Building on Family Strengths

Research and Services in Support of Children and Their Families

2003 Conference Proceedings

Research and Training Center on Family Support and Children’s Mental Health

PORTLAND STATE UNIVERSITY
Building On Family Strengths: Research and Services in Support of Children and Their Families

2003 Conference Proceedings

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About the Research and Training Center on Family Support and Children’s Mental Health

The Research and Training Center on Family Support and Children’s Mental Health, at Portland State University in Portland, Oregon, is funded by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, and by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. These grant funds support activities that complement and build upon the work of the Research and Training Center from 1984–1999. The RTC is part of the Regional Research Institute for Human Services of the Graduate School of Social Work at Portland State University.

Through a set of related research and training programs, the Center is dedicated to promoting effective community-based, culturally competent, family centered services for families and their children who are or may be affected by mental, emotional, or behavioral disorders. This is accomplished through collaborative research partnerships with family members, service providers, policy makers, and other concerned persons, and applied by multi-level research and capacity building in the following areas:

- Identifying and promoting culturally competent policies and practices as part of an effective community response driven by the needs of families;
- Clarifying values related to family partnerships and collaboration in all aspects of service delivery and evaluation; and
- Building leadership capacity of families, advocacy groups, formal and informal service providers, local communities, and state and national-level organizations through development, dissemination, and training activities related to the following Center projects:

Family Participation in Residential Treatment Programs project studies the experiences of families whose children received services for their serious emotional and behavioral disorders. Data was collected from 500 families across the country. Project accomplishments include the development of a measure of family participation across settings and refinement of a measure of caregiver empowerment. The focus of current project efforts is the dissemination of findings about family participation and contact between parents and children who are receiving out-of-home care, and the promotion of policy change related to these findings.

Common Ground? Families & Employers builds on the foundation of the Support for Working Caregivers, and studies how parents’ employment is affected when caring for a child with a mental health disorder, the strategies used by parents to manage employment issues, and workplace practices that support employees who are caring for children with special needs.

Models of Inclusion in Child Care identifies and intensively studies inclusive child care programs and strategies which result in improved access for families who have children with emotional or behavioral disorders. A comprehensive survey also explores state level efforts toward inclusion in child care settings.

Promising Practices in Respite Care for Children with Serious Emotional Disorders and their Families. The RTC participates in the production of Promising Practices, a series of monographs which describes successful practices in providing effective, coordinated care to children with a serious emotional disturbance and their families. The current study addresses respite care.
Guidance for Early Childhood Program Design is developing evidence-based solutions to assist early childhood education managers with design and implementation of effective mental health services for children and families. Technical assistance and training materials will be developed, tested, and disseminated.

ISP/Wraparound teamwork in practice: Context of Services studies the system and organizational context within which family centered Individualized Service/Support Planning (ISP or wraparound) exists. Having derived a conceptual framework describing system- and organization-level conditions necessary to support quality implementation of the ISP process, the project is constructing tools for sites that are implementing ISP to use as a part of their ongoing self-assessment and development.

ISP/Wraparound teamwork in practice: An examination of multiple perspectives on team collaboration, functioning, and effectiveness. This project studies effectiveness in Individualized Service/Support Planning teams (wraparound teams) using interviews, observations, and the intensive study of videotaped team meetings. Using the results of this research, project staff are developing tools to help teams increase their effectiveness.

Families as Evaluators is evaluating a curriculum developed by the Federation of Families for Children's Mental Health to train and support family members involved in evaluation. The project is also studying the experiences of evaluators who are collaborating with family members and will use the findings to guide the development of training materials for evaluators.

Underrepresented Researchers Mentoring Program offers Portland State University undergraduate and graduate students research opportunities in children's mental health. The project identifies women and men who are underrepresented in research—in particular, women and men of color and/or with disabilities—who have an interest in children's health and well-being. Participants are offered training and access to the supports and resources necessary to become skilled and confident researchers, and the opportunity to work in partnership with existing university and community formal and informal supports for underrepresented students.

The Learning Community-Data Trends As part of our participation in the Learning Community partnership, the RTC collaborates with the Research and Training Center at the University of South Florida to produce Data Trends, a series of one-page briefs addressing current themes, summarizing recent articles, or presenting new developments in the field of children's mental health.

Annual Building on Family Strengths Conference The primary purpose of the Conference is to provide a forum for the exchange of information about current research, evaluation and innovative programs and practices in the area of culturally competent, family-centered mental health services for children with emotional and behavioral challenges and their families.

Focal Point A National Bulletin on Family Support and Children’s Mental Health is a semi-annual bulletin that contains short articles and informational sidebars focusing on recent research in the topic area, as well as applications of that research, impact on families and children with emotional and behavioral challenges, and policy implications and/or developments. Articles are written by Center staff and other leading researchers, policy makers, advocates, practitioners, family members and youth with emotional or behavioral challenges.

Center Website is our primary means for disseminating Center information and various Center products, all of which are available in an online searchable database. We are continuously working to increase the variety and accessibility of materials available on the site by focusing on current and useful content, future changes based on information we gather from visitors, increase attractiveness and ease of navigation, and increase the circulation of rtcUpdates.
Introduction

2003 marked a milestone in the history of the Building on Family Strengths Conference: It was the 10th time people from around the United States (and, to a limited extent, from around the world) gathered in Portland, Oregon to share and learn about current research and best practice for supporting children and youth with emotional and behavioral challenges and their families. We gathered to be challenged and energized, and we were, beginning with John VanDenBerg’s keynote address “Now More Than Ever.” We gathered to become better informed, and we were, through plenary sessions on Individualized Service Planning and Early Childhood Mental Health, through dozens of high-quality workshops and poster presentations, and through many conversations with friends and colleagues, new and old alike, over the three days of the conference. We gathered, nearly 500 strong, to move forward toward the realization of the system of care principles and values that inform our work. Publication of these proceedings of the 10th Annual Building on Family Strengths Conference, held June 26-28, 2003 in Portland, Oregon, is meant to contribute toward realization of that goal as well.

The efforts of many people went into preparing for, carrying out, and recovering from the 2003 Building on Family Strengths Conference. As always, the leadership provided by Dr. Barbara Friesen, Director of the Research and Training Center, and Dr. Nancy Koroloff, Director of the Regional Research Institute, was the foundation for the success of the conference. The support of Dr. James Ward, recently retired Dean of Portland State University’s Graduate School of Social Work, for the Center’s activities was also foundational. The organizational abilities, administrative expertise, and creative talents of Center Coordinator Donna Fleming and Center
support staff Kathryn Tullis, Alicia Magee, and Andrea Hanson turned the straw of the myriad details of conference organization into the gold of the conference experience; they also served ably on the conference planning committee, along with Dr. Pauline Jivanjee, Maria Everhart, and myself. Denise Schmit, Center Publications Coordinator, and Ann Derry provided significant support before, during and after the conference as well. This year’s family member proposal reviewers included Laurie VanSi, Jan Lacy, Bright Philips, Dawn Overeem, Mary Pearce, Leanne Guthrie, Bev Stephens, J.D. Hall, Nick O’Connor, and Joe Goodley. At the conference itself, the following staff members of the Research and Training Center and Regional Research Institute, local family members, and volunteers from the community served as moderators at breakout sessions: Monica Parmley, David Jones, Depra Depew, Don Bougher, Theresa (Rea) Rice, Jeanne Schulz, Takako Kozima, Laurie VanSi, Karen Cellarius, Debi Elliott, Jennifer Bradley, Kathryn Schutte, Maria Everhart, Peris Kibera, Adjoa Robinson, Pauline Jivanjee, Eileen Brennan, Shane Ama and Keri Gordon. Ivonne Rivero translated conference materials into Spanish, and Sonja Trigo provided simultaneous English:Spanish translation throughout the conference. Katie Schultze and Martha Gordon provided transcription services for keynote and plenary session audiotapes.

A note on organization and use of these proceedings: Other than the keynote and plenary transcripts, presentation summaries are listed alphabetically by last name of the lead presenter. All presenters are listed, with initial page numbers of the presentations they contributed to, in the index. Many presentations reference PowerPoint slides; links to corresponding web-based versions of individual presentations are included when appropriate. Presentation summaries were not received from all presenters, but a complete conference agenda, with contact information for lead presenters, is included.

Thank you for your interest in these proceedings; please let us know if they are useful to you, or how they might be improved. We especially thank you for your interest in, advocacy for, and work with children, youth and families affected by emotional or behavioral challenges.

Lynwood J. Gordon
Associate Director and Conference Coordinator
Research and Training Center on Family Support and Children’s Mental Health
July 2004
Barbara Friesen: Good morning! Now we really are starting. Good morning! I would like to repeat that if you prefer to hear this plenary session and other plenary sessions in Spanish, we do have simultaneous translation available and the headsets are on the table right back there, and the woman in the chartreuse jacket is Sonja Trigo, who is the translator.

So, good morning! My name is Barbara Friesen, and I am the director of the Research and Training Center on Family Support in Children’s Mental Health, and I want to welcome you to Portland’s version of summer. Yesterday that was funnier than it is today. Apparently we are looking at perhaps weather in the 90s for the next couple of days, but we have had a very off and on kind of spring and summer, and so here in Portland when the sun shines for an hour or so, we call that summer.

Welcome! This is the tenth annual Building on Family Strengths Conference, and we have come a long way in ten years. I just wanted to find out, is there anybody here who has been at every one of the ten conferences? No. There are some of you who have been at nine or eight or seven of them I’m sure. I’ve actually been at all ten of them. So, we are very pleased to have you here. When we began this conference ten years ago, it was in the manner of a kind of grand experiment. We had the idea that it was really important to establish more of a dialogue than we had between family members, service providers, evaluators, researchers, policy makers, and so we began by saying that that was the audience that we were
inviting to the conference, and we worked very hard to get researchers and evaluators to make presentations, and people from programs that had evaluations to make presentations that everybody who was here could understand. We also said that we gave preference to proposals that included family members and youth as a part of the presentation. In the early days, that was a very… it was a little awkward because there were not very many people doing research and evaluation who included family members as a part of the team. So sometimes in the early days, we would have presentations where a family member was along who would say “I don’t really know why I’m here. I can talk about my own situation, but I have not been part of the research.” That has really changed over the years. The extent to which family members and youth are involved from the beginning in all phases of evaluation has progressed tremendously, thanks in part to the Federation of Families, Families as Evaluators work, and the work of many people across the country. So the purpose of this conference is to promote dialogue so it is not just to hear the results of research, but it is also so that evaluators and researchers can hear from you all about things that you think ought to be studied, so it is a chance to really have an exchange of information. You are going to hear more from me again tomorrow, so I’m going to keep my comments very brief. I just want to say that I’m really pleased that you are here; we are excited we have.. we were worried actually that with the budget cuts nobody would have money to travel and we have more people than we have ever had before, so we are really pleased that you are all here.

Now it is my pleasure to introduce to you James Ward, who is the dean of the Graduate School of Social Work, that is the home of the Regional Research Institute, that is the home of the Research and Training Center, and many of us who are involved with the Research and Training Center are also on the faculty of the Graduate School of Social Work. Dean Ward has been a longtime supporter of the center. He makes it clear in many ways that he values our work, and we are pleased to have him here to give you a welcome.

Dean James Ward: As always, it is truly a pleasure and a privilege to come to you today to welcome you to Portland. I welcome you to Portland State University, the conference, the annual conference, the tenth annual conference of the Research and Training Center. Like Barbara, I think I have attended all ten of these as well, if I’m not mistaken, and I have always found it to be a great pleasure to be in your company, to see people coming from all around the United States to be with us here in Portland. Just to let you know, the attendance has exceeded 500 this year. That compared to 450 in the past three years, and I think that is a tremendous tribute to the leadership and the quality of the program that we have had here at this conference. I know that with budgetary constraints upon us, scarcity all around us, retrenchments in the air, it is truly a tribute to the program and certainly a tribute to you and your sponsoring organization to see you come from afar to this place to sit down and collaborate with colleagues and friends on issues pertaining to family support in children’s mental health services. We know that Portland certainly is an attraction, but we think that the major reason that you came here is because of the information the interaction, and the experiences that you will gain from one another as you go through the next 2-3 days in collaboration on critical matters. So, I want to commend you for making that tremendous sacrifice to come here to be with us, and we are always honored by your presence. As in the past, you have come from all over the United States, and I think that is truly impressive. In addition to that, we have attendees from other nations: American Samoa, Canada, Japan, and Kenya, to mention a few. Also, as usual, the program, this one building on family strengths, is diverse and quite substantive based upon my reading, and I hope that you will find it likewise as you delve into it. You will note that a special round table discussion on international perspectives on children’s mental health is included, a first of its kind in the conference’s history. I think that it will be of interest to you, and as I understand it, that session is going to be held on Thursday evening for those of you who are interested. Additionally, cultural diversity, cultural competency, both are highlighted not only as parts of the
presentations, but through formal designation of the National Indian Child Welfare Association and Latino presentation groupings or tracks. In the Latino Track session, also a first in the conference’s history, there will be simultaneous English-to-Spanish translations. I think that will be very important to some of you who speak languages other than English at this time, and we hope that you will find it to be beneficial to you. Again, the conference promises to be an exciting one, and I want to thank you very much for taking the time out of your schedule to come down to deal with issues pertaining to families and children, something that is very close to my heart and that I think is very important for our country. Welcome to Portland. Let us know if we can be of help to you.

While at the microphone, I want to also introduce the provost of Portland State University, the Chief Academic Officer. She is my boss. She is the one that oversees the academic side of the house, which includes the educational programs in research, Mary Kay Tetrault. It is truly my pleasure to present her to you at this time.

Mary Kay Tetrault: Thank you, Dean Ward. I, too, welcome you to Portland State University and to the city of Portland. We take great pride in the Research and Training Center, and particularly appreciate the strong leadership of Barbara. When I looked at your program today, it was fascinating to see the innovative things that you are doing, that the center is doing, that have been talked about in terms of children’s mental health, and bringing in family participation. This kind of approach to serving children and communities and families is one that is very consistent with the university, and if you get a chance to walk on our campus—and I strongly recommend you walk up the Park Blocks and come down Broadway, it’s just a few blocks—but what you are doing here is very consistent with the motto of the university, which is, “Let knowledge serve the city.” Community engagement, this idea of knowledge serving the city, is very much a part of our faculty’s value system. And, programs like this, with the kind of people who are here, remind me that we really need another motto on the other side of that sky bridge that is on Broadway, which says the community contributes, or the city contributes to knowledge in the university. And so that is part of why you are here today, is to contribute to the knowledge that we all share about children and families, or should share. Let me close by saying when I thought about this gathering this morning and see all of you here, I am reminded of the African proverb that it takes a village to raise a child, and I see here that it takes a village to ensure that a country such as this understands what children need. So, welcome to you in this village, and welcome to the city of Portland. Thank you.

Trina Osher: Well, for those of you who do not know who I am, my name is Trina Osher, and I am the Coordinator of Policy and Research for the National Federation of Families for Children’s Mental Health, and I have been given the privilege of welcoming you all this morning on behalf of the Federation and families all over this country. It is truly an honor to be here. I was just chatting with Barbara just a few minutes ago about how beautifully you all fill this lovely room, and how inspiring it is to look out and see this kind of partnership at this time.

I want to start by first thanking Barbara Friesen and the staff of the Research and Training Center for all of the great work that they do. I don’t know how many of you know how much other stuff they do besides this conference. They have really been at the forefront of promoting family participation in research, and in general family collaboration for a number of years. Especially we need to thank Barbara. She was one of the very first to promote family professional collaboration. For those of you who are interested in history beyond ten years ago (I told you to brush up, Barbara): In 1985, Barbara took the initiative of inviting families to participate in a meeting called Families as Allies, and it was the very first time, the very first time, that families of children with mental health needs and serious emotional disturbance were brought together for a peer-to-peer dialogue with professionals who are serving their children around this country, and it was a landmark in the history of the family movement, and we really need to thank you for your vision and your leadership, Barbara.

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This conference is the tenth on the pathway of expanding that collaboration. It provides such a fabulous opportunity to maintain that communication, to maintain those linkages and growth them and especially at a time when evidence-base is such a key feature of service delivery and the changes in the way we are thinking about what our children’s needs are, what is going to work with our kids, what kinds of services we want to build in our communities - this research base and the role that families play in creating it and using it for that kind of advocacy is very, very important, and it is just truly inspiring to see the extent to which that is evident in this room. So, you should all thank yourselves, congratulate yourselves for being part of this very, very important movement.

I want to make two brief announcements. One is to let you know about the next great conference, which is our federation’s annual conference, which will be in Washington, D.C. in November, the 20th-23rd, at the usual place, the Renaissance Hotel, and we hope that we will see many of you there. There is still an opportunity to respond to the call for papers for workshops. The call for papers is not due until next week, so if you are interested in doing that, we really urge that you do. The theme for this meeting is in fact an evidence-based theme. It is “Families Deserve the Best.” We really hope that promising practices that you are involved in, research that you have been conducting, that you will see this as a forum to present that.

The last thing I want to tell you about is the newest thing on the horizon. It is collaboration between families and researchers, and families and providers, and families and service folks, and families that are administrators, that is now expanding. It is expanding into what we are calling Shared Solutions. Many of you may know—I hope you do already; if not, this will be good news for you—that the Federation of Families for Children’s Mental Health and American Institutes for Research have been in a collaboration for four years on a project we call the Technical Assistance Partnership. The project is funded by the Center for Mental Health Services. The project provides training and technical assistance to the federally funded system of care communities. It is out of the work with those communities that Shared Solutions has developed. Its purpose is to move this collaboration from person-to-person to family groups and communities. The goal is to help communities find their own pathway to true collaboration with families and true inclusion of families in all aspects of the work they are doing on behalf of children with mental health needs. Shared Solutions will be piloted sometime in the late summer and early fall, and so you should be looking for opportunities to participate in this in the not-too-distant future. It is basically structured as a set of tools to help a community assess its needs, develop a plan, and just as we do in the System of Care, implement that plan and achieve their goals and evaluate the impact.

Have a great time at this conference. I’m sure it will be a rich learning experience and information exchange for everyone.

Barbara Friesen: Now it is my pleasure to introduce to you the plenary speaker, John VanDenBerg. He is with Vroon Vandenberg, which is a consulting firm that does training and research. I first met John, we figured out this morning, in 1984. John was one of the first CASSP directors from the state of Kansas, and our Research and Training Center had just been funded, and a very small group of us, there were probably not more than 20 people in the room, gathered in Washington, D.C. to try to figure out what the heck it was all about. What I remember about that meeting was that when we explained from the Research and Training Center that one of the things we were going to focus on was family issues, several people in the room said “Barbara, you know most of these children don’t have families.” So that was kind of the beginning of our (laughs), we’ve come a long way since then. John was one of the very first CASSP directors, as I said, and he actually became the CASSP director because Jane Adams, a family member from the state of Kansas, was involved in writing the first CASSP grant. From Kansas, John went to Alaska, where he was the first person to try to build the concept of wraparound into the system of care, to develop a system of care-based wraparound program.
This was called the Alaska Youth Initiative. There are a few of you here, because I can look out there and see you, I recognize you, who are old enough to know about the Alaska Youth Initiative, and that was very important, ground-breaking work to try to get a whole system to take on the challenge of kids with very difficult and challenging behaviors, and basically answer the questions, “How can these kids who now live out of the home live in their homes and communities?” “What kind of support do they need?” John comes to you with several perspectives. He is the grandson of a grandfather who spent many years in a state institution because of mental illness. He is the father of a child who has had problems over the years. He is involved in his work with many states and local communities, working on building systems that make sense for children and families. He is also a child psychologist, that is his academic background. He has spent many years as a consultant and teacher the last 15 years, and the company that he works with has projects in about 30 states. When I think of John, I think of many things, but I think what stands out the most for me is I had the privilege of sitting in an actual wraparound meeting in the state of Florida—I don’t know whether you remember that, John—but what I remember is that the group began and people were talking about kind of what the problems were and things that were going on, and John had such a wonderful way, he said “Well, what’s the good news?” And what John to me embodies, is a person who from the beginning of his work has been focused on strengths, strengths of children and strengths of families, and he can find them where sometimes you have to dig for awhile, and he always takes that perspective. It is my privilege to introduce him to you and I’m sure that we are going to learn much this morning from his presentation.

John VanDenBerg: All right! What a treat to be here and see 500 of you! When I got this invitation, and thanks, Barbara, for that lovely introduction, when I got the invitation I thought nah! nobody’s going to be there. You know, Barbara said, just what a treat to see everybody here, and I know many of you have come on your own ticket and struggled to get here, and probably had to convince your bosses and it is just a delight. You know, Barbara mentioned kind of what I do, when I really get asked what I do, I can’t come up with anything, but I’m sort of a system of care and wraparound hobo. You know, I don’t ride the rails, but I ride the airplanes, and two weeks ago I was in four time zones in one week, you know, and it’s my privilege as I get to see people like yourselves innovating. I get to see where one of you just wakes up one morning as a parent, or you wake up as the director of Children’s Services for a county or a managed care company, or whatever, and you just say “I just can’t take it anymore.” I look out across this room and see so many of you who have said that, and then have changed forever where you live, and I am honored to get to speak to you.

On a private basis, I have a special honor. How many of you are raising teenagers right now? How many of you are sort of looking forward to the day when they are all raised up? All right, all right. My wife and I have been dreaming about this moment for many years, and one of our goals was that when the last one graduated from high school and we kind of were there, that she would start to travel with me, and my wife Jean VanDenBerg [is here today]. I knew I’d get emotional when I introduced her, so, I said I wouldn’t do this, but again, as I always say, when I get emotional in front of a group, what better group to get emotional with than you.

Really, this emotion comes out of something real deep, which is I believe in this work we are doing. I believe that systems of care and wraparound are a good way to do business. I believe in it. It is right here, all right, and I do get emotional sometimes in front of people, particularly when I introduce my wife, but I really believe in this. I think that we know from the work that all of us in the room are doing that it should not be optional to have a collaborative plan. We should not have to as parents and as providers, we should not have to struggle to focus on strengths rather than deficits. As I told the group yesterday that I was with, when you start saying things like “back in ‘83,” you know you are getting old, right? The reality is that Jane Knitzer, who is really the pioneer of a lot of this

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work, you know, with *Unclaimed Children*, who really first brought to the national agenda the need for thinking differently about the way we serve kids and families. I heard Knitzer say many years ago this is a long-term agenda, this is a 20-year plus agenda, and that was 20 years ago. Yet, what bothers me, and I was sorry Barbara said I was real strength based, because I can’t be real strength based at this point in my time. What bothers me is that in North America right now, today, the dominant plan for children and families is non-collaborative. That bothers me. It pisses me off! The average parent does not have voice and choice, but in fact has a very narrow range of options in front of them, if any, and increasingly those options are going away, and that ticks me off.

I think we are in a situation where we at times have been our own worst enemies. As this field has evolved, and we have achieved successes, at times we’ve said, “Oh my gosh, we’ve got this licked, you know?” I don’t know if anybody’s ever been overweight in the room? Anybody else, you know? I know me, I’ve been overweight most of my life, I lose like 5 pounds and I think, “Well, that’s taken care of!” And it’s October, way to go! And the reality is that right now in our country, with what we’re facing in this economy, and what we’re facing since the average plan that is not collaborative, is not individualized, we really have to re-examine the way we do our work. And I say this with total appreciation for so many of you in the room, who’ve really given decades and decades to this. But I think we have to look at the way we do our work [emphasis added by John]. A long time ago I used to do carpentry work, and housepainting, and stuff, to try and get through school and make ends meet, and as carpenters we had a saying—it’s kind of like Zen carpentry, you have to think about this for a minute—and that saying was, “I’ve sawed off this board three times, and it’s still too short.” All right? And I think that sometimes that’s true. I was looking ahead in the agenda, and Robert Paulson, from Florida, where are you, Robert? There you are, right there. Robert had the most wonderful title for his presentation; it says, “And now for something completely the same: Issues and dilemmas in creating integrated services, etcetera.” And I just thought, boy, that’s it, you know. And I think we’re in that place right now.

The good news is, we’re not starting from scratch. We have models, we have examples, and just look through this conference manual, look at the presentations. It just blew me away to think, to see the innovation in the presentations that are listed here today. And I want to just highlight, during my time with you this morning, what personally I consider to be some of the most exciting things that are going on.

One of the issues is around how we deal with residential treatment and institutional care. This is not going to be a residential treatment or institution-bashing session; we need those services. I was talking with Pat Miles, my friend, a consultant, yesterday, and she said, “We really gotta watch this therapist-bashing stuff, because boy, we need those therapists.” We need those people, we need those services, alright? And I want to honor all of you who worked in residential treatment and institutional care. But we see some models beginning to emerge that I think are very timely. One of these issues is using residential as a resource, and not a placement. And by that, when I used to work in residential, we said to people, “Give us your kids, we’ll fix ‘em,” as a placement. Residential as a resource says, we are a resource when linked to the system of care that can provide some very exciting outcomes; we are a part of the whole picture. Let me give you an example of this. In Yuma, Arizona, a managed care company named Excel got the money and did everything to build a big residential facility, because they had literally dozens and dozens of kids out of region in placement all over Arizona and in other states. And they said it’s wrong, so they built a big residential facility, and then a wonderful man named Michael Kudoff, who is the CEO of that organization said, “You know, I was raised in an orphanage; are we just doing that again? Can we do something better?” And Michael said, “Let’s try something different.” What he’s really done is turn it into a brief stabilization resource, and he’s looking at 30-day placements, maybe 5 weeks, tops. Now the kids are being served in it; it’s very interesting, there are
virtually—what were you saying Beth [Dague], on the phone to me?—just a couple, three kids out of region now. Of course, that whole section of Arizona, as they’ve been putting this model in. And the model is very simple: it says that sometimes kids need a safe place to be. It might be part of transition, as you come out of long-term care back to the community; we know that if kids have been long-term in institutional care and they drop back into the community, right back into home and family without any transition, sometimes that’s pretty brutal. My friend Carl Schick here, from Missouri, taught me that in Alaska a long time ago as we tried to play with models of transition of kids that came back from institutional care. And what they’re doing in Yuma is basically the kids come in, and they don’t have a wraparound plan, they don’t have a team, they don’t have a strengths discovery. They haven’t had the links between some of the systems. And they have mobile staff who go out and work with those communities, they put together teams, they put together plans, and then they are a resource after the child goes back to their community. But I think—I was talking to Larry Green, the director of this program the other day—I think that what they have is that they’re getting tremendous pressure to keep kids forever, and they’re saying, “No, we’re not going to do it. We’re here for stabilization and we’re part of the system of care.” And to me, that’s exciting.

Other innovations that I want to mention, one is this notion of how we do the wraparound process. You’re going to hear a lot at this conference about fidelity, and the notion that you have to actually do the wraparound process for it to have outcomes. That’s a shock, right? It is sad to me to say that I have heard wraparound, in one state, referred to by a parent organization as “the big lie.” And it was called “the big lie” because the passion originally was we’ll be individualized, we’ll be creative, we’ll do all these wonderful things, and what it’s boiled down to is kids now get— they didn’t used to get one service— now they get eight. And there’s no family voice and choice, there’s no individualization, there’s no collaboration. I think one of things, if you all know a man named Len Bickman, from Vanderbilt, Len has done a series of studies looking at wraparound efforts in counties across the United States, and has basically concluded that although parents typically prefer them to the typical types of services, the reality is that there aren’t big differences in clinical outcomes, in changes in the very behaviors and issues that the children came into the system for. No real difference. Well, I really think that what Dr. Bickman is giving us is a very good lesson that unless you actually do wraparound, it probably won’t work. So wraparound fidelity is a great big issue right now in this country, and how we acquire those skills, I think, is a big deal. As Barbara said, I was privileged to help innovate wraparound in Alaska a long time ago, and I remember, we collected some outcome data on our first 18 kids that we de-institutionalized from out of state. And we had some pretty neat data, I put it on a slide and we presented it at a national conference in D.C. in 1987. And I got home from that conference to a stack of phone messages like that [holds hand up to indicate size of stack].

And people are saying, “You got those kinds of outcomes with those kids?” And “How’d you do it?” And I got my first call to come train. I was sitting with Lenore Behar—if you all know Lenore, my friend of all these years—she was sitting in Oregon, of all places, in a little retreat center with some people, and I was trying to explain wraparound to them. And I remember the blankest stares you could imagine; they’re like, “What? What are you talking about?” And we struggled with how to teach this to people who were trained in the opposite way. This simple process of let’s start with the family, and the people around them, right, and the people around them, and let’s ask a simple question: “What does this child and family need to have a better life?” And that’s wraparound; okay, it’s basic stuff. And we deliver that in a system of care context which says, in the context of the broader community, all the agencies, the community, the faith-based people, everybody working together to support this child and family as much as possible. Well, that’s wraparound.

But how do you teach these skills? Well, I gotta tell you, I spent a lot of years on the road training, and I finally had to—I offer myself as an example of doing...
things differently—after all these years on the road training, getting paid for it, taking your money!

I had to realize that, y’know, we were getting pretty bad wraparound in a lot of parts of the country. I had another state say, they call it “ha” wraparound. I said, “What? What do you mean, ha wraparound?” And they said, “half-assed wraparound.” It’s runaround, it’s not wraparound. And I think we have to change this, okay?

Our switch has been to move to a coaching model, to say they training is fine, it’s good for orientation, but coaching, hands-on mentoring, direct, with-family training, coaching is the way this field has to go. We have to realize that we’re not trained this way, and to really get fidelity, we have to do coaching. And so I think that’s an innovation that’s coming around the country very, very rapidly right now.

I want to go back to fidelity for a minute. There is a new national effort around wraparound fidelity. And Eric Bruns—Eric, could you just stand up and let people see who you are—Eric Bruns, from the University of Maryland, he and the University of Vermont, and folks here from Portland State University, building on really exciting work by Nancy Koroloff and Janet Walker and Kathryn Schutte. That said, basically, we went around and looked at a lot of wraparound, and we don’t see any nirvanas out there. We see people doing a lot of stuff, but as we heard yesterday from Janet, they were in a place where three-quarters of the families in wraparound didn’t even have plans! Y’know, didn’t even have plans. So there’s a real national momentum here, and let just ask those of you who are on this new national group on wraparound fidelity to co-present with us in some of the sessions. And this family is really special to me. Last year in a training in Oklahoma City, this mother stood up and shared with us her story, and when asked her goals, she said, “Well, I want to work with other families; I want to support other families; I want to do some national stuff, I want to contribute nationally.” When I the young man, her son, what is it you want, he said, “Well, I’m really interested in guns, and weapons and stuff.” And that made me nervous, y’know? And I sorta like, okay, and I just nodded, like child psychologists nod. You know that nod, you know, it’s like [demonstrates nod to audience laughter] “Okay.” And today, I want to introduce Grace McCombs and Lance Dawson. Today, Grace is a full time family advocate; she is here for her first national training, way to go. This young man just got accepted into the Army. He graduated, what, last Saturday, Lance? From Thunderbird Youth Academy; he actually got a letter of commendation from the governor of Oklahoma. So we really see what fidelity can do. We really see in Grace and Lance what can happen, the vision of what can happen. You often hear me in trainings say, “Use the 1-10 scale of complexity. Families that are 7’s, and 8’s, and 9’s and 10’s really need the most individualized, the most creative, the most strengths-based, the most leadership and no money and local leadership, Oklahoma said “We don’t like what we’re doing to kids and families; we can do better.” And just started a five county system of care project with no money, just a little bit of re-ordered federal block grant money. They’ve since gotten a SAMHSA grant, and I hope the money doesn’t ruin ‘em, y’know. But they were doing it without any money. They really looked at fidelity and said, “What is that families really need?” They need support; they need other family members who are there for them, both as volunteers and hired; they need attention to that individualization and cultural competency and everything else. And they really have tried to do this.

Beth Dague and I, when we were invited to speak at this conference, really thought we needed to bring a family with us who really exemplified high-fidelity wraparound to co-present with us in some of the sessions. And this family is really special to me. Last year in a training in Oklahoma City, this mother stood up and shared with us her story, and when asked her goals, she said, “Well, I want to work with other families; I want to support other families; I want to do some national stuff, I want to contribute nationally.” When I the young man, her son, what is it you want, he said, “Well, I’m really interested in guns, and weapons and stuff.” And that made me nervous, y’know? And I sorta like, okay, and I just nodded, like child psychologists nod. You know that nod, you know, it’s like [demonstrates nod to audience laughter] “Okay.” And I nodded, and I kinda went “Okay.” And today, I want to introduce Grace McCombs and Lance Dawson. Today, Grace is a full time family advocate; she is here for her first national training, way to go. This young man just got accepted into the Army. He graduated, what, last Saturday, Lance? From Thunderbird Youth Academy; he actually got a letter of commendation from the governor of Oklahoma. So we really see what fidelity can do. We really see in Grace and Lance what can happen, the vision of what can happen. You often hear me in trainings say, “Use the 1-10 scale of complexity. Families that are 7’s, and 8’s, and 9’s and 10’s really need the most individualized, the most creative, the most strengths-based, the most
collaborative services.” And I would say—and I have permission from Grace and Lance to say this—this family had real complexity. When I asked Grace the other day, “What really made the difference for you, what turned the corner?” She said, “It was support. I was support—I had the support I needed from other family members, from advocates, from people, from therapists, from professionals, it was support.” So, I think that’s an answer for us as we go forward with this.

I want to switch gears; I’m sort of rapidly going through what I consider to be some of the major innovations in system of care and wraparound work. The other area is this issue of how we partner with our natural resources out in the community. I want to do a quick exercise I always do in every keynote that I give nationally. So you’ll need a sheet of paper for this, if you would please, or you can do this in your head, if you’re that type of learner. Okay? I gotta write it down or it didn’t happen, whichever learning style you are. Here’s the exercise: I would like you to think of the biggest crisis you or your family has ever had. You don’t have to share this; just think it, or write down a word, so you know what it is. Everybody got it? Usually it’s right to mind. Now, if you’ve never had one, and can’t think of one, bless you, it’s coming! It’s part of life, right? It’s like, on the highway over here, coming. But if you’ve had so many you can’t think of a top one, y’know, bless you as well. So, think of the biggest crisis you’ve ever had. Now what I’d like you to do is think of how you got through that crisis, if you have. There may be many reasons; try and think of one major reason you got through that crisis. And just think of it, or write down a word so you know what it is. Or, if you’re in the middle of it right now, just try and guess what would be the major reason you would get through that crisis. Okay—by show of hands, how many of you would say you depended on paid-for services, delivered by trained professionals like myself, to get you through that crisis? Raise your hand. I would. Anybody else? And if you’ll keep your hands up as we go through this—how many would say your family got you through it? How about your friends? How about your faith? Alright. Well, I just got ninety percent of this room with just those three things alone: family, faith and friends.

This is humbling. This does not denigrate services, I mean, I spent 13 years in graduate school, as my dear wife knows; my motto in graduate school was “I shall finish no requirement before its time,” I tell ya, I gotta say, I’m proud to be a child psychologist, I’m proud of this; we need our therapists, we need our professionals, okay? But most of you didn’t raise your hands to that, you raised your hands to family, faith and friends. This is humbling, because what we have to self-examine as professionals is how many of us in graduate school or college were specifically trained to write treatment plans that are primarily family, faith and friends? We weren’t trained that way, folks, and yet I believe that’s the single most important correlate to outcomes, is this meshing of family, faith and friends into this.

So one of the things that we’re really focusing on as an organization, the organization that Jim Rast and work in, and Beth Dague and a lot of other people, is we’re really looking at where those natural resources are the most. And I don’t care if you’re religious, non-religious, that’s up to you; your faith-based communities have got the bulk of your natural resources out there in the community. And yet, how many of you in the room have been to graduate school? Can I just see a show of hands? Oooh, thank you. Who’s still paying off their student loans? Oooh, that’s scary, alright. But what I would ask you is, how many of you had a class called “How to partner with your faith-based community”? Anybody? Alright? We’ve got one hand over here, I think, but I think actually they were waving at somebody. The reality is, we don’t know how to do this, and when we try, we typically do the wrong thing. We do it in a way that doesn’t partner with people, but alienates instead. I was just in a state that said, “Oh, we gotta get those churches and all their resources and use ‘em in child welfare!” And I said, “Excuse me! Whoa, you got this
wrong; you got to ask what you can do for them. If you don’t start there, you’re in big trouble.”

