IV MODELS FOR PERSONNEL PREPARATION

How have others addressed the personnel preparation challenges that are described throughout this book? Part IV provides information about specific models that have been developed, implemented, and evaluated to deal effectively with the issues introduced in Part I and the challenges described in subsequent sections. The information in Part IV has application at state, community, program, university, and community college levels and across all disciplines. The focus is on practical information that will assist agencies and individuals in making changes that affect the way that personnel preparation is implemented. The final chapter addresses the nuts and bolts of ''putting it all together,'' drawing on instructional strategies and examples from the previous chapters.

17 PARENT–PROFESSIONAL PARTNERSHIPS IN PRESERVICE AND INSERVICE EDUCATION

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Another doctor's appointment, probably the tenth this month. It's amazing that a 7-month-old baby who has been through as much as Chris has can still maintain an easy disposition. Although the physicians comment on his easygoing nature, it seems as though no one cares about what it takes to support an infant whose skin is raw from eczema, who can't take more than three sips from a bottle without coughing due to asthma, and who has had three surgeries and countless trips to an emergency room, all prompted by difficulties related to his circumcision. As Angela, Chris's mother, thinks back on the past 7 months, she tries to figure out why she has such uneasy feelings about the medical profession. For the most part Chris's medical needs have been addressed (not always in a timely fashion, but always ultimately addressed), but there is something unrewarding about each visit.

First came the medical student, "Tell me about Chris. Why are you here?" (as if the red, oozing lesions on his face weren't visible). You know the typical questions. With all his questions answered, he told us that the doctor, a pediatric dermatologist, would be in in a minute. At least Dr. Krusinski always talked to Angela, played with Chris, and had his secretary call to see how they were doing. He had also been honest enough to share that two treatments prescribed by other doctors had caused more harm than benefit (honesty is definitely an endearing quality). As Dr. Krusinski and the medical student entered the room, Chris looked up, quieter than usual and with no smile.

"Oh, Chris, what has happened to you? Don't worry, we'll get you better." Dr. Krusinski looked at the medical student and said, "This is typically one of the happiest little boys I see; clearly his eczema is out of control, and we need to readjust his medication." What a treat—Dr. Krusinski knew who Chris was and incorporated that knowledge into the diagnosis. He then turned to Angela and asked her to talk about how she was taking care of Chris's skin. After completing her litany of "lotions and potions" (a routine rivaled only by a professional masseuse), he turned to the medical student and said, "It's so important to ask the parent(s) what they've been doing—it makes your job so much easier. Angela has just described the perfect scenario, and look at Chris; it's obviously not working. There isn't a doubt in my mind that they need a higher-level cream." At this point Dr. Krusinski answered a number of Angela's questions about eczema and skin infections, prescribed an antibiotic, and then began to talk to her about how to make decisions on working with the antibiotic and the three levels of skin

creams Chris now has. As he ended the visit, he reminded her that his secretary would call in 2 days to see how things were going.

Once they were alone, Angela sat with Chris and thought, ''This must be what family-centered care feels like.'' They had both been the recipients of a great deal of respect. Chris was not just an infant with a skin ailment; he was a happy little boy whose skin was having a dramatic impact on his disposition. She wasn't simply the person holding Chris; she was the person who cared for this little boy, who had a routine of care, who had observations, and who had expertise. Dr. Krusinski clearly acknowledged that he couldn't do his job without her. He gave Angela the information and tools that would allow her to care for Chris in the best possible manner. In addition, he communicated that he saw her as a decision maker in Chris's treatment. He taught her how to observe and use the various ''lotions and potions'' effectively and responsively. How amazing—she was seen as a partner in Chris's care. This is what had been missing!

Partnership may well be remembered as a hallmark of the 1990s. It is a concept that is reshaping how America wants to deliver goods and services (Kagan, 1991). Across the United States, families and professionals are establishing partnerships. Parents are participating as members of task forces and advisory boards, mentors for other families, grant reviewers, participants in quality improvement initiatives, and as instructors for preservice and inservice activities (Jeppson & Thomas, 1994c).

We have learned that when parents and professionals work in partnership the results are dramatic. Parent–professional partnerships have been attributed with ''humanizing the service delivery system, improving outcomes for children, contributing to greater satisfaction for both parents and professionals'' (Jeppson & Thomas, 1994b, p. 1) and ''creating an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored'' (Bishop, Woll, & Arango, 1993, p. 29). The vignette about Chris and his mom exemplifies the impact of authentic partnerships between parents and professionals on the lives of children and their families. The partnership Dr. Krusinski established with Angela clearly illustrates what can happen when a professional steps out of a traditional approach to service delivery and views a parent as an essential partner in the delivery of services. A closer look at this partnership reveals the following key elements of parent–professional partnerships:

