised providers to offer accurate and complete

information, not dwell on the negative possibilities, explain in terms they could understand, and provide an opportunity to ask questions.

Investigation of the actual interactions between parents and providers was found in only one study, which analyzed the type of communications that occurred during early intervention home visits (Brady, Peters, Gamel-McCormick, & Venuto, 2004). Home visit intervention sessions were videotaped and analyzed using a previously developed tool. The investigators related the categories of communication of the providers to the amount of verbal involvement of the parents during the session. Because increased parental verbal participation was viewed as an indicator of the degree of family centeredness of the program, providers who talked less and asked more open-ended questions were seen as providing more family-centered services.

CONCEPTUAL FRAMEWORK

This study was guided by symbolic interactionism, a social-psychological framework (Blumer, 1969) that has as its basic premise that human beings interpret and act on things in their lives based on meanings derived from social interactions. The symbolic interactionist perspective assumes an emergent view of reality that is produced in social interaction, making it useful for understanding processes that occur in health care situations. Symbolic interaction provides the theoretical foundation for the qualitative method of grounded theory.

In concert with symbolic interactionism, this study was guided by a substantive view of communication as a transactional process with both content and relationship dimensions (Northouse & Northouse, 1992). From the transactional view, communication is a bidirectional process occurring in a relationship in which each person affects the other as he or she communicates. For parents of children with developmental disabilities and the professionals who treat them, the content dimension of communication takes place in the context of their developing and ongoing relationships within the treatment situation. These relationships are central to the communication process and the success of early intervention (Kalmanson & Seligman, 1992), and study of both partners in the relationship is central to understanding the communication process.

METHOD

The first author conducted this study in early 1994, using components of the grounded theory method described by Strauss (1987) and Schatzman (1992). These included (a) constant comparative analysis; (b) open, axial, and selective coding; (c) dimensionalizing; and (d) memoing. Grounded theory was appropriate because the study dealt with participant interpretations of complex social processes and the influences of these interpretations on their communication with one another. The grounded theory method emphasized the importance of following the lead of the participants as they described what was important to them in regard to communication and relationships in the treatment setting.

This study was also influenced by the constructionist perspective of grounded theory espoused by Charmaz (1990), which emphasizes the interaction of the

researcher with the data and the fact that the researcher constructs the analysis, which is further based on the social constructions of the participants found in the data. In that way, it departs from the somewhat positivist idea expressed in earlier writings on grounded theory (Glaser, 1992; Glaser & Strauss, 1967), of the theory being discovered within or emerging from the data. The constructionist perspective thus makes the perspective of the researcher more explicit within the analysis and acknowledges the active role of the researcher in constructing the theory.

Setting

This study was conducted at two developmental treatment centers in a Pacific Northwest community. One was a not-for-profit center that employed occupational, physical, and speech therapists, a nurse, and two social workers. The other was a private for-profit center that employed therapists but no nurse or social worker. Both centers operated primarily under a center-based model with home visits only when required due to child health issues. Families had regular weekly or biweekly 50-minute appointments on a time and day negotiated based on the providers' and parents' schedules.

Sample

This convenience sample consisted of 15 mothers and 5 fathers (representing a total of 15 children), and 14 providers, for a total of 34 participants. Inclusion criteria were that the child has a diagnosed disability or an identified delay that might include a cognitive disability, and that the primary therapist felt the family would be responsive and would not experience undue stress from participating. This study focused primarily on younger children with more severe involvement but included some older ones because of the different perspective of their parents' longer experience with receiving services for their child. Exclusion criteria were non–English-speaking families, the child's disorders' being attributed to illegal drug use of the mother, or the child's only disability being a hearing impairment. With one exception, the parents were all married couples, and with two exceptions they were both the child's birth parents. The number of siblings living in each household ranged from none (2 families) to three (2 families). The children receiving services ranged in age from 15 months to 14 years, and their diagnoses included mild and severe forms of cerebral palsy, mild and severe degrees of mental retardation, and spina bifida.

The provider participants at the two centers included 1 nurse, 2 social workers, 4 occupational therapists, 3 physical therapists, and 4 speech pathologists. Their years of experience ranged from 2 to 20 years with 10 of the 14 providers having at least 10 years of experience in pediatrics and all having at least 2 years experience in pediatrics. In addition, 10 of the 14 providers had children of their own.

