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A Qualitative Study of Parent to Parent Support for Parents of Children With Special Needs

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Objective: To examine qualitatively the experiences of parents participating in Parent to Parent programs.

Method: Twenty-four parents of children with special needs, a subset of subjects in a larger quantitative study, participated in a semi-structured telephone interview to explore the impact and meaning of being matched with a trained supporting parent.

Results: Qualitative analysis reveals a successful match is contingent upon creation of a "reliable ally" in the supporting parent, comprised of four main components: (1) perceived sameness, (2) situational comparisons that enable learning and growth, (3) round-the-clock availability of support, and (4) mutuality of support.

Conclusions: Parent to Parent support creates a community of similar others trained to listen and be supportive and provides an opportunity for matched parents to experience equality and mutuality in their relationship. Findings also identify the need for quality control in Parent to Parent programs and the importance of such programs as an adjunct to traditional professional services.

Key words: parental support; disabilities.

The challenges of parenthood are intensified by the experience of having a child with special needs. Parents of children with emotional and/or developmental disabilities experience both the typical stressors of parenting and a host of stressors unique

The Consortium to Evaluate Parent to Parent is a coalition of leaders and researchers from Parent to Parent of Vermont, Parent to Parent of New Hampshire, Family Support Network of North Carolina, Family Connection of South Carolina, and Families Together of Kansas. Judith Ainbinder is now at the University of Vermont, Lynn Blanchard is now at Lehigh Valley Hospital, Laurie Powers is now at Oregon Health Sciences University, and Janet Marquis and Betsy Santelli are now at Beach Center on Families and Disabilities. All correspondence should be sent to Lynn W. Blanchard at the Dept. of Community Health and Health Studies, Lehigh Valley Hospital, 2166 S. 12th Street, Allentown, Pennsylvania 18103. E-mail: lynn.blanchard@lvh.com.

to their child's care. The added stress confronting this population is well-researched (e.g., Breslau, Staruch, & Mortimer, 1982; Diehl, Moffit, & Wade, 1991; Gallagher, Beckman, & Cross, 1983; Singer, Irvin, & Hawkins, 1988). Some of the stressors for parents documented in these studies include difficulty accepting and adjusting to their child's disability, financial demands for necessary medical equipment and care, limited (or no) accessible information about their child's disability, time management conflicts, and appropriate respite care and other services to relieve their caretaking activities.

Although the intensity of these various stressors

fluctuates over time for any individual family, one stable and pervasive stress that seems to confront families is a society that traditionally fails to understand and accept their children. At times, parents who have a child with a disability may be conflicted by personal feelings of love, understanding, and hope for their child and a society (including physicians, neighbors, school staff, family members) that sees mainly the negative aspects of the disability. At other times, when these same parents get frustrated and angry with their situation, the world around them can misinterpret that anger as "bad parenting." These conflicts may leave the parent feeling estranged from a world in which normalcy and health are best understood and viewed as the optimum. Between the amplified stress in their lives and feelings of estrangement from a world of "typical children," parents of children with special needs frequently report feelings of anxiety, depression, loss, loneliness, and hopelessness (Winch & Christoph, 1988; Seligman & Darling, 1989).

Despite or because of enhanced challenges, many parents of children with special needs cope successfully and demonstrate a high level of satisfaction with their lives. (Trute & Hauch, 1988; Turnbull & Turnbull, 1997). Recent theory development has focused on the role of cognitive adaptation to disability in the family as a key process leading to psychological well-being (Taylor, 1983). In research on people with serious illness, certain kinds of social support, the development of a sense of meaning, and the regaining of a sense of control and efficacy were hallmarks of successful adaptation (Taylor, 1983). Singer (1993) reported on cognitive interventions with parents that have assisted some persons toward increased well-being. Nixon and Singer (1994) reported on a group cognitive behavioral intervention in which parents discussed self-blame and guilt and provided support to one another through processes that the authors described as social comparison. Ireys, Sills, and Kolodner (1996) examined the impact of a parent mentoring program for parents of children with juvenile rheumatoid arthritis. They reported a trend toward positive changes in parental mental health and social support, although they did not obtain statistical significance.

