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**Finding Common Ground: Parents Speak Out About Family Centered Practices**

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## **Abstract**

This paper offers providers and family-centered systems of care helpful strategies for inviting effective working relationships with parents of young children with mental health concerns based on recommendations provided by parents. These recommendations resulted from a participatory action research project grounded in a narrative therapy approach to exploring three aspects of family-centered practices: (1) effective help-giving, (2) meaningful parent involvement, and (3) parent-to-parent support. Co-researchers —whether parent or professional—shared personal stories, and reflections from the perspective of service seekers, and examined their experiences of power relations. This qualitative study demonstrates how cross-pollinating narrative therapy and participatory action research can contribute to knowledge about more equitable participative relationships between seekers of human services and providers and planners of these services.

### **Finding Common Ground: Parents Speak Out About Family Centered Practices**

In collaborative therapies, the professional's preferred attitude or relational stance toward the consumers of services has been aptly described as "appreciative ally", a stance in which clients experience the therapist as "on their side" in the continual search for respectful, constructive strategies that engender hope and new possibilities (Madsen, 2007). This article describes a research project that explored ways in which relationships between human service seekers, providers and planners can move beyond the traditional medical and mental health models defined by clinical distance and hierarchical organization, with the professional in the position of expert. I applied narrative practices within a community context to guide parents and professionals to give detailed accounts from life experiences of preferred ways of being in relation to each other. Throughout the research project, I explored different versions of the same question: How can service planners and providers join families without taking over? How can professionals support the autonomy and active involvement of people who seek their services? How can we create safe contexts in which we can learn from each other? What can narrative ideas and practices contribute to these questions?

"Participatory practices" such as shared decision-making, opportunities for discussion, information for choice making, and collaboration have been identified within the literature on family centered approaches as critical, yet frequently overlooked, components of effective helping (Dunst, Trivette, Davis, & Cornwell, 1994) . Even when providers want to collaborate with parents, insufficient attention is typically given in professional training to participatory practices; hence there is a great contrast between the vision and realities of "family centered practices (Adams & Nelson, 1995; Briar-Lawson, Lawson, Hennon, & Jones,

2001; Dunst, 1997; Dunst, 1995). In the field of family therapy, an equally effective, but under-utilized research strategy for improving clinical practice has been the participative research method – a method that has yet to be realized. Therefore, in this research project, narrative practice<sup>1</sup> was partnered with participatory action research (PAR) in an attempt to address these gaps in both realms and to allow for a natural pairing of two philosophically congruent practices.

### **CROSS-POLLINATING NARRATIVE THERAPY AND PARTICIPATIVE RESEARCH**

A natural kinship exists between narrative therapy and participative research, a pragmatic and productive research model which have been inadequately represented in the family therapy research literature. Participative research and narrative practice are both influenced by notions of the "linguistic" and "interpretative turns" that have emerged in philosophy, psychology and social theory (Bruner, 1990; Geertz, 1973; Sarbin, 1986). Embedded in these notions are the ideas that knowledge is inherently constructed through language rather than corresponding to an objective reality, and it is sustained through communal discursive practices. Accordingly, interpretative acts not only give meaning to people's experiences of life, but these meanings have real effects on future actions in the world.

#### **Participative Research**

Reason (1994) describes participative research as "research with people rather than research on people". It is a research method deeply rooted in a participative worldview that questions the positivist perspective that separates the knower from the known (Reason, 1994). Participative research is a form of "disciplined inquiry (research) which seeks focused efforts to improve the quality of people's organizational, community and family lives" (Calhoun, 1993). The participative research paradigm has generated multiple action-oriented research models, all of

which are qualitative, emergent and co-created through collaboration among participants (Park, 1997). Action-oriented research responds to pressures for research to be more directly relevant to the ongoing work of practitioners, and for investigators to critically evaluate power issues in the research endeavor (Ristock & Pennell, 1996; Zuber-Skerritt, 1996). These characteristics of action-oriented make it one of the most widely practiced collaborative research approaches, with established roots within educational and organizational research settings, and increasing visibility in social work research (Healy, 2001; McNicoll, 1999).

I chose a participatory action research (PAR) design for this research project. PAR brings people together with a common problem to 1) identify knowledges and action that are directly useful to a community; and 2) support people to engage with these knowledges and actions to make necessary changes in their lives, relationships, and communities (Reason, 1994). A PAR design incorporates personal reflections as research data (Park, 1999). A cyclical process of inquiry, action and reflection contribute not only to social change but to personal transformation as well (Park, 2000). **Narrative Practice**

For this project, I drew from narrative therapy concepts and practices to “co-research” more equitable participative relationships between seekers of human services and service providers and planners (Sax, 2005; White, 1991, 2000; White & Epston, 1990). “Co-research” aptly describes the collaborative process in narrative practice through which interviewers and interviewees engage in original research that centers clients’ accounts of local knowledge about problems and solutions, the relationships people have with problems and richer descriptions of unique pragmatic skills of living (Denborough, 2004; Epston, 1999, 2004; Maisel, Epston, & Borden, 2004; White, 1997b). The interviewer adopts a position of inquiry guided by specific “maps” that service seekers create to explore their own ideas, developed in the context of life

experience, about specific and unique ways to approach difficulties of life, and to document these “alternative knowledges (Epston & White, 1992).” Participating as a co-researcher can bolster individuals’ self-confidence and shape positive identity conclusions (Gaddis, 2004; White, 2001).