So, we have really begun to try and think our way through this. The first thing we did, was of course—I’ve got a Ph.D. in Child Psychology—we need to find somebody who knows their way around the faith-based community. So we recruited, and hired, and have on board a wonderful man named Pastor Norman Moon. Norman, just stand up here, I’m going to embarrass you, he’s gonna kill me for this! [Audience laughter and applause as Norman stands] And for the last year or more we’ve been putting together initiatives in three cities—Hartford, Connecticut, Colorado Springs and Denver—and what we’re looking for, folks, is a little different version of wraparound than what we’ve seen over the last 15 years in formal services, where systems drive, or staff and manage wraparound; families should always drive wraparound, wherever it is. We think a parallel development has to be that faith-based communities actually staff and manage wraparound, and that this is a good thing to do. And we have been playing with this, and we are continuing to do so, and are very excited about it. This is nothing new; the Methodists, the Catholics, the Jewish organizations, for many years have run residential treatment centers; why can’t they do wraparound? Why can’t they move in that direction? And we’re excited about this, and moving forward with this now, and I think this has tremendous potential for our nation, as many states are doing this as well.

I’m really trying to force myself to leave time for dialogue with everybody, but I want to talk about several other issues with you. One is this issue of our workforce. What really matters is kids and families, but to get there we have to think differently about our workforce, the people that actually are out there delivering services to kids and families. Traditionally in behavioral health, in mental health, what we’ve done is we’ve had people like myself as the primary workforce, advanced degree professionals. We’ve had a small smattering of case management types, who basically were there, but the primary gig was the advanced degree professionals. What we see now, though, in many parts of the country, is a real examination of that. If all you have is advanced degree professionals and you ask a family, “What do you need to have a better life?” You are stuck with delivering a service, one service to them, which is typically therapy or other types of services. Again, which we need; don’t get me wrong. But the other carpenter expression I remember from those days is, “If all you have is a hammer, everything looks like a nail,” right?

We saw this in the state of Maine, in the mid-Nineties. Do we have any Maine people here? Any Maine people? Right, right, glad you’re here! We saw this is the state of Maine, as they were sued in the Reisinger lawsuit, way back when, right? And system of care examination at that time showed the behavioral health workforce was primarily advanced degree professionals, so one of the aspects of the lawsuit said, “We’ve got kids sitting in residential treatment for long periods of time, because there’s no other options.” The lawsuit was settled, and they began to try and think through how to change that. Although Maine is not the nirvana of human services—you’re doing a good job, but not everything, there is no nirvana right now, we need one—what they’ve done is really examine their workforce. They began to put out, the state level put out contracts and RFPs [Requests for Proposals; grant advertisements] that said, “Let’s hire a whole bunch of other people, in addition to the advanced degree professionals. The workforce now is a blend of advanced degree professionals, case manager types, and then direct support staff. The direct support staff, who constitute about a third of the workforce now, are people who literally do hands-on, direct support, the same job that Grace has right now, with children and families, under the umbrella of a team and the umbrella of a plan. And I think this workforce issue is really key.

Now, let me ask you again, just by show of hands how many of you feel, at this point in your county where you live, wherever you live (and we have, I think, every state represented here, or very close to it), how many of you feel like you have access to a large number—in other words, not just a token “wraparound boutique” as Pat Miles calls it, where there’s like one or two neat wraparound programs and
everybody else gets nothin’—but how many of you feel like access to a range of direct support staff for the children and families in your county? Just raise your hand. We see some hands going up here; I see Washington pioneers here, and other people who really spent a lot of years doing this, right? And we saw Tulsa hands go up, and a few others, and yet this is change, alright? It is a re-definition of our workforce that I think has to happen, or system of care and wraparound is not gonna work. I think this workforce issue is a next step for us.

Other aspects of the workforce that we know, I was in the state of Maine, in one of those upper counties, way up there on top, you know. And I saw a probation officer who had an office in a school. I interviewed him as part of the system of care analysis that Beth Dague and I were doing up there. I said, “Well, why are you in a school?” And he said, “Well, where else should I be?” I said, “How’s it going?” And he said, “Well, over the last few years the teachers are coming down the hall, and talk to me, and the kids start coming in and talking to me, and all of a sudden we got something going on here, alright? We’ve seen a reduction in recidivism, we’ve seen kids actually get support around juvenile justice issues that we haven’t before, and we’re starting to see a change.” And it’s this co-location of staff that really begins to change the way we see our jobs very, very quickly. How many of you would say, in your communities right now, you actually have co-located staff, who are in each other’s systems? Alright; see there? I bet five years ago I would have gotten only my, Marge [Critchlow, of Tacoma, Washington] and the other Washington people up here in the front., right, y’know. And this is cool, this is coming, you need to insist on this.

Why are we at this point? Why are we at this point where I have to come here and say, “The dominant plan in North America is non-collaborative.” I really mean it, it ticks me off. After all these decades, it ticks me off. Why is this so? I want to give you a couple reasons that I think it’s so; one is, as I mentioned, I call it a syndrome, it’s PMBS—it’s Premature Backslapping, y’know. It’s like, “Whoa, we did it! Way to go!” And I think it is tough work, and it’s so human, it’s so human to declare over, and fixed, and everything’s wonderful. Tulsa, that I admire so much right now, where Grace and Lance are from, is serving 85 kids in wraparound. I told ‘em, hey, be proud of that, that’s a big facility in today’s terms, with a lot of families with very high fidelity wraparound. Doing a wonderful job. But we sat Friday in Tulsa with their community steering committee, and said, “Okay, how do we get representation from the other systems that aren’t here? How do we get supervisors on board? How do we deal with capacity? Capacity—my friend Mary Jo Meyers from Wraparound Milwaukee over here, you know, says that’s it. We’ve got thousands and thousands of kids, and if we’re doing wraparound boutique stuff, little wraparound program, where a limited number of families get this, if it is not a process that is embedded in every system, we have failed. But it is human nature to say, “Oh, we’ve got it licked.”

The other one I would call is the—this is rude—but it’s the PP syndrome. Psychologists get to make up stuff like this, so I’m doing it. This is called the personality problems syndrome. Where we start to do our work, and then we start to fight? Years ago, Barbara Huff, who’s the executive director of the Federation of Families, was there at the same time I was national chairperson for NAMI-CAN, the National Alliance for the Mentally Ill—Child and Adolescent Network. Because of my grandfather’s mental illness and other things, I really have a big chunk of me that I devote to that area. And we—this was years ago, over a decade ago—we tried to get our organizations to work together. And there was just continuous fighting and infighting on a national and a local level, and Barbara and I finally had to—and we’re buddies, I admire this woman more than anybody—we finally just had to say, “This ain’t workin.” And we had barriers we could not overcome. That is wrong. We get into personality problems, where somebody offended somebody, and now they won’t work with this person, and won’t work with that person, whatever. We have no time for that, folks. And yet it is coming into our fields. I sound alarmist here; this issue is in our field today, of system of care and wraparound and other things, and we need to get rid
of it. Yesterday we really saw the hope for a federal partnership with all the consultants and entrepreneurs and all the people around the country that are doing this work; we need one concerted effort.

In Colorado right now, we have what I call a conspiracy. I was thinking of Hillary's use of the term fidelity, it's a little different use of the term fidelity than what we're talking about, but I think we have a right-wing conspiracy going. Thank you, Hillary. I think we do. Let me tell you what's happening in Colorado right now, where I live. We have three new stadiums, we have all the wealth of Colorado, which is a very wealthy state. The other day a policy was proposed and passed, that will allow all community mental health centers not to do what they consider to be, anything that's not evidence-based practice. Family therapy—they had advocates in every large mental health center in the state, family advocates. Home-based work, alright? All wiped out overnight, at the option of each mental health center. We had our first mental health center last week, in LaHunda say, “Okay, we don’t have to do that stuff anymore, it’s gone, psst, it’s over.” I had a family member who was one of these paid advocates in these mental health centers, sitting in my office last week, crying, saying, “I just came to work and I got fired! What can we do about it?” And I think what we see is under the umbrella of EBP, evidence-based practice, we see our field being hurt. And I think we have got to be aware of this. I think we need to do several things. One is, we need to get a lot better at what we do. Fidelity, an Eric Bruns type of fidelity, fidelity to wraparound, and are we really individualized, are we really there. These issues are huge.

One of the areas that I look at is cultural competency. It's a term that gets thrown around a lot, but I look at a lot of wraparound plans, a lot of counties hire our organization to come in and review plans. And I’ve gotta tell you, most plans are culture neutral. There's no evidence of the culture of this family, and culture is a very complex issue. It involves lots of things—poverty, racism. I saw an incredible show the other night on television, a Bill Moyers show that talked about what are the primary variables in poverty in North America. Of course, education is number two, you know what number one is? It just blew me away. Number one indication, when you control for all obvious variables, of poverty in North America is multi-generational home ownership in communities that are growing. Now, if you're a grandparent owning property in a growing community, in other words, bought the house for ten grand and sold it later for two hundred grand, or whatever; or if your parent owns property, you are much more likely not to be poor today. Okay?

Now, when we look at the mix of racism into that issue, until 1967 federal housing policy pushed people of color away from neighborhoods that were growing. You could buy homes, but not in the growing neighborhoods. Literally word-for-word, federal housing policy. 1967, that's just a few years ago. So, this issue of racism really comes square into wraparound. When you ask a family, “What do you need to have a better life?” and one of the issues is poverty, you don't just say, “Well, shoot, just get a job!” There are issues going on here that are very complex.

We also look at family culture, who this family is, and how they operate. How do they make decisions? How does your family make decisions? Think right now. How do you make major life decisions? Now, with my wife here for the first time, when I give this example, I have to be very careful about this issue. But I like to think we share decision making. But right now, in Peonia, Colorado, my dad's sitting in his Lazy-Boy recliner. He's got his cup of coffee on the little table beside his recliner. My mom's sitting across the room from him. She's watching him, just eyeballin' him. I mean, they're doing this right now, I guarantee it, as we speak. When he raises his cup half an inch, like this, she jumps up and gets him more coffee. Now, in my family that I grew up in, the culture that I grew up in, the culture was dad makes the decisions. Now, if I tried that trick with Jeanine on the coffee, I'd be wearing that coffee, folks. No, don't clap, don't clap! The issue is, how does the family that comes into wraparound, that we're privileged to serve as a community, what is their family culture, around how they make decisions, how they see the
world, rituals, traditions, all these aspects of culture, racial issues included? How is their family culture represented in that wraparound plan? And I think if there’s one technical advance we have in the field, it is that if that plan is culture neutral, it’s not gonna work!

And yet, how many of you in this room were trained specifically to assess and discover culture? We get strengths, we assessing strengths; we don’t get assessing culture. And yet I think it is an incredibly important thing, that is part of what we do. The reason we’re getting hammered on evidence-based practice issues is because we have not done our job with fidelity, and we need to do it, we need to do it quick. I mean that very strongly.

Another reason of why we’re in this situation with system of care, where after 20 years we haven’t made it, and I call it “Pogo’s Rule.” Ever hear of Pogo’s Rule? “We’ve met the enemy and they are us.” Sometimes we don’t take good enough care of ourselves. One of my mentors in life, one of my heroes, is a woman named Anne Turnbull, working in the developmental disabilities field. And Anne is a parent, and a researcher, and a professor, and she said, “Sometimes you gotta step back and take care of yourself. You gotta take a break, and hand it off to other people.” And we’re all such knee-jerk do-gooders, we forget to do that. And I think we’ve gotta do that sometimes. And we need to recognize, we need to hand this off to other people.

But I just want to stress that I’m so pleased with all the innovations, in all the areas that I talked about. But if there ever was a time for recommitting to the notion of a system of care, to recommitting to strengthening families, and all the work that is done here at this university and at others around the country, if there ever was a time to recommit, it’s right now, folks. This is it. We won’t have another 20 years, folks. We can’t take another 20 years—it’s time right now.

Little something about the VanDenBerg family culture is we’ve never really had a good television, and we never had cable. Recently, we got a television—a decent one, you could really see the picture—and we got cable t.v.. My daughter Maggie, said to me, you know, she comes home and there’s a t.v. and cable and everything, and she said, very seriously, “Dad, are you having a mid-life crisis?” And I said, “Honey, when I have my mid-life crisis it’s gonna be a lot more than a television and cable t.v.!” But, I got to start watching t.v. I just haven’t seen before, and one of ‘em was cooking shows. And I saw this—I just love the cooking shows—I saw this weird little guy saying, “Kick it up a notch!” You know who I’m talking about? And I think we need to kick it up a notch, folks, I really do.

The last bit of preaching before I open it up for questions. Don’t accept non-collaborative plans. Don’t accept the plain old, plain old. Insist on a common vision in your community about what the heck they’re going to do with kids and families. Insist on a common vision: Does your community have a common vision about kids and families? Don’t accept the phrase, which is a killer of innovation, don’t accept the phrase “We already do this.” Because what that phrase covers is fear of change. People say, “Well, I already do all of this.” I say, “Great! You have flex funds?” “No.” “Family at the meetings where you do the plan?” “No, but we’re individualized.” Sorry, I don’t accept that. Walk out, walk out of policy meetings that don’t included parents and youth voice, and then walk right back in. Walk right back in and understand the strengths of the organization you’re working with, partner with them, and look for ways that you can educate and move forward with them. Alright? We can’t walk out and stay walked out; you walk out and get their attention, but you come right back. Get involved with your advocacy organizations, we need them now more than we ever have: Mental Health Association, NAMI [National Alliance for the Mentally Ill], Federation of Families. When we moved back to Colorado two years ago, I said, “This is it! After all these years of moving around, we’re where we want to stay. And I immediately contacted the Federation of Families and joined the board in Colorado, as did our daughter Maggie, as the youth representative. And I gotta say, it’s rough work, because we’re sometimes our own worst enemy, and advocacy organization fighting advocacy organization, but in Colorado, because we don’t have one single unified

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voice across all the advocacy organizations, we’re getting creamed. We’re getting creamed in the legislature. I just got an e-mail last night that has set a meeting of all the advocacy organizations in Colorado to get together and get our act together. I had to cancel a training to go to it, but I’m going to be there. I think, even if you’re an executive director, if you’re the mayor, whatever, you need to get out and get involved with these organizations, ‘cause we depend on them. Trina Osher, in her comments when we started off, I mean, we depend on Trina; we depend on everybody working in the Federation right now. This is serious business, so settle the disputes, get past it, get over it, move on with life. We can do this: we can work smarter and harder, and we’ve got to. Thank you very much.

What I would like to do, since we have twelve minutes, by my watch—it’s 10:47, I have ’til 11:00, and I’ve got 10:48 on this clock, so I have reliability between watches, okay? So we have 12 minutes for comments and questions; I tried to leave 15, but I blew it. What I would like to do, we do have mics in the room, you can spot them, in the middle, right there, or if you have an incredibly loud voice you don’t need to use it. But do we have comments and observations—brief speeches not allowed—who would like to give a comment?

**Audience Member:** Good morning. I’m a refugee from Colorado. I’d just like to share anecdotally, my experiences in trying to establish wraparound as a juvenile justice director in Grand Junction. And it isn’t just getting the agencies to talk to each other, and it isn’t about collocation; it’s within the organization itself, where the mindset of your organization is at. In other words, if you’re coming to work and you’re saying, “Reliability for us is that we’ve been doing it this way all along and it works.” And then what you find is, nobody’s calling your agency, no one’s calling on you. And what happened for me was, a wonderful process that I began to see—because I’ve worked with NAMI as well, and I’ve worked in Nevada on things of this nature—but how the people that are just the ordinary line people step out of all the fancy social work discourse and start forming relationships. And that was the key. So I can sit there and say, “Well, we want to do X, Y and Z, and we have to satisfy [inaudible].” it was the people, the parents and the children, and encouraging those relationships, that undermined all of that. I don’t know if you know western Colorado well enough, but 60,000 people in Colorado lost mental health services because of the way they designed their system. And so naturally all of the problems that go with that came along with that. My anecdote? I was walking out of a substance abuse graduation for teenagers, and two kids came out at the end of it and said, “Wow, man, I’m really glad that’s over!” And the other one says, “Yeah, let’s go get buzzed!” I followed them into the parking lot, they didn’t know who I was, and I said, “Yo, we gotta talk!”

So part of wraparound is also, I think, having the willingness to step out—to step out of the game, step out of the role, and to do those relationships. And that’s how I ended up in Oregon, I’m now here. And it was because of a very small community who had relied on traditional structures, but had no real knowledge about mental health or how to do this, but wants to do it in a different way, even at the local level. So, I applaud you.

**John VanDenBerg:** Thank you for those comments.

**Patty King:** Hi, my name is Patty King, and I work for A Common Voice for Pierce County [Washington] Parents, and several other positions doing parent advocacy in our county. And you have re-affirmed for me that we live in a very fortunate county where we live, we also live in a very fortunate state. We are doing, and we will continue to do, wraparound services where we live, and we are trying to branch out and get funding for other organizations across our state. Recently the health department has received a grant to get kids back in to school, and in Washington state we have the Becca bill that requires kids to attend school. A component of that grant was parent empowerment, that they needed to provide parent empowerment, and they contracted with A Common Voice to do so. They needed to do some evaluations on their project, and I was a stickler about separating the roles, because I wanted parent advocacy to be
looked at separately on its own. We were recently told at the advisory committee that the parent advocacy piece has turned out to be the most effective piece of the project. We are in our third year, and they had no idea what we did when we first started it, and they are proud to have us there. And you’re just affirming everything I’m teaching, all the people that I supervise, that we need to do, and I thank you for that.

**John VanDenBerg:** Yeah, thank you. And I just want to make one comment, which is, again, we see the value of this support function. And because we haven’t had the workforce to deliver that direct support, we’ve been hurting. But once we get it, we see changes in how families deal with the challenges that they have in their homes, and I think it’s very exciting to see what you folks are doing. So thank you for that. Go ahead.

**Audience Member:** I’m from Denton, Texas, and learning about all of this with the Federation of Families. I’m a mom first, and have two children with mental illness: one who ended up on the streets, and one who is still eleven and doing great, because we’ve learned a lot. I also went to school and got several degrees, and did that because I was trying to figure out what happened to the first kid, and what happened to our family, and what do we need to do different. And a concern I have, very early you were talking about direct care staff, and the need to not rely on professional staff. On the other hand, I live in Texas, which is 52nd in the country in funding, and what we see in Texas, often, is a real dumbing-down, with a lot of direct care staff that has no training, has no understanding, they’re people who basically have no other options, and so therefore we put them with our children, as far as employment. And so I think it’s also important that we look at that expansion of options needs to include the community, it needs to include parent liaisons, but again, going back to your idea of fidelity, and that we need to also have the training. With my older son, I didn’t know; I did the best that I knew how to do, but I didn’t have the skills and the tools that I needed. And we as parents need to have those skills, and we need to really focus on, it’s not just cheap. Because if we ask for just cheap, we’re gonna get Brenda Sue, who can’t get a job at the corner store, working with our kids, and she’s not gonna cut it.

**John VanDenBerg:** You raise some really important cautions, and I really have seen this around the country. That’s why I referenced the “right-wing conspiracy,” you know, there is an element that says, “Let’s just have the churches do all the services and let’s take all that money and do other things, and build roads.” But I really agree; it is a balance. I honor professionals, advanced degree folks, etcetera, who spent their lives doing this work. Almost every one of them could make more money as a plumber, alright? It is the blend, but it’s having both, that I think is the key. And having training, having support. What I love about what Tulsa’s doing right now, is I really see that these family members and others that are in these direct support roles, they really have support and training. They’re not left hung out to dry, and that’s what we need. But your caution is so well-taken, absolutely. So thank you for that.

Okay. Go ahead, one last point. Go ahead.

**Jeanette Andonian:** One last point; I want to go back to the issue—my name is Jeanette Andonian, I actually live in Portland, Maine, although I’m fairly new to Maine, I teach there in the School of Social Work—but I came from Louisiana, where I had done work with the Office of Mental Health there in children’s mental health evaluation. But I’m thinking about this whole idea about relationship, that somebody had talked about before, and how professionals are acculturated to professional life, to be hierarchical, to be experts, and how it really takes sort of an un-doing of that. And there need to be models for that, in academic settings, that train practitioners to go out there in the world. People who are more authentic, people who aren’t so overly boundaried that they become rigid in their approaches to working with people. And to think of empowerment, people think of empowerment not as something that you give to somebody else, but something that you just don’t get in the way of, that you allow, rather than something that you offer to another person. So I think that we...
have these kind of old, worn-out perspectives on what it means to be a professional, and I think there need to be more models for kind of a different paradigm of a professional out there.

John VanDenBerg: It was really interesting—can I comment on Maine, one last point?—back in '96, or whenever it was, we did the first system of care assessment, many of the advanced degree professionals, as this lawsuit had just happened and the changes were about to move forward, they basically felt it was the end of the world. It's gone, it's over.

And what's really interesting—and we code our informants, and all the researchy things we do to [inaudible]—it's really interesting when we go back and find those same professionals, fast forward what, five years, Beth [Dague]? Five years. They see the world very differently. And over and over again, in Maine, although there's still lots of problems in Maine, don't get me wrong, those same professionals were saying, “We couldn't possibly do our jobs without these other people.” And I think it is an enrichment of our professional roles. So, thank you for that.

And again, thank you for all your comments.
Friday Plenary: Fidelity and Effectiveness in ISP/Wraparound

Barbara Friesen: It is my pleasure to introduce to you Jill Erickson, who is a project officer from the Child, Adolescent, and Family Branch, the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. Can you guess that she is a fed? It is a particular pleasure to welcome Jill because Jill has the distinction, I believe, of being a graduate of our own social work program here at the Graduate School of Social Work at Portland State. So we are thrilled to have her as a fed and we are very pleased to have her here this morning to give you a welcome from the Center for Mental Health Services.

Jill Erickson: Good morning. I can’t say what a thrill it is for me to be asked to do this, representing one of the, I believe, two federal agencies giving some support to this conference. Twenty years ago I was studying the theory of change in Barbara’s program at the School of Social Work here, in the Planning, Organization and Management track, and now I have the privilege of working for an agency that gives money away to communities to change the system of care for children and families who are dealing with serious emotional difficulties. Those grants—actually we have an announcement out right now with due dates of August 5 and October 15—they run from $1,000,000 to $2,000,000 a year for six years. The catch is that the money has to be matched. Also in the theme of the conference, we are facing the federal charge to tighten up in terms of evidence-based practices. I guess the only other thing is responding to a lot of the financial constraints that a lot of the state and other agencies are facing right now, we are trying to do the technical assistance for potential
applicants for the grants by web cast rather than calling people in to conferences and spending all that money to do that. I have to slip away this morning to be part of one of those web casts. We went over and observed the web cast yesterday. We didn’t really have enough participants—only about 15. So I guess we will just kind of reevaluate that and see if it is meeting the needs. Thank you for asking me to do this.

Barbara Friesen: Now it my pleasure to introduce today’s panel. Today’s panel focuses on research pertaining to the wraparound process, individualized and tailored care. Some people call it individualized service planning. I’m going to introduce the panelists in order and then they will just stand up and do their thing in order. First Janet Walker, our own Janet Walker from the Research and Training Center, who is an Associate Director. She wears many hats and among other things, if you have looked at our web page, she has helped us take giant leaps in the last few years in terms of our ability to communicate and disseminate information on our website. Janet has a background in economics and psychology and organizational development. She is very interested in issues pertaining to children and families. She is very interested in educational reform, and her current work with the Center has been focused on the individualized service planning process. What really happens in those wraparound meetings. She has had some very rigorous and very interesting work. Julie Becker from San Diego is a parent and a Ph.D. I think that is really important. We need lots of people who bring the family perspective to the world of academia and the world of research. Julie is a professor at National University in Special Education and Psychology. She says her main forte is designing programs that are facilitated by parents and those include respite, after-school, fine arts and wraparound. The Tapestry Program that she is going to talk about today and also will be doing a workshop about is the main feature of her focus on the panel. Eric Bruns, I always think of Eric as in Vermont, but he is not in Vermont anymore. Eric worked for some years with John Burchard at the University of Vermont and Eric is now at the University of Maryland in the School of Medicine, Department of Child and Adolescent Psychiatry. He has been working on wraparound issues for ten years. His focus now recently I think has accelerated in terms of working to develop fidelity measures. As Janet is looking at what really happens, the fidelity measures are to make sure that what is supposed to be happening, happens. He also does research in the area of youth development and prevention. We are going to hear first from Janet Walker.

Janet Walker: Thank you, Barbara. Good morning.

Buenos días. Antes de empezar me gustaría decir a todos bienvenidos a Portland y bienvenidos a la conferencia también a este discurso. Espero que salgan con información útil que le servirá bien. [Good day. Before we begin, I would like to say to everyone welcome to Portland and welcome to the conference, also to this lecture. I hope that you leave with useful information that serves you well].

I know it is hard to get going in the morning. I had a hard time myself this morning. I was standing about an hour and a half ago in front of the mirror in the bathroom with a disgusted look in my face and a comb in hand. My young son, Owen, came up and there is a little step stool beside us that he uses to reach the sink so he can wash his hands. He got up beside me and he goes, “Mommy, you look totally beautiful.” I thought this is great because I haven’t even started combing my hair yet. So this must be the turnaround that I need in my day. That was a good thing and we started to smile. Actually we acted goofy for a little while and we ended up doing a little dance, and I thought everybody needs a cheerleader in life. In fact, when I got here, my parents are here, my dad gave me a big hug.

So I think one of the things we are talking about today is how everybody needs that kind of support and what a big difference it makes in lives, and how wraparound, as John was talking yesterday, is one of these vehicles for helping to augment that part of our lives in times when we need it.
I also thought that if I could just sort of package Owen and bring him along, that would help give everybody a little cheer this morning. I couldn’t do that, but I brought a little picture of him for everyone to see. Just in case there are any animal rights activists in the room, you can know that the turtle survived and he is thriving today.

What I am going to talk about today is wraparound, what we were talking about yesterday. We call it collaborative individualized service and support planning. We hope that is a descriptive term. I am going to be presenting on some research that I have been working on with my colleagues here as well as some parents who have been collaborating with our research in various aspects. I am only going to be able to talk about a small portion of what we have done, because we have been very busy. So the challenge is that I am going to sort of review it, just what John was saying yesterday, it is a very appealing idea. We call it ISP, wraparound. You have a child with emotional and behavioral difficulty. You have a family and other caregivers and they are struggling. They are struggling to keep the family safe, to maintain the quality of life, and you want to get together the people who have a stake in seeing the family succeed. You want them to come up with a plan. They are going to do whatever it takes, and they are going to help the family meet its goals in a way that is culturally competent, strengths based and so on.

It is an appealing idea, and as John was pointing out yesterday, it is not necessarily very easy to do. It does represent a new way of doing business. It asks people to be collaborative in ways that they haven’t been before. Not only does it take listening to families in new ways, but it also takes the other members of the team finding common ground that maybe hasn’t existed before. There are people from different agencies, from different backgrounds, with different goals and priorities. It turns out that achieving collaboration is quite difficult. There is also the difficulty of knowing how exactly you act in a culturally competent way and how do you know when you are doing that. What exactly is strengths-based practice? There is not really a lot of good guidance in these areas. Then there is the question, too, of creating a plan that is truly individualized, unique, and really responds to the needs of the child and family. If you look sort of one step beyond that, you look at the level of organization. There are a lot of challenges in getting organizations to collaborate as well. They need to work together in new ways. They need to train staff to fill new roles on teams. They need to pay for things and worry about who is going to fund certain aspects of the plan. Finally, at the system level, there are a lot of challenges around creating policies and funding mechanisms that are going to allow teams the flexibility and organizations the flexibility to act in these new ways.

Then we will find that what has happened is that actually, I think John said yesterday there is no nirvana, but I think there are some Cadillac programs out there, and some representatives of those programs have been talking here at our conference. We found out that there are some programs that really do the
whole package pretty well. But you also find a lot of places that are doing some things really well. There is a lot of accumulated knowledge and experience that has grown over the last decade or two, but the thing is that practice has evolved without any clear definition of how you know exactly when you are doing well enough and how you know if you are not doing well enough, and then what you are going to do to remedy the situation. Another difficulty is that because there is such a diversity of practice, it is difficult to compare or to know, again, across sites how to have standards about what is good enough.

Our goal in this project, or one of our goals, and what I am going to talk about today is to describe successful implementation of ISP, wraparound, in a way that is generic enough to accommodate the variety of successful approaches, but that is also rigid enough that you can really have some guidance in telling you what is a good enough implementation and what is something that still needs some work. What we have tried to is to synthesize information that includes relying heavily on this accumulated expertise that exists at sites around the country, to pull together existing theory and research evidence from across a wide variety of fields, and then to contribute some new theory and research of our own, and to pull that together in order to develop some useful information and tools that can help sites understand the strengths and weaknesses of their local implementation and also to develop strategies and priorities for improvement.

What we see is teams embedded in their own context. The first challenge is you don’t just want a team, but you want a team that is going to be effective in the way that ISP defines as necessary. That includes helping the family clarify its priorities, devising strategies that fit with those priorities, and then indeed helping the team realize the plan and achieve the goals that are outlined in the plan. In order to do that, you need supportive organizations that are going to be flexible and that are going to help to make an environment that will allow the teams to succeed. Then you need, in turn, a hospitable system that is going to provide the kinds of policy and funding support and the kinds of incentives that are really going to allow this to happen.

What is our strategy? Our strategy in looking at this question has been to sort of start at the ground level. What are the characteristics of effective ISP teams? Again, effective in ISP has a very special definition. It has a special set of outcomes that includes the empowerment of the family’s perspective and realizing the family’s goals. From there we did a process that has been called backward mapping. If you want teams to be effective in this manner, what kind of supports do the teams need from the organizations and then, in turn, what kind of support do the organizations need from the broader system in the policy and funding context in which they exist. We are beginning at the team level. I am going to go over this kind of quickly, but a lot of this information, if I skip over it quickly, is in the handouts. We reviewed research and theory from a variety of sources. One of the interesting challenges here is there is not a lot of research on specific factors of teamwork in ISP that are linked to effectiveness. There is a 50-year tradition of research on effectiveness in teams more generally. In trying to figure out what would apply from teams in other contexts to the ISP situation was really very interesting and actually very profitable. We feel like we found out a lot of things that actually translated very well.

We attended trainings for ISP. We interviewed expert team members. Sort of the heart of our early work was these observations. We observed 72 meetings, 26 different teams, 12 communities, 8 states and 6 communities that have been recognized for some aspect of their individualized service planning prowess in the Promising Practices Series from CMHS. We have a checklist of meeting and plan attributes that we filled out for each of these teams and we achieved a good inter-rater reliability on that. We also have a project that we are working on analyzing the data now where we videotaped teams and debriefed the team members about their experiences during the team meeting.
So what we came up with, basically, the fundamental team condition from which the backward mapping kind of proceeds, is what you can see here. Team adheres to a practice model that promotes team cohesiveness and high quality planning in a manner consistent with the value base. That is very wordy, so I will see if I can clarify that, with this incredibly simple diagram that you see here.

You will see this on your handouts. I am going to try to give you the punch line. If you want to get to the outcomes, and these are outcomes, again, highly specific to ISP but share some things in common with more generic team challenges, you need in that big rectangle the processes that happen as a group with the team. So you need the team to engage in a high-quality planning process. This is pretty straightforward. The team has a clear sense of its goals. It has a clear sense of what the strategies are that they are using to meet the goals, and also has a sense of being able to evaluate the strategy so that if something isn’t working you can discard a strategy and revisit either your strategies or your goals to try to come up with something that will work. Additionally you need what we call team cohesiveness, which a sense that everybody is on board with all of this stuff, that people are agreeing that they have goals in common. You can see that there are sort of different facets of this listed in the handout. But in the ISP context, again, you need to do all of this in a manner that is consistent with the value base. So our model basically argues that you need to do all these three things at the same time. In a way I think this makes good intuitive sense. You can have even high quality planning that is consistent with the value base, but if you don’t have a cohesive team, there are going to be some people who are alienated from the plan. Those people, directly or indirectly, overtly or subtly, are going to be able to

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**ISP Team Processes**

**Planning.** The planning process prioritizes family/youth perspective and includes attention to:
- Defining team mission* and goals* with associated strategies and performance criteria.*
- Exchanging information,* broadening perspectives,* and generating multiple options before making decisions.*
- Continually evaluating* and revising* goals and strategies.

Building team **cohesiveness**. Team members build shared perceptions that:
- Team members hold goals* and values* in common, including the values associated with ISP (cooperativeness).
- The team can be effective* and ISP is an effective intervention (efficacy).
- The team follows fair procedures during discussion and decision making* (equity).
- Team members are respected, even when they disagree or make mistakes* (psychological safety).

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**ISP Outcomes**

Team achieves appropriately ambitious goals in a manner consistent with the ISP value base.

Increased coordination between services/supports and needs

Supportive and adaptive relationships

Increased family empowerment and quality of life

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*These attributes of process have been linked to team effectiveness in studies across a variety of contexts.

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*Friday Plenary: Fidelity and Effectiveness in ISP/Wraparound*
undermine what you are trying to do. So you need to get everybody on board with your plan. That is, of course, one of the challenges. On the other hand, you can have a great cohesive team that is acting in a matter completely consistent with the value base, and if you don’t have a plan you are missing out on the sort of royal road to success and teamwork. In fact, we found when we went around and observed those 72 teams that just over a quarter of the teams we observed actually maintained a team plan. So that means that almost three-quarters of the teams did not have the mechanism in place that has been most clearly linked to effectiveness in teams across every context that you can imagine for the last 50 years. There is a sense where these things are not necessarily embedded in the practice that we see when we go out to communities.

Again, it sounds like we have to do all these three things at once. And maybe this is a difficult sort of thing, and it is. But the idea is with carefully crafted practices, you can actually address multiple issues at the same time. I want to give you an example. This is an example that focuses on developing options. What I mean by that is when teams develop options, before they make a decision about a goal they are going to pursue or a strategy they are going to use to pursue a goal, they take some time to consider several different possibilities before making a decision. In the general team context you will find that this leads to effectiveness robustly for at least two reasons. One is just the simple reason that the second and later solutions that you come up with to solve a problem actually tend to be of higher quality, on average, than the first solution that you come up with. But the other one that is also interesting and I think particularly relevant in the case of ISP—is that generating solutions you learn something about what the nature of the problem is that enables you to come up with a better match between your problem and your solution, with this additional consideration. In the context of ISP specifically, there are additional benefits, I think, to be gained from generating options. That is by presenting the family and the team with a range of options, you allow the family a choice to select between options those that meet best with its own sense of what the priorities are, what the strategies are that are going to work, what meshes with their beliefs and values, and so on. So you have promoted several elements of the value base at the same time as you are encouraging effectiveness in the sort of more general sense of having tried to match a good solution to your problem. One of the papers that we are working on explores this in great detail—what are some of these practices that actually have been shown to succeed in a variety of teamwork contexts and how can they be translated into the ISP context. Trying to look for some things that maybe people haven’t quite looked at in great detail before.

We call the practice model sort of a bundle of those practices that you would have available to you in your community. But in order to have those practices available, you need people who can pull them off and then you need organizational and systems support in order to make the plan happen. That is what I am going to turn to now. We are back at the second step of the backward mapping. If you want these things to happen in your program, what needs to be in place. Again, we are looking at combining various sources of information. We have research and theory on organizations and systems. I’m going to skip through this kind of quickly. We also did a lot of interviewing. Again, we tried to get as broad a range of stakeholders as we could and diverse range of people. Then we also had several rounds of both group and individual expert review, after each round, in which we were revising our materials. We actually kind of had another round of review after that, including comments that we just received yesterday or day before yesterday. Hopefully we will be finished with all that. Now we are asking the question, what do we need from we call lead and partner agencies? The lead agencies we see as having a very significant role. The lead agencies we think of as those who are involved in training people that have this sort of unique or special role on wraparound teams—parent advocates, wrap facilitators, care coordinators, family resource developers—people who really have to take on a new role in order to function well in a
wraparound team. Then the partner agencies are agencies whose staff might come to be on teams, but who aren’t so directly responsible for the quality of the implementation.