- Dr. Krusinski clearly acknowledged Chris as a person with a pleasant disposition that was being affected by a medical condition. His actions communicated to Angela that treatment for the condition, although related to the medical problem, was, more important, linked to helping Chris get back to his old self.
- Dr. Krusinski acknowledged that Chris's eczema was being treated on an ongoing basis by Angela; therefore, he was neither the sole provider of medical treatment nor the only individual with information that would help Chris.
- Dr. Krusinski clearly communicated that he needed Angela's expertise in dealing with Chris's condition to make an appropriate next-step decision.
- Dr. Krusinski gave Chris and Angela new information as well as a new treatment, and then reviewed how this new treatment fit with all the other information and treatments they were already using.
- Dr. Krusinski also set up a ''check-in'' visit that was not primarily related to Chris's skin needing medical attention but was designed to provide an opportunity for Angela and Dr. Krusinski to reflect on both how Chris was doing and how the treatment felt to Angela.

FACILITATING PARENT–PROFESSIONAL PARTNERSHIPS IN PRESERVICE AND INSERVICE EDUCATION

Preservice and inservice training opportunities that facilitate the preparation of professionals who are able to practice in partnership with families are grounded in family-centered principles. Such opportunities require considerable reflection and evaluation on the part of professionals as well as a commitment to an ongoing, developmental process: a journey undertaken in partnership with families. Since the 1970s, families have become increasingly involved in preservice and inservice instruction, and much has been learned from the reflections of families and professionals who have engaged in instructional partnerships. Bishop et al. (1993) described seven principles that provide the foundation for family–professional collaboration:

1. Promotes a relationship in which family members and professionals work together to ensure the best services for the child and family
2. Recognizes and respects the knowledge, skills, and experience that families and professionals bring to the relationship
3. Acknowledges that the development of trust is an integral part of a collaborative relationship
4. Facilitates open communication so that families and professionals feel free to express themselves
5. Creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored
6. Recognizes that negotiation is essential in a collaborative relationship
7. Brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special needs and their families

These principles can be put into practice by including the family at the ground level of instructional activities, using innovative ways to identify and recruit families for participation in the instructional partnership, creating partnerships with parent organizations to ensure continuity and ongoing support to both families and professionals, maintaining an array of instructional opportunities in which families can participate, and acknowledging and responding to logistical challenges in creative ways.

Involving Families as Partners in Preservice and Inservice Education

Parent–professional partnerships are the vehicle that can change the traditional culture of preservice and inservice instruction. These partnerships set a context for the preparation of family-centered practitioners by modeling the qualities of a collaborative relationship between families and professionals. Partnerships model the belief that families are valued consumers of, and competent partners in, the design, implementation, and evaluation of early intervention services. More important, partnerships communicate the need for the expertise of both families and professionals to develop and implement appropriate services for young children with disabilities and their families. Parent–professional partnerships for preservice and inservice instruction provide one of the best means of communicating the family-centered philosophy. These partnerships reinforce a belief in family centeredness and strengthen programs, practices, and practitioners. Partnerships become the enduring quality of successful preservice and inservice instruction, and they sustain family-centered practitioners.

Although parent–professional partnerships have a positive impact on all levels of the service delivery system, they are not a natural phenomenon. When they do exist these partnerships reflect a deliberate effort to include families in arenas typically dominated by professionals (Jeppson & Thomas, 1994b). Since the late 1980s, inservice and preservice instructional programs have made great strides toward establishing authentic partnerships between parents and professionals (Bailey, Palsha, & Huntington, 1990; Favrot, Steele, & Worthington, 1993; Winton & DiVenere, 1995). A report on early intervention personnel preparation programs (Campbell, 1994) indicated that U.S. universities have begun to address the need to prepare family-centered practitioners by providing students with opportunities to learn with and from families. Responses to a written survey from 100 graduate- and undergraduate-level early intervention personnel preparation programs representing 38 states and the District of Columbia suggest three distinct trends. First, parents are becoming involved in the personnel preparation process; 81% of the programs reported that parents participate as guest lecturers, and 19% of the programs reported that parents co-teach with faculty. A second trend relates to opportunities for students to spend time with families in their homes. Seventy-seven percent of the programs reported that students complete at least one assignment with a parent of a young child with a disability in the family's home, and 45% of the programs reported students complete a practicum of at least 20 contact hours over a semester or term with families in their homes. Finally, the role of families in the personnel preparation process is expanding. Forty-nine percent of the programs identified unique ways in which families are involved in personnel preparation, including participation on advisory boards ($n = 22$), supervision of students ($n = 24$), involvement in practicum ($n = 16$), and participation in a parent mentoring program ($n = 16$).

The Nature of Parent–Professional Partnerships

> Successful partnerships are characterized by an exchange of ideas, knowledge, and resources. Partners form a mutually rewarding relationship with the purpose of improving some aspect of education. The relationship must be based on the identification and acceptance of compatible goals and strategies. In addition, the partners should respect the differences in each other's culture and style, striving to apply the best of both worlds to achieve established goals. (Grobe, 1993, p. 7)

A number of concrete steps can be taken to involve family members as equal partners in preservice and inservice training. In the following sections, these steps are illustrated with a parent's voice.