I chose specific practices of narrative therapy to guide conversations to address the following questions. What helps and hinders the process through which parents of children with special needs speak out and are heard? What are the underlying cultural and professional discourses that inform parent-professional relationships? How can professional helpers become more conscious of acts of power that occur despite good intention? What are the real effects when skills, knowledge, and new developments are witnessed and acknowledged?

While the family therapy literature reflects multiple success stories of narrative therapy within clinical settings, applications to social and organizational change are only now emerging (Barry, 1997; Simons, 1997, 1998; Vodde & Gallant, 2003). Extending collaborative family therapy skills into community contexts fosters reflection, shifts in attitude, and concrete changes in family-centered practices to which I believe narrative practice can significantly contribute.

By incorporating specific narrative practices into a PAR research design, I hoped to bring more specificity to the interviewing skills of the action researcher. I believed that the marriage between narrative therapy and action-oriented research would offer opportunities to chronicle some of the ripple effects of research conversations on co-researchers as they further reflected on possibilities for more equitable participative relationships in their daily lives.

.Narrative therapy is concerned with power relations that might otherwise go unnoticed, and encourages people to become aware of how power operates in their everyday lives. Similar to within a therapeutic context, this participatory action research project encouraged people to

move beyond dependency on expert knowledge, “to negotiate passage from novice to veteran, from client to consultant.” (Epston & White, 1992). Parents were overflowing with accrued insider and professional knowledge from years of parenting and seeking help for their children, yet rarely viewed themselves as possessing valuable expertise and relevant experience.

### **Partnership Accountability**

In particular, I was intrigued with unpacking the traditional rules of engagement in the help-seeking relationship that make professionals primarily accountable to peers instead of to those who seek their services. When I discovered Schon’s idea of “a reflective contract” (Schon, 1983, 1985) I was struck by similarities with Dunst’s “participatory practices” (Dunst, Trivette, & Deal, 1994; C. J. Dunst et al., 1994), both of which orient practitioners to become more directly accountable to the client and consequently require new kinds of competencies. These shifts in attitude and practices are also the bedrock for “partnership accountability” (Tamasese & Waldergrave, 1993), which asks those with more power to take responsibility to amplify the voices less likely to be heard and to hold themselves accountable to the people most affected by their actions. Partnership accountability offered a different approach to address power relations between human service seekers, providers, and planners, and one that is in alignment with Schon’s reflective contract.

## **METHODS**

The research project emerged from my intrigue with an interview exploring power relations between parents of children with mental health concerns and professionals (White, 1998a). The interviewer, Michael White, the co-founder of narrative therapy (White & Epston, 1990) posed questions that raised the issue of accountability between service providers and service seekers. “How can a group of service providers who are very well meaning, well intentioned, caring and

compassionate still find ways to set up contexts so that they are accountable in some way to their knowledge and acts of power?" White focused on parents' self-knowledge in the face of power relations. He also acknowledged specific developments in people's lives that speak to their shared commitment to include all voices and ensure processes to identify voices that have been excluded or dropped along the way. He especially drew attention to otherwise unnoticed steps that parents, providers and agency administrators had taken in their community to become accountable to each other in their efforts to identify power relations, and to find effective ways to address them.

This study drew from a broad-based early childhood mental health initiative in Vermont called the Children's Upstream Services (CUPS) Initiative (CUPS, 2004). CUPS faced the challenge of meeting community needs for a wide range of resources and services for families with young children within the parameters of the federal grant for families living with severe emotional disturbance. As an early childhood initiative, CUPS addressed a spectrum of needs and mental health strategies ranging from prevention to high-risk intervention. Early childhood care and education programs carry a strong commitment to preventive care available as support to all families and young children in communities. This meant folding the newly established system of care into the existing Vermont early childhood network in contexts such as childcare settings, primary health care, and community resources. The children's mental health system of care seeks to create community-based services and state initiatives for children with serious emotional disturbance. These different priorities posed tensions between state administrators, families, and service providers as expressed in regional and statewide meetings.