Data Collection and Analysis

Permission to conduct the study was obtained from relevant institutional review boards. The first author attended staff meetings at each center to meet providers and explain the study, asking for their participation as well as their recommendations of

parents who might be appropriate for the study. A form letter explaining the study to parents was left for providers to hand out. Parents were approached by the first author based on suggestions by the providers or after receiving expressed interest from parents who received the introductory letter. This study was approved and conducted prior to the enactment of the Health Insurance Portability and Accountability Act of 1996; hence, there was no requirement for an "honest broker." After a period of observation at each center, participants were scheduled for individual interviews at the location of their choice (home or center). Participants were asked to describe their experiences of communication with either the parents or the providers. Most parents chose to begin with the story of their experience prior to referral to the center. Providers usually began by talking about the families from their caseload whose sessions they knew were being observed.

Data analysis was guided by constant comparative analysis. This process involves comparing data to other data, transcripts to other transcripts, and the developing analysis to everyday life experiences and to existing theory. Prior to beginning data collection at the centers, I (first author) wrote about my own professional and personal experiences as provider and parent, which served to increase my awareness of my preexisting views and increase my theoretical sensitivity. Formal, semistructured interviews were conducted with individual parents and providers regarding their communication experiences. During the data collection phase, field notes and theoretical notes were kept in a small notebook. Participant observation was conducted at each center prior to beginning individual interviews. Both participant observation and individual interviews were completed at the first center prior to beginning at the other center.

All formal interviews were audiotaped and transcribed by a professional transcriptionist for subsequent analysis. All tapes were reviewed prior to being sent for transcription, and transcripts were checked against the audiotape, both for accuracy and to make notes on inflection or tone of voice that were not apparent from the transcript. During the first analytic reading of the transcripts, open coding was done by writing marginal notes of identified concepts which were later grouped into categories. We performed axial coding, relating of categories to one another, on large sheets of paper, trying different ways to relate the identified categories into the description of a process. Field notes and notes made previously on my own views and experiences as parent and provider were transcribed and used to question and inform the analysis. For concepts such as stigma, which were identified as theoretically significant prior to beginning data collection, I made extra effort to question and confirm when they appeared in the analysis. Selective coding is the integration of the data analysis into the form of a theory through selecting the core category and identifying its relationship to other categories. This was done through a story line that described the process of striving for a therapeutic relationship. Although description of the analysis process is linear, the actual analysis was a recursive one that involved many readings of data, field notes, and memos and many reworkings of the categories and story line.

Credibility of Findings

Although generalizability and replicability are not generally claims of interpretive research, other characteristics are important to the credibility of the findings. We

addressed validity and trustworthiness for this study by using the concepts of reflexivity (Finlay, 2002; Lamb & Huttlinger, 1989; Lipson, 1991) and relationality (Finlay, 2002; Kahn, 1993) to make transparent the relationships between the researcher and the data and between the researcher and the participants rather than by attempts to ask participants to confirm the findings.

The first author's multiple roles, as the parent of a child with a disability and past colleague of some of the participants, and as a nurse, undoubtedly had effects on the findings. Parents were informed either at the first meeting or at the beginning of the interview that the first author was a parent of an adult daughter with a disability and that she had previously worked with some of the providers. They were assured that all the interviews would be completely confidential and that no information or impressions, either positive or negative, would be shared with either parents or providers.

FINDINGS

Through constant comparative analysis a core phenomenon was identified, referred to as striving for therapeutic relationships. Striving for therapeutic relationships refers to the efforts of both parents and providers to make their interactions as helpful as possible to the child and parents and rewarding to the providers. The following description presents the process of striving for therapeutic relationships.

Conditions

The conditions under which the core phenomenon occurred were the initial identification of a problem with the child's development and subsequent referral for evaluation. For many parents, the two conditions occurred in close sequence, whereas for others, there was some time between identification of a problem and referral for treatment. A delay between problem identification and actual diagnosis and treatment was often uncomfortable for parents, especially if they were the ones who raised the concern. Children whose parents participated in this study had a range of delays but were more representative of significant delays than mild ones. The source of the initial concern about the child's development and the age at which the concern was raised varied in these families. Nine of these 15 children began treatment during the first year of life, 5 by the second birthday, and 1 at age 3. Some parents sought services for their child, some accepted the referrals made by health care providers, and one initially resisted referral.