Then we step one step backwards from that to the system level to say, OK, what kind of leadership agreements and policies need to be in place from the system in order to make this happen. What we came up with is what we call the matrix. It actually not that kind of matrix, but if you see it, it is the last page in your handout [see following page]. It looks like a kind of table.

What we have done is come up what we call the necessary conditions. This is sort of the minimum level of what needs to be in place, again attempting to describe it in the sort of more generic sense, in order for ISP or wraparound to be successful in a site. We have the conditions at the team level, at the organizational level, and again, at the policy or funding or system level. The matrix, as you can see, groups these conditions into five themes. It is really difficult to present this in any other way except to provide sort of a general overview. I think just from glancing at the page, one of the things that you can see is that there is a very, very large role for the organization that I think hasn’t necessarily been emphasized—all of the different aspects or important ways that organizations need to support these teams. Sometimes this can be very difficult. For example, one of the hardest ones—if you look under the collaboration area—you need to have lead and partner agencies collaborating around the plan and the team. That means that this plan that the team develops actually carries some weight when you take it back to the other agencies, so that it is not true that you go back to your agency and develop a whole new plan that may or not be strengths based, that may or may not be developed with family input and so on, and that competes for resources and basically undermines the statement that this team is the plan that is driving this collaborative effort. In fact, that is a big challenge at the organizational level and requiring system support.

It is important at each level—we are not trying to say exactly how these conditions would be fulfilled—again, we are trying to get to the sort of generic level. So, for example, under acquiring services and supports, we talk about funding to meet the costs that are associated with meeting families’ unique needs. In many sites this would be in the form of pooled funding, but not all sites want to do pooled funded. Some sites want to have blended funds. Other sites the flexible funds may exist completely within one agency but be available to the team for the plan as a whole. Basically, again, what we are saying is that these are conditions, not sort of specifications. At the system level, you can see again—it is very difficult to describe these in any detail—but the areas of system support. What we have provided and what we have worked out now is these three levels of detail. The matrix is basically a description of these conditions, and you can see by looking at it that it is almost very difficult to say what the conditions actually mean just by reading those. That is sort of more like a picture to organize the rest of the information. What we have at the next level of detail is assessments at the team, organization and system level that contain indicators—several indicators for each condition—that help to recognize if this condition is in place. They are supposed to be very concrete and we have had pretty good feedback about the fact that people can understand them in fairly concrete terms.

Then what we have is something that was described the other day as a book, but it is basically a narrative, and it has detail. It talks about an expanded definition of each condition, and it provides information about the research rationale for why we believe that this condition is necessary, and then provides examples of strategies that are used at different sites to fulfill the condition. That should be available pretty soon. We are hoping to print that, I think by the end of July. It basically just needs to be formatted and printed.

What we have now in progress is we are working on recruiting some pilot sites to use the assessments, and if anybody is interested in that, they should come
<table>
<thead>
<tr>
<th>TEAM LEVEL</th>
<th>ORGANIZATIONAL LEVEL</th>
<th>POLICY AND FUNDING CONTEXT (SYSTEM LEVEL)</th>
</tr>
</thead>
</table>
| **Practice model**  
  i. Team adheres to a practice model that promotes effective planning and the value base of ISP.  
  Sub-conditions of practice model 1-7  
  **Collaboration/partnerships**  
  i. Appropriate people, prepared to make decisions and commitments, attend meetings and participate collaboratively.  
  **Capacity building/staffing**  
  i. Team members capably perform their roles on the team.  
  **Acquiring services/supports**  
  i. Team is aware of a wide array of services and supports and their effectiveness.  
  ii. Team identifies and develops family-specific natural supports.  
  iii. Team designs and tailor services based on families' expressed needs.  
  **Accountability**  
  i. Team maintains documentation for continuous improvement and mutual accountability.  
| **Practice model**  
  i. Lead agency provides training, supervision and support for a clearly defined practice model.  
  ii. Lead agency demonstrates its commitment to the values of ISP.  
  iii. Partner agencies support the core values underlying the team ISP process.  
  **Collaboration/partnerships**  
  i. Lead and partner agencies collaborate around the plan and the team.  
  ii. Lead agency supports team efforts to get necessary members to attend meetings and participate collaboratively.  
  iii. Partner agencies support their workers as team members and empower them to make decisions.  
  **Capacity building/staffing**  
  i. Lead and partner agencies provide working conditions that enable high quality work and reduce burnout.  
  **Acquiring services/supports**  
  i. Lead agency has clear policies and makes timely decisions regarding funding for costs required to meet families' unique needs.  
  ii. Lead agency encourages teams to develop plans based on child/family needs and strengths, rather than service fads or financial pressures.  
  iii. Lead agency demonstrates its commitment to developing culturally competent community and natural services and supports.  
  iv. Lead agency supports teams in effectively including community and natural supports.  
  v. Lead agency demonstrates its commitment to developing an array of effective providers.  
  **Accountability**  
  i. Lead agency monitors adherence to the practice model, implementation of plans, and cost and effectiveness.  
| **Practice model**  
  i. Leaders in the policy and funding context actively support the ISP practice model.  
  **Collaboration/partnerships**  
  i. Policy and funding context encourages interagency cooperation around the team and the plan.  
  ii. Leaders in the policy and funding context play a problem-solving role across service boundaries.  
  **Capacity building/staffing**  
  i. Policy and funding context supports development of the special skills needed for key roles on ISP teams.  
  **Acquiring services/supports**  
  i. Policy and funding context grants autonomy and incentives to develop effective services and supports consistent with ISP practice model.  
  ii. Policy and funding context supports fiscal policies that allow the flexibility needed by ISP teams.  
  iii. Policy and funding context actively supports family and youth involvement in decision making.  
  **Accountability**  
  i. Documentation requirements meet the needs of policy makers, funders, and other stakeholders.  |
to our workshop that we are doing this afternoon. It is going to be in the Salon at 1:00 something across the street. We are going to be going through some of the assessments and using them. If people are interesting in participating in our research on that, they can come and talk to me or Nancy Koroloff about that. Then we are doing various reports. The best way to keep up with what we are doing is to keep an eye on our website, www.rtc.pdx.edu, and you can check under our projects to see what we are doing and what we have produced. Thank you for your patience, and I am going to turn the podium over to Julie Becker. Thank you.

**Julie Becker:** Good morning. I wanted to say that I really loved the way that Janet began her presentation, telling us a little about her son. That really warmed my heart, so I am going to put away all those jokes that I learned to tell in public speaking class and I am going to share with you a little example of my own that I was thinking about as I was sitting there trying not to be very nervous and have a panic attack. This is my first large conference that I’m speaking at, so there was just a tad bit of anxiety associated with that. I was running around the house—was the hair right and the jewelry and what to pack and what to say and get my slides in order and lose my slides and find them, you know, all those really important things. Then I saw my 16-year-old son, Ryan, who is beautiful and has emotional and behavioral challenges and is still beautiful, and he was sitting there and I was practicing my speech so I didn’t go over 18 minutes. After I was done he looked up at me and he goes, “Well, Mom, that was good. If you look out there and people look a little bored, you can tell them how I am doing on the surf team.”

I am here to tell you that he has almost conquered the 360 and he is doing very, very well. If this gets really boring, I am going to show slides about his maneuvers.

I want to start by giving a really heart-felt thanks to Portland State University and specifically Barbara and Janet and Nancy for inviting me here today. I am very proud to be here as a parent. As the whole world struggles with how to collaborate with us—sort of like we are very strange beings and we are a little bit—these three individuals have—and they don’t even know it—mentored me and supported me for the last year and a half. I would find an article written by one of them and email them with my comments. I would send them something I wrote and ask them for their feedback. They always responded to me within 48 hours. That is truly exceptional.

Before I begin my presentation I want to tell you a little bit about what Tapestry is. The term “tapestry” stands for the weaving together of parents and their community. We are funded by the California Endowment to start and develop a parent facilitated wraparound program for disadvantaged Latino and African American families, in a very poor, violent area of San Diego in the central region. Aside from being parent facilitated, we have other things that sort of make us stand out and which I need to brag about right now. Tapestry is a community-based model. It was designed with a community task force and it is overseen by community advisors, who, I might tell you, are very hard taskmasters. We developed a standardized training for parent partners as facilitators. We developed a training program for paraprofessionals that includes an ongoing cultural supervision group every month. Aside from trying to improve outcomes for youth with emotional and behavioral challenges, we are really concerned about the health of families and the impact that we have upon our community.

First I have to take one little obsessional moment here and define community based. Have you ever walked around and heard these big terms and not know what they mean. Community based? Does that just mean we walk into a community and put an agency there? Does that mean we shop in the area? What does this term mean? So for two years in wrap I kept walking around and saying, “What does that mean?” And people would look at me, like, “That is a really dumb question.” So I started to operationalize what we mean when we say community based. The whole inception of Tapestry was developed by parents and faith leaders and market owners and advocates in our community. We hire from the
community, which really helps us to ensure culturally appropriate understanding, but also parents—and I’m sure you can all relate to this—know where to find stuff in the community. You know what is going on in the community. You are not from outside. You have your hand on the pulse of your community. By creating career opportunities in our community, we help a disadvantaged area at the same time. We only serve a specific community and we are culturally specific. This is our definition of what community based means.

I was very concerned about wraparound fidelity because I trained parent partners to work on three large wrap agencies in San Diego. I would send parent partners out to the teams for support. Occasionally I would visit all the teams and wraparound looked different wherever I went. We had group therapy sessions. We had chat sessions. We had screaming sessions. Sometimes it sounded like shopping sessions. They were very different. So in my obsessional need to quantify that and train parent partners, this was a major goal of mine. But also my community advisory team was very concerned about two points. One, they didn’t want sloppy services in their community. They wanted high quality wraparound. The other dictate from my community advisory board was they wanted a process to fix the program if it wasn’t working properly. Today I am going to talk about two areas of concern. How can we assure high quality wrap? How can we use that in a continuous feedback model for program evaluation? I’m not a fancy researcher so the charts are very easy.

Goal one, to ensure that wraparound was conducted according to the values, principles and processes. Now, I am basically at heart a little conservative, so we went with a very conservative model of wraparound. John VanDenBerg was our main trainer in the San Diego area. My solution to this, or my attempt to work on this was to provide parent partners with standardized trainings. Primarily, all of us in our hearts are parent partners. So we had a 32 hour training about becoming a parent partner, but then also over 36 hours of wraparound training from the county of San Diego’s wrap program. We have intense weekly individual and group supervision. I also encourage my staff to attend the county supervision so they can get a broader perspective on how other folks are doing wrap. We also have a monthly cultural supervision format that has become so popular that people from the neighborhood are coming in to join it. It is a very intense form of cultural supervision which I can share with you later.

The other thing we did, and unfortunately it didn’t make it on this slide, is we developed a mentor program where the wrap supervisors—myself and Mark Kennedy—would go out with the parent partners for three to four months to ensure that they really understood what they were conducting. We also, and this is a true obsessional trend here, is provide a flow chart of wraparound tasks. We have this over the course of six months, and you will see an example of this later, where parent partners were given specific tasks and when to do them and how to do them. Parent partners don’t have years and years of social work training or psychology. They were a little frightened of their new role and they wanted as much concrete information as they could have. It actually turned out really rather nice. We also use the Wraparound Observation Form, developed by Epstein to ensure the quality of wrap. I will talk a little bit more about that.

This is a very bad slide! See following page This is the wraparound meeting checklist. I can actually provide better copies at a later time.

Parent partners were taught what things to do prior to the meeting, what things to cover before the first group meeting, and then what things needed to be covered at the next six months worth of meetings. I think everybody stuck to this pretty closely in the first six to ten months, and then we started to see kind of a falling off of it again. So we re-instituted it. We also—and you are all going to laugh at this—we all bring our poster boards and our markers and use them in pretty standardized ways because this ensures sort of a businesslike atmosphere to the meeting. I think important, too—and this is a second
little brag and I’m probably allowed three—is I found that parents really hated the assessments that they were given on most wrap programs, where you answer 500 questions and some have to do with bowel movements and then nobody ever tells you how you did on those. We really wanted to address that, so we chose measures that 1) could be delivered by paraprofessionals, 2) that parents cared about—they understood the results and they could give useful information back to the wrap team. So what we do is we conduct family assessments that cover parental functioning—how are they doing with the Parent Stress Inventory. Youth functioning, using the Connors scale. We also wanted to look at how much knowledge they had or needed about their kid’s mental health to help them along. So after we gave these assessments, we would prepare a little report. We would bring that report back to parents. This is a little aside. I don’t know how many of you ever had psychological testing or evaluation where you stare at ink blots and tell stories to pictures that don’t exist. It goes on for four or five hours and then you never hear back. That is a really scary thing. I am not professional bashing—maybe just a little bit—but I think it is important that you give that information back to families and say, “OK, these are some areas that you might want to work on.” So that evaluation report comes back to the wrap team to help develop goals. It is not kind of kept secret.

The Wraparound Observation Form. For prepare for use of this measure, parent partners received about 12 hours of training on the measure itself. We really found that we needed—and this wasn’t all at one time, I think we did it over a couple of days—but we needed to go over each item and clarify what each item meant. Like strengths-based, if you are watching
a wrap team, what is strengths-based and what is not strengths-based? What is very concrete? I know if you are trying to assess a team and you like the facilitator, you might get a little biased. So you have to be clear about what that looks like. Then we had 8 hours of training assessing role plays. This was a lot of fun. We had different staff portray wraparound teams in various stages of their development. The rest of us would be raters, and we would rate, use the rating scale to rate what we saw in the wraparound team. We then found that we needed a long period of training on rater agreement. Why did you score that this way and not that way? What did that measure mean? How dare you do that! It was pretty good.

Following training, then, our trained raters would assess wraparound teams at approximately 30 days and later at six months. This is not a research study, as I said, so the information from this measure we just compiled it using percentages and we brought it back to staff and back to myself as a director to find out where are our weaknesses. Where are we not doing well? Where do we need to do better? Where are our strengths? Alright, this is my third brag—and I think that is all I am allowed. What we found on this measure was that parent partners engaging families in wraparound, we had like 90 and 100 percent on family empowerment, family involvement, parent voice, which was a very good thing to see. We didn't score quite so hot on partnering with professionals and I think the reason being parents had different histories with different systems people and they were a little shy in reaching out to collaborate with professionals.

The part that really upset me is we scored only 41 percent on utilizing strengths within a team context. I was, oh, my God, I'm not going to tell anybody about that one. We brought that data back to stakeholders and staff and said, “What is this?” What we found out, which was very interesting, is many of these parents were incredibly strong individuals. They had to pick themselves up by their bootstraps and raise these incredibly challenged kids because they should probably be getting a paycheck for it, and get their family on the right track. But what they tended to do with families is then be judgmental. Sort of, “If I can do it, you can do it. Come on, get off your butt. Let's go, clean the house.” And so we really needed to do much more sensitivity training. Just because you had these attributes, you need to help other families along and be a little empathic. But all the parent partners shared that they had gone through a judgmental stage in their training.

How do we use all of this information? My second mandate from my Community Advisory Team was, “If your program stinks, we want it changed and we want it changed fast.” We were like, OK, not being program evaluators what we developed was this continual feedback loop.
It happens every six months, we collect our data from our families, our finances, our wrap observation forms, our satisfaction surveys, all the data in the program, we gather it together. Then we start to sort of analyze it, put it in some kind of framework that makes sense, either percentages or scales or what have you. Then we start developing hypothesis. By the way, we are doing this with parents, kids, our Community Advisory Board and my board of directors. I have all these masters. We start developing hypotheses like, Why are we getting this? What are we doing good? What are we doing wrong? And how can we change it rapidly? That is a huge two-day staff retreat where that takes place. The data from that turns into suggestions and given to me and I have two months to implement change. So this keeps the program fresh. It keeps it sensitive to the needs of community, and hopefully allows us to develop a better program over time. That is it. Thank you.

Eric Bruns: It is really exciting that wraparound has been featured in so many forums at this conference. I feel like John VanDenBerg’s keynote yesterday and the many workshops—one of which I attended that was done by Pat Miles on the topic, Julie’s talk and Janet’s presentation—all these really seem to signal and we might be somewhat in kind of a new era of wraparound. One in which we have a better understanding of what the model is. One in which we have a better understanding of what we have to do to adhere to the philosophy of wraparound. One in which we do really innovative research, such as that that Janet talked about, that aids us in making sure we achieve high quality implementation of wraparound.

I am going to talk a little bit today about that very topic, kind of an extension of both Janet and Julie’s presentation, and give a national perspective from our research on fidelity or adherence to the wraparound philosophy. But first I thought that I would indulge myself a little bit and talk a little bit about what it is like to be a wraparound researcher. I come from a university with a very well-established division of services research, largely on adults with serious mental illness. But I am the newcomer, and if you listen to some of my colleagues and a lot of other people out there in the field, you begin to almost think that doing research on the wraparound process is kind of like doing research on the existence of extraterrestrial life. The obvious differences being instead of asking are we alone in the universe, we are asking the question, “Does wraparound really work?” Instead of asking do little green space aliens visit our planet, [we’re asking] “Is there really an actual definable model of wraparound on this planet?” Obviously the jury is still out on both of those questions, but much like the researchers at the search for extraterrestrial intelligence project, we wraparound researchers, we invent measures and monitoring tools and we point them—maybe not into airless space—but point them into some airless, windowless conference room somewhere where a wraparound team might be meeting. But for both types of researchers you get the feeling at this point that the interpretation of the results that you come up with really comes down to the question of whether the audience just simply believes in the proposition that you are researching. Whether the audience believes that it makes sense that the universe is infinite, therefore extraterrestrial life must certainly exist out there somewhere. Or in our instance, whether it makes sense that to work with a family you should let them describe their own personal vision for their future and the future of their children. That you should work with families to form a team of people that they believe in and can make that vision happen. And whether it makes sense that flexibly, using natural supports and formal resources to achieve that vision is just a good way to work with families. Because for years we have struggled with the issue of how best to research wraparound, a model that is in some ways more of a philosophy than an intervention. A model that is different for every family. A model that is different in every jurisdiction. Yet it makes sense for so many people that there are hundreds of programs in almost every state in this country and worldwide that say they do wraparound. Almost all the federally funded systems of care sites say that they use the wraparound
approach to mobilize system of care principles for families. But because wraparound is so flexible and operates at so many levels, as Janet was describing, and because it wasn’t defined by one research team or one researcher, but many creative and innovative people worldwide—parents, providers, administrators—it is hard to measure its impact. It is even hard to document its implementation. Personally I am willing to research the existence of an extraterrestrial life with the attitude that if the data point to space aliens and our methods are sound, then that is information that we need. But if, in fact, the crop circle was made by a guy with a John Deere riding mower and a stake and a rope, then we need that information as well. We need to figure out what to do with that information.

So we are continuing to take baby steps in our research with wraparound. What we are doing, really, is conducting research such as Janet and Nancy’s really pioneering work that acknowledges the flexibility and complexity of the model. What we are trying to do is determine the necessary conditions at the many different levels that Janet described at the system level—the provider level, the team level and the family member level—measure implementation of the wraparound model in the field for individual families, documenting the link between these two things. So we are documenting the link there. We also want to continue to measure child and family outcomes in a reliable and meaningful fashion. The question then, if I don’t know what that thing that flew by was: “is high quality implementation really leading to outcomes?” [referring to slide] And if so, which outcomes? Which aspects of the wraparound model are most likely to lead to outcomes for families?

Janet already discussed a lot of the work that we are doing, that they are doing on necessary conditions to support wraparound. So I am going to talk about three things really quickly. First of all, measuring wraparound implementation, which Julie talked about how their program in San Diego is doing that. Second of all, what predicts high quality wraparound implementation? Finally, as the last arrow in that previous slide suggested, does high quality wraparound implementation really make a difference? What is the relationship between fidelity and outcomes? With respect to measuring implementation, recent years have seen the development of the Wraparound Observation Form, which measures adherence to the wraparound principles within the context of the team meeting,
and also the Wraparound Fidelity Index, which John Burchard invented, and I've had the privilege of working on with him. The Wraparound Fidelity Index uses interviews with parents, caregivers, resource facilitators or care managers, and young people to determine adherence scores or fidelity scores. Now it is a valid question to ask, fidelity to what or adherence to what, because since there is really no manualized or definitive wraparound model. What we have used is the Wraparound Fidelity Index measures adherence to the wraparound elements, which is kind of a well-known and fairly fundamental set of principles for conducting wraparound. With the Wraparound Fidelity Index, each respondent on the WFI is administered four items in an interview format, and for each item there is a scale from 0 to 2. For each element you can have a score from 0 to 8.

What you see here are scores for each of the three types of respondents that the WFI interviews. The dark red being the resource facilitators or care managers, the orange being the parents or caregivers, and the yellow being the young people. You can see that we have a total WFI score in the top left-hand corner there, and then the 11 elements going across the two rows there for each of the 11 elements. At this point we have a national sample of 16 sites in 9 states. It is actually growing rapidly since we did this, From this national sample—and I have got to actually acknowledge that these were self-identified programs—they wanted to use the WFI and therefore they are probably pretty high quality programs, because they are actually wiling to monitor themselves on fidelity. But we still see some interesting things about wraparound implementation in the field. First of all, perhaps not surprisingly, we find that parents or caregivers and young people give much lower ratings of fidelity than providers do. Perhaps that is not surprising, but it is information that we need to be able to document both across the country and for individual sites. Second of all, we found that several of the wraparound elements are pretty challenging and pretty difficult to do, even in these high quality sites. So if we draw lines at about 75 percent “fidelity,” so scores of 6 out of 8, what we find that we have a couple of elements for which all three respondents give lower than average ratings of fidelity. Those elements are the youth and family team element, as well as the natural supports element. We also have two more elements for which either the parent or the youth or both give lower than that threshold of 6 score and that is the community-based element as well as the flexible resources element.

If we delve into all of the items on the WFI and look at the ones that fall significantly below average, we find several challenges that are common to many sites out there that say that they are doing wraparound. The first challenge is incorporating a full compliment of important individuals on the individualized services team. It is a pretty fundamental issue, but it is clearly difficult for a lot of these sites to do. Engaging the youth in community activities, activities that the youth does well, or activities that will allow him or her to develop appropriate friendships—again a very important aspect of the wraparound process that is often not happening. Julie mentioned the third common challenge, which is using family and community strengths to actually plan and implement services—not just doing a strengths discovery or listing out strengths—but actually using them in the planning process. More challenges that we have seen from our work with the WFI—using natural supports, providing access to flexible funds to help implement innovative ideas that might emerge from the team planning process, and finally consistently measuring and using outcome, satisfaction, and implementation data, both to aid individual teams as well as—as Julie was describing—to aid program and system development. Not a lot of sites, not a lot of programs do this. It is important to do this. These are some of the common shortcomings that we have found. We feel as though these are important things to surface and to understand, because if we believe that fidelity to the wraparound principles is important, we need to know for which ones we might need to design better training approaches, advocate for legislation and policy change and so forth.

The next logical question is what predicts high quality wraparound implementation, wraparound
implementation that might overcome some of these challenges that seem to occur in the field. This is clearly an important question. So inspired by Janet and Nancy’s work on necessary conditions at the system and program levels, we designed an interview for administrators asking about supports at the program and system level, and administered it to out sites in our national sample that had WFI data. Some of the questions that we asked these programs and systems folks and administrators were about their general site infrastructure that was supporting their program. So what was the caseload of their resource facilitators? How much staff turnover there was in the program? Kind of more generic questions like this. We also asked questions about the supports that were present at the program and system level to help teams adhere to the wraparound principles. Was there a method for insuring that there was an interagency body overseeing the wraparound project? Was there a pooled funding source or a braided funding source? Were there mandates for natural supports being used? Was there flexible funding and so forth?

What we found was that for these 8 sites that we had WFI scores on—and you can see that they range anywhere from about 5.76 up to about 6.8—was that there was a significant association between the program and the system components and the fidelity from individual families. This is a little bit complex here, but you can see that we talked about those domains on the system and program level in the previous slide. You can kind of see as you go across from left to right that the higher the score for individual family’s fidelity, the more of those kind of system and program prerequisites were in place. This is a pretty important thing to know if you are going to try and insure fidelity.

The final question is does fidelity or high quality implementation, which might be the right way of putting it, really matter? We investigated the question of whether fidelity really matters for outcomes with a study using the WFI. We did it in one system of care in the national system of care program that uses wraparound. We associated WFI scores with outcomes, several major outcomes—behavioral strengths, the restrictiveness of living environment of the child, child and adolescent functioning, and parent satisfaction with services as well as parent satisfaction with the child’s progress. We associated the fidelity not just with the outcomes as assessed at the same time, but with outcomes that were assessed six months down the road, with the question of whether fidelity at one point seemed to predict things down the road for the child and family. So here is our time one and time two.

We got our WFI fidelity scores of the parent and also got outcome data at the same time, and also got
outcome data six months later. What we found is that parent fidelity scores at time one were significantly associated with behavioral strengths as well as with the overall satisfaction with the parent. At time two, we found that the parents’ WFI scores or fidelity scores were associated with the parent’s satisfaction with the progress that their child was making as well as with the restrictiveness of living. It is important to note a couple of things. One of which is that the fidelity was not by any means associated with all of the outcomes we were looking at. But at the same time, there was no association in the opposite direction than you might expect.

On the next one, fidelity is measured as reported by the resource facilitator. We only took a look at three of the outcomes because of sample size problems. We found that resource facilitator’s reports of fidelity were significantly associated with the Kappa scores, restrictiveness of living and with behavioral strengths six months down the road as well as with the restrictiveness of the living environment of the youth six months down the road. As is the convention, I guess, among researchers, two little space aliens means it was significant at the .05 level and 1 means that it is significant at the .1 level.

To sum up, these results are all very preliminary, and to be honest we really haven’t achieved enough power in our sample sizes to address some of the really tough questions here. What aspects of adherence are most likely to lead to outcomes? What types of program supports are most important to ensuring fidelity. We do have some preliminary evidence that we have identified some important prerequisites. And Janet and Nancy are working hard on this. I think it is incredible work that they are doing. We have identified some important prerequisites that do, in fact, lead to higher quality adherence to the model for families. We also have some very initial suggestions that adhering to the wraparound principles does in fact lead to, or is important potentially, to achieving child and family outcomes. What we need to do now is determine within the flexible family-driven wraparound approach, how provider organizations and systems can best ensure that these prerequisite supports are actually in place to make sure that fidelity can happen for individual families and individual teams. So for example, how to make sure that caseloads are not too large. To make sure that there are supports being provided to teams and staff. Ensuring interagency coordination, blended funding, and so forth. Doing all these things at the system and program level. And further down the logic chain, how best to ensure that programs and child and family teams are delivering services that are truly in keeping with the wraparound model. So we need to give them specific tools. I think Julie was outlining some of the ones that they used in the Tapestry Project—specific kinds of training, flexible and creative service planning and implementation approaches, regular supervision for the providers who are working within the wraparound model, and making sure that feedback of fidelity data and outcome data are part and parcel of your program.

As John VanDenBerg said yesterday, ensuring that we have fidelity at these levels is really going to be our way of ensuring that wraparound will fully meet up to its promise for helping families, and making sure that youth and family-defined goals are being met, and making sure that as Abram Rosenblatt once said, that the young people who are being helped are at home, in school, and out of trouble. In addition, I think that this issue of fidelity and making sure that we have fidelity to the wraparound principles is the way we are going to ensure that wraparound is more of a well-defined and legitimate thing and less of an alien to so many people. Thanks very much.

**Janet Walker:** We have time for questions. Nobody has a question? I have a question, Eric. Just the time one and time two associations that you say, was time one after some wraparound had already been applied or was it at intake?

**Eric Bruns:** No, that was at six months after services were started. So it was, in fact, after there had been enough time to figure out if wraparound was happening.

**Audience Member:** Que significa ISP? [**What does ISP mean?**]
Janet Walker: Individualized Service Planning

Audience Member: Me gustaria mucho tu programa pero quisiera obtener mas informacion. [I enjoyed your program very much but I would like to obtain more information.]

Julie Becker: I will give her my business card with all the information on it.

Audience Member: The concept of wraparound—and I might have not caught this in the beginning—but what I was wondering is how can we continue to get funding for programs that support wraparound services, because what I see is that it is a great concept at all different levels, even at just community levels when it is not even formalized—say in faith-based communities. I am with NAMI and we as a group of parents sort of implement it on an informal level. But what I am wondering is—and I’ve even talked to legislators about how can they work with communities to implement some of these so they possibly get community people that have some kind of leadership to work with other people to develop this kind of thing. I am talking at sort of a global level. What do you folks think in terms of getting out in the community and just getting the educators within schools—beyond just the system providers and the formal providers. Do you guys talk about this at all? This is sort of an esoteric question about how do you spread the word? How do you get the money to do it? What do you do if the money isn’t available?

Julie Becker: I can speak to what we do at a very small community level, and that is we behave like neighbors and not like agencies. We go to all the health fairs. We give presentations at schools and preschools and day care. Our office has sort of become a sort of informal hang out place for parents with resources and help and if you need the fax, and what can we do for you. We vigorously practice no wrong door. Any request that comes into our agency, we take care of it, and a lot of it is educating. We give presentations at churches for the faith community. I think also what we do to sort of permeate the program in the community is we accept referrals from anybody in the community—teachers, faith coordinators, market owners, advocates, parents, kids—so that helps to become sort of an accepted fixture. Then gradually when we have that trust built up, that is when we start going to our local board of supervisors, our district people know us. They sort of all close their doors when we walk in. No, they are very, very nice, but we are constantly on their doorstep. “Hey, come down to the neighborhood, come to the ‘hood, find out about us and see what we are doing for you.” Then what happens is they get real proud and then they start talking about you on a broader level. But it really needs to start with forming a relationship with your community first, because then you get that momentum. You get the community members behind you.

Julie Becker: We have no budget so that answers the fiscal question.

Eric Bruns: I would say that you can’t ignore the fact that there is a broader national movement towards making sure that evidence-based practices are being used wherever possible, because that is where you are capable of getting the most legitimization for whatever you propose to those who might be funding. We really need to heighten the interaction between the community and kind of a national scope to better define wraparound so it has that legitimization and a lot of the research that is just now making baby steps toward it will hopefully give some of that legitimization so it is easier to get funding in the future.

Janet Walker: I would just like to offer that if anybody wants, there is some research, there is some evidence base for wraparound. And if anybody sends me an email [janetw@pdx.edu] I’ll email back to you a list of the articles. Sometimes it is useful to have this information in hand when you go and need to talk to agency people or when you need to talk to program people, legislators, and so on. That is a place to start. There are resources available.
Saturday Plenary:
Promoting Children’s Mental Health in Early Childhood Settings

Lyn Gordon: I would like to introduce Maureen Breckenridge, the Executive Director of the Oregon Family Support Network, who will bring you greetings from families in Oregon.

Maureen Breckenridge: I’m really happy that so many people are here. Early childhood is so very important, as we all know. Especially as our kids get older we see the things that we wish we had done. As a grandmother, I know I see things that I know as a grandmother I can do with my grandchild in the early years that I didn’t know as a parent.

First of all, I want to acknowledge the Oregon families who are here, who did some presentations yesterday. There is Jeanne Shultz here from Eugene and Don Bougher from Washington County who was a moderator for many of the panels, and Deb Depew and Carol from Zero to Three, and Jeanine is here also, and she is from a community resource center. There are some other parents who aren’t still here—Mike Rice and Theresa Rea and five children. All these people have come and done a great job—and Bill Richards. It was really exciting to see what Oregon families can bring together to the whole community. I want to thank them for doing that. These people have to leave their jobs, leave their kids, they are sleeping all together. They are bunking out, to do this. I appreciate that. It is a great message for all of us.

I have been invited to other conferences to do a welcome, and I don’t know that they want to invite me back, but they did invite me back here. I have a welcome hat so you really know that I want to welcome you, formally, so you will know that this is my official
welcome hat. I am a lady in this hat. I am going to be very nice and welcome you to Oregon and tell you everything is beautiful here and that we are very, very happy to have you here.

This is the hat, by the way, that I can wear to the legislature for you, to represent your needs to our legislators, so they know the seriousness of our job and what we do and what we bring to the community. Last year when I wore my welcoming hat it was not present, because I was only on the job a few weeks, and I don’t know if you could handle me that way. So I let you know some of my stuff background. I am a lawyer, and I have kids and all that stuff.

This year I want to tell you, the keynote speaker said that one of the problems is when you only have a hammer, you see everything as nail. Well, I have a hammer and my nails are the family voice. So anytime I get an opportunity to speak on behalf of the family voice I do it.

I have to change hats. Do you know what kind of hat this is or where you wear this hat? Oregonians, east of the mountains, where do you wear this hat? Hunting, right, so people don’t shoot you in the woods. Well, I am an advocate. I have to wear this hat. I am a family member. I have to wear this hat. This is my advocacy hat and we actually, in my groups, had little family-driven badges, so just in case you don’t know what we are all about, we are here to do this.

I want to tell you that in my opening address last year, this was the family voice I heard:

We don’t want our kids in residential treatment anymore. We don’t want to have to drive three times a week several hundred miles and leave our other kid at home, who also has their own difficulties. We don’t want to do that. We don’t want our kids in jail anymore as a form of treatment.

Guess what? This year I am here to tell you that things have changed. We were part of a lawsuit this year and the State of Oregon is now going to have a budget note and it is going to change the way things are done in Oregon in residential treatment. I am going to say that publicly, because everybody has been hushing this up, and they are acting like it is a little thing. Well, the families who put their lives on the line, to tell their stories about their kids need this to be public. So I am going to make it public, just as we did with the Bazelon Report, and say this is why we wear these hats. Sometimes you might be happy to see me and sometimes not, but in general, the families are pretty happy that we are getting this work done. I want to thank everybody for doing that.

Nancy Jambor, who is sitting over here, made the mistake of inviting me to do a welcome, too. It was Early Childhood, and I was there with a parent, from Eugene, who has a couple of kids. At the end of listening to a couple of days of what people thought about our families, and what you needed to do to work with our families and little kids, we couldn’t just give a welcome. So I gave Dave Letterman’s Top Ten Things that parents from Oregon want you to hear. That was remembered by some people and quickly forgotten by others.

But I did bring a picture of this little guy. Since I am not giving a presentation, I thought I would just bring his picture. Can you see what that is? It’s legs. These are the legs and these are the little shoes. That is my grandson, so that means I am going to put on my grandma hat, and I’m a grandma and I was sitting, on Mother’s Day, with the other grandma and my grandchild and my daughter.

The other grandmother said, “Oh, Kristin”—my daughter—“what happened with the lady? Did he ever pass those tests?”

And I thought, “hum, I wonder what that is about.” She said, “Oh, yeah, it worked out fine.”

Later I said, “What lady were you talking about?”

She said, “Mom, remember before Thomas was born, someone came to the house and they checked to see if there was lead in the paint, because it is an old house, and that I had the supplies and everything I needed for the baby. And then when you came over here when he was born, the nurse came over and she spent the week with us and showed us how to put him in the little tummy tubby where he sort of floats to get his
little nervous system relaxed and everything. And they taught us how to work with him there, because he was pretty wired up like that. So they spent the week with us doing that.”

I said, “Yeah, yeah.”

She said, “Well, I brought him in there for shots and that’s where you go to do that. One of the other ladies does a little test to see where he is and if he is learning what he is going to learn.

“It was one of those bad days, Mom, when he was throwing his arms up in the air and he was going stiff, and he was biting and he was kicking, and they said he didn’t pass this test. So they sent me to a pediatrician and the pediatrician said, ‘Ah, what is going on in life?’

“I told about moving to another house and some other stressful things.

“The pediatrician said he was over stimulated and a child with that kind of a nervous system, ‘you don’t test them when they are over-stimulated like that. So let’s just do this again, and I’ll do it here’ —he is way over where the test is...”

I said, “Why were they talking about the lady being in your house, Kristin?”