Vermont is a very small state, with a population of about one-half million people. People have more opportunities to participate in local government, and citizens have easy access to public officials. About one quarter of Vermont's population is made up of children under the age



of 18 with a greater proportion of children living under the poverty level than do any other age group. In 2000, 13.4% of children under five were poor (Census, 2000). Economic diversity is reflected in governance groups in Vermont more than in other parts of the country. Concerns for economic well-being introduce policies for livable wages, children growing up in poverty, affordable housing, homelessness and quality child care. One report described children and poverty in Vermont “Short on cash, out of gas, car needs repairs, kids are sick, boss takes no excuses, more month than money and too many mouths to feed, not enough to get by, pay the bills you can and hope the rent doesn’t go up again. A lot of wishes, few dreams, and too much hopelessness. This is the situation in which too many of our children grow up” (Forum, 2003).

The study took place over 16 months, from March 1998-July 1999. I interviewed co-researchers to explore experiences of “finding common ground” despite divisions that persist between parents of young children with special needs and professionals who work with them (Sax, 2000). The research conversations enlisted family members and professionals who were engaged in the community planning associated with CUPS to co-design local systems of care that strengthen and support families with young children. Participants in regional planning processes were from a wide range of backgrounds including parents, and professionals from child care services, parent/child centers, early childhood education, early intervention, mental health, social services, pediatrics and public health, education, substance abuse prevention, and community partnerships.

### **Co-researchers**

Seventy-five “co-researchers” were recruited for a total of 20 interviews to explore three aspects of family centered practices: (1) effective help-giving, (2) meaningful parent involvement in human services planning, delivery and evaluation, and (3) ally-to-ally support.

All participants were volunteers who gave their informed consent. Parents of children, ages birth to five with mental health difficulties were recruited by the regional CUPS planning group to engage in facilitated conversation about their preferred experiences in working with professionals. While some young children had been diagnosed with specific emotional-behavioral disorders, families did not need a specific diagnosis in order to participate.

Most the co-researchers were White, Euro-American women from diverse socio-economic backgrounds. The predominance of mothers and female human service professionals in this research project reflects broader cultural trends toward women's participation in the lives of young children. As fathers participate more fully in the day-today care of their young children, I hope that their voices will be more included in future research. However, several fathers, male service providers and planners also participated. Service providers and state planners participated from child care services, parent/child centers, early childhood education, early intervention, mental health, social services, pediatrics and public health, education, substance abuse prevention, and community partnerships. Several people in designated professional roles described themselves as straddling multiple roles, and for the interview chose to take the parent's perspective. All co-researchers shared a passion for strengthening community resources for children and families and an investment in identifying specific knowledges and actions that would make necessary changes in their lives, relationships and communities.

### **Interviews**

To generate conversation about more effective, more equitable working relationships between parents and professionals, I initially preceded the group interviewing process with a 10-minute video edit from the aforementioned interview conducted by Michael White (White, 1998b). As the project unfolded, I compiled a number of edited video selections from the series

of group interviews conducted for this project for future project interviews. The process of video selection was not systematic. Throughout the research project, I used my own judgment to decide which video to show in which setting. All of the video selections showed respectful exchanges (Lawrence-Lightfoot, 2000) between the three groups of co-researchers – human service seekers, providers, and planners – who gave personal accounts of their earnest and often provocative experiences in pursuit of mutually satisfying experiences in their respective roles.

Ten of the interviews were conducted in groups using White's four-part format for narrative interviews with outsider witness practices, as follows. (1) After viewing a video edit, several members of the group – a combination of parents and providers – volunteered to be interviewed about ideas sparked by the video. The other group members were assigned to the outsider witness position. (2) The outsider witnesses to the video and the interviewees were then asked to share their responses about what they had heard during the interviews; (3) The original interviewees were then interviewed about which of the outsider witness reflections stood out for them; (4) The entire group then shared its experience of this process, discussing which understandings became more richly developed in this context, and what kinds of steps or actions these understandings might inspire.

The other interviews also began with viewing a video edit, yet the interview format was more standard and without outsider witnesses. Each reiteration built upon previous dialogue. I consulted throughout with colleagues with specific knowledge in narrative therapy, family support services and community planning. Thus, the project involved many reiterations with reflexive pauses to step back, reflect and further inquire. I met some co-researchers for the first time when they came to a scheduled meeting out of curiosity for the research topic. As new issues or questions emerged, I strove to incorporate them into subsequent interviews. Sometimes

an issue arose during an interview that consumed my thoughts for days afterward. When this occurred, I brought this question into subsequent interviews and arranged interviews with people I thought could help shed light on the emergent themes.

Outsider witness practices helped co-researchers engage in multiple, levels of reflection and inquiry as outsider witnesses to each other's emergent ideas (White, 1995). Outsider witness practices are a unique development in the history of reflecting teamwork as reflexive practices within family therapy (Andersen, 1991; Friedman, 1995; Lax, 1995; Lussardi & Miller, 1990). Based upon the "definitional ceremony" metaphor from the work of cultural anthropologist Barbara Myerhoff (1982, 1986), this practice guides the positioning of outsider witnesses within a structured forum as audiences to the significant stories of people's lives (White, 2004). The outsider group listens carefully to the stories told, and then the positions are switched so the persons whose lives are at the center of the definitional ceremony form an audience as the outsider witness group engages in a retelling of what they heard. After these retellings, the roles are again switched so that the persons in the original interview have the opportunity to reflect upon what they have heard.