Research over the past 20 years has demonstrated the importance of social support for families of children with special needs (Crnic, Greenberg, Ragozin, Robinson, & Basham 1983; Pilon & Smith, 1985). Specifically, social support is recognized as an

effective buffer against the stress and isolation faced by this population (Santelli, Turnbull, Lerner, & Marquis, 1993). There is debate among this community regarding exactly what this support should look like: professional, self-help, or both? Within this controversy emerges a strong theoretical and practical argument in favor of support from similar others (Taylor, Buunk, & Aspinwall, 1990; Thoits, 1986). The present article reports qualitative findings on the mechanisms behind the helpfulness of one such program called Parent to Parent.

Background

"I just still feel that to have the Parent to Parent, to have that link, I just think that's vital. I just really feel that that's the lifeline for people and we all need it in some way or other."

—A parent

Parent to Parent programs offer support in a unique way: parents referred to the program are matched in a one-to-one relationship with a veteran supporting parent who has a child with a similar diagnosis. Typically, the supporting parent has completed training on support techniques and offers informational and emotional support to his or her referred parent (Santelli et al., 1993; Santelli & Marquis, 1993). The parents self-manage their contacts, usually phone calls, depending on their needs, personalities, resources, and locations. Parent to Parent is noncategorical, providing support services to parents who have children with any developmental disabilities, emotional needs, learning disabilities, and/or special health care needs. Programs are traditionally grassroots in origin, with parents coordinating and providing services to other parents referred from a wide variety of sources including medical providers and informal networks. Although there is compelling and lengthy anecdotal evidence describing the value of this support from families and support providers, systematic evaluation and research are lacking.

This qualitative study is part of a larger quantitative study that measured the effectiveness of Parent to Parent support through a longitudinal, controlled experiment (Singer, Powers, Marquis, Blanchard, Divener, Santelli, Ainbinder, Sharp, and the Consortium to Evaluate Parent to Parent, 1997). Both the quantitative and qualitative aspects of the study were designed and implemented by a

parent-researcher consortium in five states: New Hampshire, Vermont, Kansas, North Carolina, and South Carolina, with funding from the U.S. Department of Education. The impetus for this research collaborative comes from a growing need to evaluate Parent to Parent support in a scientific manner.

In the three year, multisite study 340 parents who requested Parent to Parent support were randomly assigned to one of two groups: one in which they were matched right away with a trained veteran parent and one in which they waited eight weeks before being matched. Both groups completed a set of questionnaires four times before and during their experiences. Outcomes included sense of family empowerment, sense of social support, acceptance, and everyday coping. Information was also collected about the timing and number of contacts and the parents' level of satisfaction with the emotional and informational support they received.

The findings of our parent-researcher consortium help to provide an understanding of some of the processes at work when parents attempt to help other parents of children with disabilities: quantitative analysis reveals significant effects in a variety of domains including improved coping skills, growing acceptance of the child and family, and reported progress made towards a previously specified goal (Singer et al., 1997). The quantitative study scientifically documents valuable outcomes of this program, and this qualitative study systematically provides in-depth understanding of parents' experiences with Parent to Parent.

Method

Recruitment

The sample consisted of parents from the pool of those enrolled in the quantitative study. A computer sorted the 340 participants into two groups by site and by whether or not they reported their parent to parent experience was helpful, as answered in the question, "How helpful did you find your Parent to Parent experience?" on a Likert scale ranging from "not at all helpful" to "extremely helpful." Names were randomly selected from each group to be contacted about participating in an interview. This process was used to ensure even representation of location and range of parent to parent experience. A total of 38 parents were invited before successfully recruiting the desired 24 participants.

The other 14 parents never responded to the letter.