One mother whose child had speech delays and mild cognitive delays was not able to get her child evaluated and referred for services until he was 3 years old, in spite of having communicated her concern to a health care provider before the child was 2 years old:

> But I do feel, and I have been angry about is that the general practitioner didn't think anything was wrong at two years old, because I felt that if we had started him then instead of waiting another year that things would have been better. You know, you start it earlier and start working; the earlier you start the better it is for the child. So. But since that was the first time I had ever confronted a problem with a child, that I just assumed that the doctor knew best.

Consequences of the identification and referral process were threefold. First, the process affected how early the child was referred for treatment. Second, it affected the expectations and feelings the parents brought with them to the treatment situation. Finally, knowledge of how the referral process had gone affected how the providers at the center viewed and interacted with the parents. Knowledge that parents had changed physicians due to dissatisfaction with the diagnostic and referral process sensitized providers to be more "careful" of doing anything to upset them. Providers felt that one family's "firing" of doctors was a message to not tell them anything they did not want to hear. In the parent interview with the above family, however, the family described dissatisfaction that seemed to have more to do with the way in which the information was given by the doctors than with the diagnosis itself.

Context of Uncertainty

The context in which the core phenomenon, striving for therapeutic relationships, occurred was one of uncertainty for both parents and providers. Parent uncertainty comprised lack of information about the here and now and the future for their child, and lack of trust or confidence, both in the providers as competent and in themselves as parents of a special needs child. All families wanted help for themselves and their child, but few of them understood the nature of therapy for a young child. Most families came to the center with very limited ideas of what to expect from therapy. One mother said,

> And in the hospital I didn't know we were going to be doing all this stuff. I had no idea what we were doing when we came home. I never knew therapy existed like this.

Another expressed her fear about therapy:

> And so then at that point they said that she would be going to therapy and I was really nervous about it at first because I didn't know what they did. I'd never been around a special needs child.

Many parents had difficulty identifying what, if anything, the therapist was doing that was therapeutic, which was eased as they learned by asking questions and watching what the therapist did. Therapists were aware of the confusion produced by the fact that therapy looked like play and attempted to explain to parents what they were doing and why. Once parents decided the therapists were knowledgeable, they tended to trust the therapists were doing something useful, even if they could not identify what the ultimate purpose was:

> She talks, like when she's working with utensils and things like that, she tells me what she's doing. Like "I'm looking for her tongue to do this and this" and I really don't know why her tongue needs to do what she's trying to get her to do, but that's okay. I know there's a reason there. [She] is doing this for a reason. Eventually it's all going to come together, you know.

Parents expressed a great deal of uncertainty about the child's prognosis. They varied in the degree to which they discussed the future for their child. Some

preferred to take one day at a time, whereas others asked the tough questions and wanted to know. Those who took one day at a time did not discuss the future or discussed it as if it were going to be perfectly normal.

Provider uncertainty about the parents occurred with regard to where the parents were in their understanding of the child and in their readiness to be involved with treatment. This uncertainty was at a maximum when a new family began treatment. One provider said,

> I've just started with this new family and I don't know her at all and I'm still trying to feel out kind of where she is and what she's been told and what she believes, how much she's ready to talk about, you know.

Providers talked about trying to "get a sense" of where parents were or "get a feel." Early in the relationship, they did more formal questioning with regard to concrete areas, such as the form in which parents would like to receive information and whether they found written materials, pictures, or verbal descriptions helpful.

Provider uncertainty about the child centered on the child's abilities and temperament as well as his or her diagnosis and prognosis. Whether the child was irritable and how much he or she would tolerate being handled was critical to how the sessions were managed and how the providers related to the parents. If the child did not give clear cues in response to interactions and handling, the providers enlisted the help of the parents in reading the child's cues or states. There was a reciprocal interaction between the providers getting help from the parent in reading the child and the parents getting support from the providers in living with a difficult child.

> With [child] in particular, I ask [his mother] quite a bit. Or I'll tell, I'll tell [child's mother] what my observations are and how I'm interpreting them about his behavior. He's a really different little guy in terms of being able to read his cues. One of the most challenging I've worked with in terms of really being able to read his cues.

Variabilities

Variabilities in the experience of striving for therapeutic relationships were explained by differing perspectives of parents and providers, and change over time. Parent perspectives varied according to their past experience with the health care system, their parenting experience, and their personal views and expectations. The parents' view of the child and how the child fit in the family and their expectations for him or her influenced how they responded to the child's developmental difficulties. Parents' past experiences with disabling conditions and their attitudes toward disabilities in general were also important. One mother mentioned her previous attitude toward persons with "handicaps," which she described as fear. Several parents had concerns about their child's self-esteem with regard to attending therapy.