Outsider witness practices are structured by a specific tradition of acknowledgement that provides the foundation for retellings (White, 2004). Reflections in outsider witness practices are in response to specific accounts that resonate with members of the audience, often transporting them "to become other than who they were on account of witnessing these expressions and responding to these stories in the ways that they do" (White, 2003).

## **ANALYSIS**

Each of the 20 interviews was video or audiotaped, and then transcribed. HyperRESEARCH, a qualitative data analysis software program, provided tools to handle, code, and manipulate the

large quantity of data involved in this research project. My study was divided into 21 data sets or “cases.” As I re-read every source, I highlighted passages that stood out as being relevant to the research question. I then assigned a code to each selected passage. Code assignment involved either creating a new code or assigning an existing code. The purpose of such coding was to mark selected text so that I could readily retrieve portions of coded source material and organize the selected text into themes.

The narrative approach offered additional opportunities for research reflexivity. As I moved between interviews, I brought videotape and stories with me from prior interviews. Many times, co-researchers described ways others’ stories contributed to their thinking, awareness of possibilities, and prospective actions. When I brought back to communities and individuals stories of ways in which their words have impacted on others, co-researchers were noticeably touched to know that their words made a difference to others. The research conversations also had a powerful impact on my own thinking and relationships, since I was privy to all 20 interviews. Thus, research data included audio taping, journaling, and letter-writing of my own reflections within a reiterative process in which I continually asked myself, What does this mean for me? How are my practices and ideas changing, as a result of participating in this project? By recording reflections throughout the research project, I created space to notice and inquire into emergent themes.

## **FINDINGS**

The research conversations provided ample opportunities for parents, human service providers and planners to step into the experiences of others. Parents spoke about what is most important to them in their relationships with providers. Professionals put themselves in the shoes of service seekers and shared stories from their own professional and private lives. While parents

heard an insider view of what it is like to be a service provider, conversations centered on the service seekers' perspective. The intent of decentering of professional experience appropriately amplified the voices of the people with less power and invited further commentaries from parents (Tamasese, Waldegrave, Tuhaka, & Campbell, 1998).

Unanticipated themes emerged in the early interviews which shaped the research project. For example, I began the project intent on exploring two aspects of family-professional relationships: meaningful parent involvement and effective help-giving. As family members spoke to the importance of parent-to-parent support, I arranged for people from family organizations who are especially knowledgeable about parent-to-parent resources to be included in the subsequent interviews.

Certain themes became more richly described over time. When I began this project, my focus was on experiences when human service seekers, providers, and planners move out of the grip of "us and them" positioning to engage in earnest dialogue as human beings with a shared commitment to address the needs of children. I was excited to realize that this phenomenon fit well in narrative terms as a unique outcome. The challenge of developing accountability practices between service providers and service seekers was another emergent theme, which began when the interviewer in the initial interview acknowledged the professionals for their commitment to hold themselves accountable to the people they aspire to serve, and posed the following question, How can a group of service providers who are very well meaning, well intentioned, caring and compassionate still find ways in those circumstances to set up contexts so that they are accountable in some way to their knowledge and acts of power. As the interviews progressed, the theme of power relations became more central to the concept of common ground experiences, and co-researchers gave personal accounts of their struggles to embrace new

possibilities for common ground experiences in the face of cultural and professional discourses that run counter to these developments.

In their accounts of preferred relationships between service seekers, providers and planners, co-researchers identified several consistent themes. Parents reflected on their roles as service seekers, how difficult it can be to get anyone to hear their worries, how often they feel discounted and patronized by professionals, their anger and tears, the growth of their self confidence over time, and the central role of friendships that emerge when sharing their stories, helping each other and their children. Service providers grappled with the real effects of bureaucracy on their lives and the challenges posed by a professional agenda, how often they feel beleaguered by working with systems that are slow to change, the need to be recognized as humans who make mistakes, and the need for attitude change. In various contexts, they acknowledged their privilege of access to resources, and pondered ways to render these privileges more transparent, with resources more at the disposal of service seekers. Human service planners spoke of the unique challenges they face to stay in touch with the voices of service seekers and providers when they spend most of their time removed from direct service work.

In the following section, I further describe several noteworthy themes:

### **Two-Way Accounts**

In two-way accounts of therapy, therapists identify, acknowledge and describe specific ways therapeutic conversations have or might contribute to their own lives (White, 1997a). This approach has emerged from an understanding of engagement that differs from traditional therapeutic practices in which therapists do not reveal personal details and it is assumed that only the client is affected by therapeutic conversations. Two-way accounts undermine the hierarchy of

knowledge of presumptive power relations, making it possible for people to learn some of the real effects of their stories on others—including those in the designated role of professional.