Parents were invited to participate in the qualitative study via a mailing that included an introductory letter and consent form soliciting permission to record the interview. Parents were informed that interviews would be conducted over the phone by the coordinator of the quantitative study, an individual trained in psychology research. The letter explained that the interviewer was not a parent of a child with special needs nor associated with a Parent to Parent program. Parents were assured that their responses would be confidential and their identity would not be revealed to their local Parent to Parent program. They were also informed they would receive \$25.00 for participation. Interested parents signed the consent form and mailed it back to the researcher in charge of the investigation. After receiving a signed consent form, the researcher called the parent and set an interview time at the parent's convenience.

Subjects

All 24 parents recruited were biological parents, 23 mothers and one father, ages 22 to 51, with an average age of 37. The sample was 83% Caucasian and 17% African-American. The majority of parents were married (63%), and all but one had completed at least a high school degree. Annual household incomes for the majority of families (61%) were below \$35,000. The children's ages ranged from 1 to 16, with an average age of 7. Thirty-eight percent of the children were under 5 years of age, 54% were between 5 and 13, and 8% were older than 13. The 16 boys and 8 girls in the sample all lived at home. Disabilities ranged from mild to severe and diagnoses included cerebral palsy, epilepsy, developmental delays, mental retardation, learning disabilities, hearing and/or vision deficits, and several chronic illnesses. These demographics, including the predominance of mothers, are representative of the larger study and the general population involved in Parent to Parent programs

Interview

One interviewer conducted all interviews by telephone. This method was chosen as it allowed for consistency in interviewing parents spread out geographically. In a review of literature comparing telephone and in-person interviews, Miller (1991) reports that although people tend to give shorter

responses over the telephone, they disclose as much personal information and express the same views as when given different interview methods.

Interviews were semi-structured, using a standardized interview guide. The interview guide was developed by both the parents and researchers on the consortium. It began with the general question: "Imagine I know nothing about Parent to Parent support. How would you describe your Parent to Parent experience?" The interviewer used more specific probes if parents had difficulty initiating a description of their experience, including what motivated them to seek Parent to Parent, how and when they talked with their supporting parent, and whether it was what they hoped for. Questions later in the interview addressed specifically what was/was not helpful about the experience, areas for improvement, how it compared to other support they received, and whether they would recommend it to family members and/or friends. Throughout the interview, topics of personal significance were explored (as initiated by the parent), in addition to the questions on the standardized interview guide. This approach resulted in a data set balanced with both standardized areas of inquiry and personalized feedback.

Interviews lasted from 15 to 45 minutes. The shorter interviews occurred when the parent had not found the program particularly helpful and had limited (or no) contact with his or her supporting parent. Generally speaking, when a parent had been greatly involved in and helped by the program, the interview lasted longer. In all, 21 interviews were recorded and transcribed. Three interviews failed to record clearly due to technical difficulties. However, detailed notes provided a level of information appropriate to include in some analyses.

Coding

Transcribed interviews were coded using an interactive process in which we identified themes as they emerged from the reading of the transcripts according to the constant-comparative procedures described by Lincoln and Guba (1985). This approach relies upon an inductive strategy in which data are divided into categories that are, to the maximum extent possible, unconstrained by prior assumptions about what parts of the phenomena are most important. First-level coding followed the questions and probes in the standardized guide, with the ma-

ior categories being aspects of Parent to Parent that were helpful and not helpful. During this process, we identified that, when asked, "What was not helpful about Parent to Parent support?" parents moved the discussion to what had prevented their match from working, giving precise reasons why their particular match did not work. (This qualitative probe differed from the question on which subjects were randomized in that it asked specific aspects of their experience that had not been helpful rather than a general rating of how helpful the overall experience had been.) As a result, responses were coded to analyze factors that kept Parent to Parent from working. The interviewer and two other researchers involved in the investigation reviewed the overall structure and made suggestions for improvement, resulting in consensus regarding the preliminary coding system.