She said, “When we moved to this new house, the lady came over to see how Thomas as adjusting and she was helping me.”

I said, “Oh, is that why you are asking him, ‘Do you want to wear the red socks or the black socks, Thomas? Do you want to eat potatoes or rice?’”

She said, “Yeah, they taught me that he is upset because of the move and the things in his life and we speak two languages and everything. They were teaching me how to give him some choices so that he can manage his own life.”

I said, “Isn’t that terrific?”

Then she called him, “Thomas, come here, I need to talk to you. Look in my eyes, Thomas, look in my eyes.”

He is only two, and I brought him to school and she was talking to the teacher and how they got together with those ladies, too, and how they are discussing what kind of a school Thomas will go to in the town, and how probably he should have some more structure. That is going to be helpful for him. He has a real big IQ and so we want to make sure that he gets more individualized attention. You can imagine how good I felt leaving my grandchild, knowing that there were other ladies—grandmas, whatever—who are helping my daughter to raise this child.

The interesting thing is that everybody in this community gets that. Her girlfriend is a multi-millionaire and she had to learn how to work with her little kid, but she didn’t know anything different was going on because she was an only child and she didn’t know to give the child some independence. Her other girlfriend who had a premature baby, she had a live-in person there who was helping her with her two little children who were young. All the mothers were sitting around talking about these ladies.

Right now you are probably wondering where she lives, right? She lives in The Netherlands, and this is what is possible. The word mental health has never come up. There is no split in who is doing what. There are people who are developing citizens and I am so very happy that that is where my grandchild is. My sister works in Ireland in this work, and they, too treat their children as their families and their children. The boundaries aren’t there that we have.

I hope that when you talk about the hammer and the nails and everything, and you really want to pound the same nails, that you can see that maybe there are new adaptive micro-systems that were put in through computers or whatever else, and you don’t have to go around hammering nails.

Bill Richards, at the Oregon Family Support Network youth presentation said, “OK, everybody, put your arms up like this.” (Holds arms wide.) I am going to ask you to do the same things. Ready? Put your arms out like this. What is this? What is that? It is all the possibilities. That’s what we have. So welcome to Oregon.
Steffen Saifer: I am a faculty member at Portland State University and with the Regional Research Institute as well as the Director of the Child and Family Program at the Northwest Regional Educational Lab. We are off to a roaring start here, except we are cutting off our caffeine at this point.

Welcome to the first plenary session for this conference on early childhood mental health, or as we are calling it, Promoting Children’s Mental Health in Early Childhood Settings. I am honored and delighted to be the moderator of this panel on this issue. It is very exciting. It is a field I’ve been working in for many years, and it is also introduces the first of many conundrums we are going to be dealing with on this panel, which is what does it mean, “early childhood and early childhood settings”—how do you define early childhood? Well, generally for our purposes we are defining it from birth to school-age, birth through five, but depending on who you talk to and which constituents, it could be birth through grade three. For early childhood education folks, that is early childhood. Definitions, coming to terms, is going to be a big challenge with us this morning.

I purposefully called this Helping Children with Challenging Behaviors. That is very purposeful and very thoughtful and it has gone through many iterations over the years that I have been working in this field. Helping Children with Challenging Behaviors is another way of looking at this issue which I think is easier and healthier. Have you seen a three-year-old with mental health issues? Well, maybe. But have you seen a three-year-old with challenging behaviors? Oh, yeah. Calling it challenging is good, I think, because it doesn’t put an evaluation, it doesn’t put a judgment on it. I could be a perfectly functional, in fact a healthful behavior to the child in that context, but be challenging to you as the parent or the teacher. The challenging part, I think, takes the judgment out of it. Helping, of course, puts it on a positive note, because what is our goal here. Our goal here is to help these children with these challenging behaviors to get their needs met in a better way, to get them happier, put them on a positive note.

The next conundrum is that all these players that come together in the field of early childhood mental health, they come from different backgrounds in terms of their education, their cultural social history of these fields, come out of different places. We have parents, of course. The first two are the people that spend the most time with young children, the parents being primary. The way I am going to frame it is by looking at the different perspectives of how people view the term “early intervention.” Parents here, how many of you knew what that meant the first time you heard early intervention? Very few. Probably what happened as a parent, your jargon flag went up. Oops, “early intervention,” here is some jargon. You know it is jargon because you can’t figure out what it means through any kind of logical reasoning. Or it could mean so many different things that you aren’t sure what it means. It is one of those jargon terms.

The second most amount of time young children spend with child caregivers, is with early childhood teachers. For this group of people, early intervention generally is age-related and it is generally like three to five, pretty much. For some people it is younger. The next group, early intervention for special educators has a very specific age-related meaning. It is birth through three, because three to five is called something else. You can imagine all these people in the same room using the term and not knowing what they mean.

Mental health specialists is the next group. For them early intervention could mean, for many of them, the time when you do the intervention. So you get into the problem early, as opposed to waiting for it to become a crisis. So it is not age-related, but it is temporal, or time related.

Then there are pediatricians who are very involved in this, of course. For them early intervention means that you have a 7:45 appointment in the morning. That’s not fair to pediatricians, but it was sort of a good joke for this time of day.

In our work with early childhood folks, child caregivers, Head Start teachers, primarily, we came across another interesting other conundrum, another problem, which is we noticed that they were not
effectively helping children with challenging behaviors. What we saw is that they were kind of ambivalent— not all of them, of course—they tend to be inconsistent, unsure. They felt a little guilty when they were too directive and as one of the consequences they used ignoring a lot. Another way of ignoring was pretending not to see that this kid was strangling the kid next to him. Here was the problem, and then we try to figure out where this was coming from.

What we discovered in talking to other early childhood educators and the teachers themselves and supervisors is that the problem was that they had this dichotomy, and I think it is a false dichotomy that was set up for them, which is you can either be child-centered or you can be teacher-directed. You can’t do both. They are mutually exclusive. Child-centered is good, so you have to do that. And teacher-directed is bad, so you don’t do that. But then you have this child who needs a lot of teacher direction. You are not supposed to do that. So they were in this dilemma, this conundrum themselves, not knowing what to do.

One way we helped them get out of this dilemma was to create another view of it, a less dichotomous view, where you look at child-centered and adult-involvement—not teacher-direction, but adult-involvement—kind of the intensity of help. The intensity of help is based on the need of the child. The more need, the more intense help.

As a curriculum, a way for you to see how these kind of four quadrants work out, is from the curriculum perspective. So low child-centered, in the bottom left corner there, an example of that is worksheets. Low child-centered, low adult-involvement. That is sort of the worst of both worlds, if you will. So child is working on his or her own, on a worksheet. It is not child-centered because they didn’t choose it. It is Monday morning, so this is the curriculum at 9:00. The child has no choice and the teacher is not very involved. Then if we move up on the left side, low child-centered, high adult involvement would be something like drills or flash cards. There is a lot of interaction and adults can do this very well. They can even make it kind of fun. They could be responsive to the kids’ individual needs, where they are at in terms of these math issues or something. But low child choice. The child isn’t choosing to do this. The child would probably rather be doing something else.

At the bottom right is high child-centered, low adult involvement. The classic example is recess: 300 kids out on the playground with one teacher. The kids, that is the most important time of the day for them. All these incredible social relations are going on. The boys are chasing the girls, the girls are chasing the boys. And often in terms of developing skills, social skills in this case, it is a negative thing, because there is no adult involvement, so the kids who are good at manipulation or bullying get to win. That is the problem there. So the ideal is this high adult involvement, high child centeredness. A good example of that, when it is done well, are projects based on children’s interests, where it is very interactive and the adults monitor it. It happens over a long period of time. It is very hands-on, and it has high educational value.

How does this same thing look in terms of behavior, the kid with a challenging behavior? Low child-centered, low adult involvement—time out, we will stick you over there, and hopefully something magical will happen during the time you are in time out and you will come back and you will be a perfectly wonderful child. On the upper quadrant is a reward system. High adult involvement, very structured by adults, low child centered, no choice here. Everything is done to you. The bottom right quadrant is the high child-centered, low adult involvement is you ignore it or you pretend not to see it. And the ideal high adult involvement, high child-centered where you teach the appropriate behavior to the children to help them get their needs met and their problems solved in a way that is not hurtful, is socially acceptable, and is effective. So why is it high child-centered? Because you are looking at what the child is trying to accomplish, what the child’s problems that they are trying to solve are, and you are helping them do that in a more effective way that is positive for themselves and for others.
I put down some guiding principles that I would say all the players in the field could abide by and if they did, we could avoid some of the miscommunication and conundrums that all the players have.

The first one is whatever it is, we individualize. What may work with one child may not work with another. We may need to be very directive with one and even the same child in different circumstances.

The second point is assume ignorance not malice. Now three and four-year-old are perfectly capable of malice, as we know. But approaching it from that perspective isn’t helpful to them or to us. So assume ignorance. Assume it is an issue that they just don’t know, and help them learn, teach them the appropriate behavior. Fix the program or yourself, your own response to the behavior, not the child.

The next point is give as much help as is necessary, but no more. It doesn’t matter what player you are, use the principles that work, from whatever field you are coming from. Have a full toolbox of positive strategies. There is that hammer and nail metaphor. You can’t just have a hammer in your toolbox, you need lots of tools because there is going to be a different array of problems. Even the same child, you will need a variety of tools to help that child in different circumstances. Keep moving toward less intrusion and more controlled child choice. This is another way to help people out of the child-directed, teacher-directed problem, which is, yes, you may be very directive now. You may be physically directing a child with challenging behaviors, but you are not going to stay there. You are going to help build capacities so you can move out of that and help that child become more independent and do those behaviors on his or her own.

Expect inclusion, that is the first resort. I guess if there is a last resort, there can be a first resort, right? So expect inclusion as the norm, and only under very dire circumstances would you not do that. What we find a lot is that in terms of challenging behaviors, this is the one area of “need” or disability where people feel it is just perfectly acceptable to segregate kids out by their need, when in fact they need good role models of kids with good behavior. Check your assumptions. Ask questions, don’t assume you have all the information regardless of which one of those roles or positions you are in. Find and use allies for help and support. No single person on that list can do this alone. We all need each other. Some of those people will be helpful and some of those people will not be. You have to figure out who your allies are, and stick with them. You tell your allies what you know, what you need, and you teach them how to speak your language. “This is what I understand. This is how I can understand it. Speak my language.” If you are a professional working with a parent, “this is what this jargon term means.”

Next we have our panel. The first to speak is Beth Green. Beth Green is a Senior Research Associate with Northwest Professional Consortium. She has been involved for many years with the National Evaluation of Early Head Start and is co-principal investigator for Guidance for Program Design: Addressing the Mental Health Needs of Young Children and their Families in Early Childhood Education. Beth is with the Research and Training Center on Family Support and Children’s Mental Health at Portland State University.

Abbey Alkon will speak next. Abbey is at the University of California, San Francisco, where she is an associate professor in the School of Nursing. She is the principal investigator of the Health Child Care California Project, the Child Care Health Linkages Project and Health Line. She serves as the director of the California Child Care Health Program.

Both Beth and Abbey will be focusing—not exclusively, but a lot—on mental health consultation to early childhood programs.

Then Eileen Brennan, who is here at Portland State as a professor of social work. She is the principal investigator for Models of Inclusion in Child Care and the co-principal investigator for Support for Working Caregivers Project. They are also both projects based at the Research and Training Center.
Glen Dunlap is here from Florida, Professor of Child and Family Studies, Director of the Division of Applied Research and Educational Support of the University of South Florida, Louis de la Parte Florida Mental Health Institute. He is the director of the Research and Training Center on Positive Behavior Support, and that is going to be the topic that he is going to address, which is an approach called Positive Behavior Support, and also the Center for Evidence-based Practice: Young Children with Challenging Behavior—there is that great term again—at the University of South Florida.

So first up is Beth Green.

**Beth Green:** This is great to see so many people here on a beautiful Saturday morning. I know if you are from Portland or Oregon, giving up minutes in the sunshine is very difficult. If you are from out of town, I want to let you know that if you are feeling bad because you are missing the famous Portland Saturday Market, that it is actually open on Sundays, too. So you can sneak down there if you are here tomorrow.

I am going to be talking to you today about effective models for early childhood mental health consultation. Since we have a minute, I am going to acknowledge the hard work of our project team. We have been working now for almost four years together on this project looking at early childhood consultation in Head Start Programs. Maria Everhart who is down in the front is our project manager and has been working really hard. And Lyn Gordon, who you have already seen many times, we are lucky to have him with us on our project. Maria Garcia-Gettman, who is not here today because she is home with her new baby, has been our graduate research assistant for all these many years. So that is the team that has been behind some of the work that I am going to be talking about today.

The first question is just the general one of, “why do early childhood programs need to provide mental health service?” First, and many researchers have noted, there seems to be an increasing prevalence of behavioral and emotional problems within children under five. That is what I am talking about in terms of my definitions of early childhood. Second is that behavior and emotional problems in preschool children are especially challenging for families and teachers. I like the words,” challenging behaviors” or “challenges in young children.” I have a two-year-old so I know something about challenging behaviors in early childhood.

One of the things that we found in our research is that one of the major problems for teachers is that challenging behaviors really shift the focus in a classroom away from—even in the most well-intentioned teachers—being able to provide good positive support for the group as a whole toward behavioral control of the child (or children) who has a problem. In particular we see aggressive behavior as being a big problem. We are talking about pinching, biting, hitting, strangling, whatever, that this leads teachers to seem to put aside any of their more supportive, family-friendly, child-focused kinds of strategies, and really think about exclusion. They think about, “This kid is disrupting the classroom. He or she needs to be somewhere else.”

I want to share with you a little anecdote. This research is within the Head Start setting where, of course, we have children who are at high risk for challenging behaviors because of their socio-economic risk factors and other things. But my child is in a day care center—a pretty good, mostly middle class, kind of day care center. I was picking her up one day and I saw the teacher jump up, scream at the top of her lungs, “No, biting, Tom!”—let’s say “Tom”, it wasn’t Tom—grab the child, run to the other side of the room, throw the child into his seat and then come back and say to me, “We have to do this. We were told by his pediatrician that this is how we are supposed to deal with his biting behavior.” She was embarrassed, I could tell. You could also tell the room, all the other kids stopped. My little girl ran over to me and looked at me and said, “Tom is sad.” It just broke my heart, needless to say. I didn’t think this was the most appropriate way of dealing with aggressive behavior in a classroom full of two and three year olds. I went and talked to the administrator and said, “You know, I have the name of someone you might be able to call who might be able to give you a little more guidance.”
“Not to bash pediatricians,” as we already have a little bit this morning, “but perhaps this pediatrician is not giving you the right kind of advice on how to deal with this aggressive behavior.” The good news for me is that they were not throwing him out. But the bad news was it totally disrupted the classroom, and all of the effort of this teacher was directed on keeping this child from biting. I tend to be nonchalant about the biting issue, because my little girl went through a biting problem herself. My point is even this middle class, very positive, very NAEYC-accredited kind of day care, still, when faced with a kid sort of beyond what they were used to dealing with in terms of aggressive behavior, really didn’t know how to deal with it, really didn’t know how to face the problem.

About ten years ago an article in American Psychologist came out by Petrokowski and Jane Knitzer and some other folks, really calling for a new way of addressing the growing issue of challenging behavior in very young children, especially in the Head Start context. What they tried to argue was that the traditional way of involving mental health professionals in early childhood settings, that is, bringing in a mental health consultant to deal with a problematic children, often taking that child out of the classroom and doing some play therapy or some other sort of individualized treatment, was not going to be an effective strategy for promoting children’s mental health in Head Start more generally.

In Head Start, of course, you are dealing with more children who have challenging behaviors and conceptually needing to support a more positive view of how to deal with children's mental health problems, behavioral challenges. So they called for what they called a paradigm shift away from this traditional problem-focused view of early childhood mental health toward a more holistic way of approaching children's mental health. Basically what they argued was that in order to really be effective you needed to do prevention. You needed to support the entire classroom. You needed to have integrated mental health consultants so that the Head Start teachers and staff didn’t feel like mental health was a separate issue that you had to bring in a professional to deal with, but that part of their job and part of working with the mental health consultants would really help the teachers be able to promote positive social and emotional well being on a day-to-day basis.

The revised Head Start performance standards called for programs to adopt this more comprehensive approach, and called for programs to provide sufficient mental health consultation to meet the children’s needs. That is how it was worded. Other than that, the performance standards did not give a tremendous amount of guidance around what sufficient mental health consultation would mean.

One of the things, in trying to adopt this paradigm shift, a number of researchers—Roxanne Kaufman in particular—have begun to make a distinction between what they call child-centered consultation, which is the more traditional model that I described, where it is problem-focused, child-focused, working with a particular child on his or her particular problems out of context primarily, versus program-centered consultation. Program-centered consultation is where a mental health professional works with the staff, works with the program managers and administrators to do a variety of things—everything from providing training, formal training, to providing informal support, case consultation, working with the director to develop a mission statement, to develop a more holistic, program-wide approach to how to think about mental health issues and how to support children’s positive mental health. That is a distinction that I am going to come back to.

Head Start programs are not given any guidance about which kind of consultation they should have. Ten years ago there were very, very, very few programs that were doing this kind of program-level consultation. Piotrkowski and her colleagues found that only about 18 percent of Head Start program directors knew about and were implementing some kind of program-level consultation. There is really an exclusive reliance on the external consultant model. In our research we have conducted a survey of 79 Head Start programs, including 800 staff directors and consultants. The good news is that we found that on average about 60
percent of the program directors were doing at least some kind of what we would consider to be program-level consultation strategies. This is important if you think about the shift toward a more holistic, integrated mental health approach. You want the staff to be empowered. You want them to see consultation as part of what they are doing and not as a stand-alone, separate component. However, we also found that only about 7 percent of the programs involved the mental health professional in program-level kinds of activities frequently. Still the predominant model we are seeing is focused on individual child, problem-focused consultation.

Just to give you a few more examples. One way to integrate mental health into a program’s functioning is to have a mental health professional who is on staff, as opposed to an external, contracted consultant. We basically found that the number of programs with a salaried mental health professional had not increased in the past ten years. We found very low levels of program spending on mental health, averaging about 2 percent and that did not vary particularly widely. We found that overall programs reported about 1 to 1 ½ hours of consultation per year per child. We averaged out the number of hours of consultation that they had and the number of kids they were serving and that was about what it worked out to. So a relatively low level on a per child basis.

Our question became, if they are not hiring salaried mental health professionals, and if they are not spending a large proportion of their budgets, and given that programs—Head Start programs and any program—have a limited budget and financial resources, how can you make best use of those limited mental health care dollars on things that made a difference in how programs structured their mental health consultation relationships, did it make a difference?

As I said, we have been involved for about four years in a research project, and if you are interested, we are going to have a session at 11:30 that goes into much greater detail on our project. But basically what we found is through some qualitative studies that we did, there seemed to be an issue of how the relationship with the mental health consultant was established. That is, even given limited amounts of consulting or limited dollars for consultation, those programs in which the mental health consultant was seen by staff as sort of part of the team, as someone they could go to if they had an issue, as someone that they worked with and knew by name, that person was approachable and available to them, that those programs seem to be doing a better job in implementing positive strategies for dealing with challenging behaviors. So in our survey, we looked at the difference between programs where the consultant was rated as highly integrated into day-to-day activities, basically programs in which the consultant was really seen as part of the team, versus programs where the consultant was less integrated.

The first thing we looked at is, are these programs structured differently? Are they spending more money to have an integrated model? Are they having more consulting time? Basically what we found was no.

There were no differences between programs where the consultant was highly integrated versus programs where there was less integration in terms of the hours of consultation per child, the amount of their budget that they spend on mental health services, their use of in-kind services for mental health, the number of children needing mental health services, or a wide variety of other demographic characteristics related to the programs.

We did, however, find that integrated programs—and this was interesting—reported that their consultants did more overall, more frequently provided services, even though the hours were not different. So that was interesting. Then they did both program types of consultation, working with staff and management as well as individual child-focused types of consultation. We did find that these programs tended to bring in other funded streams for mental health, significantly more than low integration programs, and they were more likely to have their consultants on staff. They also, interestingly enough, were significantly more likely to have a written mission statement specific to...
children’s mental health. These were programs that maybe were thinking about mental health more, had a more cohesive vision for what they wanted, and had good relationships with consultants who provided a lot of frequent activities.

The next question, then, was does integration make a difference? Does it make a difference in how staff behavior and does it make a difference in terms of the kinds of outcomes that the programs are getting? Basically what we found is that staff from integrated programs had much higher levels of prevention-focused approaches, strengths-based services, parent involvement in services, and culturally competent services. These are based on staff reports of their behaviors. That is important to keep in mind. But they were, anyway, reporting that their program was much more likely to do these things. There were no differences, interestingly enough, in the desire for therapeutic classrooms—they all wanted them—and the perception that some children would be better served outside of Head Start. This goes to this issue of inclusion and the problem where we are still seeing—even with programs who are doing more prevention, more strengths based, more family-focused kinds of services—that they are still struggling with how to deal with these children with challenging behaviors. They are still reverting to, “Well, maybe the kid will be better off somewhere else because then I could focus on the other kids in my class more.” So that’s a challenge.

In terms of the overall program functioning, they also basically rated their programs as much smoother in terms of transition and much more positive classroom environment, less need for improvement in their services, shorter times between referrals and assessments. And importantly, they also reported that their mental health services were much more helpful in terms of supporting a variety of positive child outcomes, such as increasing positive behavior, and reducing externalizing behavior and internalizing behavior.

What we are finding is that even for controlling for the amount of consultation that programs have, programs that are able to structure their consulting relationships in ways that really integrate the mental health professional into the overall program, and how that program works and what staff are doing, seem to be more effective.

What does this say in terms of what programs can do? First, programs should require a broad range of activities. This model of bringing in a consultant to provide limited child-focused kinds of services is simply not going to be able to have much of an impact. Have consultants who are available and responsive. Even if their contracted amount of time is relatively small, have someone who is willing to work with staff on a closer one-to-one basis at least so they all know the consultant’s name and who he or she is, and that they can call them if they have a problem.

Strong leadership support for mental health. We found that programs who were higher in integration also tended to have leaders who advocated for more resources in the mental health area and who promoted a more cohesive vision of mental health across staff levels.

Written mission statements. That again goes to leadership and the importance of having programs, early childhood programs, that see mental health in this more holistic ways, that don’t see mental health as specific to children with problems, but see it as something that is a part of everything they do.

A final note, who you hire as your consultant, at least in terms of the data that we had, didn’t seem to make a difference. It didn’t matter if they were school psychologists, or working for a non-profit, or what level of education they had, or how long they had worked with the program. It was integration of the consultant and working with them to be integrated across levels of program functioning that really made a difference.

Steffen Saifer: I think there is some really important research that Beth is working on that is going to be a really great practical help, not only to Head Start programs, but all programs who work with young children. It is great that her work is setting some future
directions. How can you effectively use the money you do have, that you are putting into mental health services, better? That is the kind of information that programs need and this project is providing it. It is great to see high practical application to research.

Our next presenter is Abbey Alkon.

**Abbey Alkon**: Good morning. Today I am going to talk about two different evaluation projects. One of them is in San Francisco. We did a mental health consultation evaluation project in the late 1990’s. I am also going to talk about a statewide program that we have in California—the Child Care Health Linkages Project.

The background to our work is that we know that the prevalence of behavior problems has increased in young children. Some nationwide surveys have shown that it has been as high as 20 percent. We also know that 63 percent of 0 to 5 year old children attend child care today. We know that prevention efforts are important and that child care staff can really help us identify children with behavior problems. We also know that early identification of problems can hopefully lead to a decrease in the incidence of these problems for adolescents.

The San Francisco mental health consultation project was called Early Childhood Mental Health Initiative. It was a program that involved four different agencies that provided mental health consultation to over 40 childcare programs. These programs served low income, ethnically diverse children ages 0 to 5 years old. It was funded and supported by the Miriam and Peter Hass Fund in San Francisco. The goals of this initiative were to enhance children’s emotional lives and social abilities, and to strengthen child care staff’s ability to work with children who have difficult behaviors.

The initiative included four different programs, and all of them had core mental health services that were similar across the agencies. They all provided supportive counseling which encouraged a relationship between the mental health providers and child care staff. There were some differences across these four programs in terms of the intensity, the duration and the number of sites that they served.

The research questions that I will be addressing in this evaluation study were, “what were the most common mental health consultation activities?” “Does mental health consultation improve teachers’ level of competence?” “Is the duration of mental health consultation services associated with teacher turnover, center quality, or teacher’s self-efficacy?” In a more qualitative way, we wanted to know how the child care staff think the mental consultant’s services changed the care at their centers.

Our study design was over one year. It included 25 centers and 14 of those centers had never had mental health consultation before. At Time 1 and Time 2 we had interviews of the directors and administrators. We did center observations, which included a quality measure, the Early Childhood Environment Rating Scale. We have surveys that the directors and teachers completed on demographic information, activities of the consultants. One was called a Goal Achievement Scale, which told us how much change happened during the mental health consultant’s time in the center. The other was a teacher opinion survey which looked at teacher self-efficacy, or their sense of competence in this area. We also conducted focus groups with the teachers and the consultants. At Time 2 we added some case studies.

I’m going to talk about some of the results now. In terms of our teacher demographics, most of the teachers were female. The average number of years they worked in child care was about 10. The mean number of years that they worked at the particular center where we were studying this evaluation was about 6. Another question that we asked on this survey was we just wanted to know about the number of children that the teachers were worried about in their class to get a sense of their concerns about kid’s social and emotional problems. The average in the classroom was about 5. Our results also showed that the most common consultation activities, as reported by teachers and directors, were in this order: first, it was observing children; next, consulting with the director;
followed by consulting with individual teachers. Then came meeting with individual families, participating in staff meetings, and consulting with groups or teams of staff.

In terms of the teacher’s level of competence, it was reported that they had an improved understanding of children’s difficult behaviors based on the intervention. They also had an improved understanding of children’s social and emotional development. And they were able to work more effectively with parents. Some areas that they felt they still needed to improve after the one-year evaluation were they still needed to know about referrals to mental health agencies, and they wanted more knowledge and comfort in referring children and families. They also wanted to see some more improvements in their work environment, particularly the degree of supervision and support from their directors.

Another result was the teachers’ self-efficacy improved. And here [Figure 1, below] you can see at Time 1 the score was lower than at Time 2. This showed that the teachers felt more competent in managing challenging behaviors.

**Figure 1. Results: Teacher’s Self Efficacy Improved**

![Chart showing self-efficacy scores](chart.jpg)

Next, I will just highlight three of the items in this scale that changed over time. The way it was written on the form was, “There are some children in my classroom that I simply cannot have any influence on.” The change was in the positive direction by Time 2, and it was significant for the 35 teachers that filled out this form. The next one is, “As a preschool teacher, I can’t really do much because the way a child develops depends mostly on what goes on at home.” That also significantly changed in the positive direction. The last one I felt was actually even more important. It says, “I feel a sense of hopelessness about the future of the children that I work with.” Luckily, with this intervention, there was a positive increase in people feeling better about this from Time 1 to Time 2.

Now I’ll talk about the duration of services. What we looked at was the length of mental health consultation. It was associated with lower teacher turnover rates, positive changes in center quality and an increase in the teacher’s self-efficacy. The way we looked at duration of mental health consultation was really that the significance happened when mental health consultation was involved in that center for over one year. So the centers that had consultation less than a year did not have these significant changes.

In the more qualitative ways with focus groups and interviews, we asked how the teachers felt they changed based on mental health consultation. They felt they had a greater curiosity and empathy about behavior, even when the behavior was difficult to manage. They developed new skills, in particular in observing, assessing, and planning, and they were taking more responsibility for changes in the classroom. So our conclusions are that the effective consultation was really positive for the child care staff. Mental health consultation improved several different aspects of the center life. Teacher turnover rates, center quality, and the teacher’s increased self-efficacy skills.

We conclude from these findings that mental health consultation is needed, but we know that it is not always available in most child care facilities, at least in the Bay Area and San Francisco. Mental health consultation improves the quality of child care centers. Children’s emotional and behavioral development is enhanced in high quality centers. So we hope that we can have more mental health consultation so we can improve the quality in general of our child care centers.

Now I’d like to talk about a statewide program that I am presently involved with on health consultation, which includes both the physical and mental health. I
am the director of the California Child Care Health Program, which is located in Oakland, and serves statewide programs in the state of California. I work with an interdisciplinary team of nurses, physicians, child care providers, researchers and administrators. The website [http://www.ucsfchildcarehealth.org/] is there if you want more information. There is a lot of information there that you can download for free on health and safety for providers and parents.

I am going to focus the rest of my talk on the Child Care Health Linkages Project, which is a statewide project. In particularly I am going to target the information we’ve learned about children’s health and behavior.

The background to this study is that children in out-of-home child care have more illnesses than children cared for at home. We also know that many child care facilities do not comply with the National Health and Safety Performance Standards. These are standards that have recently been revised in 2002, and are recommendations from the American Public Health Association and the American Academy of Pediatrics, to try and improve the health and safety in all child care centers in the country. We also know that child care health consultation is a new role for health professionals. There are few child care programs associated with child care health consultants in California. Evaluations of health consultation programs are needed.

The purposes of the Child Care Health Linkages Project is to improve the health and safety of young children attending child care facilities in 20 counties in California by providing county-level health consultation services. This project is funded by First Five California, which is a proposition that is taxed on our cigarettes to help fund services for 0 to 5 year olds. The key components of this project are education, service, and research. The education component is that we have a California Training Institute where we provide standardized training for child care health consultants, child care health advocates. Some of the content covered includes scope of practice, regulations, research, cultural competence, and many other topics.

I just want to explain a little bit about what is a child care health consultant. It is a health professional, many times a nurse, sometimes a physician or health educator, who provides guidance and technical assistance to child care providers in health and safety issues in child care. Their activities include on-site assessments, advice and other things.

The next slide talks about the service. We fund 20 county health consultation programs, and provide technical assistance to the staff, which is phone consultation, strategic planning, and resources and project management. The child care health consultant focus is broad. The consultants will make sure the children have medical homes, health insurance, immunizations, oral health, and you can see, last, but not least, we have social and behavioral health problems. So it is one of many priorities that is important to the child care health consultants program.

Our research goals for this project are to evaluate the California Training Institute, describe the health consultants’ roles and responsibilities, describe the county-level health consultation programs, evaluate changes in the children’s health status, and to monitor the child care facility’s compliance with the key National Health and Safety Performance Standards.

In terms of what I want to talk about today on behavioral health goals, what we wanted to do is identify behavioral health themes within the Linkages study, using qualitative and quantitative methods, and describe the behavioral health concerns and priorities of child care and health professionals. Briefly, just to say, in our study design we included health consultants, child care directors and administrators. In terms of the behavioral health concerns that the child care consultants said were most common that they were dealing with at the child care center were concerns about aggression, biting, bullying and hitting, social relationships, disobedient and defiant behavior, internalizing behaviors with shy and withdrawn children, and children with clinically diagnosed problems.

The results of our qualitative focus groups and interviews show that there were three themes that
arose from the consultants and the directors in terms of behavioral health. The first theme is physical health and behavior. Hearing and vision problems can be misinterpreted as behavior programs. Second, the child care provider needs guidance. Providers are not certain what to do when a child has a challenging behavior. Immediate assistance is needed. We need more training to manage children with behavior problems. The third theme is individual children’s needs, where the child care health consultant sometimes conducts individual behavioral assessments and provides referrals to mental health services for children with behavior problems. They said we need trained health professionals in child care to provide mental health services and facilitate communication with parents about behavior problems. From one of our surveys to the administrators, we asked the question, “What are the health problems you are most concerned about for children in child care?” and 78 percent chose behavioral/ emotional problems for infants and toddlers, 94 percent chose behavioral/ emotional problems for 3 to 5 year-olds.

Just to share some quotes from the child care providers and health consultants on the first theme, which is physical health or behavior, one child care provider said, “The majority of the children who have speech problems also have behavior problems.” The health consultant said, “His behavior is not because he is a bad kid. It is because he can’t hear you.” Child care provider needs was another theme. One child care provider said, “I’m not a trained person to handle children who have severe behavior issues.” The health consultant said, “Providers are screaming for help in managing behavior, because it is the burr under the saddle. It is the thing that causes them a lot of grief.”

Our conclusions are: The child care providers, health consultants and child care administrators are concerned about children with behavior problems in child care. Child care providers want help working with children with behavioral problems. There is a lack of available, accessible mental health resources for children 0 to 5 years old in California. The implications of this work is that mental health professionals are needed to support and guide child care providers working with children with behavior problems, to consult with child care health consultants and child care providers, to provide direct services for some children ages 0 to 5, to empower child care staff to identify children at risk for behavioral and emotional problems, and to provide training for child care and health professionals on behavioral health issues. Thank you.
The reason that we decided to do this project was that we found through working with caregivers who had children with emotional or behavioral challenges, that one of the biggest challenges was finding child care. It was very difficult. Arthur Emlen of our Institute had done a survey of over 800 parents, and a high percent of these parents had children with emotional or behavioral challenges. Those that did found that child care arrangements were less stable, of lower quality, and the children with emotional or behavioral challenges were 20 times more likely to be asked to leave, to be expelled, in common parlance, kicked out of the child care centers. That was a relatively distressing finding for us all. So we aimed to find child care centers that successfully included children with emotional or behavioral challenges alongside children who were typically developing, that were inclusive, family-centered, culturally appropriate and high quality in their services.

We used the inclusion definition offered by special educators Kontos, Moore and Georgetti and adapted it. What we wanted to see were centers where children with emotional or behavioral challenges received a whole range of services along side their typically developing peers, and that they got to participate in all the activities that their peers did, but maybe those activities were slightly modified. We also looked for family support. What was it that these centers did that helped the families? We used the constellation of formal and informal services and tangible goods that are determined by families, the Federation of Families definition, to talk about family support in this study.

So what did we do? First of all we asked family support organizations, state-level child care administrators, and heads of child care resource and referral networks throughout the United States if they knew of programs that did this successfully. We had 109 nominations, which was wonderful. We used an advisory committee of family members, child care experts, researchers and children’s mental health practitioners to choose nine of these programs. We used a qualitative method approach where we went out and observed and we did interviews with parents and with other family members, as well as the directors and the center staff. You can see that they are scattered throughout the United States. You will see [below] that the five centers that we visited were actually from coast to coast. On the next slide [below] you can see that for additional centers that we contacted people through the telephone and did telephone interviews. The next slide [below] shows the entire set of participants—9
directors, 40 staff, 40 family members, and 25 children who were observed interacting with staff and peers.

What did we find? Well, we found a number of things. Today I am just going to be hitting the highlights of two of these. Jennifer Bradley and her group will be talking about family support and how the families were worked with in a session after this one. If we can talk about inclusion philosophy, this was shared by the directors and the staff. They believed in these principles. All of the directors and 29 of the staff—even though they weren't asked, “What is your philosophy?”—talked about the ways they approach children. I'm not going to read all the quotes from them, but you can take them away from you on this sheet where the PowerPoint is. But just to let you know that they established an inclusion mindset. To be able to work in these centers, you had to believe in this. If you didn't believe in this, your job was terminated. So they bought into this. They communicated this to every staff member, including those people who drove the kids around and those people that made the lunches.

The first and most important principle was to value and accept all children, regardless of their abilities or challenges. They simply accepted those children that walked in the front door with their families. They provided a natural environment for care, which meant that if they were going to give services to the children that were mental health services, it was done on the playground, or in the classroom for the most part. A few of the centers still had people that gave pull-out services—individual one-on-one services—but they tried to have people come in and give it on the floor with the kids. They adapted the program to meet the individual needs of the child. They all said—all the directors—“We do not change the child to meet the program. We change the program to meet the child.”

The fourth was also that they developed and delivered family-centered services. They made it clear, “You can’t really serve the needs of the whole child unless you really try to meet the needs of the family as well.” So they were clear about this. The fifth thing that they all bought into was that they wanted the families and children to have success. One of the directors said, “You tell the parents three positive things that happened before you say anything negative about the child.” They wanted people to know their children were succeeding at least in part.