This research project demonstrated an application of two-way accounts beyond the therapeutic relationship. Frequently, parents recounted positive effects when someone in a professional role showed a little bit of herself. For example, in one group gathering<sup>ii</sup>, Prudence described her experience as a single parent on social assistance when her worker took a minute to connect with her 10 years ago: “She showed me a picture of her grandson who was the same age as my son, and we had this dialogue. When I go into her office, the first thing we do is have a 10 minute dialogue over her grandson and my son. (She) made a connection and that has transcended 10 years....! That's going somewhere! And that was 10 minutes that really made a difference.”

After hearing parents’ appreciation of therapists who share pieces of their own lives with their clients, Lee, a family therapist, described her relief in a letter, “What a pleasure it was to hear from you that it matters to you when therapists can be themselves with you. I remember reading about theories of feminist therapy in the late 70s, which talked about power imbalances between clients and therapists that occurred if you didn’t share relevant parts of your own life, but that was considered quite radical. I felt right at home with this, but never told any of my supervisors that I did it, for fear of their disapproval.”

Parents’ personal stories often became a springboard for professionals to tell stories from their own lives and parenting experiences. At a community meeting, Isabelle, a young low-income mother of three, spoke about the isolation she experienced when services available during her teenage pregnancies abruptly ended, and the frustration she felt when waiting too long for services. Isabelle often felt discounted in her experiences with professionals.



A lot of times they'll talk, but when you try to talk, it will seem like they'll always say no, or will think of something else, so you end up feeling like your opinion isn't important. After you get turned down enough with people telling you, 'Your child isn't definitely diagnosed or this or that,' you get to the point where when someone comes in you think, 'Oh yeah, here I go again. They're not going to do anything. They're not going to listen.' It took a lot to get anybody to listen to me. I don't know what I'm supposed to do as a parent. You wouldn't believe the phone calls I tried to make when I was in crisis and no one could help.

In response to hearing Isabelle's description of her frustrations in working with professionals, several providers shared some their own experiences. Kate, an early childhood provider, told a story about her own experiences as a mother. "One thing I noticed was when we found out my daughter had hyperactivity. Being a young mom and not knowing a lot of other young moms, I didn't know where to go. The big thing was how to contact someone. We don't know what else is out there until someone shows us."

Joyce, an early childhood education provider, shared a personal experience of feeling intimidated and patronized by service providers. "People who know me can't imagine that I might be intimidated. But I remember as a parent going to school to meet with an educator, and feeling extreme apprehension. I felt I knew my child, but they were the experts. That was a real interesting thing for me to experience as a parent." Joyce also spoke about her recent experiences as service seeker since her elderly parents came to live with her. She recognized the parallel between her experience with home health agencies and descriptions by parents of young children who feel like people do not listen. "I experience the same thing: intrusions into my

home, feeling that they come in with their agenda, don't listen to what I have to say, and are not really sensitive to stress that I am feeling in this situation.”

When given the opportunity to reflect upon what she learned from this exchange, Isabelle remarked, “This is the first time I actually feel like I am equal with everybody who is in this room. You don't know how good that feels. You asked me questions. I can tell that you guys are actually listening and understanding. I know that not everyone feels the same way. But when they disagree, they've said it in a way so that I can understand better why.”

I later showed a video edit of the candid exchange between Isabelle and the providers in her community to Nancy and Jo from Vermont Parent-to-Parent, a peer support and advocacy organization for parents of children with disabilities, both of whose life's work expresses a profound commitment to family support and family-centered care. Nancy responded that this exchange clearly illustrated the need for professionals to earnestly engage in conversation with parents and hear what families have to say. She observed Isabelle sit up straight when she said, “Yes, and I am at a different place than I was a couple of years ago!” Nancy credited the providers who, within the interview, asked what they had done to make this possible. Nancy remarked, “You can feel the power of that question. And Isabelle responded, ‘You asked me questions!’ But it was questions based on a response to what she had said. That is a conversation.” Nancy was impressed by how far Isabelle had come, and how the providers in the room recognized this. She described the need for professionals to acknowledge parents' accomplishments along a tough journey. “Families are not recognized by professionals enough for the fact that they are resilient, that they cope and they acquire their allies.”

### **A Range of Experiences with Professionals**

Like others before them, the parents who were part of this project shared how difficult it can be to get professionals to hear their worries and that they often feel discounted and patronized by professionals. They expressed how they handle their anger and frustration, how self confidence grows over time, and how friendships emerge when sharing their stories, helping each other and their children. Many parents identified specific professional practices that contribute to negative or positive relationships with professionals. Pam gave an apt illustration of this contrast.