Maintaining an Array of Options Winton and DiVenere (1995) identified four types of roles that parents may fill, including instructors, practicum supervisors, team participants in staff development, and planners and policy makers. Each role translates into a broad array of actions that increases the potential of capitalizing on the expertise each family has to offer. The uniqueness of each family and family context enhances participants' opportunities to understand the intricacies of a family-centered philosophy as it relates to different situations. The extent to which families have opportunities to participate as instructors directly affects participants' opportunities for learning. Table 17.1 identifies sample activities that can be associated with each role.

The journey toward creating partnerships with families must be driven by constant attention to the ways in which families are included in training activities. In a study by Capone (1995), 52 parents who had been involved in preservice and inservice training activities were interviewed and participated in follow-up focus groups to describe their

TABLE 17.1. The roles of families in parent–professional partnerships in training

Families as instructors

- Participation on panels
- Teaching a module
- Co-instructor for a course
- Co-instructor for a workshop

Family practica experiences

- Pairing students and families for a home visit
- Participation in semester-long practicum experiences

Families as participants in a team-based model of staff development

- Participating as decision-making partners in defining how programs can move toward more family-centered practice

Families members as personnel preparation policy makers and planners

- Membership and leadership roles on state interagency coordinating councils
- Participation on personnel subcommittees of the interagency coordinating council
- Participation as paid consultants and staff on various innovative instructional grants funded federally or locally

perceptions of the role of parents in training activities. Parents in this study discussed a desire to participate as equal partners whereby they are partners in all aspects of the instructional activities in which they are asked to participate (i.e., planning, implementing, evaluating). The phrase that was used frequently by parents during the interviews was ''involvement at the time of conception.''

> Parents are advocates for children; they have information about strategies that work for kids as well as strategies that can help the system function in a more efficient and responsive manner. Parents' experiences have tremendous potential for not only informing, but also promoting system change. It is, however, very difficult to be in a reactive stance. For example, it's difficult when someone else has already established the goals, and often developed the materials for a training session, and then asks you to please provide your perspective on these goals and materials. It would feel so much more like a partnership to be involved from the beginning—to be a part of identifying the goals and developing the materials. (Capone, 1995)

When parents state, ''At all levels and in all activities parents should be viewed as equals in the partnership,'' they are describing a frustration that stems from not being provided with an opportunity to understand the larger whole. When parents are not included as partners at the point of conception, it limits the potential value of the knowledge and experience they have to share with professionals.

> What I do and say, as a parent, can and should depend on the format of the presentation and what my experiences have been. I have a great deal to share beyond ''what my family story is.'' In order for this to happen I need the same tools: perhaps encouragement, but most definitely information. Information about the overall goals of the training. Information on who else is speaking and what they are going to say. Information on how to best organize my presentation. In short, parents would like to be involved in the total process: planning and imple-

> menting as well as being prepared to participate in training, not so that they will be professionals, but so that the parent perspective will be presented well. (Capone, 1995)

Parents in this study also applied the concept of participating as equals in the partnership to the evaluation process occurring at the end of most training sessions.

> Professionals appear to have specific ''expectations'' relative to parent performance. If I knew what they were I would be better able to meet them. Perhaps, a mentorship system could be set up to support parents as trainers (e.g., visiting other parent training sessions), or perhaps, when we think of supporting parents as training partners we can also think of support as the opportunity to explore the training issues with others who are also involved in the training. (Capone, 1995)

Parents are speaking about what might be described as ''mutual obligations and expectations,'' a partnership in which all participants understand the goals and objectives as well as their specific role in realizing those goals. Therefore, participation in evaluation of the activity provides an opportunity for dialogue and trust building, two key elements in establishing equality among partners.

Partnerships are most successful when all presenters are included in all phases of the instruction, from planning and implementation to evaluation and follow-up. Including families at all levels increases the effectiveness of the instruction and ensures that family-centered principles are clearly reflected in instructional partnerships. In one study (Capone, 1995), parents spoke about the issue of respect: respect for what parents have to say, respect for their experience, and respect for their commitment. Respect, as parents discussed it, can take many forms: payment, scheduling accommodations (e.g, doing instruction when it is most convenient for the parent, including options to support child care during the instruction), being involved as an equal partner (e.g., knowing what everyone else knows), and the opportunity to have equal time to present. When parents participate in instructional activities, attention should be given not only to the content of a presentation but also to the whole presentation, from logistics, to introductions, to summarizations. When introducing parents during instruction, even the tone and the attitude expressed are reflective of the level of partnership that exists between parents and professionals: ''Being introduced [by someone with a] 'This is the Parent' tone implies much to the audience'' (Capone, 1995).