How did they put inclusion into practice? They devised what I called promotion strategies and transformation strategies. Some things were clearly to develop good social and emotional skills. Some things were clearly to handle negative emotions and negative behaviors. That chart that you have in the handout [Editor's note: please see complementary handout], that will be in our monograph, looks at what the adults did, what the peers did, and then lastly how they changed the environment. I am just going to be talking today about what the adults did. I will give you the nine strategies of each of those very briefly.

The first one is to **build a relationship with the individual child**—especially children with emotional and behavioral challenges—very, very well. Develop that bond, because the child will test the bond.

The second thing is to **team with family members**. Determine what does a family want for the child, what are their goals for the child. Learn about the child’s home culture and make the child care center conform to the home culture rather than expecting the child to fit into the child care’s cultural center.

The third strategy is to **work from knowledge about individual children**. The parents are the experts. They see the child the most. The family members do. So they learn from the family members and they also got consultation with individual children.

The fourth strategy was to **build a developmentally appropriate curriculum**. I would just like to briefly talk about what one very experienced special educator who worked in a wonderful child care center did. She talked about doing circle time. They did exercises like deciding what they would put in soup. She said, “Here are some dry noodles for everybody, all the way around the circle, and then gives the antsy ones something that they can legitimately fiddle with while we are making the list of what needs to go into the soup.” The kids with behavioral challenges are focused...
because it is hands-on. So they adapted that notion of talking and contributing so that it would be useful for the kids with emotional or behavioral challenges.

The next one is balancing consistency with flexibility. So designing a consistent, predictable environment while maintaining flexibility.

[The sixth strategy is] assisting children to stay safe and calm. This was critical. The children had to feel safe. This came up over and over again. Many times the aggressive behavior was them feeling unsafe. So they taught self-soothing behaviors, and they let the child remove themselves to a quiet space.

They also used multiple sensory channels. Drawing pictures out to show what the behavior was that was the good behavior, the accepted behavior, within that setting, using physical guidance, touching the child to keep the child focused.

A strategy was supporting the children through times of transition, sometimes removing them before and inserting them back in the classroom after transitions. Giving them transitional objects to take home with them so that the time of leaving wasn’t traumatic.

The ninth strategy—promoting social and emotional development as necessary for learning.

The next set of strategies were aimed at dealing with difficult behavior.

They engaged in pre-emptive planning. They looked ahead. They knew when stormy clouds were arising and they changed the environment around the child to short circuit negative behaviors.

The second strategy was to use consultation to develop formal and informal supports. We have heard a lot about that this morning.

The third strategy was to assist the child to use verbal self-expression. All behavior communicates, and in fact, many of the children just needed language help. They also taught the children to use signs rather than scratching and biting to get what they needed if they had low verbal skills.

To substitute more appropriate behavior, many people used art as a vehicle of expression. They used drawings to illustrate desired behavior.

They fostered problem solving in children and sometimes that had tremendously positive affects on children, as you can see from this example.

They employed redirection, so when a child was distressed, they redirected to new physical activity or mental activity.

They focused attention appropriately. That is, they focused not on the negative behaviors, but on positive behaviors. So if a child slugged another child, they focused on the victim. “Oh, you are very distressed, but you are handling it so well,” ignoring the child that did the negative behaviors.

The eighth thing was they had to plan for the safety of the children. This does not work if the parents of all children don’t feel their child is safe. So there were safety plans, acknowledging the individual needs of children.

The ninth strategy was to work as a team to address negative behaviors. One of the staff members said you have to bring in fresh patience. Fresh patience was really critical. They also met as a team and they confessed to each other that they were losing it, that they were not able to handle certain children. They bring in another staff member when they need it and they plan together and they work with the parents.

Finally, then, these next slides show just a boy with uncontrolled behavior was stopped in his tracks, literally, by teaching the peers how to handle that behavior. I hope that you will get a chance to read this in the slides.

The next one was a girl who was not able to go to kindergarten because she couldn’t look adults in the face and she would not talk to anyone except her parents. She was brought to the child care center and a wonderful teacher who we observed working with art, got the girl to start talking about her art and worked so that she felt safe, she started revealing her inner feelings, and she was able at the end to talk to anyone. But it was a really remarkable experience for this
woman, who felt privileged to engage in it, and in fact, this woman was trained as an art teacher and did not have any mental health training, but she was able to do this with this child.

So what are the implications of this study? That you can care for children with pretty serious emotional or behavioral challenges alongside typically developing children. This is safe and it is good for the typically developing children who know how to work in a real world environment when they leave the child care center.

The second thing is it is crucial to adopt a staff philosophy that we will care for all children and we will embrace inclusion.

Thirdly, that inclusive care required creative and innovative practice based on knowledge of individual children and their family, and on consultation with mental health service providers and solid staff development. The training has to be there.

Then lastly, family support needs to be a part of the services offered in an inclusive center, in some ways almost the heart of the services, because the children cannot succeed if the families are not getting their needs met.

I thank you very much and am looking forward to hearing Glen Dunlap’s presentation.

Steffen Saifer: Thank you, Eileen. We got some great, practical specific information about what front-line early childhood teachers do to help children with challenging behaviors. Wonderful examples. We will let Glen get ready to go.

Glen Dunlap: Actually I will be really quick. I have a meeting at 10:15. I am going to take a look. Maybe the person I’m meeting with is here. Eloise Boterf, are you here? I’m going to have to go really quick then. Actually I hope she will understand. It is probably not the first time that a general session has gone over a bit. I do appreciate your patience. You have been here for some time. You are actually attending and all that kind of stuff. I really like that a lot. I hate to be up here presenting to empty tables. So could somebody get these tables out of here—this one, that one, that one. And bailiff, could you bar the door.

This is a real pleasure for me to be back in Oregon. I lived in Oregon for a year some time ago, and I remember most of the time—I love the sun, you see—I lived in Eugene and drive up the McKenzie Highway and go over the crest of the mountains and sit in Sisters or Bend and see places where it is always sunny. And here it is sunny now, which is great. Maybe I will move back. This is nice.

Your handout pertinent to this session, which I will make brief, is the yellow one. That has the slides. Actually it has some of the slides and it has some repeated including the data slide on the back pages enlarged thanks to the clever person who was responsible for this.

Lyn, thank you.

On the white handout [at the end of this article], which has the resources, I would like to point out the ones that I want to refer you to if you are interested in this kind of thing. Under the websites on the first page, the first two websites are pertinent. Those are websites that I either manage or my folks do. They have information relevant to the content that I am presenting. Further down, the OSEP [Office of Special Education Programs Technical Assistance] Center on Positive Behavior Interventions and Supports, that also includes material that I will be sharing. Then a little further down, the Research and Training Center on Positive Behavior Support, that is a key one.

If you flip over, the articles—this is not a coincidence—that have Dunlap in them, those are related to the content that I am going to share with you. So if you look for Dunlap and also Fox—my close colleague Lise Fox has done a lot of the work. Then further down there is a book by Lucyshyn and colleagues, which is titled Families and Positive Behavior Supports, so that title might be a clue that it is relevant to what we are talking about and to this conference.

The case study that I was going to share with you, which I will not share with you, but I will share some
pictures, and maybe some real big messages, is presented in this book. There is a chapter written by the mother and by Lise Fox and by myself which describes the case study. That is important stuff.

Here’s my plan. I want to talk generally about what positive behavior support is and then talk about what positive behavior support with young children is. Here I was going to do a case study, but I’ll just whip through that pretty quickly and then sum up. If you are still here and we have time for questions, that would be wonderful. I’m really just going to hit big points, no details here, because I have just been blowing too much time talking about tables and barring the door and things like that. So here is the definition of positive behavior support.

Positive behavior support is a values-based, empirically valid—meaning it is research-based—approach that is derived from social, behavioral and biomedical science—meaning it is not aligned strictly with one specific conceptual orientation but rather draws upon a multiplicity of frameworks that are values-based, and that include hard data that we can replicate. Finally it is for resolving problem behaviors and helping people lead enhanced lifestyles. Yes, it is focused on challenging behaviors and challenges in behavioral adaptation in general, but the goal is to help people lead better, enhanced, and more satisfying lives.

Some procedural features of positive behavioral support: Usually when I present on positive behavior support to folks who don’t know it very well, the first question is, “What does it look like.” Can you show me a videotape of this technique? It is not a technique, it is a process. That is a very, very important distinction. It is a process that is based on an individualized understanding of the individual and the context in which she lives and interacts and behaves. The understanding is obtained through a process of functional assessment and person-centered planning. Positive behavior support uses multiple components from a behavior support plan that is derived on an individual basis from the assessment process. Those multiple components are many, many different things. The behavior support plans includes like where you provide interventions and support, when you do it, how you do it. It usually means to build competence through instruction so that people don’t need the challenging behaviors and then redesigning the environment so as to help prevent the occurrence of challenging behaviors to make it more nice for the person who is challenges with these problem behaviors. Finally, as I said before, the goal is to build skills, relationships, resilience, quality of life, and secondarily to reduce the occurrence of challenging behaviors.

Historical foundations: Positive behavioral support sort of emerged in the mid-1980’s to late 1980’s, principally as a function of painful aversive stimuli being applied to individuals with severe disabilities. This evoked lots of understandable concern from advocates and family members and some professionals. So this was a major inspiration. But at the same time, the movements of deinstitutionalization and least restrictive environment were becoming prominent and these kinds of intrusive, painful, stigmatizing interventions were just not allowed in general education class, or in McDonald’s, or in libraries, or anywhere else that we all live. Then there was also research contributing to a functional understanding of problem behavior.

Conceptual foundations: A lot of the foundational intervention strategies are based on applied behavior analysis and instrumental learning there, but also humanistic psychology and philosophy, person-centered values, and an ecological perspective. And then a pragmatism and an appreciation for multiple disciplines and multiple methods of investigation and intervention. Positive behavior support has been sort of exploding in many ways. There have been literally hundreds of published research studies in the last 15 years, primarily using case study methods, single subject experimental designs, and qualitative methods of inquiry. But we have also seen the principles and procedures are established in federal and state laws, including IDEA—although we are waiting to see what happens with that—federal and state funding initiatives to develop community capacity in positive behavior support and as I said, many research articles

Saturday Plenary
Promoting Children’s Mental Health in Early Childhood Settings
in journals including the *Journal of Positive Behavior Interventions*. If you would like information on this I would be delighted to share it with you.

Here we are in terms of positive behavior support. First of all since the mid-1980’s, positive behavior support has expanded greatly from populations that were principally folks with developmental disabilities to include children who are identified as having emotional and behavioral disorders and severe or serious emotional disturbances, general education students, and young children and early intervention. A lot has been going on there. Initiatives in most state now exist to build capacity in functional assessment and positive behavior support. It is beyond the individual level. I’m not going to talk about that, but if you go to these websites you can learn about that. Many efforts to integrate positive behavior support into additional systems, including mental health systems, child protection systems, and so on. These are some websites. We are involved with these. All of these have downloadable information. They are on your handout, so let’s go on to the next one.

I want to spend just moment with this and turn now to positive behavior support with young kids. We are really focusing in the needs of those few kids, maybe five per classroom, maybe three per classroom, maybe two, who present with the kinds of challenging behaviors like tantrums and biting and resistance and elopement and all kinds of stuff that drive teachers, caregivers, therapists, family members nuts, and they don’t seem to be resolved with the universal and secondary kinds of prevention efforts. But we also like to emphasis this model, or this triangle, [see facing page].

At the bottom you see building positive relationships. That is universal prevention. Many, many children don’t display challenging behavior as long as they have positive relationships with adults, with parents and with peers. This is universal and we need to start there. We don’t like to talk about individualized interventions without ensuring that we have a basis of positive relationships in place. Next, classroom preventive practices—Eileen talked a lot about this—having classrooms in the right way. Next, social and emotional teaching strategies. These are targeted group interventions. There are many good ones out there. Caroline Webster Stratton’s fine work and Incredible Years curriculum, Hill Walker’s on First Steps to Success and so on. These are like targeted group kinds of things. But then you get to those few kids who are really pushing the buttons and for whom these other programs don’t work. These are kids who need more individualized and more intensive kinds of interventions. These are the kids for whom we are focused in regards to positive behavior support. I am going to not spend time here, but the positive behavior support components, these are in the articles—comprehensive assessments, team building, person-centered planning. If you are not familiar with person-centered planning—I suspect that most of you are—it is an incredibly powerful strategy for building teams and supporting families and supporting kids and building a unified vision and a unified approach. Our families buy into it. This [facing page] is a picture of an invitation that some parents put together for persons that are planning a meeting around their son Mikey. If you get a big magnifying glass you might be able to read it in your handout.

Functional assessment: That goes to a big comprehensive behavior support plan, including communication-based interventions and family support and many other components. It is also followed by issues with respect to longitudinal support. This is the case I am not going to share. Again, if you are interested I can send you materials and you can look on websites. We have some stuff on Joe and he is in this book. Nila is Joe’s mother and you will see a picture of her soon. I show this and my evaluations usually go up a bit.

Actually if I had the foresight and the funds, I would have brought Nila and Benito with me, because whenever I present with her—and I do often, every chance I get—my evaluations go through the roof. You can see this case study. Isn’t it fascinating? It is really good. I love all the detail that I’m sharing with you. The support plan was actually many pages. It is reproduced in this book that I mentioned to you. If
Figure 2. Model of Prévention and Intervention for Challenging Behaviors

Mikey's Invitation

On May 2, 2001, my mommy and daddy are inviting you to dinner and a meeting. Dinner starts at 6:15 pm and the meeting will start at 7:00 pm. The meeting is about me. The fancy title of the meeting is Person Centered Planning.

Mommy and daddy want to develop a plan that will help me and them. You're a special part of my life so you're included in the plan. So please come. You will get some yummy food and you will learn lots about me and how you can help.

Some really neat people from C.A.R.D. (Center for Autism and Related Disabilities) are going to be helping us all out. They work at the University of South Florida.

Mommy and daddy want you to try to be on time 'cause there is lots to talk about. Oh, please call mommy or daddy if you need directions or have any questions. Our number is [redacted]

I'll see you at the meeting,

Mikey
you are really interested in this, I can send you information about it.

This is a research session so there is data. This [Figure 3, below] shows his tantrums in child care. He was about to be booted out of child care and then at home, on the abscissa (the horizontal axis) are days, and the vertical axis (the ordinate) presents number of tantrums per day. So you can see that good things are happening with Joe.

**Figure 3. Case Study: Tantrums in Child Care and at Home**

This is happening back in 1996, I think. Family support—they had real extended family issues which was a huge, huge priority for this big Italian family. Self-advocacy was a big thing, and Nila had become about the most effective self-advocate that I’ve worked with, and I’ve worked with many. Respite and in-home assistance, these were key features of the family support plan. This is a picture, and here is another picture. This is Joe later when he went to his family to Cozamel for a vacation, which had been a dream of theirs on the person-centered plan when we first started working—to be able to go as a family on vacation was a big deal. They went and they were all smiles. Joe is now 10 years old and he is included in his general education classroom. He has autism, but he communicates and he gets along with his peers and most importantly with his family.

Let me quickly sum up in 10 seconds or 20 seconds. Right now we have about 50 or 60 studies that have been published using positive behavior support with young kids. By young kids I am talking about 3, 4, and 5-year-olds. We don’t have too much with toddlers. It is mainly with preschoolers, not surprisingly. But that is being changed. There is more work being conducted now with toddlers. We are also involved with a lot of development efforts to integrate positive behavior support approaches within full community systems, including early childhood mental health systems, as well as to look at positive behavior support as a mechanism for helping entire programs, like early childhood centers and things like this. We are working on that right how. In Tampa, in Hillsborough County, we have a really exciting partnership developing and some federal research moneys to help evaluate it and do research on it. I hope that at a subsequent conference I will have some more data to share with you. Thank you very, very much.

**Steffen Saifer:** Well, my evaluations of you are very high, even without your partners. I’m sorry we ran a little bit late. Most of us are doing presentations afterwards, so you will have an opportunity, we are going to be around. Please ask us questions. One last hand for the whole panel. Thank you very much for hanging in there.

Editors’ note: Slides from these presentations can be viewed on the Portland Research & Training Center website at [http://www.rtc.pdx.edu/pgConfProc.shtml](http://www.rtc.pdx.edu/pgConfProc.shtml)
RESOURCES
PROMOTING CHILDREN'S MENTAL HEATH IN EARLY CHILDHOOD SETTINGS
BUILDING ON FAMILY STRENGTHS
CONFERENCE, PORTLAND, JUNE 2003

Selected Resources from the Panel: Steffen Saifer, NWREL; Beth Green, NPC Research; Abbey Alkon, UCSF; Eileen Brennan, PSU; Glen Dunlap, USF

Center on Evidence-based Practice: Young Children with Challenging Behavior.
http://www.challengingbehavior.org/

Center on the Social and Emotional Foundations for Early Learning
http://csefel.uiuc.edu/

The Child Care Bureau. Comprehensive information regarding child care policy and research in the United States is available at this web address, including recent initiatives in the mental health area. Includes links to specialized websites on afterschool care, child care information, and child care program and research initiatives.
http://www.acf.hhs.gov/programs/ccb/

A Good Beginning: Sending America's Children to School with the Social and Emotional Competence They Need to Succeed. The Child Mental Health Foundations and Agencies Network (FAN).

Healthy Child Care America. Web materials for family members, child care providers, and providers of professional services are available on this site which is sponsored by the American Academy of Pediatrics. The Healthy Child Care 2000 national campaign included action steps to improve children's mental health.
http://www.healthychildcare.org/

http://www.surgeongeneral.gov/library/mentalhealth/toc.html#chapter3

The National Center for Children in Poverty. This website includes many important publications regarding the Center's research, aimed at improving the situation of children and families who live in poverty. Important studies involving children's mental health are available.
http://www.nccp.org/

http://www.nimh.nih.gov/childhp/goodstart.cfm

OSEP TA Center on Positive Behavior Interventions and Supports.
http://www.pbis.org/

Project SUCCEED in Head Start.
http://www.rri.pdx.edu/pgProjectSUCCEED.shtm

Research and Training Center on Family Support and Children's Mental Health. Our website features research projects focusing on early childhood mental health and family support, and provides links to summaries of key research studies and mental health websites.
http://www rtc.pdx.edu/

Research and Training Center on Positive Behavior Support.
http://www.rrtcpbs.org/

Zero to Three. This organization which promotes optimal development in the early years maintains a website for families and care providers that has important information concerning infant mental health.
http://www.zerotothree.org/


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Authentic Parent-Professional Collaboration in Defining and Evaluating Children’s Mental Health Service Needs

PURPOSE AND BACKGROUND

The purpose of this study was to develop further a research methodology that includes as partners the parents of children with severe emotional and behavioral disorders (SEBD) in Louisiana. This project was part of an ongoing research collaborative between the Louisiana Office of Mental Health and the Tulane University School of Social Work. The Louisiana Office of Mental Health has a strong commitment to parent-professional partnerships in evaluation.

The needs of children with SEBD and their families have been a major focus of concern nationally over the past two decades. In the Report of the Surgeon General’s Conference on Children’s Mental Health (Department of Health and Human Services, 2000), both the need to involve families in mental health services and the importance of improving assessment of children’s mental health needs are identified as major components of the National Action Agenda. Determining which services meet particular needs has been a long-standing problem in mental health practices. All too often, services and practices are assigned, in a general sense, to children with SEBD and their families rather than tailored to the needs identified by the families themselves.

Defining needs is one of the great challenges in mental health practices and service delivery. Traditionally, mental health professionals have defined the needs of the people they serve, and their perspectives take precedence over the expertise of parents and families. In this standard approach to practice, the voices of families are relegated to the margins, and they may
become passive recipients of “professional” recommendations about their needs rather than active partners. Consistent with the system of care philosophy (Simpson, Jivanjee, Koroloff, Doerfler, and Garcia, 2001) that emphasizes a collaborative approach at all service levels, this study aimed to access the collective voice of parents through using a parent-run focus group methodology for defining mental health service needs. This qualitative data was then used in the development of a survey to gather information about service needs from a larger parent constituent group. The parent team was trained and worked to develop the survey, gather data, and interpret the research findings.

**METHODOLOGY**

With an investment in understanding more fully parent perspectives on the service needs of children and families, the aim of this study was to bring parent voices into the forefront by developing methods for “authentic” collaboration, or parent-driven evaluation, in the process of constructing a new survey. In this approach, parent knowledge and expertise are central. Parents were involved in the process of defining, conceptualizing, and evaluating mental health service needs. Three parent service recipients in southern Louisiana were hired and paid to work on the research team through all phases of the study.

The procedures for the study were based on an adaptation of a Participatory Action Research (PAR) model in which “subjects” are also participants (Rogers & Palmer-Erbs, 1994). Chesler (1991) notes that PAR approaches are consistent with the ideology of self-help, which emphasizes “highly participatory membership, a professional leadership, local and grass roots orientation and respect for experience-based knowledge”. PAR principles are consistent with the system of care philosophy (Simpson, Jivanjee, Koroloff, Doerfler, and Garcia, 2001) which emphasizes the importance of partnerships with families. Through the use of PAR methods, parents become insiders to the research and their perspectives and experiences drive the process.

The work for this project began with the parent team meeting regularly to “brainstorm” items to potentially include on a service needs survey. The team was then trained in focus group methods and worked with this researcher to conduct a focus group to gather qualitative data from other parents. The team analyzed this data using content analysis techniques to condense and make meaning of the data. The findings were utilized to validate or modify existing items, and to generate new items for the survey. The result of this process was the development of the Services-Needs-Utilization-Gaps Survey (SNUG).

**DESCRIPTION OF THE SNUG SURVEY AND FIELD TESTING**

The SNUG consisted of 62 items each reflecting a need as defined by the parent team and focus group participants. These items were organized across ten higher order categories of need: five of these domains focused on child needs and five reflected parent needs. For each item, there were two corresponding 4-point Likert scales, one to indicate “how much is needed” and the other to indicate “how much need is now met”.

**Example:**

<table>
<thead>
<tr>
<th>Mental Health Needs</th>
<th>How Much I Need</th>
<th>How Much Need Is Now Met</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual counseling to help me handle my own feelings and stresses related to caring for my child</td>
<td>N/A 0 1 2 3</td>
<td>N/A 0 1 2 3</td>
</tr>
</tbody>
</table>

[Note: N/A=Not applicable; 0=Not at all; 1=A little; 2=Moderately; 3=A lot]

Once the survey was constructed and formatted, it was distributed to other parents, professionals, and experienced researchers for review and feedback. The team made some modifications to the survey based on suggestions made by people who were outside of the process.
The parent team underwent a half-day training session in survey methods, using the SNUG specifically in the process, as part of the preparation for the field-testing phase. Although the survey was to be completed by individuals alone without using an interview format, it was expected that some respondents would need assistance in the process. The training focused on the acquisition of a range of skills for administering surveys, including instruction on issues such as approaching a potential respondent while respecting a person’s refusal to participate, sensitizing to matters of confidentiality, supporting and assisting participants with completing the survey without steering their responses and data organization and management. The training session utilized methods such as didactic instruction, open discussion, and role-playing.

Sixty parents/caregivers whose children utilized state services in several southern Louisiana community mental health centers were asked to complete a survey when they came in for their scheduled appointments. The participants were recruited into one of two groups: the “intake” group, for those families entering the clinic for services for the first time, and the “in-service” group, for families who had been receiving services for at least six months. The primary caretaker for the child service recipient was the person approached to complete a survey by one of the parent evaluation team members. Once the study was explained and the individual agreed to complete a survey, written consent was obtained along with the completion of a non-identifying demographic dataform, followed by the survey.

**SNUG DATA ANALYSIS AND GENERAL FINDINGS**

The SNUG data were analyzed using several statistical methods. Analysis of Variance (ANOVA) was conducted to compare the mean responses of the two groups. In addition, frequency analyses were used to examine in more detail the patterns of responses of the two participant groups. Correlations were calculated as part of a preliminary factor analysis to examine the strengths of the relationships among the survey domains, to ascertain the possibility that responses in one domain could predict responses on another, and to explore factors that might explain interrelationships among the categories. The primary purpose of this data analysis was to gather preliminary information about the reliability, validity and the usability of the SNUG survey to be utilized in refining the survey later.

The study findings provide preliminary support for the reliability and validity of the SNUG survey. The ANOVA results revealed that there were significant differences in the responses of the two groups. The intake group indicated high levels of need as they entered services and revealed that their needs were met at a very low level; the in-service group indicated that while level of need was still experienced as high, they felt that their needs were met at a high level. The frequency analysis supported this major finding indicating that the SNUG was sensitive enough to detect differences between the two groups. Further, the differences between the groups were in an expectable direction. The correlation findings were also informative with numerous significant correlations between domains (correlations >.60 were noted as significant). This suggested that there was cohesion in meaning among the survey categories, implying that the information obtained from the SNUG was relevant to mental health services and parent concerns. These findings also serve the further development of the SNUG by providing a starting point for identifying areas of redundancy on the survey and informing ways to condense some of the domains.

**BRIEF REFLECTIONS ON THE RESEARCH PROCESS**

The study procedures were driven primarily by the parent team and much support was provided throughout the process. While the parent team had no prior research experience, their skills, knowledge, and expertise as parents of children with SEBD provided the foundation for their work. Parent-driven research using PAR methods requires that researchers relinquish the authority they are trained to exert over
the process and share it with parents while still offering guidance, support, and training. The role of the researcher in part becomes that of a process facilitator, helping parents to develop their own skills and a sense of ownership over the research. This facilitation role is a difficult one to enact consistently in the most authentic sense. For some aspects of this project, there was more success with this than in others.

For instance, the focus group component proved to be much more compelling and interesting for the parents, and they were able to take ownership of most of the aspects of this process more readily. Once they had the training and felt secure in what needed to be done and how, the tasks involved in the planning an implementation unfolded easily. In this research experience, it was evident that the focus group methodology was more “parent friendly.” The team was very enthusiastic and highly engaged in this phase of the project.

The quantitative component of the project was far less compelling to the parent team; however, they persevered and invested tremendous time and energy, even if the outcome was far less interesting to them. The reason for less interest is understandable: the data gathered from a survey is not as inspiring as the experience of hearing the actual voices, personal stories, and emotions that emerge in a focus group. The parent team felt that the development of the SNUG was anticlimactic in comparison to the experience of planning and conducting the focus group and even in comparison to the excitement they felt when analyzing the qualitative data. Once the data was gathered from the SNUG, enthusiasm waned further and the team expressed concern that this data would not spur the kind of results they wanted to see in service provision in Louisiana.

Part of the process of training parents that, in error, was given only cursory attention in this study was how to help parent researchers to feel they are part of a larger whole: that results do not happen quickly in service systems yet their efforts make a large difference in shaping the way systems conduct the business of evaluation and monitoring of services. While this was discussed at various stages of the research process, the tasks at hand often overshadowed the larger picture. In the end, the parent team did feel a sense of accomplishment for their work and a sense of competence about the skills they realized in themselves, even if it was not exactly as they expected at the outset.

The parent team members maintained active roles in the mental health system in the state following the project—as advocates, liaisons, and contacts for other parents. The parents involved in the project were supported to develop confidence about the talents and skills within them as well as the capacity to continue to use these competencies in making positive changes in their own lives. The parents were encouraged to use these skills to advocate for improvements in the mental health system and to support others in finding and using their inherent strengths.

REFERENCES


Identifying Factors that Influence Youth Violence: A Community Participates

INTRODUCTION

The High Point Youth Violence Initiative is an outgrowth of a larger community-based effort to address issues of violence in a community. High Point, North Carolina, is a city of approximately 75,000 persons with historically a strong manufacturing based economy in textiles and furniture. Over the past ten years, with shifts in the economic base and the move off-shore of much of textile and furniture manufacturing, the city has experienced an economic decline resulting in some central city neighborhoods having an unemployment rate of 33.6% (U.S. Census Bureau, 2000, Table P47), over 5½ times the national rate. High Point is reported to have lost 20-30,000 jobs in manufacturing during the 1990’s. In some neighborhoods, it is reported that over 32% of the residents reside at the federal poverty level or below.

In the mid-1990’s there was an increased incidence of violent crime in the city. Citizens responded with grave concern, resulting in the formation of several community task forces to address issues of community violence. Over time, it was acknowledged that all would benefit by combining efforts, and thus the High Point Violence Task Force was formed, led by the Chief of Police and leadership from the community hospital. Membership on this Task Force included representatives from all law enforcement entities (police department, parole officers, court officials, federal law enforcement agencies, etc.), community organizations such as the Chamber of Commerce and Family Service of the Piedmont, the City government, leaders from the faith community, the University of North Carolina at Greensboro, and concerned citizens.
Over time much attention was given to developing a community response to violence and violence prevention, resulting in a collaborative approach based upon the Boston Model of parolee call-in’s to remind persons of the need to remain crime free and to offer support services, such as referrals and assistance for housing and employment.

Recognizing that all of the adult convicted persons were “once young”, the Task Force increasingly became focused on ways to address the needs of young people, both from a crime prevention perspective and from an intervention perspective should a young person be convicted of a crime and enter into the Juvenile Justice System. Out of this focus, the High Point Youth Violence Initiative was formed.

OVERVIEW OF THE YOUTH VIOLENCE INITIATIVE

As a first step, a community-based committee was formed with similar representation of the adult-focused task force. The primary focus of the Youth Task Force was addressing preventing the escalation of violence among young persons adjudicated delinquent, so that their life trajectory was shifted and increased violent behavior did not lead them into the adult judicial system. The Center for the Study of Social Issues at UNC-Greensboro and the local collaborative for the Prevention of Youth Violence initiated an “action-research” project to intervene with middle school and high school youth that have been court-adjudicated for a violent offense. As part of the High Point Youth Violence Initiative, the collaborative successfully interviewed youth and caregivers to identify risk and protective factors, and then implemented a System of Care intervention with nearly 30 families.

FRAMEWORK OF THE VIOLENCE PREVENTION TASK FORCE

Three principles form the framework that guides the youth violence prevention and intervention efforts. First is a focus on development in context. That is, at any given stage of development, young people with unique mixes of strengths and limitations seek to master developmental tasks, and they do so in different communities and across different social contexts. Second is a concentrated emphasis on building a community-based collaborative. Violence prevention programming has seen a shift away from punitive and oftentimes fragmented approaches, to comprehensive, coordinated, community-wide solutions. In this case, the community made the choice as to which problems to address, which program models to adopt, which individuals to serve, how those services will be delivered, and how to measure effectiveness. Third, our work has stressed a family-centered approach. Families are at the core, rather than the periphery, of the planning, coordination and implementation of services. Families are not required to conform to established (and often fragmented) programmatic niches. Rather, families are central to defining their own strengths, supports, and needs for services.

DEVELOPMENT OF PROCESS TO DETERMINE SOCIAL ENVIRONMENT

The task force members determined that it would be helpful to understand the factors that influence youth people’s lives if the Task Force was to design intervention programs that could be effective for the individual youth. Bronfenbrenner’s (1986) ecological framework underscores the importance of elucidating the links between adolescent development and social context. Based upon an ecological perspective, experiences in multiple contexts (family, person, peer group, neighborhood, and schools) accompany youths’ transition into early adolescence. Although there is quantitative research that has identified risk and protective factors for violence and delinquency across multiple ecological contexts (e.g., Hawkins et al., 2000), there is a need to hear adolescents’ “everyday understandings” of their life experiences (Burton, 1997). Qualitative investigations have provided greater insight into the interplay of adolescents’ feelings and perceptions with elements of the social environment (Jarrett, 1997; Pugh-Lily et al., 2001; Reese, Nevine & Paulin, 2001)
Using an action research methodology, members of the Task Force met with researchers from UNCG to develop an ethnographic interview process for adjudicated youth in the Juvenile Justice system and their caregivers.

**ACTION RESEARCH DESIGN METHODOLOGY**

The university researchers identified and summarized for the members of the Task Force the literature on youth violence risk and protective factors to form the foundation for the interview protocol and presented it to the Task Force composed of ministers, school principals, parents, youth, university faculty and representatives from law enforcement, juvenile justice and social service agencies. The Task Force members used this information, in combination with “what they wanted to know” about the youths’ lives to develop an interview questionnaire. Key questions were developed across thematic areas such as family, school, neighborhood, peer group, and personal strengths and weaknesses.

The interview instrument was pilot-tested on two groups of middle school and high school-age youth, who were made available by a pastor on the project team. The feedback from the youth was “Be more specific” and “Ask what you want to know”. As the pastor recounted, “These youth are players…they know how to play a good game and if we do not approach them in their own language in terms they understand, they are going to take us for a real ride and we will end up with a load of data that is not worth much in the real world.”

What the members of the Task Force wanted was understanding of the problems that lead to youth violence and the context within the community in which it occurs.

**METHODOLOGY OF INTERVIEW**

Throughout the process of developing the interview questionnaire, a Ph.D. anthropologist consulted with members of the Task Force. With final decision about the interview questions, this researcher agreed to train the interviewers who were volunteers from the High Point community and thus had a common set of experiences as the interviewees. The two 2-hour training sessions were followed by a debriefing time after the initial interviews and was a resource for questions that arose from the interviewers.

The interview was arranged once a youth was adjudicated in the local court office by a Service Coordinator who was a part of the application of a System of Care valued approach of intervention for the youth and family. The caregiver and youth were invited to participate and the interviews were conducted in a place that was comfortable for the interviewee, often the family’s home.

The interviews were tape-recorded and the youth and caregiver were interviewed separately. The interviews generally lasted about one hour. 14 court-adjudicated youth (9 boys, 5 girls), ages 12-16 participated.

**DATA ANALYSIS**

Interviews were transcribed and entered into qualitative analysis software (*The Ethnograph 5.06; Seidel, 1998*). Marshall and Rossman (1999) contend that data collection and data analysis must be a simultaneous process in qualitative research, thereby allowing for a continuous emergence of codes, categories, and themes. Accordingly, coders began reading and reviewing the transcribed interview data while still in the process of collecting interview data. The constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1990) was utilized to facilitate data reduction into emerging themes and categories. Further, conceptually related cluster matrices (Miles & Huberman, 1984) were derived to assist in identifying common, as well as irregular, patterns in the data.

**RESULTS**

First- and second-level coding of the interview transcripts has revealed several patterns emerging from various domains of the adolescents’ everyday experiences. A non-exhaustive overview of emerging themes (grouped by ecological context) and verbatim excerpts from the adolescent interviews is presented below. Analyses have revealed numerous other coding
categories including drug use among friends, barriers to success, desire for someone to talk to, positive parental influences, and self-reliance.

**Neighborhood (34 text segments)**
- **Negative.** “I don’t like the neighborhood because all these people just causing all this trouble and the police every time you turn around they got to be on this neighborhood ‘cause something wrong.” (14-year-old male)
- “You walk out that door, you don’t see nothin’ but people walkin’ by, like drug dealers and prostitutes and all that…My neighborhood isn’t no good neighborhood to be in.” (15-year-old male)
- **No Opinion.** Responding to what would you change, “I couldn’t even tell you to tell you the truth, cause I be in the house all the time. The only time I step outside the door is to go to school.” (15-year-old female)
- There was little mention of neighborhood as positive and/or supportive context.