In subsequent iterations we identified themes within these categories as patterns of similar responses emerged. Next, two randomly selected interviews were coded by two investigators using the coding scheme. Extensive comparisons of the coding led to refinement of the coding structure. Several codes were merged to prevent redundant coding, and some new categories emerged. Although we did not set out to test a theory in this process, most of the themes that arose were congruent with ideas on the literature on self-help (Thoits, 1986) and social comparison (Taylor et al., 1990). For example, comparison to similar others is central to social comparison theory, and "perceived sameness" was described by many of the parents.

All interviews were coded using the final system with the assistance of HyperQual, a computer software program (Padilla, 1991). Twenty percent of the interviews (five in total) were randomly selected and coded by a second investigator as a reliability check. Differences were minor, and, in almost every instance, resulted from level 2 themes that were somewhat overlapping. For instance subthemes of "perceived sameness" included "connection," "full understanding," and "no judgments." In several instances, subtle differences in interpretation in these level 2 themes resulted in coding differences. Through discussion, these differences in interpretation were resolved, which further clarified the coding. Finally, the whole set of interviews was reviewed in light of these discussions and clarifications.

After coding, the statements were re-examined

with the goal of simplified, thematic interpretation. Similar topics were collapsed into broader, unifying themes. Below we describe these themes as a way of understanding the helpfulness of Parent to Parent support.

Findings

How Is Parent to Parent Helpful?

Interviews revealed that Parent to Parent support is particularly helpful to families when the supporting parent is perceived as similar to the referred parent. Common experience enables a full understanding of the parent's situation, acceptance of his or her thoughts and actions without judgment, and help coping with difficult situations by sharing personal experiences and relevant feedback. Furthermore, a helpful supporting parent is easily accessible or available to provide support, and the support giving between the two parents is bi-directional. This relationship can be defined as a "reliable ally." Qualitative analysis revealed four main components of this reliable ally: (1) perceived sameness, (2) comparable situations for learning relevant skills and gathering useful information, (3) availability of support, and (4) mutuality of support.

Perceived Sameness

Perceived sameness is the most basic principle of self-help support. A perception of sameness is established because the support giver typically has experienced the same challenges as the support recipient. Parents considered a perception of sameness with their supporting parent to be an important and distinguishing feature in a Parent to Parent match. As one parent expressed, "You could be trained to listen, but you can't appreciate what everybody goes through. You just don't know. What it says in the book is not necessarily what parents feel." When the referred parent discovers her similarities with her supporting parent and that the supporting parent has "been in her shoes," an immediate and intense connection is established. There is a feeling of understanding and compassion that does not exist in the parent's other relationships, including family members. The referred parent can openly and honestly release her emotions, concerns, and thoughts without the fear of negative judgments: "It's like I made a friend for life; more

or less a family member. . . . And I don't get close, I don't trust nobody anymore and this lady. . . . I don't know how she did it but she managed to get through me."

Another parent describes the outward understanding of her child's behavior she gets from a parent "who knows" compared to parents who do not have children with disabilities: "There's a compassion there and there's still an outpouring of love instead of a label and just an annoyance that she's disrupting them in some manner, and it doesn't feel like their eyes are boring in on you. . . . And then once you pass through it, they're there to put their arm around you and you know, just, you know, 'that was a rough one.'"

Perceived sameness in Parent to Parent connections can be achieved on two levels: in the children's situation and in the parents' personalities. In the most successful matches, perception of sameness is established on both levels. One parent describes her lucky circumstance: "I guess I was very fortunate to have a parent who was very similar and not just because of our child, but in our background and, you know, in a social strata of things—we were matched very well." It is unrealistic to expect perfect match-ups for all parents. Fortunately, most matches are helpful when there is some basic similarity in the children's situation and/or the parents' personalities. "I think parents . . . feel good knowing—talking to parents who have went through the same kind of situation; not exactly the same but at least something similar so you can kind of base your, you know, what's your dreams and . . . what's going to happen. I mean, I'm aware that no child is the same but just to give you an idea."