It is important that family partners have numerous and varied ways of sharing their perspectives and experiences. Family input can be as formal as creating paid staff positions or as informal as holding a coffee hour on a hospital unit for families to share their perspectives on the hospital experience (Jeppson & Thomas, 1994b). In a family focus forum on parent–professional partnerships in instruction, parents expressed the view that every interaction with professionals is an instructional opportunity (Capone, 1995).

Recruiting Families The effectiveness of instructional partnerships is largely dependent on including families from diverse backgrounds with a wide range of experiences. Attention should be given to including families who are existing consumers of services as well as experienced families and ensuring that the families in the partnership reflect the composition of the community in which the instruction occurs. Family members (Capone, 1995) have spoken of the diverse perspectives that they have to offer based on their backgrounds, the age of their children, their experience as instructors, and their particular role in their family (e.g., mother, father, sibling). Almost all parents noted the need to ensure that instruction provides participants with opportunities to hear varying perspectives on any given issue: ''One parent was always approached because of being a 'black, visible parent.' It is an asset to have culturally diverse parent representation, especially in a region like New York'' (Capone, 1995).

There are a variety of ways to identify and recruit families, keeping in mind the importance of including a diversity of parent perspectives. The following list was adapted from one described in ''Essential Allies: Families and Professionals Working Together to Improve Quality of Care'' (Jeppson & Thomas, 1994b):

- Contact local or statewide Parent to Parent organizations.
- Post notices on community bulletin boards and in medical, educational, recreational, and social service programs.
- Contact organizations that serve particular cultural groups.
- Develop radio, newspaper, or television public service announcements in the languages of the communities being served.
- Use cultural mediators (i.e., knowledgeable individuals within cultural communities).

Ensuring Support Through Parent Organizations Establishing partnerships with parent organizations strengthens as well as supports a network of families as instructional partners. In addition, many parent organizations have resources to support families before, during, and after their involvement in instructional experiences. As the quote suggests, parents will face a variety of new issues and emotions as they begin to share their experiences in new and different arenas. It is essential that support be available to assist them in both naming and working through those issues.

> Parents could use support to explore their role in the partnership. As parent–professional partnerships become more complex, with parents assuming more responsibilities, parents need support to reflect on issues/concerns around a perceived sense of loss of identity as a parent. (Capone, 1995)

Winton and DiVenere (1995) described three categories of support for parents: 1) emotional support, 2) informational support, and 3) instrumental support. One of the roles of a parent organization is to support parents in the ways they have identified as essential to facilitating their parent voice. One example of the kinds of support available to families before a presentation is provided by Parent to Parent of Vermont, which created a set of guidelines to assist families in planning and organizing presentations for preservice and inservice instruction (see Figure 17.1).

Parent to Parent of Vermont suggests that professionals who have invited families to make presentations offer to help families prepare for their presentations. It is important to talk with families about issues that may arise during a presentation such as how to cope with unexpected emotions and how to answer personal questions. It is also important to remember that each parent presenter is different. Professionals should develop an array of strategies to ensure that parents feel comfortable and supported in assuming the role of instructional partner. Furthermore, Parent to Parent of Vermont urges professionals to call families shortly after their presentation to thank them and offer feedback: ''Hearing from participants that my participation broadened and enhanced an understanding of disability and chronic illness of individuals and their families lets me know I am making a difference!'' (Capone, 1995).

Responding to Logistical Barriers One barrier that is frequently raised is the ability of professionals to have access to appropriate reimbursements for their training partners. The types of preferred reimbursement should be explored with the family. In addition to offering stipends, many professionals offer families access to fax machines, telephones, child care, and mileage reimbursements. Most universities have discretionary funds in their departmental budgets that can be allocated for family partners. In addition, universities can offer free coursework, access to the gymnasium (with pool and exercise equip-

HOW TO ORGANIZE A PRESENTATION

1. **Invitation to participate in preservice and inservice instruction.**
2. **Determine request:**
   - √ Will you be presenting alone or with a partner?
   - √ How much time is available?
   - √ How many participants? What are their needs for information?
   - √ How experienced are participants?
   - √ Who requested the information? (Is the need for information unanimous, or do some people believe they "already know/do this"?)
   - √ Is there a common philosophy among participants?
   - √ Is this a one-time-only opportunity to meet? (Depending on their needs, it might be helpful to schedule a follow-up 4–6 weeks after the initial session to problem-solve and discuss issues after they have had a chance to try out information/philosophy.)
   - √ Discuss stipend and travel expenses.
   - √ Send written confirmation of your understanding of the request, time, place, date, and so forth.
3. **Prepare the presentation:**
   - √ Review all the instructional materials available to you.
   - √ If the presentation is to be "solo," select appropriate materials based on #2 above.
   - √ If you are presenting with an instructional partner, allow time to discuss/select materials and roles for collaborative presentation.
   - √ Be sure you will have access to equipment (e.g., VCR, slide projector), if you will be using them.
   - √ Prepare handouts, overheads, agenda for the day. (Try to add humor using overheads and other equipment.)
   - √ Practice exercises that are not familiar to you. Imagine questions that may arise. Think about how you would respond to questions.
4. **The day before the presentation:**
   - √ Review your materials.
   - √ Be sure you have everything you will need: nametags, markers, masking tape, flipcharts, and so forth.
   - √ Call for directions if you are unfamiliar with the area.
   - √ Consider bringing along a picture of your child or family.