When I first went to Reach Up, I found out that my worker worked in a parent group that I went to for childcare. So that made it comfortable. I could ask her for things. She got my children into day care so that I could do other things. It was a great relationship because I didn't see her as my worker. I saw her more as a friend. The first thing she would do when she came to my house was pay attention to my children, sit and read them stories and ask me how things were going.

On the flip side, she changed jobs, and I have somebody new that I didn't know before. So I am back at that point because it's now, "She is a provider, and here I stand." We don't connect. She doesn't converse with me. She doesn't ask "How are the kids?" It's always, "Okay, you need to do this and I will do this. And when are we going to meet next? What are you going to have for me?" I don't even like to meet with her.

Pam also described a very different kind of relationship with a new Head Start visitor. "She looks to me as a mentor in Head Start! It feels really weird. As she puts it, I'm a parent who has been around the block a few times, and I'm only 24. I don't think of myself as having that kind of knowledge. I find it really odd because I know a lot of the answers that she doesn't have!" Imagine what it does for a parent to have a provider treat her as a consultant, and look to her for guidance, rather than always being the dispenser of professional knowledge.

### ***Anger as a Catalyst for Action***

Parents who have had frustrating experiences with service providers frequently described the intense anger they felt. Anger can also be a catalyst for finding one's voice and taking action. Isabelle described how her relationship with a family advocate helped her channel her anger. "Now I am at the point where I'm getting so angry that people aren't hearing me that I am starting to speak out for myself. This really feels kind of awkward because I've never been a person who would do that. I've always been quiet, withdrawn, and let everyone tell me what I need to do. Now, through having a family advocate for two years, I'm actually at the point where I've got a voice."

Meg spoke about her desire to help other parents avoid getting stuck in the anger. "You can get in certain cycles or get caught in certain parts of your life. I hope to help someone else realize that's where they are, and to move on to advocate in a positive way. I have lost my temper and gotten enraged, and it doesn't get you very far!"

Pamela, another parent, at one point during her community meeting said she was too angry to speak, having lived through her own share of frustrating experiences with the provider system. When she finally spoke up, Pamela offered an exquisitely insightful perspective. I was especially moved by her choice of a positive approach to transform her anger into language that professionals could hear:

*The family might be going through situations that are very stressful to the parent, which may not be realized by the provider. Something can trigger a situation from the parent's past. Something that seems small to a provider can be the opposite for a parent. Show some compassion. It's okay to say, "I don't know the answer." Also, ask the parents what they think since they know that child a lot better. If you do it together, it's a great opportunity...Providers*

*may be experts in their field of service but they need to understand that the person who is the parent knows the child better...If you go into the family atmosphere, just go in there as another person, maybe as another parent. Share some of your own experiences. This makes the parents feel that they are not alone. You are not just coming in there to tell them what to do, to show them this or that, to change something. You are also coming there with how you have grown from your experience.*

### ***A Yearning for Acknowledgement***

Often, parents described their yearning to be recognized for all they do in response to the challenges they face with their children, including being their children's best advocates. Parents described feeling a sense of urgency in getting help. Lori, the mother of two young children diagnosed with autism, spoke about how her love for her children this informed her impatience:

When you want the best for your child, nothing is fast enough. When we go to a provider, we expect to hear (something helpful) about our children. You get impatient when you've been to all these programs and you wait. It's going to take time to change services and to get things more positive. Meanwhile, my six year old daughter's face looks like she always has the chickenpox because her younger brother takes out his frustration on her. As a parent, you have a sense of urgency. You always want the missing link. Maybe this will help?

Susan still vividly remembers a time that a professional acknowledged her competence when her now adult son was still a young child:

Andreas was a kid for whom nothing would work. I remember thinking, "I'm trying the best that I can, but I don't know what the hell I am doing! Nobody does." The

pediatrician had absolutely no answers for any of Andreas' problems. What helped me the most was that every single time I would go in that door he would say, "You are doing an incredible job." I get emotional right now thinking about it. He didn't know that I was doing a decent job; I didn't know that I was doing a decent job; but he told me I was, and that made me feel like I could do it.

### ***Feeling Untitled and Devalued***

Co-researchers spoke candidly with each other about the role of the service seeker as culturally of less status than that of service provider, and the real effects of income differentials on the rules of engagement. Several parents described how their input in community meetings was typically questioned, and how unusual it was to feel as though their experiences were valued. Parents experience themselves as being "untitled." As Prudence put it, "Everyone else is going around introducing themselves as the director of this, a psychologist, a practicing therapist. Parents don't have ways to describe themselves that has equal weight, although their work is just as real." Many parents described feeling devalued and frustrated in their search for help for their children. Frequently, they acknowledged underlying class issues that are often recreated in the context of meetings when parents are asked to participate, yet it is assumed that they will volunteer their services. Pam described how she often feels that her input in meetings is questioned "as a low-income person because of the services you receive/" Prudence described the stigma associated with being a "low income" parent as related to her by a parent who was on the Board of Directors for Community Action.