Providers had a broader perspective from which to view the situation. They had more awareness of the possible outcomes for the child and how intervention now might affect the child in the long term. These opinions varied from one provider to another, affected by their professional discipline, their past work experiences, and their own personal experiences. Opinions ranged from believing that the interventions were critical to the child's development to believing that their interventions must be considered within the context of the family and that the family life was

most important. Some providers identified changes in their beliefs as they gained more professional experience or after having their own children.

As the parent and provider relationship developed, change occurred in the child, the parents, and the providers. As the child developed and matured, the degree and rate of developmental change began to suggest the significance of his or her delays. Uncertainty decreased for both parents and providers as the child's development unfolded and as parent-provider relationships developed. Uncertainty was never totally absent, however, and continued to have an influence on the communication between the parents and providers and on their relationships.

Strategies for Striving for Therapeutic Relationships

The data from this study revealed multiple and interrelated strategies used by both parents and providers for developing therapeutic relationships. The major strategies were Balancing, Questioning, Reading the Cues, Managing the Sessions, and Managing Uncertainty.

Balancing

Balancing was subdimensionalized into Balancing Competing Needs, Balancing Competence and the Need for Intervention, Balancing Parent and Provider Roles, and Balancing the Here and Now and the Future.

Balancing competing needs. As is often the case with families, the needs of one member might be in competition with the needs and priorities of another, or of the family as a whole. Siblings' or parents' need for attention during the therapy sessions sometimes competed with the needs of the child in treatment. Some therapists felt the child's needs came first and expected the parents to comply with all their recommendations. Others took into consideration their assessment of the family's needs and capabilities in making their recommendations. The needs of the provider, although less explicit, were also in competition with child and family needs.

Balancing competence and the need for intervention. A goal of treatment expressed by providers was to identify problem areas and offer interventions or information which could be used to ameliorate the problem. Identification of problem areas was also necessary to justify the need for intervention. However, the constant focus on problems can be very disconfirming. Balance between acknowledging and affirming the competence of both the child and the parents and documenting the need for ongoing services was accomplished through such strategies as normalizing, affirming, and taking one step at a time.

Normalizing refers to focusing on the normal aspects of the child and family, having normal interactions with them while talking about the disability as a part of everyday life for the family. Providers focused on what the child was currently doing and what they could do to help the child reach the next step. They alternated between affirming helpful things the parent was doing to promote development and making suggestions of adjustments or further activities. They watched for cues from the parents to indicate how much to say and when to stop.

Balancing the here and now and the future. The third category of Balancing related to issues of the here and now versus the future. The uncertainty inherent in the nature of developmental delays and disabilities makes anticipating the future difficult. In addition, the future implications of developmental delays can be quite upsetting to parents. A way of dealing with this situation for many of the informants was to focus on the here and now. Others preferred to know the range of possibilities, even if they were unpleasant, to prepare to deal with them. For providers, it was difficult to directly pose a question about such preferences to a parent without implying that there was undisclosed information. If the parent did not directly say what his or her preference was, providers attempted to figure it out without asking directly.

Providers also varied in their approach, with some leaning toward fuller disclosure in response to the tough questions and others continuing to fall back on the uncertainty of the situation. For providers there was often advantage in taking the living-in-the-present approach, because it avoided the difficult and unpleasant task of discussing an uncertain future.

Balancing parent and provider roles. Balancing was also necessary for the many roles identified for the providers and the parents. In addition to the obvious roles of provider of direct treatment services to both the child and parents, provider roles identified by the parents included advocate, therapist, friend, family, and mother. Roles the providers identified for themselves were role model and normalizer, whereas self-identified roles of parents included not only parent and family roles but also advocate, therapist, nurse, teacher, and pharmacist. Among all the identified roles, those of Parent as Therapist and Provider as Friend seemed critical.

The degree to which parents were therapists was negotiated with the providers. Providers varied in the degree to which they believed the parent could or should be a therapist for the child. There was generally consensus among providers that 1 or 2 hours of therapy intervention each week were not enough to make any significant change in the child's life and that some carryover by the parent at home was necessary, but how much is enough was a very murky issue. Therapists with a more family-oriented view were more flexible in their ideas and practices.