**Family (114 text segments)**
- **Negative relationship with caregiver.** “He (father) doesn’t trust me because I give him a lot of reasons not to trust me. But, I mean, I try to show him lots of reasons to trust me again and he doesn’t take them. So I don’t care if he trusts me or not anymore.” (15-year-old female)
- **Positive relationship with caregiver.** “…I get my temper and stuff from her (mother) but when I’m real upset I can talk to her. When I go through stuff, she’s somebody I can relate to, to tell me to do the right thing…” (15-year-old female)
- **Communication with family.** “Yeah, me and my mom talk, but we don’t talk as much stuff like me and my daddy do. ‘Cause, you know, my daddy a man, and I can’t talk to my mamma like I can my daddy.” (15-year-old male)

**Peers (141 text segments)**
- **Negative influence.** “…She smoked weed and drank and got in trouble. That’s where I got, I think I got, my attitudes from.” (15-year-old female)
- **Positive influence.** “She (girlfriend) like to have fun, but like on the weekdays when it’s time to go to school, she call me every morning, ‘Get up, time to go to school.’ Or when, whenever we get off the phone in the nighttime…she’s like, ‘ten-thirty is the limit’, know what I mean, ‘we’ve gotta go to school tomorrow’…” (15-year-old male)
- **Activities with peers.** “We all get our bicycles and go to the rock quarry sometimes.” (16-year-old male)
- “We go to the mall, to the movies and hang at home.” (14-year-old female)
- “We’ll chill, go get some movies, get some popcorn, get something to eat, go in the living room and watch the DVD...watch movies all night.” (15-year-old male)

**School (81 text segments)**
- “I just wasn’t paying attention, gettin’ up in class. I just basically did not want to be there.” (15-year-old male)
- “I don’t like the hours of school…I don’t like the teachers there. The teachers always be calling me out. They be calling my name out all the time and it’s not me talking or whatever.” (14-year-old female)
- “I just go to my classes, do what I gotta do and get out. I don’t say nothing to the teachers unless I need help.” (15-year-old female)
- “I didn’t like school but I went ‘cause I liked the teachers and hanging out with my friends.” (16-year-old male)

**CONCLUSION**

Developmentalists are increasingly cognizant that assessing the multiple contexts of adolescent life, and the associations among them, is intrinsic to a fuller understanding of adolescent development. In this inquiry, court-adjudicated adolescents provided rich
descriptive data regarding the social contexts that they encounter on a daily basis. These data have particular utility for informing and refining intervention efforts, since effective interventions must be responsive to the developmental system in which youth are embedded.

REFERENCES


Involving Students in the Parent Experience: Using Experiential Methods to Teach System of Care

This paper presented a case study of an interdisciplinary course taught at the University of North Carolina at Greensboro, *Family Centered Interdisciplinary Practice: System of Care*. This course is adopted by five academic departments including Psychology, Social Work, Child Development and Family Studies, Recreation, Parks and Tourism and Public Health Education. Students from Specialized Education Services, Nursing, and Counseling also participate in the course. The course is taught by an interdisciplinary faculty team and has two parents as co-teachers.

One of the challenges of moving from a traditional service delivery model to a system of care framework is the difficulty of professionals fully understanding the challenges and competencies of the families that they serve. Students need to build understanding of family-centered care, cultural competence, and community-based services in order to put into practice the collaborative and strength based service system that best meets the needs of children with serious emotional disturbance and their families. One of the ways of dealing with this challenge is to provide experiences in the coursework for pre-service students that not only provide information to new professionals but also influence their emotional intelligence so that they are empathic and congruent to the experience of parents.

The faculty team with the parent co-teachers designed a series of experiences that reflect the “real life” of parents, their life challenges, their needs to access public services, and their concerns about best meeting their child’s needs. These experiences are provided both in class and in the community so that students...
gain insight into living life with a child with special needs.

The semester begins with the entire class experiencing a Poverty Simulation. Based upon the concept of a community of families living in poverty who have to access both non-profit and community public services in order to meet their basic needs, the students “live” as a family. Meeting the basic needs of rent, food, and transportation become paramount but are compounded by the challenge of purchasing childcare and living in a neighborhood with drug trafficking and thievery. In the course of three hours, the students gain profound insight of the life that families have and many students report their lives and their “world view” is drastically altered by this experience. The Parent Co-Teachers can provide reflection upon their lives, generously sharing their personal experiences that are reflected in the simulated scenarios.

Students are assigned a family whose child is enrolled in the Child Mental Health System in our county. With the assistance of the Parent Co-Teacher, the students arrange a home visit with the family either at the beginning of the day when children are getting ready for school or at the end of the day when homework and supper are being completed. Students complete a confidentiality form before making the visit. The families are prepared by the Parent Co-Teachers and asked to present themselves as they “really are” so that the students can gain insight into the challenges of managing a family with a child with a special need. The students report back to the entire class on their insights and experiences and write a personal reflection about what they witnessed and their thoughts about the experience. Also, students are assigned a Child and Family Team observation, again completing a confidentiality form before attending. The students reflect on this experience through their journals and in small group discussions during the class. These two experiences are included in the class experience because the Parent Co-Teachers believe that witnessing the lives of families in their “real” settings is more powerful than simply reading or talking about the challenges they face.

Another experiential learning during the semester is a visit to the county Department of Social Services. Students are given a written assignment that describes the expectations. Each student is to visit the Department of Social Services, traveling by bus, and is to spend an hour in the waiting room in the Food Stamps office. (This has been pre-arranged with the Director of the Department.) Students immediately want to know the address of the office, which bus to take and where to get the bus, whom they should ask for when they arrive at the Department office, how to find the Food Stamp waiting room, etc. The faculty and parents offer no additional information to clarify the assignment, reminding the students that they are hungry and need to determine their eligibility for food stamps in order to make a trip to the grocery store. The students write in their journals about this experience and only at the end of the semester when every student has completed the assignment do they share their reflection with their classmates.

A final experiential learning during the semester is a visit and observation at a local school. Students are assigned a teacher of a special education class to contact and arrange the visit. The university students must spend at least an hour in the class and if invited can participate in the classroom activities with the youngsters. The Parent Co-Teachers present on the challenging experiences their children have had in school, the ways they have worked with the schools to identify special programs and placements for their individual children and relate the joys and sorrows of their children’s schooling experiences.

A final component of this course focused on developing empathy with families and youth challenged by mental illness is a set of presentations by youth living with this illness and their siblings. The youth recount the pain of their illness but also the successes they have experienced, particularly once they found a school placement that met their needs or identified a mentor/friend who could support them. The sibling panel shares with the university students the challenges of being the younger “older” brother because the chronologically older child does not have the capacity to be the family leader. Another shares
the experience of being embarrassed at school by their sibling's behavior or the experience of standing up for their sibling when witnessing her being ridiculed and teased. The university students write their reflections and a typical remark is “I had no idea how painful it is to be different…never again will I stand idly by while someone is being teased so much.”

The Parent Co-Teachers and the Faculty Interdisciplinary Teaching Team have identified these experiences as being ones that deepen the students' understanding of the principles of System of Care. Many students write in their journals that this course has provided more insight into the challenges of partnering with families, why it is important to recognize the strengths of the child and family, and why focusing on the individual needs of the child is critical in developing partnerships with families.
Children’s and Mothers’ Reactions as Research Participants

BACKGROUND

In June 1996, the Nation Institutes of Health (NIH) cosponsored a workshop with the American Academy of Pediatrics focused on issues of children’s participation in research. NIH and Congress were concerned about the use of medical treatments with children based on data from studies involving adults. The National Institute of Child Health and Human Development reviewed a sample of NIH-supported clinical research projects and concluded that between 10% and 20% inappropriately excluded children. This proceeding resulted in the NIH developing a policy mandating the inclusion of children unless there was a strong justification for not doing so (NIH, 1998).

While this new policy promotes the inclusion of children in research, it focuses primarily on children participating in intervention studies in which they may receive some direct benefit. Although the policy clearly permits children’s participation in research involving minimal risk, even when there is no direct benefit to them, other regulations governing the conduct of human subject research designate children as a “vulnerable population” and provide them with additional protections (Department of Health and Human Services, 45 CFR 46, revised 2001).

Despite the federal policy on the inclusion of children in research, a recent ruling by the Maryland Court of Appeals concluded that parents cannot consent to the participation of their minor children in research that posed even minimal risk of harm if the research was “non-therapeutic” and offered no direct benefit to the children (Grimes v Kennedy Krieger Institute, 2001). Although the Court subsequently clarified its ruling making it more consistent with existing federal regulations (Mastroianni & Kahn, 2002), the case
exemplifies the tension between the goals of science and the protection of children from risk (Glantz, 2002).

Protection of all research subjects from risk whether physical (e.g., drug side effects, death); legal (e.g., loss of job, arrest); social (e.g., stigma); psychological (e.g., stress, fear) is a foundational principle outlined by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1978) in the Belmont Report. The Commission used the term beneficence to highlight researchers’ obligations to protect participants from harm. The general rules the Commission provided to guide researchers were to “do no harm” and to “maximize possible benefits and minimize possible harm.”

Hoagwood, Jensen, and Fisher (1996) note that one challenge faced by researchers is the paucity of literature regarding what constitutes harm to children and how to adequately evaluate it. Herjanic, Hudson, and Kotloff (1976) attempted to establish guidelines for assessing the risks involved in administering structured interviews to children. Follow-up surveys completed by parents and children led them to conclude the risks were low; approximately 1 in 63. The federal regulations provide limited guidance for researchers. 45 CFR 46.102 (i) state that; “minimal risk means the probability and magnitude of harm or discomfort to the subject anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life during the performance of routine physical or psychological tests.”

Professional organizations have attempted to provide guidance to investigators studying children. For example, the Society for Research in Child Development (SRCD, 2002) has ethical standards specific to research involving children. The standards stipulate that investigators are obligated to always use the least stressful research procedure. Although the SRDC acknowledges that psychological harm is difficult to define, they maintain that investigators are nonetheless responsible for defining and determining means for reducing or eliminating any possible harm.

FRAMING QUESTIONS

Despite these efforts to assist researchers, the softness of existing guidelines regarding harm and risk should cause investigators studying children to reflect and ask themselves:

• What are the severities of risks to children participating in nontherapeutic studies?
• How do we know that these studies pose minimal risk?
• How can we best inform children and their caregivers about potential risks?
• As researchers, how do we estimate the probability and magnitude of harm to children associated with ordinary daily encounters?
• More importantly, how do we determine how these risks compared to those associated with most behavioral/social studies involving children differ?

To begin addressing these key questions, this study examined the reactions of adolescent girls participating in a study examining welfare reform. Given the protocol included sensitive questions, we wanted to better understand the emotional impact on the daughters and their mothers by assessing the extent to which the questions were perceived as intrusive, were upsetting to respondents, and raised concerns about the confidentiality of their responses. Additionally, respondents were asked to assess the adequacy of our informed consent procedures as well as their overall experience and likelihood of future study participation.

METHOD

Participants

Participants were part of a larger project funded by the Florida Agency for Health Care Administration (Contract #M0107) examining the current well-being and future aspirations of adolescent girls living in families receiving Temporary Assistance to Needy Families (TANF). A sample of 125 mothers currently receiving TANF and their adolescent daughters participated. To be eligible, mothers had to be
receiving TANF, have a daughter between the ages of 13 and 18 living at home, and reside within a five county area in west central Florida.

Table 1 summarizes the characteristics these mothers and their daughters, including their age, race/ethnicity, marital status, and educational status. Mothers’ ages ranged from 30 to 53, averaging 38.4 years old (SD = 4.99). On average daughters were 15.5 years old (SD = .99) and ranged from 13 to 17. Approximately 41% of the mothers were white, 38% Black/African American, and 11% Hispanic. Their daughters were more culturally diverse as 34% were white, 41% Black/African American, and 26% Hispanic. Most of the mothers were divorced, separated, or widowed (50%) or never married (33%) and only 13% were currently married or living with someone. Slightly over 50% of the mothers had not completed high school and 28% of the daughters had dropped out of school by the time of the interview.

Table 1. Characteristics of the Mothers and Daughters

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Mothers (n = 125)</th>
<th>Daughters (n = 125)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Age:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>38.4</td>
<td>15.5</td>
</tr>
<tr>
<td>SD</td>
<td>4.99</td>
<td>.99</td>
</tr>
<tr>
<td>Range</td>
<td>30 - 53</td>
<td>13 to 17</td>
</tr>
<tr>
<td>Race/Ethnicity:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>40.7%</td>
<td>33.6%</td>
</tr>
<tr>
<td>Black/African American</td>
<td>38.2%</td>
<td>40.8%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>21.1%</td>
<td>25.6%</td>
</tr>
<tr>
<td>Marital status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or living as married</td>
<td>12.8%</td>
<td>0%</td>
</tr>
<tr>
<td>Divorced, Separated, or Widowed</td>
<td>54.4%</td>
<td>0%</td>
</tr>
<tr>
<td>Never married</td>
<td>32.8%</td>
<td>100%</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dropped out of school</td>
<td>50.4%</td>
<td>28.0%</td>
</tr>
<tr>
<td>Completed high school</td>
<td>49.6%</td>
<td>NA</td>
</tr>
</tbody>
</table>

Interview Protocols

The interview protocols contained a number of psychometrically tested, respondent self-report health, mental health and substance abuse measures. Additional questions focused on issues concerning risk and protective factors associated with the daughters, perceived social supports, self-esteem, engagement in high-risk behaviors, and their hopes and aspirations for the future. Regarding reactions to research they were specifically asked: 1) To what extent were questions perceived as intrusive or upsetting; 2) Did questions raise concerns of confidentiality? 3) How adequate were the informed consent procedures? 4) What was the overall experience of being a research participant? 5) What is the likelihood of future study participation?

Procedures

Approximately 1,000 mother and daughter pairs thought to meet the eligibility criteria were identified using the Medicaid eligibility data. Letters were mailed to 873 prospective participants informing them about the study. Staff hired and trained specifically for this study contacted mothers and daughters in January 2002, explained the purpose and scope of the study to them, and invited them to participate in the study. A sample of 125 mothers and their daughters were recruited.

Mothers and daughters agreeing to participate signed informed consents and provided permission to link their interview responses to existing administrative data. Separate structured face-to-face interviews were conducted with the 125 mothers and their daughters. Daughters were interviewed about themselves while mothers were interviewed about their daughters. Interviews lasted between 1 and 1½ hours and each participating mother and daughter was paid $40.00 as compensation for her time. Follow up interviews were conducted in 2003 to permit the examination of changes over time.

RESULTS

The majority of the mothers (95%) and their daughters (87%) reported the study consent disclosure
Table 2. Prevalence of “Adverse Reactions” Across Time
Mothers and Daughters Reactions to Being Research Participants

<table>
<thead>
<tr>
<th>Questions (% Yes)</th>
<th>Daughter 2002(n=125)</th>
<th>2003(n=116)</th>
<th>Mother 2002(n=125)</th>
<th>2003(n=113)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Felt pressured to participate</td>
<td>0%</td>
<td>.9%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Unaware of study goals</td>
<td>18.9%</td>
<td>14.7%</td>
<td>7.3%</td>
<td>5.4%</td>
</tr>
<tr>
<td>Questions were intrusive</td>
<td>12.9%</td>
<td>15.5%</td>
<td>23.4%</td>
<td>11.5%</td>
</tr>
<tr>
<td>Questions anxiety producing</td>
<td>2.4%</td>
<td>1.7%</td>
<td>4.8%</td>
<td>4.4%</td>
</tr>
<tr>
<td>Afraid information would be disclosed</td>
<td>8.0%</td>
<td>2.6%</td>
<td>6.5%</td>
<td>5.3%</td>
</tr>
<tr>
<td>Any adverse reaction</td>
<td>29.6%</td>
<td>23.3%</td>
<td>32.0%</td>
<td>21.2%</td>
</tr>
</tbody>
</table>

procedures were adequate. Although not statistically significant, inspection of the odds ratio indicated mothers were 1.75 times more likely to report the consent procedures as adequate compared to their daughters. None of the mothers or daughters reported feeling pressured to participate in the study. Table 2 provides a descriptive summary of the daughters and mothers reactions to being research participants at two points in time.

In 2002, 39 of the mothers (32.0%) reported some type of adverse reaction, while 8 mothers experienced more than 1 event. Of the daughters (29.6%) or 37 reported a reaction, with 7 daughters experiencing more than 1 event. In 2003, 24 of the mothers (21.2%) reported a reaction, with 6 mothers experiencing more than 1 event and 27 of the daughters (23.3%) report a reaction with only 2 daughters experiencing more than 1 event. This trend implies that as the participants are more comfortable with the process of research, then the experience is less anxiety-provoking.

The type of questions mothers reported as producing “adverse reactions” included question about their daughters’:
- sexual activity (11)
- drug and alcohol Use (5)
- finances (2)
- religious practices (2)
- others (4)

In contrast, questions producing “adverse reactions” in daughters focused on their:
- sexual activity (10)
- drug and alcohol use (7)
- others (3)

Given the mounting evidence indicating that some participants are emotionally impacted by questions concerning sexuality and mental health there is a need to pre-warn participants of potential discomfort and distress and to ask them how they are feeling during the process. If respondents acknowledge that they are feeling anxious or uncomfortable or report no concerns, as researchers we need to establish protocols for assisting them in dealing with adverse feelings and/or establish protocols in case they develop concerns at a later time.

DISCUSSION

The adolescent girls participating in this study were less likely to report questions as intrusive, anxiety producing, and expressed fewer concerns about the confidentiality of their responses than did their mothers. However, compared to their mothers, these teenagers were less likely to understand the goals of the study and less likely to perceive the consent disclosure procedures as adequate. Overall reaction to study participation was perceived as positive by both mothers and their daughters. In regards to the likelihood of future participation most mothers and
daughters reported they would likely participate in future studies.

Although these findings are quite positive, researchers need to continually intensify their efforts to minimize risks to study participants, no matter how small they may seem. Boothroyd (2000) provided recommendations for researchers that are useful to reiterate here. First, investigators need to always ensure that individuals only participate because they want to. In this study, given that none of the mothers or daughters felt pressured to participate, suggestions that this objective was achieved.

Boothroyd (2000) also suggests that researchers inform potential participants about the nature of the questions to be asked as well as any potential discomfort that might be associated with answering them as part of the consent disclosure process. He even suggested that examples of potentially sensitive questions be included in the consent form. Given that one of five mothers and one of eight daughters perceived the questions as intrusive, one might question the extent to which potential participants were adequately informed about the full nature of the questions they would be asked.

Third, Boothroyd (2000) suggests that researchers provide ongoing reminders to participants regarding the purpose and intent of the study and give them opportunities to ask questions. While this is particularly appropriate in longitudinal studies, the fact that one in five daughters were unaware of the study goals is troublesome. Given that their mothers were clearer about the study goals, suggests that perhaps more time is needed during the consent process with children summarizing and reiterating what the study is about.

Finally, Boothroyd (2000) has advocated that researchers provide participants with a toll free telephone number they can call with any questions or concerns that might arise after the interview has been completed.

REFERENCES


Mission-Driven Sustainability: Art Programs for Recreation, Support, and Revenue Generation

PROJECT DESCRIPTION

The Hillsborough County Chapter of the Federation of Families for Children’s Mental Health obtained funding through a grant from the University of South Florida Collaborative for Children, Families, and Communities to conduct three Recreational Art Programs, or RAPs. These programs were designed to meet multiple goals that included: 1) introducing children with emotional and behavioral problems to the enjoyment of art expression, 2) enhancing the social supports of their families, and 3) promoting the sustainability of the Federation chapter through generating revenue and increasing membership.

The project involved the close collaboration of various community partners, the university, and most importantly, parents of children with emotional and behavioral problems. Central to the project’s success was the local chapter of the Federation of Families for Children’s Mental Health in partnership with two university academic entities. Other key collaborators in this effort included the local CMHS system of care site, the public school system, and the local community mental health center.

The RAPs were specifically targeted for children and youth 5-18 years of age who have been diagnosed with an emotional and/or behavioral problem. Participants included children living in the three Florida communities in which the programs were held: Plant City, University Area of Tampa, and West Tampa. Given that a goal of this project was to increase Federation membership, emphasis was placed on recruiting children from families who were not current Federation members.
Each of the three RAPs were one day in length (6-7 hours) and intended for children to have fun through art expression. The theme selected for the programs was “Be Yourself, Feel Good, Celebrate Life.” During the RAPs children received basic instruction and had an opportunity to create their own artwork. At each RAP, children were divided into six groups of varying ages. Each group had a respite worker assigned to it. There were six art stations through which the groups rotated. The stations had five to seven seats each and were staffed by parent volunteers who received pre-program training. The six art stations included watercolors, collages, using hand/foot prints to create pictures, object art, self-portraits, and freestyle drawing. At the conclusion of the day each child selected and submitted one piece of artwork. They titled their pieces and included personal statements describing the themes of their work. The artwork was then judged according to the children’s ages and relevance to the program theme for possible inclusion in the Federation of Families calendar. The calendar was produced and continues to be sold as a fund-raiser.

All participating children received a certificate of participation and a RAP t-shirt. Children whose artwork was included in the calendar received a $50 savings bond. Additionally, the children's artwork will be posted on the Federation of Families website. Framed originals will either be auctioned off or used to solicit corporate sponsors for the Federation.

Following the completion of each RAP, the parents and other family members of the participating children were invited to a social reception. During this reception, the parents viewed the artwork their children created. The reception was also used as an opportunity to provide information and materials to the parents about the Hillsborough County Chapter of the Federation of Families for Children's Mental Health. Efforts were made at the reception to enroll parents and family members into the organization in order to increase the local support base of the Federation. Media coverage, both local newspaper and television was sought for each RAP as well as for the judging of the artwork as part of the community-based social marketing effort to facilitate the sustainability of the Federation. All of the artwork was displayed providing family members with an opportunity to examine the artwork created by the children during the day.

PROJECT EVALUATION

The project evaluation consisted of three components. The first included a series of concrete process and outcome indicators related to the conduct of programs and their impact on sustainability. The process indicators of program success included: the number of children who participated in the three RAPs and the number of family members who attended the accompanying social gatherings.

The outcome indicators included: the number of new parents and other individuals who joined the Hillsborough County Federation of Families for Children's Mental Health, the amount of revenue generated from the silent auction of the children's artwork and from calendar sales, and the sustainability of RAP, (i.e., the degree to which revenues received exceeded program costs).

Secondly, child and parent assessments of the RAPs and the associated social reception were obtained. Specifically, children and parents were asked to indicate the extent to which they enjoyed the program, if they would recommend the program to others, and for any suggestions they might have for improvement of the program. Evaluation forms were available in both English and Spanish. Nearly three quarters of the children reported having ‘lots of fun’ at the programs. Additionally, the majority of parents reported satisfaction with the program.

Finally, key informant interviews with collaborating organizations were conducted at the conclusion of each RAP to assess the success of the collaborative effort, the strengths of the partnerships, and to determine areas in which collaboration could be strengthened. This information was used to make changes and modifications in subsequent RAPs.

EVALUATION RESULTS

Eighty-seven children participated in the three RAPs and nineteen caregivers attended the social gatherings.
Eighty children completed evaluations for a response rate of 92%. Of these children, nearly a third were eight years old or younger, about half were between 9 and 12 years old, 14% were 13 to 15 years old, and 5% of the participating children were over 15 years old. Slightly more girls (54%) attended the R-APs compared to boys (46%).

Overall, the R-APs were well received by the targeted children. A majority of the children reported enjoying the programs. Figure 1 summarizes the amount of fun children reported having at the R-APs. Nearly three quarters of the children (74%) indicated they had “lots of fun” while 15% reported they had “quite a bit of fun”. The remaining 14% were somewhat less enthusiastic about the program indicating they had “some fun” 8%, only “a little fun” 3%, or “no fun” 1%. The amount of fun children reported was significantly associated with their ages (rage & fun = -.49; p < .001). Children under 8 reported having the most fun, followed by those in the 8 to 12 year old range. Children in the 13 to 15 year old range were next while children over 15 reported having the least amount of fun.

Children were asked to select which art activity was their favorite from among the six available activities. These results are summarized in Figure 2. Each of the six art activities was selected as the most favorite by at least 13% of the children. Children most often selected the body art as their favorite activity, chosen by 20% of the children. The watercolor table was ranked close second, selected by 19% of the children. The marble painting closely followed in third, selected
by 18% of the children. The free drawing table ranked fourth, selected by 16% of the children. The self-portrait was chosen by 14% of the children and ranked fifth. Finally, the tissue paper collage activity ranked sixth, selected by 13% of the children.

Select comments from the children about what they liked most included: “It was fun and something different to do. I enjoyed everything in this program” (11 year old boy), “I met a lot of new people. I liked everything” (11 year old girl), and “I liked drawing and painting was fun” (15 year old girl). Among the children’s comments about what they liked least about the program were: “It was really noisy” (16 year old boy), “It was boring” (17 year old girl), “I don’t like to get messy” (13 year old girl), and “The paper stuck to me” (11 year old girl).

Caregiver evaluations indicated additional favorable reactions to the RAPs. In general, they were happy with the program’s logistics as well as the opportunity for their children to participate in art expression. Forty seven percent of caregivers indicated they were considering joining the Federation chapter. Several caregivers reported they would like more information about the Federation. Sample comments included: “Would like to have further information on this Federation” and “I don’t know anything about it the Federation.” Eleven new members joined the Federation chapter as a result of RAP activities. Only 19 caregivers, however, participated in the social receptions indicating the ongoing challenge related to engaging new individuals in an organization.
All of the caregivers indicated they would tell other families about the program and many offered positive comments about the program. Sample comments included: “My child gets an opportunity to share his talent of art, to socialize. Because he loves to draw and one day he’ll be an artist”; “The friendly staff. They really seemed to enjoy bringing smiles to all of the participants’ faces”; and “My daughter loved the program there is no art program at her school.”

Results of revenue generation, and therefore, sustainability of the RAPs, are still unknown as the calendars have just recently been printed and sales are ongoing.

SUMMARY

Given the children’s positive responses to the program, the RAPs were definitely successful in providing them with a safe and fun environment in which to discover the enjoyment of art expression. The level of children’s engagement in the various art activities was quite extraordinary. Clearly, the RAPs were successful in promoting the Federation of Families and in developing consciousness in the community regarding the services of the agency. New families are aware of the assistance offered by the Federation, and the media attention afforded to the individual programs and receptions helped inform the community of the Federation’s mission and goals. However, the extent to which the RAPs were successful in generating revenue for the Federation of Families is still unclear. Calendar sales have just begun and the Federation hopes to recoup expenditures for the RAPs through these sales and potentially, the sale of coffee mugs decorated with children’s artwork.
Parent Perceptions of Service Delivery: A Family / Youth / Professional Collaborative Research Study

BACKGROUND

Hillsborough County was the first site in the state of Florida to be awarded a Comprehensive Community Mental Health Services grant from the Center for Mental Health Services (CMHS). These funds are awarded for communities to improve and expand their systems of care and meet the needs of children with serious emotional disturbances (SED) and their families. While there is flexibility within the grant requirements concerning organizing individual community systems of care, each site is required to include families as partners in designing their local system. Our community’s grant program is called the Tampa-Hillsborough Integrated Network for Kids (THINK). Throughout the grant program, THINK has been committed to involving family members in all aspects and at all levels of our system of care, including site evaluation activities.

The THINK Evaluation Team is a group of researchers, representatives from local funding agencies, and family members who are involved with the THINK system of care. Their charge is to provide feedback on the status and findings of the national and local evaluation efforts of our site. After much consideration, the team determined that although the evaluation provided a broad view of child and family outcomes, implementation of system of care values at all levels of system development, and feedback on individual family team functioning, feedback from families was still missing. Families didn’t have a way to communicate how changes in service delivery were affecting them nor were they given the opportunity to identify which changes were helpful and which
were not. The Evaluation Team recommended that a separate sub-study be developed to capture this crucial information and that a team of family members and professional researchers should work together as equal partners in the design, implementation, interpretation and dissemination of the study findings. This recommendation led to the development of the “Parents’ Perception of Service Delivery Study” described herein.

PRESENTATION FOCUS

The focus of our presentation was to highlight how this collaborative effort has allowed for a broader perspective on service and support delivery and its impact on children and families. Further, the parent-professional partnership has provided a richness and relevance that neither family members nor researchers could achieve independently. This partnership will allow us to collect data that is richer in content, appropriately answer the questions asked, and reflects what families have experienced as they seek services and supports for their child and family. The team selected a flashlight analogy to explain the multiple perspectives of the THINK evaluation efforts. Other THINK evaluation studies were beaming lights into the family’s world, through the longitudinal child and family outcome study, observations of the family team planning process, and interviews with staff and caregivers concerning implementation of system of care values. While these studies give valuable insight into what family’s experience, they do not provide a complete snapshot of what families encounter (Figure 1). The Parents’ Perspective study reflects THINK’s commitment to family leadership in evaluation and recognizes that family members are adept at holding and correctly focusing the flashlight at themselves and reflecting back what it was like to live through their experiences (Figure 2). This reflection gives us a much broader view of how their lives are being affected by system changes.

STUDY ACTIVITIES

Two family members from the THINK Evaluation Team developed the original questions for this study. In order to focus on changes in service delivery directly related to the THINK system of care, the questions were formulated using the core values and key guiding principals from system of care philosophy (Stroul & Friedman, 1994). Once we formed our study team, our first task was to pilot these questions (Figure 3) to see if they were able to draw out the information we were looking for. This was accomplished with a group of parents that met together regularly as a support group. After asking a couple of our questions, it was apparent that the questions used language that really wasn’t a part of these parent’s everyday speech. This made the questions difficult for them to understand and respond to appropriately. As a result of this pilot, it also became clear that adding the perspectives of ‘identified’ children and siblings were needed to gain a complete family perspective.
Revising these questions showed us just how valuable the combined expertise of a parent-professional team can be. Initially, two family members from our team worked together to reword the questions into language that was a familiar part of their everyday lives as family members. Despite their thoughtful approach to the task of rewording, they encountered some difficulties in trying to simplify the questions without losing the intent and focus of the original set. The most challenging question was the one that asked whether or not families felt they were receiving culturally competent services. To overcome this challenge, the family member duo enlisted the aid of one of the professional members of our team who is doing her graduate work in communication, and has many years of experience conducting focus groups in the private sector of the business world.

As soon as the team started reviewing the questions together, they realized the advantages of including their differing perspectives and expertise, and reviewed and revised all the questions a third time (Figure 4). Once the team was satisfied with the revised questions and prompts, the facilitator manual was updated and training for each of the three different types of groups, parent, youth, and sibling, was scheduled.

One of our easier decisions concerned who should facilitate the groups. Our team immediately agreed that for each focus group conducted, two-person facilitator teams would be used consisting of one family member and one professional. This was something most of our team members had done before, so we were already aware of how valuable this arrangement could be. This team approach to interviewing allows a family member to only take the lead, when and if they feel comfortable doing so because they have the support of the more experienced professional right there with them. Conversely, the professional has the benefit of having a partner who the respondent will many times relate to and trust their explanations more readily, just because of the simple fact they both have the shared experience of being primary caregivers of a child who has SED. The team encountered difficulties, however, in reaching a consensus about the definition of family member. The team agreed that the primary caregiver of a child who has SED would be considered a family member. The difficulty occurred when we tried to expand the definition to include other people who lived with children who have SED, or siblings of children with other disabilities. After much discussion, the team finally agreed that a sibling or any other person living with a child who has SED is a family member since their lives were also affected. This allowed us to broaden our study team to include yet another staff member with a unique perspective and area of expertise, a sibling of several children who have SED. Further, the team also realized this person would be an ideal facilitator of the sibling focus groups.

Balancing and respecting the perspectives and responsibilities of the parent-professional team continued even to the level of planning and logistics.
of the groups. For example, the team agreed that family members should be provided with a meal as an incentive for them to participate. Deciding where to conduct the groups and what kind of meal should be served highlighted the differences in the family and professional perspectives. The family members and even one of our professional team members thought families should be invited to dinner at a local restaurant or hotel. The professional team member responsible for this study’s budget did not agree. It really took a team effort to come up with an alternative that would encourage families to attend, but not deplete our budget. The team agreed to prepare the meals for families and conduct the groups in facilities that did not charge for usage.

Having such a variety of perspectives has also proved to be beneficial when debriefing after a focus group session. Each team member has pointed out problems and interpretations that the rest of our team members would never have picked up on. This made it easier for us to share problems we encountered in conducting the groups. For example, at the first focus group, professional (paid) family advocates attended and participated in the caregiver focus group, but the professional team members were unaware of this. One of the family members pointed out that this had occurred and that it seemed to inhibit the responses of other family members in the group who receive services from the professional (paid) family members. Family members on our study team were not comfortable explaining this to providers, however, so professional team members assumed responsibility for contacting the providers and straightening things out. This provided an important example of how the ‘professional’ members of our team supported the family members of the team and helped to determine a course of action that would keep this issue from coming up again.

CONCLUSIONS

Family involvement at all levels has been a cornerstone of this research study. The parent-professional partnership has resulted in a study where family members have or will take the lead in every step from question design and clarification, study methods and data collection, to data analysis, dissemination and utilization of findings. To date this partnership has enhanced and enriched both the design and data collected from a study in a way that neither professionals nor family members alone could have accomplished.

What has been unique about this study is that while our team was demonstrating family involvement, we have also been studying our THINK system of care to determine if families receiving services feel they are full participants in all aspects of planning and delivering the services they receive. The purpose of our study was to be able to capture what a moment of time is like, in its entirety, for a family accessing services in a system of care. As family members, we realized that when we are in crisis, our perceptions are very different than when everything is moving along smoothly. Therefore, we were very aware that the snapshots we have been gathering can’t document a families’ entire experience with the system of care, but we do hope to be able to capture similar themes across the families that participate. These data will then be used as feedback for service providers to better understand what works for the families they serve. Family members will also be able to use these findings to advocate for policy makers to pass legislation that meet the needs expressed by families in this study.

REFERENCE

Families that have children with emotional and behavioral challenges often face great obstacles in finding child care that meets their needs (Rosenzweig, Brennan & Ogilvie, 2002). Lack of appropriate child care prevents parents from doing paid work, and from participating in other activities that contribute to economic security and to the wellbeing of the family.

In this paper, we discuss the role of family support in the inclusive child care center. Family support involves not only access to the services and resources that the family needs, but also an approach that empowers families and builds on their strengths (Family Support America, 2003). The findings presented here are part of a larger federally-funded qualitative study, designed to investigate inclusion approaches and strategies, and barriers to inclusion in the child care setting (Brennan, Bradley, Ama & Cawood, 2003). Nine diverse childcare centers across the U.S., nominated for their success in including children with emotional and behavioral challenges, participated in the study.

THE SAMPLE AND PROCEDURES

The sample of center directors, center staff, and parents with one or more children in the center, is described in Table 1 below. More than half (59%) of the parents interviewed reported having a child with emotional and/or behavioral challenges enrolled in the center.

Individual interviews were conducted, either by telephone (in four centers) or face-to-face (in five centers). Interviews lasted approximately 60 minutes, with a range of 30 to 120 minutes. Family members and center staff received a $30.00 stipend in return for their participation. Interview data were coded by
at least two members of the research team, and entered into NUD*IST (Qualitative Solutions and Research Pty Ltd, 1993) for further analysis. Coding and analysis procedures were guided by grounded theory methods (Morse, 1994).

**THE FINDINGS**

Data analysis indicated that family support was important for inclusion in three ways, as described below.

1) *The centers worked to create and maintain “a family environment.”*

   The directors and staff in the centers viewed childcare as part of a larger support system required by families, and recognized how important the support of the whole family was to the well being of the child. The centers were proactive in helping families identify their needs and linking them to appropriate resources, both within and outside of the center. One parent said that she viewed the center as ‘a second house’, indicating how important the support system provided by the center was in the life of her family. Similarly, in some of the centers, parents and staff noted that the center was characterized by a family atmosphere.

2) *Family support encouraged family participation*

   Families in these inclusive centers learned that staff was committed to meeting the needs of each child, whether or not they had unique challenges. Staff made great efforts to develop relationships with families based on openness, trust, and mutual respect. They got to know the families well, and appreciated the strengths of the family and the stressors they experienced in their lives. At some centers, staff was able to visit families at home as part of the program. This expanded the lens through which staff could view the child in the classroom, and helped staff to learn more about the needs of each family. These close working relationships between staff and families were crucial to the inclusion of children with challenging behaviors. The centers had access to both community and specialized health support that enabled the family to gain access to flexible and comprehensive resources and services. The needs of families were often dynamic, and ranged from food and shelter to intervention from mental health specialists. This partnership with families and with the community was important supporting the child’s continued participation in the program.

3) *Family support enabled retention of children with challenging behavior in the center*

   The directors and staff recognized that providing family support was crucial to the success of the child, particularly if the child had challenging behavior. Many parents of children with challenges had experiences of having their child expelled from previous arrangements because of behavioral issues. However, in these inclusive centers, expulsion was a rare
occurrence. Instead the staff worked with the child and family to facilitate their retention in the program. A partnership with the family facilitated the sharing of strategies that supported the child at home and in the classroom. This consistency was important in promoting the child’s success, and supporting retention. Access to appropriate support, including the provision of mental health support as required, was a crucial part of this success. In contrast to previous experiences when parents were often worried that their child care arrangements would fall through, the provision of family support in these centers contributed to the development of partnerships with staff, and the creation of a safe, stable and nurturing environment that promoted the development of the child.