When she goes to the meeting, within the first five minutes, it's established not only who the other people are, what they are the directors of, but that she is a "low income" parent and that she is 100 percent below the poverty line. She said the doctor sitting next to her

doesn't have to disclose his income. "Nobody asks him how much money he makes and how far he is above the \$200,000 income line. She said something like, "I refuse to think of myself as a low income parent. I am presently economically challenged."

### **Peer Support and Advocacy**

Parents in this research project frequently expressed their utmost appreciation for the concrete help and self-determination that peer support provides. They highlighted the importance of providing families with peer advocates versed in advocacy, support, and self-determination practices. They also spoke about their desire to be of use to others, as long as they truly feel welcomed. They underscored the need to connect with other parents and with people who have "been there." Increasingly, family support organizations offer such parent-to-parent services.

Often mothers shared their yearning for more parent-to-parent contact. After hearing several parents on videotape, Jo, a service planner from Vermont Parent-to-Parent (a peer support and advocacy organization) posed the obvious question: "Why aren't service providers and planners getting parents' message about the priority they place on parent-to-parent support?" She observed how Prudence had developed an eloquent voice over her decade of contact with professionals. "Parent-to-parent resources can help parents develop their voices much sooner."

*The Centrality of Friendship in Mothers' Lives.* The mothers in this research project expressed a profound appreciation for their friendships with other mothers. There was almost unanimous appreciation of the value of opportunities to talk with other parents who have been through similar experiences and support from an ally. Through sharing their stories, helping each other and their children, mothers become allies. They call each other on the phone. They attend meetings and conferences together.

Such connections reduce the isolation that frequently goes with the territory of parenting a child with special needs. As one parent stated, “It helps just knowing that someone else has experienced this thing. You feel really alone, like no one else has ever experienced this before in the whole world.” Often, contact with other parents was the factor mothers cited as most important in increasing self-confidence and feelings of competence. Over and over again, women said: “I don’t know what I would have done if I didn’t have another mother’s support.”

One parent described how important it is to have connections with other people who “get it.” She feels that her husband does not get it, but considers herself lucky because she knows so many parents and providers who do. She wondered how parents in other communities could feel their own power and wisdom with no one to reflect back to them.

Often there is a “big sister” quality to the connections between a mother and her less experienced ally. With pride, Carol, a parent advocate, described her relationship with Julie, another parent, and Julie’s growth in self-confidence: “Julie has told me her feelings, and her story, and I have told her mine. Julie is just getting stronger and stronger. I think everyone here can see this. She is not afraid to say what she feels, whereas she may have been years ago.”

Like many of the mothers, Pam described her desire to assist other families. She knows that “those pieces that I carry from my past will help me understand and provide empathy for the person that I’m working with.” As a former teen mom, she could remember what it was like and could help others. “You feel really badly about yourself when you are a teenage mom because there is this big stigma. I can think back and I can say, ‘You know, you are not the only one. There are other people who have done it and gotten through it. I am one who did it.’ ”

*The Role of Family Organizations.* Parents often described professional services as only one component of their quest for support, advocacy and leadership. Isabelle attributes her



growth in self confidence and parenting skills to a match made through a local family organization with a family advocate. She described her relationship with her family advocate in glowing terms, stating that she wouldn't be where she is today without her support. "She didn't come into my home telling me what to do or where to go, or any of that. I felt like she put it in my ballpark and was able to support me." Isabelle shared the importance of having her advocate with her at meetings. "She'll make eye contact, or pat me on the shoulder to let me know she's there and that it's okay, and that's her job. She's given me the boost that I needed to get going."

### ***Cross-Pollination of Agentive Initiatives***

Sometimes, specific ideas were cross-pollinated across regions. Julie encouraged her planning group to adopt "parent-partner" practices from another region to link every parent with a professional in the group. "As a parent, I know that a lot of times in our process I felt really lost. There was one meeting in particular when I thought, 'What is going on here?' Somebody could have helped me through the process. I could have said, 'What's going on' at the break or something." Julie's region followed through to institute parent-professional partners with the commitment to develop further strategies for meaningful involvement of parents in planning meetings, service delivery, and training events. When I returned to this group a few months later, Pam, described how partners now connect with each meeting. "If someone says she does not know if she will be able to make a particular meeting, her partner will call her." Even when Pam did not have a phone, her partner knew to call Prudence's house. This kind of contact helped make it "a more comfortable experience now when I go."

When I then brought Julie and Pam's regional ideas back to the original "parent-partners" community, this propelled them to reflect on how their original idea was going and to make

adjustments. Together, they queried into how best to meet families' needs within the professionals' meeting culture: "I was thinking we need to figure out better how we can check in with each other to see how people are doing: parent-to-parent and parent to provider."