The role of Provider as Friend summarizes the personal nature of the relationships that tended to develop. These relationships were not balanced when compared to outside friendships, because the parents rarely knew as much about the personal life of the provider as the provider did about theirs. Some parents identified this discrepancy as a concern, whereas others seemed to find it acceptable. This mother had some concerns about the appropriateness of toys used in her child's sessions but did not feel she could say anything because of the personal relationship.

Mother: And so, those kinds of things are frustrating for me. And you know, I've gotten friendly with the gals, so, "Hey . . . he's bored, let's, you know, think of something new." And he's been there for a long time, so it's probably hard for them to always come up with new ideas.

KW: So in a way getting friendly with them almost gets in the way of being able to . . .

Mother: It does, but you pretty much, they're in your life, and they're such a big part of your life two days a week that it's hard to keep that parent-therapist relationship strictly that way. They just become involved in your life. More so . . . they're involved in our lives. We're not really involved in theirs, you know. I know very little about

their families and things like that, but they know every detail of our life, you know, which makes them seem like they're my friend and somebody I can confide in.

KW: But you don't feel like you can say anything?

Mother: Oh, no. Sometimes I don't. I feel like I don't want to cause any waves because I don't want it to be reciprocated onto [my child]. And I think that's a lot of it. A lot of things we keep, like them treating him in a way that we don't think, it's not harmful, you know what I mean, as long as it's not endangering his person, you know. But then by the same time is he benefiting the most from the therapy he's getting? But we don't say anything because I don't want anybody to have hurt feelings and then inadvertently, I don't think purposefully or anything like that, but take it out on him. And so, no, we don't say things that bother us a lot of times. We just kind of shrug it off. We know it's going on, but we don't really, you know what I'm saying.

Questions and Questioning

The strategy of asking questions was used by both parents and providers to get information and evaluate the other person's attitudes and knowledge. Early in the relationship, providers asked questions designed to reveal how much the parents had been told about their child's problem, how they felt about this information, and what they expected or wanted from the provider, both for the child and for themselves. Concurrently, the providers evaluated questions the parents asked to help them determine the level of the parent's understanding of the child's condition and how interested the parent was in the technical aspects of the diagnosis and treatment and in the prognosis. Some providers believed that parents might not have enough information to ask relevant questions and attempted to educate them and encourage them to ask questions. As the relationship developed over time, some providers used the strategy of asking questions to bring up issues they thought the parent should consider and encouraged the parent to ask their own questions.

Another questioning strategy used by providers was posing questions to one another during treatment sessions as signals that a topic should be explained more fully or to bring up an issue the other provider was not addressing. One provider described herself as asking "ignorant" questions for this purpose. The social workers and nurse reported using this strategy as well as asking questions on behalf of the parent during sessions. Asking questions on behalf of the parents was also reported by providers who accompanied parents to medical appointments:

> We went over to [the children's hospital] for a couple things for her. Just to hear what they were going to say to her so I could kind of follow along. And it was helpful because [the parents] are still not, I mean I think they will in time be more assertive, but they still are not very assertive about asking questions that they have or asking for clarification.

Parents identified using questions to find out information and to "test the waters" when they had concerns but didn't want to "rock the boat" or "put up walls" in terms of communication with the therapist. They judged how well they might be able to work with the provider by the provider's responses and openness to questions. Parents used questions not only to get information, but also to determine how competent they thought the providers were. One father put it this way:

> You know, some of them are competent and some of them aren't. So I am real into asking questions and trying to understand—I'm the same way with my car. If I go

> into a mechanic, you know, I've got to find out, and it takes a while to figure out, does this guy really know what he's doing. So part of that sometimes is just asking small questions. You know, I don't want everybody to feel like I'm grilling them or testing them. So you just make conversation and learn from how they respond to things how knowledgeable they are.

Reading the Cues

Providers spoke frequently of trying to read parent cues, or get a "feel" or a "sense" for "where parents are" in regard to their needs and knowledge levels. Cues included facial expressions, body language, questions asked, and comments made by parents. Many providers could not articulate exactly what the cues were that told them a parent wanted or did not want certain information, whereas others were very clear about what they watched for or what they had observed that led them to their conclusions about parents' needs. The worst situation seemed to be when the provider could not read the cues:

> And then there are parents that you can't read, or I feel like I can't read at all, and I have no idea if in fact they want more information or less information, and I don't have a good sense of what's helpful and what's not.

Another provider said,

> And it seems like every situation is so different, and every parent is so different that sometimes it's difficult to read that initially. How much information they want to give, how much information they're comfortable in giving and how much they want to keep to themselves.