CONCLUSIONS

Families that have children with emotional and behavioral challenges often receive little or no support. Increasingly, child care is part of the natural environment for children and families (Lombardi, 2003), and thus it is crucial that child care centers are prepared to include children with such challenges. Children, families, employers, and communities can benefit if families of children with unique challenges are adequately supported. The findings of this study suggest that if child care is to be more successful in including children with diverse needs, there is a need to make existing arrangements more comprehensive and to explore ways to integrate child care and family support.

REFERENCES


This study is funded through the Research and Training Center for Children’s Mental Health at the Louis de la Parte Florida Mental Health Institute, University of South Florida by the National Institute on Disability and Rehabilitation Research and the Center for Mental Health Services.

Understanding Collaboration in Systems of Care

INTRODUCTION

In the early 1980s Jane Knitzer (1982) published the results of the first national survey of mental health services for children with serious emotional disturbance. She reported that two-thirds of these children had not received needed services. While it is historically true that children with multiple special needs, particularly those with complex emotional and behavioral disorders, have not been served well by the traditional fragmented approach to care, in the last 15 years there has been a move to encourage collaboration among child-serving organizations to increase the efficiency and improve the outcomes associated with care.

Two initial well-designed studies of system of care interventions (Bickman, Heflinger, Lambert, & Summerfelt, 1996; Bickman, Summerfelt, Firth, & Douglass, 1997) showed that the outcomes of system of care were not superior to outcomes of non-system of care or traditional approaches to providing care. This finding has prompted the reexamination of approaches to studying systems of care leading to a focus on process and system level outcomes before moving to studies of child and family outcomes. The mechanism used to establish systems of care and the resulting level of collaboration may be important factors influencing the achievement of client level outcomes.

The purpose of this study was to determine the relationships among policy development, policy implementation, and the development of collaboration in systems of care. Collaboration is thought to be a critical factor in the development of systems of care that may influence the relationship between the mechanism used to establish systems of
care and the resulting child and family outcomes. The major study hypotheses are:

- Policies that have used capacity-building and system change approaches for development and implementation will be more successful than policies that have used mandates.

- Collaboration is more likely to occur when policies reflect system of care principles and have clearly articulated goals and target populations.

- Policies that have been developed and implemented using a backward mapping approach (or beginning with the system location where the maximal impact is desired; Elmore, 1987a), will be more successful in producing effective collaborative systems at the community level than policies that have been developed using a forward mapping (or top down) approach.

- Policies that provide or build adequate human and financial resources will be more successful than those with less adequate resources.

METHODS

This study, supported by a Research and Training Center grant at the Luis de la Parte Florida Mental Health Institute, has two phases. Phase 1 comprised a national survey of state directors of children’s mental health that requested information on the policy approaches used to establish systems of care for these children and their families. The common approaches used to develop and implement policies such as systems of care include: legislation, mandates or rules, inducements or transfer of money to achieve outcomes, capacity-building or investment of resources, and/or systems change or transfer of authority among agencies (Elmore, 1987b). The principal child mental health person for each state was contacted twice by letter and once by phone if they did not respond to our written request for information about the development of system(s) of care within their state. They were asked to submit all materials related to developing and establishing the system(s) of care within their state.

Of the 50 states, 39 (78%) sent materials regarding their systems of care, of which 5 (12%) indicated that they did not have a system of care. Two raters independently coded the data from each state on a number of dimensions including the policy instrument or mechanism that established the system(s) of care, when the initiative occurred, the foundational principles of the system (Stroul & Friedman, 1986), and the child-serving agencies involved. Differences in coding among raters were reconciled through presentation to the five-member study team and required a second review by the study team. Data were entered into a computerized file for analysis using SPSS.

Of the respondents 68% (n=34) reported the development of a system of care that was verified by the researchers based on the materials submitted. Allowing for multiple approaches, 82% used legislation, 15% used inducements, 41% used capacity building, and 44% used other methods including mandates.

The data were subjected to cluster analysis using Clustan (Whishart, 1999). The optimal solution produced five clusters each with similar approaches to developing systems of care. In each cluster an exemplar state was identified as being most representative of the policy approach used, the agencies involved in the effort, and the principles of care identified as important in the state’s effort. There were 8 states in Cluster 1, which had the most comprehensive list of agencies involved. Cluster 2 contained 9 states that identified education and 4 of the principles of a system of care, while Cluster 3 had 7 states that focused on families, used a system change instrument and included juvenile justice. Cluster 4 contained 4 states that had a multi-system approach, while states in Cluster 5 reported no specific guiding principles, type of policy instrument or agency involvement.

In Phase 2, each exemplar site was visited by two members of the research team. Data were gathered by interviews, focus groups, observing inter-agency meetings and reviewing records provided by the site.
A backward mapping approach was used to collect data, that is, data collection began with focus groups of parents at the local level, then interviews with case managers and their supervisors, and finally interviews with local and state policy makers. Service providers and policy makers at the state and local level were asked to complete the Collaboration within Systems of Care Scale developed by Greenbaum & Brown (2001). This instrument has three subscales to measure attitudes about collaboration, perceptions of collaborative behaviors in systems of care and knowledge about the system of care. The highest mean that can be achieved on each subscale is 5.

RESULTS

Table 1 below presents the results of the analysis of the collaboration data.

Table 1. Mean Scores on Collaboration Scales by Site

<table>
<thead>
<tr>
<th>Site</th>
<th>N</th>
<th>Attitudes</th>
<th>Behavior</th>
<th>Knowl.</th>
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<tbody>
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<td>Cluster 1</td>
<td>15</td>
<td>4.522</td>
<td>3.474</td>
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<td>42</td>
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<td>Cluster 3</td>
<td>17</td>
<td>4.466</td>
<td>3.194</td>
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<tr>
<td>Cluster 4</td>
<td>14</td>
<td>4.128*</td>
<td>3.308</td>
<td>3.843</td>
</tr>
<tr>
<td>Cluster 5</td>
<td>26</td>
<td>4.480</td>
<td>3.591</td>
<td>4.150</td>
</tr>
</tbody>
</table>

(*p = .004)

It is important to note that, regardless of the policy approach used to establish the system of care, respondents in most states scored well on attitudes, behaviors and knowledge related to collaboration. The respondents in the Cluster 4 state, however, showed a significantly lower score on attitudes toward collaboration than respondents in the other states. This state was characterized by the inclusion of multiple child-serving systems and citation of a principle related to a multi-system intervention. It relied on a systems change approach.

The qualitative data collected at the Cluster 4 site provided data to explain this result. Cluster 4 had two different organizational approaches to developing systems of care. Different agencies were involved in each and the target population varied by county or region. Child welfare was not represented in the system of care. The two different types of collaborative organizations had been competing for the same funding. In addition, some respondents indicated that there had been too much money too rapidly, causing competition for these funds rather than collaboration. Finally, respondents reported no clear direction from the state resulting in conflict among agencies.

Qualitative data were also examined for their support of the study's hypotheses. Hypothesis 1 indicated that higher levels of collaboration would occur with capacity building or system change approaches. The data supported this hypothesis. Hypothesis two proposed that higher levels of collaboration would occur when system of care values and principles and target population were clearly defined. The data provided mixed support for this hypothesis. Hypothesis 3 stated that a backward mapping approach would be more successful in fostering collaboration. Data did not support this hypothesis in any state. Finally, hypothesis 4 postulated that policies associated with adequate resources would be more successful in fostering collaboration. The data provided mixed support for this hypothesis.

CONCLUSIONS

This study represents an initial examination of collaboration in systems of care. The findings indicate that a variety of approaches or policy instruments have been used to establish systems of care and that these approaches may be associated with varying levels of collaboration. Because of the mixed support for a number of the hypotheses, the study team decided to conduct another round of site visits. One state from each Cluster was randomly selected for a site visit in the spring or early summer of 2003. These visits have recently been completed, but the data are not yet analyzed. The additional data will permit us to examine within cluster as well as across cluster differences in levels of collaboration.

One of the findings of this study, although not unique to the study, was the importance of using a mixed methodology when studying complex phenomenon
in real world settings. If we had relied solely on the data derived from the collaboration scale, we would not have been able to understand or explain the lower attitude scores that occurred in the Cluster 4 state.

When available, the final results are expected to enrich our understanding of the processes that exist between state level policy and local implementation. We also intend to identify critical mediating and contextual variables that play an important part in establishing systems of care and influencing their outcomes. Finally we hope to provide information to guide efforts to develop more effective policies and to foster more effective collaborations within systems of care.

REFERENCES


Using Research for Evaluation and Advocacy of Custody Issues in Maryland

INTRODUCTION

In their quest for services, caretakers may meet resistance from many agencies. When a caretaker persists in demanding services, by means such as refusing to take a child home from a hospital setting without a discharge plan, or refusing to have a child live at home without adequate services, there may be threats of charges of abuse, neglect or abandonment (Dembner, 2000). In the extreme case, the caretaker may be told that giving up custody of the child is the only way to get these services (Blankenship, Pullmann & Friesen, 1999; Friedman & Walker, 2000; Giliberti & Schulzinger, 2000; McManus & Friesen, 1989). Friesen, et al. (2003) provided a comprehensive summary of the research on this “custody problem” and how it has contributed to policy change. Current state policies on the issue have been further documented by studies completed by the National Alliance for the Mentally Ill (Gruttadaro, 1999, 2000), the Bazelon Center for Mental Health Law (Giliberti & Schulzinger, 2000), and the U.S. General Accounting Office (2003).

The practice of relinquishment is the consequence of several factors (Friedman & Walker, 2000). Inadequate funding of mental health services and support for children and their families is the major reason families turn to the child welfare system for help. Lack of incentives to develop effective community-based systems of care to help families keep their children with emotional, behavioral, or mental disorders at home, in school, safe, and out of trouble also contributes to the problem. Insufficient mental health benefits in private and public insurance plans cause families to exhaust benefits before the
mental health needs of their child are fully addressed. This is especially true when the child’s condition is chronic and intensive intervention is periodically required.

There is a growing opinion that custody relinquishment to obtain services is no longer a serious problem. The argument is that at this level of need children are more easily becoming eligible for Medicaid, which pays the cost of residential treatment. In addition, it is argued that caretakers can more easily do a voluntary placement without giving up full rights to their child. The purpose of this study was to provide empirical data to determine the extent of this problem. These important custody issues have rarely been empirically examined with large samples and quantitative methodology.

**METHODOLOGY**

**Sample**

The overall sample consisted of 176 families residing in the state of Maryland with children hospitalized for mental health issues within the last 2 years. An initial survey was collected from each family. Of these 176 children, 38% were female and 62% were male. The average age was 12.8 years (SD = 3.4). The majority of children were white (90), 74 children were African-American, 2 were Hispanic, one was a Native American, and 7 were biracial.

**Measure**

The primary measure used was the Listening & Learning From Families Survey. This survey instrument was developed based on a review of the literature and input from families. It provided information on hospital length of stay, type and intensity of services delivered, prescreening living arrangement, placement stability, demographics, and diagnosis. It was tested on a group of family members and modifications were made based on clinical relevance and likely impact on the model.

**Procedure**

Surveys were distributed in a variety of ways. The bulk of the surveys were mailed out from the State Mental Hygiene Administration. Surveys were also distributed by local agencies such as the area Core Service Agencies and Departments of Social Services. Advertisements were also placed in local newspapers and the survey was placed on the website of the Maryland Coalition of Families for Children’s Mental Health. Completing the Families Survey involved putting a check beside the appropriate responses.

Upon completion of the screening survey, 48 families qualified for a follow-up telephone interview. Families qualified in three different ways. The first way was if they had been told by someone that their child could receive needed services if they relinquished custody. Another way was if someone had threatened them with being charged with abuse, neglect or abandonment if they did not bring their child home from the hospital. The third way was if they had already lost custody.

**RESULTS**

A series of cross-tabulations and chi-square tests were used to determine the relationship of various clinical and demographic variables to issues of custody. There were no significant differences in custody issues across race, ethnicity, number of children in the family, gender of the child, or whether the child had any other disability. Non-birth families, adoptive families in particular, were more likely to be confronted with issues of custody relinquishment ($X^2 = 4.47, p < .05$). Only 7% of the families were told about voluntary foster care placements. Parents who knew about the concept of voluntary placement were told that it was not an option in their area.

From the 176 completed surveys, 48 families (27%) reported that they were advised to relinquish custody, were threatened with abuse, neglect, or abandonment, or said they refused to bring their child home from the hospital. This percentage is consistent with data from national surveys conducted in 1989 and 1999. Only five of these 176 families (3%) actually lost custody of their child.

There were several factors that were shown to significantly increase the likelihood that families would
confront issues of custody relinquishment including: 1) a large number of hospitalizations for a child; 2) a history of physical or sexual abuse; 3) aftercare services that did not meet a child’s needs; 4) reliance on private insurance exclusively or private insurance together with Medical Assistance; 5) the caretakers’ caption of a general deteriorating condition of the child.

A stepwise logistic regression was used to develop a model of whether or not a family would face a custody issue using demographic, clinical, and insurance variables derived from the Listening & Learning From Families Survey. A series of 11 predictor variables were selected for their clinical relevance, low frequency of missing data, and likely impact on the equation based on the preceding chi-square analyses.

From the original predictors, four were selected through the logistic regression analysis to be included in the model. Caretakers’ perception of their child’s readiness to come home and number of hospital visits contributed the most to the prediction equation, while type of insurance and family unit played a moderate role in the equation. Using these four predictors, the logistic regression results shown in Table 1 generated a statistically significant model of the family likely to have child custody issues (model $X^2 = 50.68, df = 11, p < .001$), suggesting that the predictors classify significantly better than the base rate. The overall accuracy of the model was 83.33%.

**DISCUSSION**

It was shown that advising families to relinquish custody or to leave their child in the hospital or residential facility is a common practice. Most of the families in this study did not relinquish their children. Instead they brought their children home under pressure and threat of losing custody. Families were most likely to consider custody relinquishment when one or more of the following factors were present: a) repeated hospitalizations, b) children were being cared for by non-birth families including adoptive families, c) the family felt the child was not ready for discharge from the hospital, and d) the family had private insurance.

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<th>df</th>
<th>r</th>
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The impact of caring for these children was financially devastating for the families. Many caregivers lost jobs or could only work part time as a direct result of their child’s intensive needs and repeated crises. Families also expressed exhaustion, depression and hopelessness for themselves. They had grave concerns for the well being of their other children who were less demanding and consequently received less of their parent’s time, energy and family resources.

The children involved had lengthy histories of serious, chronic mental health disorders with early onset of serious difficulties. In spite of a variety of services and numerous hospitalizations, the children’s behaviors deteriorated. However, families demonstrated incredible perseverance and often reported going to five or more agencies seeking assistance. Safety in the home and protection of siblings were the key reasons families stated their child could not return home, and why caretakers risked charges of abandonment for refusing to pick up their child from the hospital. Finally, caretakers felt they were at the mercy of their insurance companies. They had limited choices of therapists, limits on the number of hospital days covered, costly co-payments for medication and for treatment, especially when therapy was required several times a week.

In summary, custody relinquishment and the underlying inability of families to obtain necessary mental health services for their children are major policy issues affecting the well being of children and families and straining public agencies, providers and public resources. The issues warrant the highest priority of public policymakers.

REFERENCES


Project SUCCEED in Head Start: A Training Curriculum Addressing the Mental Health Needs of Young Children

PROJECT OVERVIEW

Project SUCCEED was a research demonstration project funded through the U. S. Dept. of Education, Office of Special Education Programs (OSEP). Its purpose was to develop and test an approach to assist early childhood teachers and parents to address the mental health needs of young children in their care. The project was a collaborative effort between Portland State University’s Regional Research Institute, Mid-Willamette Valley Family Head Start of Marion County, Oregon, and Community Action Organization Head Start of Washington County, Oregon and ran from September 1999 through December 2002.

Some specific goals of Project SUCCEED were to:

• Reduce problem behaviors at home and in the classroom,
• Increase social, cognitive, and emotional competence,
• Increase family empowerment & advocacy,
• Increase adults’ skills and confidence in helping children with challenging behaviors, and
• Reduce parent and teacher stress.

In order to reach these goals, Project SUCCEED developed a 12-week curriculum focused on helping family members and Head Start staff effectively intervene with children that demonstrated challenging behaviors such as throwing tantrums, physical aggression, and extreme withdrawal. SUCCEED developed its curriculum with the guiding principles...
of participation, comprehensiveness, replication, inclusion and collaboration. Additionally, SUCCEED relied on family members as well as Head Start staff to review and revise the curriculum and to serve as peer trainers during the process. Another important feature of SUCCEED was the one-on-one coaching that participating teachers received six times during the program.

Previously reported findings of Project SUCCEED (Friesen et al., 2004) indicated that all participants rated classes as meeting their needs “very well” or “well” and that participants valued holding joint English-Spanish groups rather than separating the training by language. Additionally, participants found the small group exercises helpful and valued the parent-teacher workgroups for creating a tailored curriculum.

RESEARCH FOCUS, PARTICIPANT RECRUITMENT & DESCRIPTION OF STUDY PARTICIPANTS

The focus of this presentation was on how Project SUCCEED influenced stress levels of parents and teachers of children with challenging behaviors. The data were collected during the 2001-2002 school year from 18 teachers and assistant teachers and from parents of 136 children.

PARTICIPANT RECRUITMENT

Prior to individual family recruitment, SUCCEED staff collaborated with Community Action (Washington County) Head Start administrators to select potential intervention and comparison classrooms for the ensuing program year. Each classroom needed to have at least one member of the teaching team (head teacher, assistant teacher, or classroom aide) agree to participate in the training program. Six of eight identified comparison classrooms and all eight nominated intervention classrooms elected to take part in this program.

At the start of the 2001-2002 program year, families were informed about the project through flyers, presentations at parent meetings, and teacher reminders. Of the 108 comparison and 144 intervention families eligible, 54 families from comparison classrooms and 82 families from intervention classrooms agreed to participate in the evaluation.

As part of the normal Head Start evaluation protocol, the Devereux Early Childhood Assessment (DECA) was completed in the fall semester of 2001 for each child in the program. Participating intervention classroom families whose student(s) had a DECA score (subscales or total) that fell within the clinical ranges were invited to participate in Project SUCCEED. Structured interviews with families and self-administered questionnaires for teachers provided the means for gathering the remaining assessments that were part of the overall project. At the conclusion of Project SUCCEED, Time 2 interviews were scheduled and completed by early summer 2002.

PARTICIPANT CHARACTERISTICS

The 136 children included in the study were evenly split across gender and ranged from 3 to 5 years old (mean = 4.38, SD = .65). The overall study had six comparison classrooms with a total of 54 children and eight intervention classrooms with 82 children. However, as noted above, the invitation to participate in the training program was only extended to parents of children with a DECA Behavioral Concerns subscale score over 60. A score of 60 or above is considered to be in the clinical (or ‘concern’) range. Therefore, some children in the intervention classrooms did not receive what we referred to as “full intervention.” Full intervention for us meant that a member of the teaching team from the child’s classroom as well as the child’s parent attended at least six of the twelve weeks of the program. 65% of the parents chose to complete a Spanish version of the assessment instruments; however, some bilingual parents whose first language was Spanish completed the English version of the instruments.

After initial analysis revealed significant differences between scores on instruments completed in Spanish and English, it was decided that instead of comparing groups strictly by intervention and comparison
classrooms, we would incorporate the language of the assessment into the grouping. Therefore, subsequent analysis had four groups: Intervention/English, Intervention/Spanish, Comparison/English, and Comparison/Spanish. When considering the distribution of children with challenging behaviors across these four groups, we found that a total of 87 students had a DECA score over 60. The percent of children with a DECA over 60 for each group ranged from 42% in the Comparison/Spanish to 71% in the Comparison/English. The intervention groups had either 64% or 65% of children with a DECA over 60.

RESEARCH FINDINGS: TEACHER STRESS

Seventeen teachers from eight intervention and six comparison classrooms were asked to complete two different teacher stress measures. The first measure was a global measure of their stress as a teacher. The second measure, which will be discussed later, was child-specific stress and compared ‘challenging’ children to ‘typical’ children.

For analysis purposes and because of design complications, this analysis was conducted twice. First, teachers were grouped by intervention classroom or comparison classroom. The second time, teachers were grouped by whether they personally participated in the training sessions. The second analysis was needed because there were instances in which the classroom representative during the training was not the lead teacher but an aide.

When asked, “Overall, my role as a teacher is stressful” on a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree) there was no statistically significant difference between groups. Please refer to Figure 1. Teachers who were in an intervention classroom at the beginning of the study scored 2.50 and at the end scored 2.40. For teachers in comparison classrooms, their average score was 2.00 and increased to 2.86. Trained teachers scored slightly higher at Time 1 (2.63) than non-trained teachers (2.00). However, trained teachers decreased to 2.50 at Time 2 while non-trained teachers increased to 2.67. While these patterns were non-significant, teachers in the intervention classrooms as well as trained teachers showed a decrease in overall stress while teachers in comparison classrooms or non-trained teachers showed slight increases in reported stress.

In order to examine stress specifically related to children with challenging behaviors versus stress related to typical children, an adapted version of the

![Figure 1. Teacher Response to, “Overall my role as a teacher is stressful,” by classroom condition and training participation levels.](image-url)
Index of Teaching Stress (Greene, Abidin, & Kmetz, 1997) was used. Adaptations with permission to the original measure included changing ten items to be scored in the positive direction. Each teacher completed four measures at both time points—two for challenging children and two for typical children. Analysis was conducted based on Training (Trained vs. Not Trained) and Child Type (challenging vs. typical).

Reliability and factor analysis of the revised scale found four subscales: Concerns about home & parent ($\alpha = .77$); Need for resources availability ($\alpha = .72$); Negative response to the child ($\alpha = .96$); and Positive response to the child ($\alpha = .83$). Two of the items in the original Index of Teaching Stress were not included in our final scale due to low factor loadings.

The grouping for this analysis was based on teacher participation in SUCCEED's training (trained vs. not trained) as well as the type of child being asked about (challenging vs. typical). This resulted in four different groups. The purpose of the grouping was to determine the effect that training and the type of child affected teacher stress.

The first of the four subscales, Concerns about the Home/Parent, was a five-item subscale with a possible range 5-25. In this subscale, higher values indicate a higher level of teacher concern about the Home/Parent. Example items include “I feel this child comes from a very poor home situation”, and “I feel supported by this child's parents” (recoded). A three-way repeated measure ANOVA found a statistically significant decrease in this subscale score across time [$F_{(1, 48)} = 14.93, p < .01$] and by child type [$F_{(1, 48)} = 6.418, p < .05$]. The average Time 1 subscale score for the four groups was 12.43; this decreased to 10.93 at the end of the program.

The second subscale was Need for Resources. This subscale was also a five-item scale with a possible range between 5-25 with higher scores indicating more need for resources. Example items included needing more help with a student than the teacher was provided or receiving less support than she or he expected. There was no statistically significant difference found between the groups described above. The average Time 1 score was 10.05, while the Time 2 mean score was 10.02. This non-significant finding was not surprising as all the Head Start teachers had multiple resources available to them to assist in their classroom and in helping children with challenging behaviors.

The third subscale, Negative Response to Child was a 23-item subscale with a possible range of 23-115. Higher values indicate a higher level of negative response to the child. Example items include, “I feel trapped by my responsibilities as this child's teacher,” and “I have doubts about my ability to handle being this student's teacher.” While there was a significant difference based on child type, there was no significant difference over time. Challenging children received an average score of 57.00 while typical children received an average score of 32.00 at Time 1. At Time 2 average scores for challenging children dropped to 55.2 and typical children remained stable at 31.87.

The fourth subscale, Positive Response to Child was a nine-item subscale with a possible range between 9-45. Higher scores indicate a higher positive response to the child. Example items include the child wanting to be close to the teacher and the teachers’ belief that the child appreciates extra efforts expended. Again, a difference between child types was seen with challenging children being rated differently than typical children not dependent on teacher training. However, an statistically significant overall change over time was not found. The average score for typical children was 34.55 at Time 1 and decreased slightly to 33.65. Challenging children had a lower Time 1 rating with an average score of 27.06 with an increase to 28.89 at Time 2. This interesting pattern, although not significant, suggests that Positive Responses to the Child increased with challenging children, but remained constant when considering typical children.

To summarize the teacher stress findings, across all the subscales, Challenging Children were rated differently than Typical Children, independent of
teacher training. Also, all groups decreased in the Concerns About Home/Parent Subscale. While the reported Need for Resources remained nearly constant across groups, the rating of Negative Responses to difficult children were higher for both trained and not trained teachers. Difficult children were initially rated lower for positive responses but this increased over time.

RESEARCH FINDINGS: PARENT STRESS

Since parental participation was a key element of the design of Project SUCCEED, participants were broken into three groups for this analysis. The three groups were: Full Intervention, meaning that a parent and a teacher from the child’s classroom attended more than six training sessions; Partial Intervention, meaning that the parents attended less than six training sessions; and finally, the comparison group. When these three groups are mapped on the language of the parent that completed the assessments, we found a fairly equal distribution of language across the levels of intervention ranging from 11 to 14 children in each group, with the exception of only four English-speaking subjects in the Full Intervention category.

The outcome variables in this analysis were from the Parenting Stress Index-Short Form (Abidin, 1990). Within this standardized measure there are three subscales that are based on percentile ranking: Parent Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. These three subscales can be used to create a Total Parent Stress Summary Score.

When considering subscale and total scores by language and levels of participation in the program, there was a non-significant program effect for those participants that took the English version of instruments. We speculate that these non-significant findings are related to the fact that only four participants received the full intervention and took the assessment in English. Even so, patterns of change from Time 1 to Time 2 indicated that Parental Distress decreased for partial and full intervention participants, and increased for participants in the comparison group. When considering the Parent-Child Dysfunctional Interaction subscale, there was an inconclusive pattern to participation in the program. For the Difficult Child subscale, participation in the program (both full and partial) showed a slight increase in percentile rank while participants in the comparison group, the percentile rank slightly dropped. Considering the specific subscale findings, it was not surprising that the Total Parent Stress score was also inconsistent. It is important to note here that while participants who chose to take the assessment in English showed no statistically significant change over time, even taking into consideration levels of program participation, we believe that the very small sample size is influencing these findings.

When considering program effects for participants that chose to complete the assessments in Spanish, a very different pattern emerged on the PSI-SF subscales and total score. In all cases, irrespective of level of program participation (including comparison group membership) participants who chose a Spanish translation show statistically significant decrease in percentile ranking from Time 1 to Time 2. At this time, we are unsure of the reasons for this finding. We can only speculate that there are larger influences that are driving the change in Spanish group. It may be that other services that Head Start offers to Spanish-speaking families are influencing both intervention and comparison families confounding the results for Project SUCCEED.

DISCUSSION

Due to the nature of the program and the research design, there are several limitations of this research. Specific limitations include possible selection bias, history, teacher training, teacher experience, and non-equivalent comparison groups. However, the largest issue was the small sample size. During the program implementation, this did not appear to be an issue as we had adequate numbers of children in classrooms. However, once we began examining the data at smaller and smaller increments, this became a challenge.
Another issue that may have contributed to inconclusive results was that in some cases assistant teachers or classroom aides attended the training, not the head classroom teacher. It is highly likely that the intervention was not powerful enough to influence the head teacher through the aide's participation. Additionally, there was no direct child-level intervention, nor was coaching offered to parents in their homes (as it was within participating classrooms). Thus, while we relied on child-level outcomes, such as the DECA, we failed to intervene directly in addressing children's behavior.

Furthermore, during data analysis it was found that the Spanish translation of materials had a massive impact on this study. Results indicated a translation effect, instead of an intervention effect. Further research is currently being done to explore this profound effect on our results and make recommendations for future work involving translation of standardized materials. Similarly, it may be that Washington County’s Spanish speaking services were so powerful that they overrode the specific questions being addressed here.

Overall, our findings suggest that the SUCCEED training program holds promise for decreasing teacher and parent stress. However, in order to demonstrably decrease challenging behavior in young children, an even more focused approach is needed with parents, teachers, and the children themselves.

MORE INFORMATION ON PROJECT SUCCEED

More information on Project SUCCEED, including copies of the curriculum and full slides from this presentation, can be found at http://www.rri.pdx.edu/pgProjectSUCCEED.shtml

REFERENCES


INTRODUCTION

The Individuals with Disabilities Education Act (IDEA) of 1997 mandates strengthening the role of parents and ensuring that families of children with special needs have meaningful opportunities to be involved in the special education team process. Efforts to increase involvement of family members—especially family members from culturally and linguistically diverse backgrounds—in the team decision process have increased, but schools must do more to develop successful partnerships between schools and parents of children with severe disabilities (Bauer & Shea, 2003).

Parents of children with severe disabilities want their children to have academic success. They recognize that a positive working relationship with their child’s school is an important factor in their child’s education. Likewise educators genuinely want their students to have academic and social success in school, as well as having active parental involvement. Given the complexities of the educational and family dynamics, parents and teachers often do not know how to build positive and productive parent-teacher partnerships.

In order to gain insights into special education and parents’ perspectives regarding parent-teacher relationships, informal conversations were conducted with parents of children with severe disabilities and their teachers. The goal of having conversations with the two groups of individuals was to accrue information on how to establish and enhance effective parent-school collaborations. Conversations were held within a three-month period with parents who have children with severe and multiple challenges that
include visual, speech and language, hearing, motor, cognitive, behavioral and physical impairments. The twenty parents who participated in the conversations were from varied socioeconomic, cultural and ethnic backgrounds. Conversations were also held with six special education teachers from two elementary schools.

ENGAGING IN CONVERSATIONS

The conversations with special education teachers and parents were held in the classroom, bus stop, cafeteria, family homes, staff and grade level meetings, and various community settings. Gadamer (1992) tells us that a conversation occurs when two people can make themselves understood through language by talking together. Conversations provide parents the opportunity to ask questions, negotiate meaning, articulate thoughts, and reach an understanding on a child’s disability. Conversations can also provide an opportunity for educators to gain a better understanding of the family system the child lives in.

TRADITIONAL PROCESS

Traditional school events such as parent-teacher conferences and/or Individualized Educational Planning meetings (IEP) have been held where parents have the understanding that they will be told by the teacher how their child is performing at school. The teachers have the expectation, either from seeing it modeled in their student teaching or from personal experiences as a parent, that a teacher is to tell the parents about their child and present information to defend his/her assessment of the child’s performance (Harper & Nelson, 1998). Consequently, the parent’s contribution to the IEP meeting often begins and ends with the question, “How is my son doing?” This is often followed by a long period of silence when the parents listen to the teacher’s assessment based on his/her classroom knowledge of the child. Seldom are parents asked to be active participants in the assessment of their child or in the educational program planning for their child. Nor are they given enough time to truly voice their concerns, to tell their stories of real-life conflicts, hopes, dreams and desires for their children.

RECONSTRUCT PROCESS

Schools need to reconstruct parents’ roles to offer parents meaningful input into the education of their children. It is the responsibility of educators to help parents understand the special education system and in so doing allow them to reach new meaning and understandings as they interact with the school, community and their own families (Parette & Petch-Hogan, 2000). When a parent is invited and encouraged to tell a story about a life experience it not only provides the opportunity for thoughts to be expressed, but also because telling a story entails reflections, it thereby encourages more awareness from the experience (Tappan & Brown, 1989). Parents retelling personal stories in relationship to their many experiences living with children with severe disabilities are as important as anything else in the scheme of the child's educational program.

ISSUES OF TEACHER PREPAREDNESS

As teachers enter the classrooms they are often not prepared to successfully facilitate collaborative relationships with families of severely disabled children. Teachers enter the classrooms with their own familial and cultural experiences which may positively or negatively affect how they interact with families in regards to sharing information, attitudes, communication styles, perceptions and values (Dennis & Giangreco, 1996). These interactions are often ineffective because of the lack of understanding and preparation by the teacher as to the family dynamics involved in having a child with severe disabilities.

Realizing that engaging families of children with severe challenges in the education process is not a simple undertaking, teachers can begin with an understanding and awareness that they will most likely work with families that will be very varied and different from the families of their own experiences. A prerequisite to effective school-family partnerships is learning to know and understand the family. There needs to be an acceptance and respect of the many diverse racial, cultural, and linguistic groups and families within a classroom (Lynch & Hanson, 1992). All teachers would benefit from incorporating strategies built on
knowledge gained from interactions with families to improve this vital parent/teacher relationship component.

LESSONS LEARNED: PARENTS PERSPECTIVE

One of the key points the parents involved in these conversations shared was their sense of being violated by professionals such as doctors, therapists and educators who have total access to the lives of their children and subsequently every aspect of their family life because of the intense nature of the disabilities involved. The families sensed there was a complete lack of privacy, as their lives appeared to be under a microscope for everything they did and said. Due to the constant input of advice and solutions to aid in their child's development, the parents sensed that they were being judged as inferior parents.

Many parents were of the opinion that most of the professionals’ advice was “ill-advised” because they had not “walked a mile in my shoes” and thus had no reference base to give advice. Parents also felt strongly that it was arrogant for the schools to assume that families needed help to become informed and skilled at understanding their children. As parents they believe they know what is best for their children. The role of the teacher is to teach their children what they need to know in order to be successful outside of the home.

The care of a child with severe disabilities is an intense responsibility. Many of the parents viewed the school setting as respite, a break from the constant and challenging demands of caring for their child. Parents stated that they did not have the time, energy or desire to become involved in all of the resource training and information professionals make available to them. The parents also expressed that they didn’t want to constantly be in the problem-solving mode regarding their special needs children. One of their goals was to establish some semblance of a normal family life.

One other key point addressed by the parents was the issue of participating in the Individualized Education Plan (IEP) process. Parents stated that even after years of participating in this process, they continued to feel intimidated by its complexities and technical terminology. They reported that they often felt so overwhelmed with the process they would ultimately agree with the IEP without fully understanding what was mandated to occur in the course of the plan’s implementation.

Lessons Learned from Our Conversations

Parents

• “Walk a mile in my shoes”
• Respect our privacy
• Avoid making assumption about us
• Refrain from judging us
• Understand our need for respite
• Slow the process down
• Recognize our family strength

Educators

• Tap into the family’s strength
• Be aware of our own preconceived notions
• Critical to engage family’s input
• Need parent follow through
• Understand/apply family system theory
• Understand & demonstrate respect for culturally and linguistically diverse families

LESSONS LEARNED: TEACHERS PERSPECTIVE

Special education teachers who participated in the conversations generally felt that they were genuinely trying to help parents benefit from their expertise and did not view themselves as intrusive or condescending. The special education teachers did feel frustrated when parents did not follow through with collaborative efforts. They also vented frustration that six hours of school instruction in all domains are ineffective if parents do not consistently follow through with their specific recommendations. The teachers also voiced their opinion on parents often sending their children to school with poor hygiene issues, with illnesses, and...
inappropriately dressed. Due to the nature of the special education system, teachers discerned that parents generally have not been given the knowledge base to gain a sense of empowerment and subsequently parents often defer to professionals in meeting many needs of the families. The special education teachers were resentful that parents expect professionals to facilitate ideal results for the children independently of parent input. Often time teachers are called on to take on roles other then being a teacher, which adds to the pressure of trying to meet the individualized needs of all the students in their class. The special education teachers believe that the educational system is too compartmentalized and that all teachers should receive the same training and skills to teach children of all learning differences.

CONCLUSION

By making time to engage in genuine conversations parents and educators have the opportunity to learn from each other, a first step in the process of developing student success and effective home-school partnerships.

REFERENCES


The increasing proportion of Head Start children in need of mental health services led Piotrkowski, Collins, Knitzer & Robinson (1994) to call for a “paradigm shift” in the way that Head Start programs address children’s mental health needs. Effective mental health services, they argued, should not rely on traditional problem-focused services provided by clinicians outside of the program context. Instead, services should take a holistic approach, emphasizing prevention, family involvement, and integration of mental health services with other Head Start components. However, despite changes in Head Start performance standards, mental health services vary widely across Head Start programs, with many programs continuing to take a traditional, narrow view of mental health (Yoshikawa & Knitzer, 1997). Consultants are often used in limited ways (e.g., only for time-limited observations and assessments), and are not considered a core part of service delivery to all families.