(*continued*)

Figure 17.1. Guidance for families involved in preservice and inservice instruction. (Adapted from Winton & DiVenere, 1995.)

Figure 17.1. *(continued)*

5. The day of the presentation:

- √ Allow plenty of time for travel.
- √ Be yourself.
- √ Help people feel relaxed.
- √ Make an effort to learn and remember people's names. Refer to participants by name (if possible) when they ask questions.
- √ Use your sense of humor.
- √ Remain nonjudgmental.
- √ Involve the audience. When questions are raised, turn them over to the entire group before answering yourself.
- √ Have fun!

ment), access to the library, and other gifts that would support the important work of family instructional partners.

Parent–professional partnerships encourage a different way of thinking about the design, implementation, and evaluation of preservice and inservice training opportunities. Instead of asking the question ''How can parents be a part of the delivery of a specific curriculum content?'' professionals need to consider how the planning and implementation of the instructional opportunities facilitate and model communication, cooperation, and teaming among parents and professionals.

In summary, the discussions about the qualities of effective partnerships support the need for parents to be involved in all aspects of instruction, from conception to evaluation; to be provided the support necessary to accomplish their task effectively; to represent a diversity of experiences; and to be treated with respect. The parent voices used to illustrate these points mirror Kagan's (1989) definition of a collaborative partnership; that is one that is characterized by intense joint planning and a sharing of resources, power, and authority. This kind of partnership means more than ensuring that parents and professionals appear together at training sessions. It challenges parents and professionals to engage in ongoing, honest discussions to develop a shared understanding of each partner's role in the development, implementation, and evaluation of preservice and inservice instructional opportunities. Figure 17.2 provides guidelines for considering different approaches to establishing and maintaining parent–professional partnerships for preservice and inservice education.

TWO PRESERVICE MODELS FOR PARENT–PROFESSIONAL PARTNERSHIPS IN INSTRUCTION

Two programs at the University of Vermont provide examples of parent–professional partnerships in preservice training. The first model, The Medical Education Project, represents a collaboration between the University of Vermont College of Medicine and Parent to Parent of Vermont. The second model is a partnership between the Early Childhood Special Education Master's Program at the University Affiliated Program of Vermont, in the University of Vermont College of Education, and Parent to Parent of Vermont. Both programs represent a partnership between parents and professionals in preservice training.

1. **Include families at the ground level of instructional activities.**
   A. Families are included at the conception and planning level of instruction.
   B. Families are given information necessary to support their role.
2. **Use innovative ways of identifying and recruiting families for participation as instructional partners.**
   A. A variety of options exists for identifying and recruiting families.
   B. We have identified families who are current consumers as well as veterans.
   C. Our instructional partners reflect the composition of the community in which our personnel preparation occurs.
3. **Create partnerships with parent organizations to ensure continuity and ongoing support for families and professionals and to acknowledge and respond to logistical barriers in creative ways.**
   A. Families are supported before, during, and after their involvement in instructional experiences.
   B. Families are provided with emotional, informational, and instrumental support based on their preferences and needs.
   C. We have developed partnerships with parent organizations in our area.
   D. We have explored a variety of options for reimbursing family partners.
4. **Maintain an array of instructional opportunities.**
   A. There are both formal and informal opportunities for families to participate in personnel preparation.
   B. We have included opportunities for family involvement in each area of our instructional experiences from conception to implementation to evaluation.

Figure 17.2. Guidelines for involving families as partners in preservice and inservice instruction.

Medical Education Project

The Medical Education Project, a collaboration between the University of Vermont's College of Medicine and Parent to Parent of Vermont, was established in 1985 as a required component of the clinical rotation in pediatrics for all medical students. Created long before the concept of family-centered care was an established approach, this project relied on families as teaching partners. The Medical Education Project was founded on the belief that families are experts in the care of their children and that individuals with disabilities are competent, experienced advocates for their health care.