Parents also looked for cues about how the provider viewed their child and his or her abilities and them as parents of a special needs child, such as comments by the provider that she was happy about the progress the child had made. Several parents reported the therapist had said she had not thought the child would make "this much progress" in such a short time. Two parents reported that the therapist said their child was the reason why the therapist said "Never say never." Another indication that the therapist took a personal interest in them and their child was when the therapist saw a toy or activity appropriate for their child in a store and told them about it or purchased it. Therapists also frequently adapted ordinary toys and equipment for children using tri-wall cardboard and foam. Some of these efforts were seen as going "above and beyond" by parents.

Managing the Sessions

Most of the communication took place in the treatment sessions, although there were also telephone calls and written communication. In the beginning, the providers managed the sessions, and the parents accepted them more passively, assuming that the providers knew best about what should be done. Uncertainty was decreased over time as parents learned more about their child, the disability, and the treatment. Parents began to have opinions about the treatment sessions, feeling disappointed if the sessions were not providing all they might or bothered by sessions starting late or being very routine with no new ideas. Fears of hurting the feelings of

the provider or of unintended repercussions to the child were given as reasons for not speaking up and seemed to be the costs of a close personal relationship with the provider. Parents weighed their concerns against the possible repercussions and made tradeoffs based on their assessment. The same was true of situations where the parent wished to change providers or centers. Costs were weighed against benefits and action taken accordingly. Parents sometimes expressed feelings of vulnerability, even in situations where there was a very positive relationship with the provider. Although most parents had positive feelings about the relationship they had with their primary provider at each center, very few felt completely free to say to the provider all the things that concerned them about the child's treatment sessions.

Managing Uncertainty

Uncertainty and attempts to manage it were pervasive in the relationships between parents and providers and colored all their interactions. Parents varied in the degree to which they wanted to decrease their uncertainty, and providers varied in the degree to which they felt it was their job to decrease parent uncertainty. Most providers consciously tried to read parents' cues and stay within the perceived boundaries, whereas a few felt they should provide a certain level of information to parents even if they were not asking for it. Parents generally expressed satisfaction with the amount of information they were given. In the case of one severely involved child, providers reported that the parents gave mixed messages about what and how much they wanted to know, and the providers found the situation very disconcerting. Most providers found that there were times when they needed to encourage parents to consider unpleasant information or make difficult decisions. When they found it necessary to push the boundaries, they put much effort into approaching these topics carefully by setting the stage, including warning parents in advance of topics that would need to be discussed in the future, asking alerting questions of the parents, and making comments about child needs or changes. Some parents expressed awareness of these provider efforts to be gentle with them and were very appreciative.

Consequences

The consequences of all the communication processes were some degree of therapeutic benefit to the child and parents and some degree of satisfaction or feeling of accomplishment for the providers. Parents reported feeling increasingly competent as parents and learning more about their child and the service delivery system. Some of them gave credit to the providers for helping them to be better parents. Parent views of whether the relationship with the provider was therapeutic for them and their child were quite variable. All parents reported satisfaction with the early stages of treatment, the kindness, and the information they were given, but some became disillusioned as time went by. Their expressed dissatisfaction was always specific to certain circumstances, and they often offered reasons the providers might behave in the way that was disturbing. All of them emphasized that the helpful aspects of the relationships outweighed the negative experiences.

Providers attempted to identify ways in which they were therapeutic to families and children and ways in which they could tell that their efforts were appreci-

ated. Positive feedback from the family or indications they were being helpful to the family were much valued, especially when the child did not respond to treatment or was severely impaired. Positive child change was not always required for the relationships to be perceived by the providers or the parents as therapeutic and affirming.

DISCUSSION

The core category of Striving for Therapeutic Relationships constructed from the data in this study reconfirms evidence that interpersonal relationships between parents and providers contribute toward the well-being of the family and child. Providers were identified by their professional roles with the family, such as advocate, teacher, therapist, but also as friend, "like family," "she mothers me." Some families and providers saw each other socially. This aspect of the relationships corresponds to the idea of empowering families described by Dunst, Trivette, and Deal (1988), in which families come to identify providers among their informal support network rather than, or as well as, their formal support network. These findings confirm previous studies indicating the importance of relationships that are personal and informal rather than distant and professional (Minke & Scott, 1995).