Learning Practical Skills and Useful Information

Talking with a similar other offers a useful mechanism for learning important and relevant information about yourself and your situation. At times parents reported that the simple act of "just comparing" with a similar other is helpful in and of itself. Parents are relieved to find someone else whom they can compare their lives with; someone whose similar experiences prove that there is nothing "abnormal" about their situation. "It really did help to know that some of these things we were thinking and feeling were perfectly normal; that there wasn't anything wrong with it."

Gaining ideas and information from similar

others ultimately leads to better management of day-to-day challenges. Specifically, hearing the supporting parent's stories and sharing similar experiences, the referred parent gains practical parenting tips, linkages with other support services and information about their own child's disability.

I do take my child to behavior specialists and psychiatrists and everything else, and that's nice and good to talk to them, but they don't have to deal with the child that has these problems. And I think a parent going through similar circumstances can sometimes tell you how they handled something and you think oh, that's a good idea, I haven't tried that. And you aren't going to get that from a doctor.

Another added benefit from comparing with similar others is gaining future reassurance. When the supporting parent's child is older than the referred parent's child, he or she can help the referred parent anticipate future events and maintain a hopeful outlook.

I wanted some reassurance that [our daughter] is likely to have most of the same things everybody else has, as far as you know, going to school and having friends, going out and doing things. And [our supporting parent's] daughter's involved in a lot of things. She's got a good life. And that gave me a great deal of hope about the future for our daughter, that she can have a good life, too.

Another specific circumstance that sets the stage for helpful comparisons is when the supporting parent's child has more severe challenges than the referred parent's child. In some situations, the referred parent gains a new perspective on his/her child's disability infused with feelings of gratefulness and luck. These comparisons are frequently called "downward comparisons" (Taylor et al., 1990). "It made me feel like I was very lucky to have a child like [mine]. Where her's is very severe and mine's just mild. But it makes me thankful every day that [my son] can do stuff where she can't."

Availability of Support

Another unique component of Parent to Parent is the round-the-clock availability of support. Parents in this study frequently commented that one of the best things about their supporting parent is the feel-

ing that they can pick up the phone and call him or her at anytime. The concept of dependable and convenient support should be understood not as the act of talking with the supporting parent, but as the feeling that the supporting parent is available if/when needed. The quantitative study demonstrates that less than three supporting parent contacts in a limited period of time is very helpful for some parents (Singer et al., 1997), and most parents do not maintain frequent contact over time. It is the ongoing sense that the support parent can be called upon as needed that gives referred parents a feeling of dependability. Parents are free to select times to talk at their convenience, unlike more formally scheduled programs of support. "With your Parent to Parent [you felt] that if you just called and said hey, I need to talk, that the phone call would be back there."

Mutuality of Support

Self-help programs such as Parent to Parent promote equitable relationships between the supporting and referred parents. Unlike professional counselor-client relationships, the two parents in a Parent to Parent connection share a similar background. Both parents have learned through life experience and are experts in their children's care. Inherent in an equitable relationship is mutual provision and reception of support. Hence, the helpful parent-to-parent comparisons described above are frequently bi-directional.

There appear to be benefits to mutual support giving: many interviewed parents reported that giving support is just as important and helpful as receiving support. Not only does it feel good to help others, but parents describe a sense of satisfaction in finding someone who recognizes and values their expertise. Strikingly, the importance of giving as well as receiving support was a recurrent theme, despite the fact that all parents interviewed were referred, not supporting parents:

By listening to that other person's story or experience, that calls to mind something that you, too, may have experienced and you can think back and relate to, perhaps how you handled the situation, and if you handled it different and it worked, you can pass that information on to the parent, and they gain. . . . And I felt that perhaps my hope too, was that maybe I could be of help to them; not always just for my support.

Personal Growth

The creation of a reliable ally through Parent to Parent support leads to many positive outcomes for the referred parent. As described above, parents gain feelings of normalcy, tips on how to manage their day-to-day challenges, security in having an available support, and the benefits of helping others. In addition, some parents reveal fundamental personal changes that occur after connecting with a supporting parent: enhanced feelings of empowerment, reduced isolation and a general sense of personal well-being.