Goals The goals of this project, developed collaboratively by families and physician faculty, guide each of the four sessions:

- To give medical students an opportunity to step out of their student role and into the role of a parent
- To give medical students an opportunity to learn the art as well as the science of practicing medicine
- To help medical students recognize and acknowledge their own biases and personal beliefs to avoid imposing them on a family or person with a disability or illness
- To give medical students an opportunity to see beyond an individual's illness or diagnosis—to see the person at home, in his or her own community

Description of the Sessions Students are required to attend four sessions that are designed to promote dialogue and decision making that enable students to understand the following: 1) the importance of providing accurate, unbiased information to families;

2) the need to meet with, and be supported by, immediate and extended family members and friends as part of the decision-making process; and 3) the ways values and beliefs affect how decisions are made.

Before students arrive for the first session, they have been randomly ''matched'' with a family. Students are given the names of the family and the child and are asked to make contact with their family early in the rotation and to set up a meeting time convenient for the family. Students are not provided with any information about the child's diagnosis or disability because they are not there to interview, assess, or evaluate but rather to listen and learn from the family. Families wanting to participate are sent a letter of welcome (Figure 17.3).

Each session encourages students to take on a parental perspective. During Session 1 students are asked to make a decision—a decision every parent who has a child born with hypoplastic left heart syndrome must make. Students are asked to return the following day with their decision and the reasons they chose either compassionate care, transplantation, or a three-part surgery called the Norwood Procedure. Following this discussion, facilitated by the two pediatricians who have been with the project since its inception, students are asked to decide which of four diagnoses (i.e., Down syndrome, third-degree burns that include the child's face, cystic fibrosis, and meningomyelocele) they would find most difficult and least difficult as a parent and why. As students discuss their decisions, they are supported to explore how those decisions reflect their values, biases, and attitudes about disabilities. In addition, faculty from Parent to Parent encourage students to explore the relationship between their personal attitudes about parenting a child with a disability and their interactions with parents. During the final session, students reflect on their home visits and consider their experience in the context of the entire seminar. Because families direct the discussion during the home visit, students come away with unique learning experiences, which they in turn share with colleagues during the final session.

Role of Families Families involved in the Medical Education Project participate in an orientation meeting, agree to host a medical student for an evening or an afternoon, and identify at least three points they want students to take back with them. Following the home visit, families are asked to complete a Parent Feedback Sheet (see Figure 17.4).

Role of Parent to Parent Staff An essential component to the success of this project is the opportunity to process and discuss each part of the seminar. Medical students appreciate not only the lessons learned during the home visit but also the willingness of physician faculty and Parent to Parent staff to talk about ethical dilemmas, values, and beliefs. Students are also extremely impressed by witnessing the impact of an ongoing health condition or disability on all family members and the critical role of family members in providing and advocating for health care. Parent to Parent staff participate in all aspects of this seminar. The staff write to families following the last session, sharing comments from medical students' testimony that the home visit made a difference.

Families continuously report that the reason they participate is because they know their experiences and those of their children are listened to and learned from. This collaborative model has launched additional parent–professional partnerships.

Early Childhood Special Education Program

The Family-Based Practicum Experience for Early Childhood Special Education Master's students at the University of Vermont College of Education was collaboratively designed by university-based faculty and faculty from Parent to Parent of Vermont. This year-long practicum provides students with in-depth experience with a family of a child with a special health care and/or educational need and incorporates a variety of opportunities for interns and family members to interact.

Dear Fellow Parents:

Welcome to the Medical Education Project. As parents, you are the best resource in providing accurate information to medical students regarding the qualities you and your family find most helpful in a physician. Since 1985, families have graciously agreed to bring students into their lives. During these visits students have learned directly from families in the relaxed and informal atmosphere of their homes.

In addition to home visits, medical students are required to attend three lecture/discussion sessions taking place at the beginning and the end of their 8-week pediatric rotation. In preparation for the home visits, you are requested to attend one orientation session. The orientation is held to introduce you to some of the families already involved in the Project; meet with Drs. David Stifler and Don Swartz, our two physicians involved in the Project, to help you consider the points you would like to get across to students; and to help you structure your home visit. Information about the dates and times of the orientation, along with a response card, is enclosed.

I wanted to share comments from medical students with you to let you know how important your participation in this project is. The following comments are from students who have completed their home visit with a family:

"I think that the home visit was important. It gave me an opportunity to see that families with children who have chronic illnesses live very normal lives and that their medical problems are a small part of their everyday life."

"I feel that these home visits are invaluable not just because I met some wonderful people who gave me some insight as to what it is like to take care of and keep abreast of the needs and potential of a chronically ill child, but because I learned and saw for myself the human side of medicine and how people deal with illness and emotional needs outside of the hospital setting. I plan to see my family again because they have become friends. Thank you!"

Based on feedback from family and student participants in the past, it is recommended that you give careful thought to how the visit will be structured. Consider what has been significant, both positive and negative. Remember that as parents you are a vital resource in providing helpful information. For instance, if you have a lot of thoughts you would like to share regarding your family's experiences, being at the dinner table with an active family may not be the best arrangement. However, if your message is to have the student experience firsthand how your household functions, being in the midst of the juggling scene of a family dinner may be just the right setting. Above all, do what is best for you and your family!