The unique contributions of this study include describing the effort expended by both parents and providers to make relationships work and the degree to which parents might be constrained in their interactions with providers, even when there is a positive and valued relationship. Comments by parents and providers indicate they each discussed what occurred during sessions and interpreted the meanings and implications. Both parents and providers put a great deal of energy into their relationships.

Study results suggest several considerations for clinical practice. First, the role of the provider as a normalizer and destigmatizer for families with a child who has developmental problems seemed very important. Normalization is a term used to describe one response to a situation in which a family member has an illness or disability (Knafl & Deatrick, 1986). It has been discussed by Davis (1972, 1991) and includes behaviors such as "engaging in usual parenting activities, limiting contacts with similarly situated others, making the child appear normal, avoiding potentially embarrassing situations, and controlling information" (Knafl & Deatrick, 1986, p. 217). The role of the providers in this study seemed to consist of attending to the normal aspects of the child and family and of allowing them an opportunity to normalize the abnormal aspects of their lives. The center was a place where the family could experience "disabled as normal" or what was "normal for them" (Morse, Wilson, & Penrod, 2000, p. 663). Normalization efforts must be distinguished from denial, in which the fact of the disability is denied.

Second, the role of questions and questioning as a strategy for both parents and providers was striking. It appears important that providers not rely too heavily on the questions parents ask as cues to the parents' knowledge level or desire to receive information. There are those parents who are hesitant to ask questions for various reasons or do not have an adequate knowledge base from which to formulate questions. Often parents express their needs and questions in veiled ways that might sound like simple requests for reassurance (Sabbeth & Leventhal, 1988). Providers must continue to be alert for veiled requests for help. This practice was exemplified

TABLE 1: Striving for Therapeutic Relationships

Conditions	Identification of child delays
	Referral for treatment
Context	Uncertainty
Variabilities	Differing parent and provider perspectives
	Change over time
Strategies	Balancing
	Balancing competing needs
	Balancing competence and the need for intervention
	Balancing parent and provider roles
	Balancing the here and now and the future
	Questioning
	Reading the cues
	Managing the sessions
	Managing uncertainty
Consequences	Parent-provider relationship perceived as therapeutic
	Provider-child relationship perceived as therapeutic
	Parent perception of competence in parent role
	Provider perception of competence in provider role
	Positive changes in child competence

in this study by a mother who mentioned repeatedly how she would "put out little flares" to bring up a topic or question in a nonthreatening way. Her efforts were often overlooked, much to her distress.

Third, although the personal relationships between parents and providers are very important and therapeutic for many families, there are still constraints on communication related to parent dependence on the provider for child and family services. Providers should continue to ask questions of the parents about their concerns and preferences and offer opportunities for change, even in an established relationship. Providing parents with the opportunity to speak periodically with a provider who is not providing direct services to the family might facilitate communication of difficult concerns.

Finally, providers must remain cognizant of the effects of the process of change on the needs, knowledge levels and concerns of parents. Resources offered at one point in time might not be remembered when needed at a later point in time. The relevance of specific information or services may be obscured by grief or lack of knowledge. Provider should revisit previous offers of information and services which might be helpful to parents. For example, the offer of an educator who makes home visits might sound ludicrous to the parents of a young infant just beginning a developmental program. The same offer might sound very helpful and desirable to the same parents after 6 months of experience and increased awareness.

SUMMARY

We have presented the results of a grounded theory study of parents and providers of children with developmental disabilities. The core concept generated in the data was striving for therapeutic relationships, which focused on the communication processes between parents and providers. Striving for therapeutic relationships was dimensionalized into the specific strategies of Balancing, Questioning, Read-

ing the Cues, Managing the Sessions, and Managing Uncertainty. Balancing was subdimensionalized into Balancing Competing Needs, Balancing Competence and the Need for Intervention, Balancing Parent and Provider Roles, and Balancing the Here and Now and the Future.

REFERENCES

Bailey, D. B., Jr., Blasco, P. M., & Simeonsson, R. J. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal on Mental Retardation*, *97*(1), 1-10.

Blumer, H. (1969). *Symbolic interaction: Perspective and method*. Englewood Cliffs, NJ: Prentice Hall.

Brady, S. J., Peters, D. L., Gamel-McCormick, M., & Venuto, N. (2004). Types and patterns of professional-family talk in home-based early intervention. *Journal of Early Intervention*, *26*(2), 146-159.

Charmaz, K. (1990). "Discovering" chronic illness: Using grounded theory. *Social Science & Medicine*, *30*(11), 1161-1172.