Empowerment: [Parent to Parent] made me feel like I'm an extraordinary person because I can deal with two disabled children. It made me feel special because I could still handle [these two] and my two other children. [My supporting parent] made me feel like I was doing this most incredible, most wonderful thing in this world and I was doing such a good job at it. She was proud of me and didn't even know me.

Reduced Isolation: It's a support for me, not only for my children but for myself as far as getting out and socializing with people and getting a life. . . . Because I had been alone for seven years . . . I just sat at home and you know, go take care of my quadriplegic sister or my mother or something like that. I never really got out, and once I started with the support and it's like oh, there's really people out here that understand me and you know. . . . And I call that my home away from home.

Emotional Well-Being: I think it really lifted my spirits. I'd get off the phone and I'd just really feel good. Even if things had been going smoothly, I felt myself even higher. And if it has been tough, if I've had a situation that has been kind of exasperating or trying, just talking about it to somebody who understood, I feel better, and I could stop maybe beating myself up a lot.

When Parent to Parent Does Not Work

Some of the parents in our study did not find their experience particularly helpful. These parents pinpointed why their match did not work yet still expressed belief in the value of parent connections. In fact, many were eager to try again with another supporting parent, and all but one said that they

would recommend Parent to Parent to friends and family.

Parent to Parent matches are less helpful to families when a reliable alliance is not created. Often, logistical factors prevent a match from developing (or ever starting); other times inherent differences between the parents' and/or their children's situation shortcircuit the development of a reliable ally.

Logistical Barriers

Two categories of logistical barriers preclude success in the Parent to Parent match: those that end matches prematurely and those that prevent a match from ever starting. Barriers in the first category include parents' busy lives, long distances between the matched parents, difficulty paying for the cost of the phone conversations, lost phone numbers of the supporting parent and/or the program, and negligence in supporting parent follow-up efforts.

Parents' Busy Lives: Unfortunately I wish I could speak to her more, but I have such a hectic life that I'm lucky if I get five minutes to myself to be able to talk on the phone or something. There's always something else going on, and just being able to find time to talk on the phone is kind of hard.

Long Distances Between Parents/ Difficulty Paying for Phone Bills: Just to discuss more things that we can't, you know, because see they're both long distance so we don't really talk too long on the phone. . . . [I]f they were closer, I would talk more often, but like when its long distance, we just don't talk that often.

Lost Phone Numbers: I lost her phone number . . . to be very honest. She hasn't called and I haven't—I don't know who to get in touch with.

Negligent Supporting Parent Follow-up: [My supporting parent] was going to call me back and then, you know, she never did. I never got her number. I mean, it's been so long I don't even remember her name.

Parents in this study who were better helped by the support were also the parents who had more contact with their supporting parent. The 12 parents who were greatly helped by the support had an average of 5.75 contacts with their supporting

parent, while those who found problems with their match had an average of 2.1 contacts. In general, parents long for more contact with their supporting parent and, at times, feel responsible for making this happen.

She had left a phone number if I needed to call her back, you know, and I could if I wanted to. I just, you know, I just never did. I'm more of one that's not willing always to call and if there had been some things that had come up, I probably would have discussed with her if she had called back. . . . I was kind of hoping for more contact, and maybe that's my own fault for not getting back with her.

Some Parent to Parent matches never get started. This study did not provide a large enough sample of unmatched parents to fully understand the issue, although one clear reason for a non-connection is the limited number of supporting parents in each program's network. At the time of interview, two parents had not been connected with a supporting parent (several months had passed since they were first referred to their local Parent to Parent program). One parent was told explicitly that an appropriate match could not be found because of his unique circumstances. The other parent had no idea why she had not been connected yet and was still eagerly waiting to hear from someone. Both parents were "on hold" for the time being and were disappointed that matches had not been found.