Before the visit we ask that you formulate three points that you want to communicate during the visit. Think back to your initial contact with physicians, for instance, and what your family would have appreciated (e.g., language used, information shared).

The benefit of having an ongoing program of this kind is that we can make adaptations over time, as necessary. For this purpose, your feedback is of great value to us here at Parent to Parent. Your comments have a great impact on the implementation of the project and are given the utmost attention. Please return the attached forms in the envelope provided. Feedback is to be sent in as soon as you have had your home visit. We know your time is precious and are grateful for all your efforts!

If you have any questions at any point about your experience in the Medical Education Project, please call us anytime at 555-5290.

Sincerely,

Nancy DiVenere
Director

Figure 17.3. Medical Education Project welcome letter.

1. Explain how you feel the visit went overall. Was it a positive experience for you and your family? If not, why not?

2. You thought about specific points you wished to convey to the student during the visit. Based on the student's reactions or comments, do you believe you got your point(s) across?

3. Do you believe that these home visits are an important component to the medical student's experience on his or her pediatric rotation?

Figure 17.4. Medical Education Project: Parent feedback sheet.

Goal The experience was designed to prepare family-centered practitioners and provide students with the opportunity to learn directly from a family rather than from reading or attending lectures about families.

Description of Practicum The experience (Phase I) begins in the fall semester, in a somewhat unique and definitely unsettling manner. Student interns are asked to enter the family without a role. Students are prepared to listen and respond to families from the heart. In conversations with families, students learn what is important for the child and family. Students accompany families to meetings with health care providers, educators, and advocacy groups. The goal is for students to experience the complexity of issues and concerns facing families and meet the myriad professionals involved in the lives of families whose children have a special health care and/or educational need. Because this practicum experience is guided and directed by the families themselves, students experience the lives of families from a vantage point different from that typically available to students in traditional professionally driven practica opportunities. Based on the relationship established during the first semester, students and families design an action plan for the second semester (Phase II) that outlines goals and activities that consider both the family's priorities and the intern's learning needs. The following are two examples of second semester action plans:

- Developing a videotape of a preschool child with disabilities that shows the child effectively functioning in a variety of community settings (e.g., child care, gymnastics); this videotape was then used by the family for transition meetings as their son entered kindergarten
- Creating a home-care book that outlined the variety of medical procedures, preferences, and so forth of one young child so that the family could quickly and easily orient a new caregiver to the important routines and characteristics of their child

The activities that students implement during Phase II facilitate the acquisition of an understanding of the elements of a family-centered approach. These experiences develop the intern's ability to incorporate the elements of the family-centered approach into all aspects of his or her practicum requirements and to develop an understanding of ways in which existing systems and policies can become more responsive to family concerns and priorities. The partnerships students establish with families have proven to be essential components of their master's program. Students rely on their relationship with the family

as a safe place to explore family issues and begin to define themselves as family-centered practitioners.

Role of Parent to Parent Staff The Family-Based Practicum Experience provides a vehicle for modeling parent–professional partnerships in two critical ways. First, Parent to Parent staff identify, recruit, and help nurture the families who participate in the Family-Based Practicum Experience. The second critical component is the supervision provided by Parent to Parent of Vermont. Parent to Parent staff maintain close contact with both families and students. In their role, Parent to Parent staff have helped students and families ''negotiate'' their relationship, and, perhaps more important, Parent to Parent staff help students relate the relationship established with a family in their family-based experience to the types of relationships they establish with families in the more professionally driven early intervention system. Parent to Parent supervisors bring a perspective to this practicum experience that could not be provided by other members of the instructional team.

Although students enter this practicum experience without a defined role, they report that it is through this experience that they develop an understanding of their role as an early interventionist. The appendix at the end of this chapter presents an outline of the Family-Based Practicum Experience.

CONCLUSION

Partnership—such a simple word for some very complex and challenging activities. Partnerships are established so that final products are enriched by the expertise of separate individuals, but in true partnerships, the individuals work in such concert that the group perceives itself as one. As people become more skilled in working together, sharing expertise, and moving toward collaboration, incredible things can be accomplished.

Parent–professional partnerships in preservice and inservice education can take a variety of forms, from participation on panels to co-teaching courses. The partnership sets a context for preparing family-centered practitioners, by modeling the belief that families are valued consumers of, and competent partners in, the design, implementation, and evaluation of services. Such a partnership communicates that it requires the expertise of both families and professionals to develop and implement appropriate services for young children with disabilities and their families.

RESOURCES

Jeppson, E.S., & Thomas, J. (1994). *Essential allies: Families as advisors.* Bethesda, MD: Institute for Family-Centered Care. Cost: $10. (301) 652-0281.

Lots of very practical information, illustrations, and resources for supporting family involvement in leadership roles, including instruction. Developed to ''help bridge the gap between providers' past training and new expectations of collaboration and partnerships with families'' p. 1.