Davis, F. (1972). Deviance disavowal: The management of strained interaction by the visibly handicapped. In F. Davis (Ed.), *Illness, interaction and the self* (pp. 388-397). Belmont, CA: Wadsworth.

Davis, F. (1991). *Passage through crisis: Polio victims and their families*. New Brunswick, NJ: Transaction.

Dinnebeil, L. A., Hale, L. M., & Rule, S. (1996). A qualitative analysis of parents' and service coordinators' descriptions of variables that influence collaborative relationships. *Topics in Early Childhood Special Education*, *16*(3), 322-347.

Dinnebeil, L. A., Hale, L. M., & Rule, S. (1999). Early intervention program practices that support collaboration. *Topics in Early Childhood Special Education*, *19*(4), 225.

Dunst, C., Trivette, C., & Deal, A. (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA: Brookline.

Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, *12*, 531-545.

Glaser, B. G. (1992). *Emergence vs. forcing: Basics of grounded theory analysis*. Mill Valley, CA: Mill Valley Press.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Kahn, D. L. (1993). Ways of discussing validity in qualitative nursing research. *Western Journal of Nursing*, *15*(1), 122-126.

Kalmanson, B., & Seligman, S. (1992). Family-provider relationships: The basis of all interventions. *Infants and Young Children*, *4*(4), 46-52.

Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1992). Parents' views of health care providers: An exploration of the components of a positive working relationship. *Children's Health Care: Journal of the Association for the Care of Children's Health*, *21*(2), 90-95.

Knafl, K. A., & Deatrick, J. A. (1986). How families manage chronic conditions: An analysis of the concept of normalization. *Research in Nursing and Health*, *9*, 215-222.

Lamb, G. S., & Huttlinger, K. (1989). Reflexivity in nursing research. *Western Journal of Nursing Research*, *11*(6), 765-772.

Lipson, J. G. (1991). The use of self in ethnographic research. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 73-89). Newbury Park, CA: Sage.

McGonigel, M. J., & Garland, C. W. (1988). The individualized family service plan and the early intervention team: Team and family issues and recommended practices. *Infants and Young Children*, *1*(1), 10-21.

McWilliam, R. A., Tocci, L., & Harbin, G. L. (1998). Family-centered services: Service providers' discourse and behavior. *Topics in Early Childhood Special Education*, *18*(4), 206-221.

Meeropol, E. (1991). Parental needs assessment: A design for clinical nurse specialist practice. *Pediatric Nursing*, *17*(5), 456-458.

Minke, K. M., & Scott, M. M. (1995). Parent-professional relationships in early intervention: A qualitative investigation. *Topics in Early Childhood Special Education*, *15*(3), 335-352.

Morse, J. M., Wilson, S., & Penrod, J. (2000). Mothers and their disabled children: Refining the concept of normalization. *Health Care for Women International*, *21*, 659-676.

Northouse, P. G., & Northouse, L. L. (1992). *Health communication: Strategies for health professionals* (2nd ed.). Norwalk, CT: Appleton and Lange.

Pope, A. M., & Tarlov, A. R. (1991). *Disability in America: Toward a national agenda for prevention*. Washington, DC: National Academy Press.
Sabbeth, B. F., & Leventhal, J. M. (1988). Trial balloons: When families of ill children express needs in veiled ways. *Children's Health Care*, *17*(2), 87-92.
Schatzman, L. (1992). Dimensional analysis: Notes on an alternative approach to the grounding of theory in qualitative research. In D. R. Maines (Ed.), *Social organization and social process: Essays in honor of Anselm Strauss* (pp. 305-314). New York: Aldine de Gruyter.
Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development*, *18*, 259-282.
Strauss, A. (1987). *Qualitative analysis for social scientists*. New York: Cambridge University Press.
Strauss, S. S., & Munton, M. (1985). Common concerns of parents with disabled children. *Pediatric Nursing*, *11*, 371-375.
Summers, J. A., Dell'Oliver, C., Turnbull, A. P., Benson, H. A., Santelli, E., Campbell, M., et al. (1990). Examining the individualized family service plan process: What are family and practitioner preferences? *Topics in Early Childhood Special Education*, *10*(1), 78-99.
Walker, D. K., Epstein, S. G., Taylor, A. B., Crocker, A. C., & Tuttle, G. A. (1989). Perceived needs of families with children who have chronic health conditions. *Children's Health Care*, *18*(4), 196-201.

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