Situational Differences

As mentioned earlier, perceived sameness is a fundamental ingredient for success in a Parent to Parent match. Without a perception of sameness, there can be no full understanding and mutual, helpful, and relevant comparisons. While dissimilar others can certainly be "available," the support lacks the richness and power of a true self-help connection. In summary, a dissimilar supporting parent is not likely to become a reliable ally.

Lack of perceived sameness in the children's situations was frequently cited as a cause for failure in a Parent to Parent match. The most obvious example was when the children have different diagnoses leading to entirely different challenges. (It is important to note if the diagnoses are different but the day-to-day challenges similar, the match may work very well).

It was just that her little boy has autism and no language or anything like that. . . . Just at that time I didn't feel that she could understand what my situation was. . . . There's been a lot of times in the last six years that I've felt like nobody could understand because nobody has ever dealt with a child like this.

Earlier, downward comparisons were described as helping referred parents to gain perspective on their children's disabilities and feel fortunate by finding others who are worse off. However, there is a limit to the extent to which downward comparisons are helpful to the referred parent. When the supporting parent's child is facing more severe challenges and/or is much younger, the referred parent may feel limited in how much can be shared with this other parent. Additionally, he or she may find himself or herself providing most of the support, and receiving little for herself.

And the other thing I've found with her is, her baby is not doing very well sometimes. I think she has a lot of pneumonia and aspiration and they're really not sure what's causing it. . . . She asks how my baby is and he has been very healthy, thank God. I don't want to say "doing great." . . . And that's what I'm talking about where you play this game of not wanting to say "well my son is doing this. He's standing up and blah, blah, blah," knowing very well how her daughter is. . . . We don't share a lot about our children, actually, which is kind of what I would like. . . . I find the only time I really want to call her is if I have a problem because then I don't feel bad about saying "I have this problem and what do you think I should do?"

Although downward comparisons have potential positive and negative outcomes, "upward comparisons" almost always prevent a Parent to Parent match from succeeding. When the supporting parent's child is doing much better than the referred parent's child, there is little common ground for a helping relationship, and the referred parent may be left feeling, by contrast, that her situation is more severe than she had first realized.

[My supporting parent's son] could walk and different things like that. My son doesn't walk on his own and different things. It just sounded like that maybe he wasn't at the same level as my son. . . . I guess it was a little disappointing

that they couldn't find somebody even if it hadn't been [my child's diagnosis]; if they could have found somebody more on the level of [my child].

Individual Preferences and Values

Although situational differences have a tremendous impact on Parent to Parent matches, individual preferences and values are critical to effective matches. The interviews reveal that perceived situational sameness alone will not lead to a successful Parent to Parent match without some further basic connection between the two parents. Regardless of the level of situational similarity, dimensions of parenting preferences and values can either "make or break" a Parent to Parent match. Those that parents talked about included communication style, parenting style, outlook on disability, and future vision for the children. Matches did not work well when parents were well matched on situational variables but had clashing beliefs on one or more of these dimensions.

We have different styles of dealing with our children and we realized that very quickly. I think that part of that . . . there's a personality difference. I think we would probably talk more often if it were more helpful. . . . In fact what we found when we were put together is that we have a lot of the same people helping us. But we have very different impressions of those people. . . . But, again, she has a very different way of looking at things. . . . [H]er point of view about things is different. So in some ways I don't feel so great after talking to her sometimes. It's really important to take care of your psyche, I think, when you have a special child and to know when somebody is going to be helpful and somebody's not.

Discussion

The interviews provide a means for examining degrees of helpfulness in the Parent to Parent match. In a helpful Parent to Parent connection, a reliably established through perceived sameness and the resulting useful comparisons, as well as availability and mutuality of support. When a match does not work, there are logistical barriers to parent contact or inherent situational and/or personality differences.

For parents of children with special needs, there are no obvious and objective criteria for self-evaluation in their daily lives. Parent to Parent support creates a community of similar others who are trained to listen and be supportive. Parents who are matched are relieved to finally find a source of social comparison. They compare experiences, fears, ideas, and hopes with one another and jointly work toward the goal of improved parenting.