McBride, S.L., Sharp, L., Hains, A.H., & Whitehead, A. (1995). Parents as co-instructors in preservice training: A pathway to family-centered practice. *Journal of Early Intervention*, *19*(4), 343–355.

Describes benefits and challenges, based on experiences of several teams with family–professional coinstruction in preservice settings. Addresses the following: recruitment and selection of family members, preparation for coinstruction roles, student evaluations of coinstruction experiences, supports for family members and faculty in coinstruction roles, and diversity issues.

Winton, P.J., & DiVenere, N. (1995). Family–professional partnerships in early intervention personnel preparation: Guidelines and strategies. *Topics in Early Childhood Special Education*, *15*(3), 296–313.

Article describes types of and rationale for some of the roles family members can play in personnel preparation efforts and offers guidelines and strategies for facilitating family participation in ways that model collaborative family–professional partnerships. Strategies provided apply across multiple contexts (e.g., preservice, inservice, policy making).

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Winton, P., & DiVenere, N. (1995). Family–professional partnerships in early intervention personnel preparation: Guidelines and strategies. *Topics in Early Childhood Special Education*, *15*(3), 296–313.

APPENDIX

EARLY CHILDHOOD SPECIAL EDUCATION MASTER'S PROGRAM

Family-Based Practicum Experience

The family-based experience provides interns with the opportunity to learn directly from a family rather than from reading or attending lectures about families. This practicum component provides interns with an in-depth experience with a family of a child with a special health care and/or education need(s). Through this experience, interns will acquire an understanding of the elements of a family-centered approach and knowledge of the ways in which existing systems and policies can become more responsive to family concerns and priorities.

Each intern has a Parent to Parent supervisor who is available to provide resources and support. A minimum of two meetings with each intern will be held during each of the fall and spring semesters. However, the Parent to Parent supervisor will be available to meet with individual interns on a weekly basis to discuss any issues regarding the implementation of a family-centered approach. It is the responsibility of the intern to communicate any additional supervision needs to the Parent to Parent supervisor.

Family-Centered Care for Children Needing Specialized Health and Developmental Services (Shelton & Stepanek, 1994) is an excellent resource for this activity. Parent to Parent of Vermont, located at the Champlain Mill, also has a lending library with many valuable resources.

GUIDELINES

The family-based experience has been designed to be implemented in two phases. The requirements and written components of each phase are described here.

Phase I: (Fall Semester) Getting to Know the Family

1. Maintain a log of the time spent with the family

   You will be asked to submit a log of the time you spent with the family throughout the year including a brief description and a brief reflection of each activity. Phase I activities include the following:

   A. Initial visit with the family

B. Ongoing contact with the family (weekly or on a schedule that meets the family's needs)
C. Attending a physician's appointment
D. Attending an IFSP or other conference held with the school
E. Observing the child in a setting where services are being provided (school, child care, home, therapy)
F. Having a meal with the family
G. Providing respite (spend enough time with the children so that the parents will have time to ''get out of the house'' if they would like to)
H. Selecting two additional experiences that you and the family identify as valuable (e.g., attend a parent support group meeting, attend a birthday party)

2. Reflect on your experience
   A. Identify an aspect of your experience with the family and write a reaction paper discussing your perspective on this experience.
   B. Facilitate a discussion (during practicum seminar) regarding the experience you discussed in your paper.
3. Set goals for Phase II (spring semester)

   Together with your family, identify the goals and activities you will engage in during Phase II. The goals and activities should be mutually beneficial and should consider the intern's learning needs and the family's own priorities. You will also want to develop a time line for your goals and activities. The goals and time lines should be written and handed in with your reflection paper on the assigned date at the end of the fall semester. You may also want to discuss the ways in which you and the family ''negotiated'' the goals and activities for Phase II.

Phase II: (Spring Semester) Implementing a Plan

Phase II activities require you to spend 48 hours with your family over the course of the semester. The goals and activities addressed during these 48 hours are those that were identified with the family in the fall. Your 48 hours can be divided to allow you to accomplish these mutually determined goals. In the past interns and families have been very creative in defining their goals and activities for Phase II of the Family-Based Experience. These ideas have included but are not limited to the following:

- Developing a ''Fun and Care Book'' that the family could share with baby-sitters about their child
- Providing child care for the child and/or siblings
- Assisting a family in applying through Medicaid for wheelchair funding

1. Maintain a log of the time spent with the family

   Submit a log of the time you spent with the family throughout the year, including a brief description and a brief reflection of each activity.
2. Reflect on your experience
   A. Identify an aspect of your experience with the family and write a reaction paper discussing your perspective on this experience. You will want to discuss any changes you made in your original plan for Phase II. How were those changes ''negotiated''?
   B. Facilitate a discussion (during practicum seminar) regarding the experience you discussed in your paper.