### **CONCLUDING THOUGHTS AND PERSONAL REFLECTIONS**

This research study took place with a select group of people in a small rural state in North America. While I believe their stories have application well beyond the Vermont context, I do not want to imply that they speak universally for others. Most of the co-researchers were White, Euro-Americans who share particular cultural assumptions and experiences. My concern is that this inevitably projects an ethnocentric view of human services. This project did not adequately mirror the cultural diversity in North America or other nations of the world. I hope that future research can explore the impact of diversity on the organization of common ground experiences.

However, the findings point to the importance of more equitable participative relationships between seekers of human services and providers and planners of these services that could potentially facilitate more efficacious relationships for all involved in social service relationships. **Joining The Community Of Family Support**

In my work with families with young children, I am often struck by differences between the professional cultures of early childhood and mental health. Many early childhood service providers have been working together in different capacities for years and share a deep commitment to principles of family support and strengthening community-based resources. In contrast, mental health professionals are less often familiar with other providers, less focused on community planning of preventative family support services, and most concerned with finding effective interventions for those who are already experiencing difficulties. Necessary

changes run counter to the professional discourses that encourage professional distancing, one-way accounts of the help-seeking relationship, and token involvement of parents in the planning, delivery, and evaluation of human services. I believe it is time to find ways for mental health practitioners to join the community of people working together to support families through challenging times.

### **Peer Support And Advocacy**

Family members say again and again that they need most of all to form alliances with people who have been there and to feel connected to community. Parents frequently expressed their desire to be of use to others, as long as they truly feel welcomed. Yet parent-to-parent relationships and community supports are typically viewed as less important than professional services –especially by therapists. Therapist training often leaves out the voices of service seekers and does not provide adequate opportunities to learn about parent support services and other relevant community resources.

### **Facilitating Social Change**

The field of family therapy has been greatly influenced by systems thinking, challenging highly individualized understandings of life and personal experience. Many family therapists wish to move from the isolated private world of therapy, and join larger communities that share social justice concerns. Participatory action research and narrative therapy offer rich possibilities for facilitating social change. Together they infuse the research process and the action outcome with intimately personal processes. Such change at the community level, initiated by and affected at the personal level, elegantly captures the essence of social change, which, in the final analysis, begins and ends with the personal.

Many medical schools now train physicians in specific participatory practices for collaborative care. Family support organizations offer family support, advocacy, and leadership trainings generally oriented toward parents and other community members. How can therapists join in interdisciplinary learning opportunities that combine technical and relational skills, and develop strategies to continuously consult with family members about what works best for them?

### **Encouraging Reflective Practices**

Narrative practice and participatory action research invite reflections on the multiple effects of the conversation on co-researchers' lives and relationships. Narrative practitioners pay particular attention to two-way accounts of how a conversation transports people – including the interviewer – to new understandings that may have a personal impact. PAR approaches reflection as a living practice within an emergent, trial-and-error process with second order effects on all co-researchers including the primary researcher; the cyclical process of inquiry, action and reflection contribute to both social change and personal transformation.

My participation in this research study has changed my outlook on human services. Reckoning with one's own privilege is humbling experience. I am more acutely aware of my participation in the privileging of professional services, and in the inadvertent silencing of the voices of service seekers. Seven years hence, in my work as a family therapist, at times I still neglect to connect parents with other parents and to link them with family organizations. I realized how ingrained this way of thinking is, to put professional knowledge in the forefront and the knowledge of service seekers as a backdrop. While I always abide by an ethic of confidentiality, with the permission of family members, many opportunities can emerge in which to link people's lives around shared themes (Lobovits, 1995).

Parents who seek meaningful involvement in human services have described how they prepare themselves with questions like these to keep themselves grounded in what is most important: What does this mean to me, and to children and families? What is my contribution to this conversation? I would argue that all human service practitioners – including family therapists – need to ask themselves similar questions. How can I best use my privilege as a professional to truly be of service to families, according to their priorities? What is my contribution to this conversation?

This article is dedicated to the memory of Julie Finkle, whose gutsy presence made a significant contribution toward developing family centered services in Vermont. A heartfelt thank you as well to my colleagues who reviewed earlier drafts of this paper: Brenda Bean, Chris Behan, Christine Demment, David Epston, Frances Hancock, Bill Lax and Michael White. I also extend a special thank you to Anne Lezak and Carolyn Tubbs for their masterful editing skills in helping me to see both the forest and the trees.

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<sup>i</sup> Whenever possible, I use the term “narrative practice” rather than “narrative therapy” since I believe the applications extend beyond therapeutic contexts. For further interest, consult <http://www.dulwichcentre.com.au/>.

<sup>ii</sup> Near the completion of this project, Michael White joined a small gathering in Vermont focused on this research project. Judy, an experienced colleague, interviewed three mothers and me about our experiences with the research project. Michael was then interviewed about his reflections, followed by a group of 15 colleagues who added their inquiry and reflections as outsider witnesses. Several participants in this gathering shared further reflections in letters. All of these became further rich sources for data collection.