Dissimilar or upward and downward comparisons have both potential positive and negative emotional effects depending on the nature of the comparison and how it is interpreted (Taylor et al., 1990). Upward comparisons are helpful when the source of comparison is subject to change and the prospects for improvement are high. Alternately, when the source of comparison is relatively stable, threatening, and important, as is the case for some parents in this study, upward comparisons are not helpful. Without a clear prospect for improvement, the person making the comparison is likely to focus on the fact that he or she is not very well off in contrast to others.

The research on downward comparisons also substantiates the findings reported here. People in other kinds of threatening situations use downward comparisons to "regulate their emotions," or feel better in the knowledge that they are better off than others (e.g., Gibbons, 1985; Wood, Taylor, & Lichtman, 1985).

These findings also support the importance of equality and mutuality in supportive relationships. According to theorists (for a review, see Stewart, 1989), clients in equitable relationships with their support providers are more comfortable with, and better helped by, the relationship because the support giving is bi-directional. Maton (1987) found that bi-directional support in a religious setting leads to greater life satisfaction and more positive attitudes than unidirectional support. In the study reported here, bi-directional support seems to prevent feelings of indebtedness and inferiority and may actually lead to feelings of self-worth and empowerment.

Recommendations for Practice and Research

This study demonstrates many unique properties of Parent to Parent support. The self-help nature of Parent to Parent promotes highly efficacious relationships between referred and supporting parents. Many parents in this study gained from a reliable

ally built on perceived sameness, comparable situations, and dependable, convenient, mutual support.

Our findings identify a need for quality control in the management of Parent to Parent programs. Specifically, programs would benefit from improved matchmaking and follow-up efforts. Program coordinators need to be aware of each referred parent's needs and hopes to make an effective match based on perceived sameness. After the match is made, it is essential to maintain consistent and timely check-ins with referred parents to provide the needed level of contact and to offer a new match when there are situational or individual style differences.

Improving the effectiveness of matches also has implications for training of supporting parents. Given the difficulty of determining individual preferences and values prior to a match and the complexity of interpersonal relationships, supporting parent training should include discussion of differences, information on assessing how a match is going, and strategies for what to do if the supporting parent's style and preferences are in conflict with their referred parent's. As some respondents noted that their supporting parent seemed to need support more than to give it, supporting parent training also should underscore the importance of personal readiness to take on a supportive role with each match. Additionally, Parent to Parent programs that do not already do so should consider providing ongoing opportunities for supporting parents to share experiences and gain support from one another and program staff.

Physicians and other health professionals can partner with their local Parent to Parent program to provide best services to parents. Parent to Parent can be used as an adjunct to existing support programs, or as a starting point for families new to disability. Partnerships should extend beyond referral: community providers can assist Parent to Parent by maintaining their own check-ins with the referred

parent and offering to contact the program when a parent is not satisfied with the support. There is also a need for programmatic funding to cover the phone costs of parent contacts. Many parents in this study lost or limited their contact because they could not afford the phone bills. Community partners and funding sources need to address this issue with grants to help keep parents connected.

This study highlights areas for future research. Our experience with both quantitative and qualitative examination of Parent to Parent matching underscores the value of designing research to provide both types of data. Future studies can explore what contributes to perceived sameness and allows people to successfully manage differences in the Parent to Parent connection. The benefits of mutual support also warrant a closer look. Studies of supporting parent experiences and outcomes along with best practices of Parent to Parent would provide important insight.

The present study provides a more complete understanding of cognitive adaptation to disability. Talking, sharing, comparing, and learning with similar others is essential in this process. Parent to Parent programs offer a unique form of support that can effectively complement professional services. As one parent in this study firmly concludes: "I just feel that to have the Parent to Parent, to have that link, I just think that's vital. I just really feel that that's the lifeline for people and we all need it in some way or other."

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