To facilitate effective services, Yoshikawa and Knitzer (1997) urge programs to involve mental health professionals on-site and in an expanded role in program delivery, especially by providing “program-level” consultation (for example, training and meeting with staff; Cohen & Kaufmann, 2000). However, there has been little research to document the benefits of this more integrated model. The present study was designed to address this gap, and posed three primary research questions:

1. What is the nature of mental health consultation in Head Start settings? (Have programs developed more integrated, holistic models of early childhood mental health consultation?)
2. What is the evidence that these more integrated models of consultation are effective?

3. What can Head Start program managers do to help facilitate more effective mental health consultation?

METHODOLOGY

79 Head Start programs agreed to participate in a mail survey. Programs were selected from a stratified random sample representative of core Head Start programs. 1265 surveys were sent to a random sample of 12-18 staff in each program, including a variety of staff positions. 803 surveys were returned (63%).

Survey Instrument Domains

The survey collected data about five areas as listed here. Additionally, program directors completed an addendum that provided descriptive information (such as total children, sites, consultant characteristics, program budget, etc.).

1. Mental Health Consultant (MHC) Activities: 10 questions asked about the frequency with which consultant(s) engaged in different activities, rated from 1 (rarely/never) to 5 (weekly or more).

2. Mental Health Consultant (MHC) Characteristics: Staff rated the MHC’s quality of relationships with staff and parents, cultural competence, and level of integration into the overall Head Start program.

3. Mental Health Leadership: Staff rated the quality of leadership specific to supporting children’s mental health, and the level of training and support provided for staff.

4. Staff Practices: These questions asked staff the extent to which their program’s mental health services were: inclusive, strengths-oriented, prevention-focused, family-centered, culturally competent, and integrated across program components.

5. Effectiveness: Staff rated the extent to which their program’s mental health services were effective in supporting or preventing specific kinds of child behavior, as well as the effectiveness of the service delivery processes.

RESULTS

The survey was completed in February 2003, and analyses are still ongoing. Preliminary results, organized according to the primary research questions, suggest the following:

#1: Are Head Start programs providing integrated, holistic mental health services?

As can be seen in Table 1, there remains considerable variability in the level of consultation that programs provide, and in the nature of consultant services. However, compared to the survey results of Piotrkowski, et al. (1994), more programs appear to have consultants who are engaged in activities beyond individual, child-focused therapy. Our results show that a number of programs (n=47, or 60%) use program-level strategies (e.g., formal and informal training of teachers) at least every other month.

In other ways, however, change is less apparent, at least at the structural level. For example, Piotrkowski and colleagues reported that 19% of their sample (15 programs) had mental health specialists on staff, which is similar to our finding of 21% (15 programs).

#2: What is the evidence that these more integrated models of consultation are effective?

Programs were grouped into “high integration” and “low integration” categories, based on average staff ratings. Analyses were conducted comparing these groups (see Table 2). As can be seen, compared to low-integration programs, more integrated models were generally perceived as being more effective. Staff from these programs reported higher levels of “promising practices”, and perceive their program’s services to be more effective.

#3: What can Head Start program managers do to help facilitate more effective models of consultation?

As a first step to address this question, we examined the role of mental health leadership. Programs with strong leadership in the area of mental health appeared to structure mental health services differently,
Table 1. Characteristics of Mental Health Consultation

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<thead>
<tr>
<th>Low-Implementing Programs</th>
<th>High-Implementing Programs</th>
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<tr>
<td>• 57% (31) of programs report fewer than 1 hour of consultation per child, per year</td>
<td>• 26% (13) of programs report more than 2 hours of consultation per child</td>
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<td>• 37% (20) report fewer than ½ hour per child</td>
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<td>• 71% (35) of programs report less than one half-time mental health consultant</td>
<td>• 29% (14) of programs report one half time mental health consultant or more</td>
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<td>• 37% (30) of programs report consultants who provide child-focused services less than 1-2 times per year</td>
<td>• 16% (8) report one full time consultant or more</td>
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<tr>
<td>• 40% (33) of programs report consultants who provide program-level consultation less than 1-2 times per year</td>
<td>• 11% (9) of programs report consultants who provide child-focused services at least monthly</td>
</tr>
<tr>
<td>• 79% (56) of programs rely on contracted mental health consultants</td>
<td>• 7% (6) of programs report consultants who provide program level consultation at least monthly</td>
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<tr>
<td>• 46% (31) have less than one ½ time mental health services coordinator</td>
<td>• 21% (15) of programs report that they have at least one mental health consultant who is a salaried staff member of the program</td>
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<tr>
<td>• 54% (36) have more than a half time mental health services coordinator</td>
<td>• 18% (12) have a full time mental health services coordinator</td>
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compared to those with weaker-rated leadership. For example, programs with stronger leadership spent a higher percentage of their Head Start budgets in the mental health area (3.8% vs. 3.0%). Programs with stronger mental health leadership also had consultants who were more integrated into program functioning, and who provided a wider variety of services. In regression analyses, leadership accounted for significant additional variance in the frequency of both program-focused and child-focused consultant activities, even after controlling for the total amount of consultation time provided.

DISCUSSION

This survey represents one of the few large-scale attempts to gather data about the kinds of mental health consultation being implemented in Head Start programs, and about the effectiveness of those services from the perspective of Head Start teachers, administrators, and others. Data suggest that although some Head Start programs are beginning to change their approaches and adopt more holistic models, a large number continue to rely on consultants who provide relatively limited levels of child-focused services. Results also suggest that developing integrated models is a worthwhile venture, even for programs with limited resources. Analysis of informative qualitative data describing program training activity, staff development strategies, and creative approaches to leveraging mental health resources was also included in the presentation.

REFERENCES

Table 2. Mental Health Program Structure, MHC Characteristics, Staff Practices, and Outcomes for High vs. Low Integration Programs.

<table>
<thead>
<tr>
<th>Mental Health Program Structure</th>
<th>Low Integration Programs</th>
<th>High Integration Programs*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hours consultation per child</td>
<td>1.57 hrs</td>
<td>1.95 hrs</td>
</tr>
<tr>
<td>% of budget spent on mental health component</td>
<td>3.6%</td>
<td>3.3%</td>
</tr>
<tr>
<td>Frequency of program level consultation (1=rarely/never; 2=1-2x/year; 3=every other month; 4=monthly; 5=weekly or more)</td>
<td>2.2</td>
<td>3.1***</td>
</tr>
<tr>
<td>Frequency of child-focused consultation (1=rarely/never; 2=1-2x/year; 3=every other month; 4=monthly; 5=weekly or more)</td>
<td>2.3</td>
<td>3.0***</td>
</tr>
<tr>
<td>% with Salaried MHC</td>
<td>16%</td>
<td>24%**</td>
</tr>
<tr>
<td>% with written MH mission statement</td>
<td>78%</td>
<td>85%*</td>
</tr>
<tr>
<td>Total hours of MH consulting</td>
<td>810</td>
<td>1150 hrs**</td>
</tr>
<tr>
<td>% with other sources of funding for MH services (beyond core Head Start funding)</td>
<td>27%</td>
<td>37%**</td>
</tr>
<tr>
<td>% with in-kind commitments for MH services</td>
<td>62%</td>
<td>63%</td>
</tr>
<tr>
<td>% with more than 25% of children needing MH services</td>
<td>16%</td>
<td>16%</td>
</tr>
<tr>
<td>MHC Characteristics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1=strongly disagree; 2=somewhat disagree; 3=somewhat agree; 4=strongly agree</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Culturally Competent</td>
<td>2.7</td>
<td>3.5***</td>
</tr>
<tr>
<td>Positive Relationships with Parents</td>
<td>2.5</td>
<td>3.4***</td>
</tr>
<tr>
<td>Positive Relationships with Staff</td>
<td>3.2</td>
<td>3.9***</td>
</tr>
<tr>
<td>Available when Needed</td>
<td>2.8</td>
<td>3.6***</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Staff Practices</th>
<th>Low Integration Programs</th>
<th>High Integration Programs*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inclusive</td>
<td>2.8</td>
<td>2.7</td>
</tr>
<tr>
<td>Difficult to serve behaviorally challenged children</td>
<td>1.9</td>
<td>2.2</td>
</tr>
<tr>
<td>Prevention orientation</td>
<td>2.3</td>
<td>2.7**</td>
</tr>
<tr>
<td>Strengths Orientation</td>
<td>3.2</td>
<td>3.6***</td>
</tr>
<tr>
<td>Parent Involvement</td>
<td>3.3</td>
<td>3.6***</td>
</tr>
<tr>
<td>Cultural Competency</td>
<td>3.2</td>
<td>3.5***</td>
</tr>
<tr>
<td>Child Behavior Outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve positive behavior</td>
<td>2.9</td>
<td>3.5***</td>
</tr>
<tr>
<td>Reduce internalizing behavior</td>
<td>2.6</td>
<td>3.2***</td>
</tr>
<tr>
<td>Reduce externalizing behavior</td>
<td>2.7</td>
<td>3.3***</td>
</tr>
<tr>
<td>General Program Outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Classroom transitions are smoother</td>
<td>2.8</td>
<td>3.5***</td>
</tr>
<tr>
<td>MH services need improvement</td>
<td>3.1</td>
<td>2.5***</td>
</tr>
<tr>
<td>Staff feel supported</td>
<td>2.8</td>
<td>3.3***</td>
</tr>
<tr>
<td>Staff practices are improved</td>
<td>3.2</td>
<td>3.6***</td>
</tr>
<tr>
<td>Other Outcomes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time between referral and assessment</td>
<td>3.0</td>
<td>2.5***</td>
</tr>
<tr>
<td>1=1 week; 2=1-2 wks; 3=2-4 wks; 4=1-2 months; 5=&gt; 2 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of children who received group screening</td>
<td>4.7</td>
<td>4.8</td>
</tr>
<tr>
<td>1=&lt;5%; 2=6-25%; 3=26-50%; 4=51=75%; 5=&gt;75%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Statistical tests compared high vs. low integration programs using ANOVA for continuous dependent variables and Chi-squared for categorical dependent variables.

*p<.05

**p<.01

***p<.001
This study examines caregiver strain among families of adolescents with substance abuse problems, compares their experiences with those of caregivers of youth with mental health problems, and proposes that the concept of caregiver strain is as important for adolescent substance abuse treatment and research as it has been found to be in the mental health field.

In recent years as researchers and practitioners have come to acknowledge that families and caregivers play a central role in bringing their children into treatment, shaping their children’s service and treatment experiences, and supporting clinical gains in the home, school, and community (Koroloff & Friesen, 1997). Caregiver strain, in particular, has received considerable attention (Brannan, 2003). The term caregiver strain refers to the negative consequences and emotional impact on caregivers and families related to the additional demands of caring for a relative with special needs. Although there is an emerging literature focused on caregivers of minor children with mental health problems (Brannan & Heflinger, 2001; Angold et al., 1998; Yatchmenoff et al., 1998), the impact on the family of caring for youth with substance abuse problems has been largely ignored. However, preliminary studies have found that in samples that included youth with substance abuse disorders with and without co-occurring mental health problems, caregiver strain was a significant predictor of use of any service, type of service used, days of service used, and days of inpatient or residential treatment (Aarons, Garland, & Hough, 2003; Heflinger, Brannan, McKenzie, & McKenzie, 2002).
METHODS

We conducted secondary analyses on existing interview data from two studies of caregivers of children and adolescents living in Tennessee who were Medicaid beneficiaries. The first of these was the Adolescents in Substance Abuse Treatment Study (ASAT), where youth were recruited and interviewed as they entered publicly-funded treatment for substance abuse problems (Heflinger & Simpkins, 2000). The second sample was from the Impact of Medicaid Managed Care (IMMC) study, for which a stratified random sample of Medicaid children and adolescents was recruited and interviewed to examine the impact of a shift to Medicaid managed care on services to youth with mental health problems (Heflinger et al., 2000).

Sample

For this study, youth were selected from the two existing datasets if (a) the youth was between the ages 12-17 years at the time of the interview, and (b) the youth’s caregiver completed the adult interview including the assessment of caregiver strain. Youth from the IMMC sample were selected if they met Child Behavior Checklist borderline or clinical criteria for internalizing or externalizing problems. Hence, the IMMC sample represented youth with emotional or behavioral problems. The ASAT sample represented youth with primarily substance abuse disorders.

Demographic characteristics of the youth and their caregivers are presented in Tables 1 and 2 [Editors’ note: not provided with manuscript; please contact the authors if complete demographics are desired]. Although the caregivers in both samples were predominantly female, the ASAT sample had a larger proportion of male caregivers (17%) than the IMMC sample (3%). The mean age of the caregivers was 41 years in both samples. Caregivers in this study were usually biological parents. However, a larger proportion of caregivers in the IMMC sample were other biological relatives (e.g., grandparents, aunts). Caregivers in the ASAT sample were less likely to have finished high school. Both samples were comprised of Medicaid youth and per capita monthly family income was generally low. However, income was higher, on average, in the ASAT sample.

Data

Youth mental health symptoms were assessed with the Child Behavior Checklist (CBCL; Achenbach, 1991). The CBCL internalizing (i.e., sadness, worry, fear) and externalizing (i.e., conduct problems, aggression, delinquency) scales scores were used. The Columbia Impairment Scale (CIS; Bird et al., 1992) assessed youth’s psychosocial functioning. Youth also reported on the type of substances used, frequency of use, and consequences of use. Caregivers reported their own physical health, and completed the Center for Epidemiological Studies – Depression scale (CES-D; Radloff, 1977) to report depression symptoms. The Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger, & Bickman, 1997) was used to assess the impact on the family of caring for youth with emotional, behavioral, or substance abuse problems. Caregivers also reported their own substance use. Per capita family income data were collected. For all these instruments, youth and caregivers reported on experiences in the past six months with the exception of caregiver substance use for which a 30-day time frame was used.

Analyses & Results

We conducted descriptive analyses to compare the characteristics of youth and families, including caregiver strain, across the two samples. The caregivers of youth with primarily mental health problems (IMMC) and primarily substance abuse problems (ASAT) both reported their physical health, on average, in the good to fair range. The mean CES-D scores for both samples were above the clinical cutoff of 16 (Radloff, 1977), however, the IMMC sample included a larger proportion of caregivers who met clinical criteria and had higher scores on average.

Caregivers were similar across samples in terms of their substance use. Approximately one-third of caregivers in each sample reported using alcohol in the previous 30 days. Among those who drank any alcohol, the average days of alcohol use was between
There were no statistically significant differences in reported illegal drug use across samples, with the proportion of users between 5% and 7%, and roughly 12 average days of illegal drug use among those who used any.

Caregivers in both samples reported similar levels and types of caregiver strain at the sub-scale and item levels. Both samples reported greater subjective-internalized strain than the other two forms of caregiver strain. At the item level, the highest item means for both groups were from the subjective-internalized subscale including: being worried about the child’s and family’s future, feeling sad and unhappy, feeling tired. There were significant differences in mean item scores between the two groups on only two items: trouble with neighbors, community, or law enforcement with higher scores for the ASAT sample; and feeling sad and unhappy, with the IMMC sample having higher mean scores.

Youth in both samples demonstrated high levels of mental health problems on the CBCL externalizing and internalizing scores, with group mean scores above the borderline or clinical cutoff (Achenbach, 1991). A larger proportion of the IMMC sample met borderline or clinical criteria on both CBCL scales and had significantly higher mean internalizing and externalizing scores. Many youth exhibited problems with psychosocial functioning on the CIS, with mean scores above the clinical cutoff of 16 (Bird et al., 1992); however, the youth in the IMMC were experiencing significantly more impairment. Youth in the ASAT sample, all of whom were in treatment for substance abuse problems, were more likely to have used substances within the past six months and to have endorsed at least one substance dependency item. Among substance users, the ASAT sample also reported more days of use and endorsed more dependency items.

We used standard multiple regression analysis to examine whether similar child, caregiver and family characteristics explained caregiver strain across the two groups. We also ran the regression analyses with the combined ASAT and IMMC sample. Analyses were conducted separately for each of the caregiver strain dimensions (i.e., objective strain, subjective-externalized strain, subjective-internalized strain). Findings are summarized in Table 1.

### Table 1. Significant Predictors of Strain across Samples

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Objective Strain</th>
<th>Subjective-externalized Strain</th>
<th>Subjective-internalized Strain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Variables</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than H.S. diploma</td>
<td>+</td>
<td>+</td>
<td></td>
</tr>
<tr>
<td>Biological parent</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Global health</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Youth Variables</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dependency items</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Days of substance use</td>
<td>+</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Girl</td>
<td>-</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internalizing behavior</td>
<td>+</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Externalizing behavior</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Social functioning (CIS)</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Family Variable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Per capita income &lt; $295</td>
<td>-</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*None of the variables provided unique power to explain subjective-externalized strain for the ASAT sample. The proportion of the variance explained by the overall model was not significant.

**Approached significance.
Objective strain. Objective strain refers to observable negative occurrences resulting from the youth’s problems (e.g., trouble with community; interruption of work and personal time; disrupted social activities, family relationships and routines). Across all three samples, objective caregiver strain was associated with the caregiver having more symptoms of depression and the youth having more problems with social functioning. For the IMMC sample (i.e., youth with primarily emotional or behavioral challenges) caregivers with more than a high school diploma tended to report more objective strain. For the ASAT sample, the caregiver being a biological parent and more youth externalizing behavior problems were associated with greater caregiver strain. Also, being in the lowest income category (i.e., per capita monthly income less than $295) was related to less objective caregiver strain.

Subjective-externalized strain. Subjective-externalized caregiver strain involves outwardly directed feelings related to the youth’s problems such as anger, resentment, and embarrassment. In general, the variables in the regression models did a relatively poor job explaining subjective-externalized strain. Indeed, we were wholly unable to explain subjective-externalized strain for the ASAT sample. In the IMMC sample, only youth characteristics explained differences in subjective-externalized strain. After controlling for the other variables in the model, the fewer internalizing symptoms (i.e., sadness, worry, fear) the youth exhibited, the more subjective-externalized strain reported. However, more youth problems with externalizing behavior and poorer social functioning were related to more subjective-externalized strain.

Subjective-internalized strain. Subjective-internalized strain relates to inwardly directed negative feelings associated with the youth’s problems such as sadness, worry, guilt and fatigue. In both the IMMC and ASAT samples, greater subjective-internalized strain was associated with being a biological parent, and the youth having poorer social functioning. In addition, caregiver’s global physical health was associated with greater subjective-internalized strain and youth internalizing behavior was related to less subjective-internalized strain. More caregiver depression and more youth externalizing problems were related to greater subjective-internalized strain in the IMMC sample. Youth substance use was positively related to subjective-internalized strain only for the combined sample. This is likely because the combined sample provided more variability on youth substance abuse than either sample alone.

It is notable that several variables provided no unique contribution to the explanation of any of the caregiver strain dimensions. These include race, caregiver gender, caregiver having less than a high school diploma, caregiver substance use, youth age, and family per capita monthly income between $295 and $395. Caregivers of youth with primarily substance abuse problems reported similar levels of strain for both subscales and individual items as caregivers of youth with primarily mental health problems. The only item for which caregivers of substance abusing youth scored higher than the IMMC sample was for trouble with the community (i.e., neighbors, law enforcement). This stands to reason as many of the youth in the ASAT sample were brought to treatment through the juvenile justice system. In addition, there were similar patterns among the variables that predicted objective and subjective-internalized strain across the samples. Some important exceptions include the difference in the role of caregiver education and youth gender. Caregiver’s global rating of health and family income also appeared to be more important predictors for the ASAT sample. For both samples, it seems clear that caregivers are more negatively affected by externalizing symptoms (i.e., acting out behavior) than by internalizing problems. Youth substance use provided unique power to predict subjective-internalized strain indicating that having an adolescent with substance abuse disorders is distinguishable as an added stressor that increases the demands placed on caregivers at a given level of symptoms and psychosocial functioning.
IMPLICATIONS FOR TREATMENT AND RESEARCH

This study documents that families of youth with substance abuse problems experience caregiver strain at levels comparable to that of families of adolescents with mental health problems, especially for objective and subjective-internalized strain. It is likely, therefore, that caregiver strain exercises similar influences on the substance abuse services and treatment youth receive, as suggested by research with children with emotional and behavioral problems (Bickman, Foster, & Lambert, 1996; Brannan, Heflinger, & Foster, 2003; Farmer et al., 1998) and youth with co-occurring substance abuse and mental health challenges (Aarons et al., 2003; Heflinger et al., 2002). It stands to reason, therefore, that caregiver strain has the potential to impact youth outcomes related to substance abuse treatment and should be addressed by practitioners and researchers.

As the field of mental health services research has been learning (Brannan, 2003), substance abuse treatment and research would benefit from a better understanding of the relationships among caregiver and family characteristics and adolescent substance abuse and treatment. By failing to consider the impact of adolescent substance abuse disorders on the family, the field risks overly simplified and unidirectional interpretations of results (i.e., family factors causing youth substance abuse). Findings from this study support the use of transactional models in the study and treatment of adolescent substance abuse disorders.

REFERENCES


Clark County Child Care Resource Team: A Key to Quality Care

BACKGROUND AND CONTEXT

In 2002, with funding from a U.S. Department of Education Early Learning Opportunities Act Grant, and additional funding from the United Way of the Columbia-Willamette, the Clark County Child Care Resource Team began providing training and technical assistance consultation to licensed child care providers in Clark County, Washington.

This interdisciplinary Resource Team includes a public health nurse, an early childhood specialist and a mental health specialist. The team combines the perspectives and expertise of three service systems—public health, early childhood education, and mental health—as well as three community agencies. The team is coordinated through the Educational Service District 112 Child Care Resource & Referral program.

The Clark County Child Care Resource Team is a pilot project for a service delivery model to improve the quality of child care by providing education and support for caregivers. The Resource Team offers current, practical and relevant information, delivered through training sessions and on-site visits. The overall goal for the team is to build capacity of child care providers to foster healthy development, to practice responsive care, and adopt effective methods to retain children with challenging behavior in care.

Consultation services in child care is a model that is becoming more familiar in early childhood settings. This approach to education, support and quality improvement in caregiving practices shows promise as a means to reduce provider isolation, increase retention of children as well as staff, and to realize
the potential for health promotion and primary prevention efforts early in a child’s development.

DESCRIPTION OF SERVICES

Training and consultation are the main avenues for contact between the Clark County Child Care Resource Team and child care providers. Services are described in further detail below.

Team members schedule consultation visits in response to provider-initiated requests. Child Care Resource & Referral’s Provider Services Specialist facilitates the linkage between providers and the team. Services are available at no cost to providers.

Training

Clark County Child Care Resource Team members design and deliver training sessions on a variety of topics of interest to providers, including early brain development, health and safety, guidance strategies, early literacy and communication with families.

Training takes place in various community settings (including on site trainings at child care centers, conducted during naptime) as well as at the Educational Service District 112’s Conference Center. Training sessions are designed to address general topics of importance for early childhood (i.e., health, safety, literacy, social and emotional development) and are delivered using interactive methods. The Resource Team also provides training to meet specific requests from child care providers.

Consultation

Team members are available for individualized technical assistance consultation initially by phone, with frequent follow-up at on-site visits. The consultation process begins with developing rapport with the provider, identifying strengths, and assessing the provider’s readiness to make change in their practices. Initially, a team member works individually with a provider, gathering information and background on the situation and the stated need for assistance. The Resource Team member provides knowledgeable support, information and suggestions to guide the child care provider in their decision-making response.

Outreach

The Child Care Resource Team has devoted considerable time to making contact in the community of service providers in order to publicize the availability of these services. The general isolation of childcare providers makes it difficult for them to make connections for needed resources and support. Team members have found a variety of ways, both formal and informal, to “get the word out”. Social workers, public health visiting nurses, librarians, family resource center staff, and fellow providers have been effective links in the referral process. Often, a provider will call for assistance when someone else has encouraged them to call.

Linkage with Community Resources

An important function that the Resource Team members fill is helping to connect providers and family members to agencies and organizations in the Clark County community when additional specialized services seem necessary. Connecting with specific individuals in community partner agencies has become an important adjunct to the frontline work. This networking process includes gathering information about available services, demystifying the access and eligibility procedures, and supporting a cooperative problem-solving process between providers and family members.

Providers often call the Resource Team feeling desperate about a particular situation they are facing. They want information and resources to help them manage the care of children with challenging behavior, or whose developmental processes are concerning to the provider. Providers may believe that an individual child needs additional help; they often do not know where to turn to find that help. Screening for hearing difficulties, developmental delays, health concerns, and mental health treatment (often for disruptive aggression, trauma, or threat of self-harm) are some examples of questions that arise for which providers do not feel equipped.
Resource Team members use the Ages & Stages Questionnaire (ASQ) and the ASQ-SE as tools to help providers and parents sort out some of the developmental concerns. This has proved to be an effective way to begin the process of problem solving, focusing on the child’s strengths as well as potentially identifying areas of development that are lagging. Because the ASQ offers specific activity ideas to bolster development, this tool also provides some interim actions that parents and providers can take, even while a referral for more in-depth screening is underway.

The Resource Team member will do the “legwork” to locate resources and takes the information back to the provider. The Resource Team members frequently work with both providers and parents to broker access to these services. Other times, the Resource Team member provides the information and the guidance for the provider and/or the family to initiate the contact with the agency.

DYNAMICS OF CHILD CARE

The Resource Team has identified key patterns in consultation and training contacts, which provide critical insights for planning effective service delivery. Child care providers typically ask for assistance when they are in crisis. The team members work with providers to help them understand that a “quick fix” is often not the best answer for a challenging situation, and does not provide a feasible approach to promoting social and emotional health for young children. The team members work to gain the trust and cooperation of teachers and providers in order to engage them in the deep and ongoing work of relationships with children and families.

All three Resource Team Specialists find daily challenges in working with providers, children and families. Gaining the trust of providers is an ongoing challenge. Identifying and building on strengths requires care, patience and skill. Clearly identifying appropriate and doable next steps for providers and parents is an often surprising and rewarding process. Many times, the biggest challenges revolve around providers/parents lack of knowledge and inappropriate expectations for children. Encouraging providers to continue the hard work of dealing with challenging issues instead of discontinuing children from care is a big task.

On May 14, 2003 the Clark County Health Department organized a community meeting to discuss concerning findings of the Resource Team. The Children’s Roundtable drew nearly 40 community members from diverse fields (i.e., law enforcement, public health, mental health, child protective services, child care, child care resource and referral, medical practitioners and others). The consultations that encouraged the community meeting entailed violent actions or threat of violence by children under the age of eight. The Resource Team has also followed up on a large number of referrals involving violence to children under the age of eight.

APPRENTICE PROJECT

As part of grant responsibilities, the Resource Team has designed and is currently implementing a project to develop a group of twelve apprentices attached to the Clark County Child Care Resource Team. The apprentices, staff working in child care center programs, will be recruited, trained and supported as a capacity building effort for the community system of early learning services and supports. As a result of their participation, this group of caregivers will be better able to provide knowledgeable support and problem-solving responses to peers in child care settings.

Apprentice training will provide a common foundation of information about current brain research, linked with effective strategies for promoting social, emotional and behavioral health among all children birth through age five in their care. Training sessions include Comprehensive Health Education Foundation (C.H.E.F.) curriculums called Healthy Beginnings and Social Beginnings, as well as skill development in managing the change process in child care (Comfortable Change in Child Care). The content of this portion of training is based on motivational interviewing, and forms the scaffold for the Resource Team’s consultation process.
Training is complemented by implementation and support meetings and individualized mentoring visits. Connecting training information with everyday practices in the child care setting is a critical feature of the apprentice development project. Specific assistance to apply learning, and facilitation of support network among the apprentices are essential to assure apprentices are best able to implement better practices in their own programs.

The apprentices will become part of a “first-line” response for Clark County providers who need assistance, support, and guidance in meeting the challenges of the work. The apprentices will augment the capacity of the Resource Team to respond to questions and concerns from child care and early learning staff.

The apprentices will be formally and informally connected to the Resource Team. The Resource Team will provide the training and follow-up support for the apprentices, to ensure consistent messages which are well-grounded in best practices for early learning and child care environments.

NEXT STEPS & SUSTAINABILITY

The Resource Team will continue to develop plans to address trends in child care, particularly as they relate to children with challenging behavior, identified through the consultation process. Documentation of outcomes, and description of the impact of the Resource Team on retention of children in care, improvement in practices in child care, and appropriate utilization of community resources are ongoing. In addition, the Resource Team is active in continuing efforts to secure funding to sustain this work in Clark County.
Measuring Fidelity in Wraparound Implementation

The presentation on measuring fidelity in wraparound implementation had four main goals: to describe one parent’s experience with two very different wraparounds and the fidelity of each of those experiences to the wraparound model; to discuss the importance of fidelity and adherence to the wraparound model; to describe the Wraparound Fidelity Index version 3.0 (WFI-3.0) and how it is used in quality improvement; and finally, to describe future research directions.

One parent’s experience with wraparound by two different providers showed that, according to results of the WFI, the second wraparound experience had much higher fidelity to the principles of wraparound than the first wraparound experience. Primarily the first wraparound experience was described as having poor services that were limited and lacked essential components, one important component being family inclusiveness. The service providers were also unresponsive to the family and the client. The second wraparound experience had flexible and creative treatment plans. These plans offered a complete array of services and supports. The service providers were both responsive to and respectful of the family. This leads to the importance of measuring fidelity.

Measuring fidelity is important for many reasons and on many levels. At the system level, it can be used to justify funding needs and as support for the quality of services being offered. At the program level, it can be used in both program development and program evaluation. At the provider level, it can be used in training both new and existing service providers and in providing feedback to those working with specific families. However, there are many challenges in assessing fidelity, specifically fidelity to the wraparound
model. It is difficult to assess adherence to the wraparound model both because of the complexity of the model and the flexibility of the model.

The WFI-3.0 User’s Manual (Suter et al., 2003) outlines both the structure of the WFI-3.0 and how to use the instrument. The WFI-3.0 is comprised of three separate respondent forms: the caregiver, youth, and resource facilitator forms. The caregiver and resource facilitator forms are very similar and are comprised of 44 questions broken down into 11 elements. The youth form is different from the caregiver and resource facilitator forms in order to make it more understandable to youths. The youth form has 36 questions broken down into 9 elements (the last two elements are omitted due to youth’s lack of knowledge about these elements). The 11 elements are

- Parent and Youth Voice and Choice,
- Youth and Family Team,
- Community-Based Services and Supports,
- Cultural Competence,
- Individualized Services and Supports,
- Strengths-Based Services and Supports,
- Natural Supports,
- Continuation of Care,
- Collaboration,
- Flexible Resources and Funding, and
- Outcome-Based Services and Supports.

Administering the WFI has three main components: training interviewers, conducting the interviews themselves, and using the WFI data. Training interviewers begins with identifying people who are not directly involved with providing services to the youth and families. These third-party individuals should be trained in both wraparound and in the WFI-3.0. Conducting the interviews involves identifying all three respondents, the resource facilitator, youth, and biological parent whenever possible; and engaging resource facilitators to both participate in the interview itself and to present the WFI-3.0 to the families they work with and obtain informed consent. Presenting the WFI-3.0 to the families is important because the resource facilitators are often the first step in obtaining family participation. The benefits of using the WFI-3.0 need to be communicated to the resource facilitators so they in turn can communicate them to the families. These benefits include giving feedback to the site, to youth and family teams, and to stakeholders; identifying areas of needs; and defending the need for more site funding. Caregivers and youth need to give informed consent and informed assent, respectively, before interviews can be completed with an emphasis on confidentiality. A variety of data management tools are provided by the Wraparound Evaluation and Research Team (WERT), including how to assign identification numbers, how to track families, and introduction scripts to be used when conducting interviews. Once the data has been completed, it should be entered into a database provided by WERT and transmitted either electronically or via mail to WERT in order to be used in the national sample of collaborators. Feedback is then given to the sites in the form of a summary report containing graphs that include the following: overall total scores; caregiver, youth, and resource facilitator total scores; overall element scores; caregiver, youth, and resource facilitator element scores; and item level analyses.

Future directions for the WFI-3.0 range from continuing to obtain a national sample of collaborators to studies looking at the relationships between wraparound fidelity as measured by the WFI-3.0 and outcome measures. Work is also in progress on a Spanish translation of the instrument. WERT is also working on revising and adding to the WFI website. In order to participate in the national sample of collaborators, sites should go to the University of Vermont website at http://www.uvm.edu/~wrapvt/ that discusses how to request a copy of the WFI and request collaboration with WERT.

REFERENCE

INTRODUCTION

The logic model for the system of care program assumes that if funds and technical assistance are provided by federal, state, and local agencies to grant communities, activities congruent with system of care principles will take place that will impact upon the local administrative structure and service delivery, ultimately leading to improved outcomes for children with serious emotional disorders and their families. The Comprehensive Community Mental Health Services for Children and their Families Program of the Center for Mental Health Services includes an evaluation component, conducted by ORC Macro and its partners, that tracks system development and individual child and family outcomes in funded grant communities. Findings from system level assessments indicate that system of care is developed incrementally, so that a grant community may not be at a mature stage until the third year of grant implementation (MACRO, internal site visit reports). But the evaluation of child and family outcomes generally compares measures between baseline and follow-up time-points, thus assuming that system of care is fully implemented from the first point of data collection.

In this report, we present findings on changes in service system performance indicators that occurred between 1997 and 2002 and the validity with which the system of care model has been implemented. One-year outcomes of children and families enrolled in the first years of the grant are then compared with those enrolled in the last two years when system of care is presumably at a more advanced level of development. We hypothesize that outcomes for
children enrolled in the first part of the grant period will differ from those enrolled in the last part.

BACKGROUND

North Carolina Families and Communities Equals Success (NC FACES) was funded in 1997 by CMHS through the NC Division of Mental Health/Developmental Disabilities/Substance Abuse Services to implement a System of Care program for children with serious emotional disorders and their families in four sites. The grant communities of Blue Ridge, Cleveland, Guilford, and Sandhills built upon unique strengths but all had the same essential elements, the most basic of which were the following:

• a Community Collaborative of public and private child-serving agency representatives, family members of children and youth who are in the system, university partners, and other interested community stakeholders that acted as the local governance structure for the development, implementation and monitoring of the local System of Care in each site;

• consumer, family, and community involvement that was required at all levels of the project and in all aspects of the service delivery planning, implementation and evaluation;

• Child and Family Teams that include the child, his or her caregivers and other significant people in the child’s life, as well as representatives of agencies involved in the management of the child’s behavioral problems;

• individualized service plans that maximize and integrate formal services from traditional service delivery systems and incorporate informal community supports;

• the implementation of strategies to ensure that the local System of Care is culturally responsive to the families and communities it services;

• training and technical assistance supports for the local System of Care development; and

• evaluation of the program to continuously improve the local System of Care.

Midway through the NC FACES grant period, the state initiated the implementation of System of Care through the mandated Comprehensive Treatment Services Program (CTSP) for children at risk for institutionalization or other out-of-home placements. With CTSP, System of Care principles became incorporated into existing structures and practices. Interagency collaboration was formalized with Memoranda of Agreements signed by representatives of child-serving agencies including the Division of Mental Health/Developmental Disabilities/Substance Abuse Services, the Division of Social Services, the Department of Public Instruction, and the Office of Juvenile Justice and Delinquency Prevention. Community Collaboratives were formed at the local level. The State Collaborative for Children and Families was established to promote collaborative implementation of System of Care. Training on the application of strengths based assessments and other System of Care principles to service delivery was made available to a wider array of providers. Organizations were funded to facilitate family participation.

METHOD

Service Testing

The North Carolina System of Care projects supplemented the tools of the national evaluation with a local quality improvement protocol that included service testing. Developed by Ray Foster and Ivor Groves (1995), service testing assesses system level development through a review of services provided to a selected group of children served by a program. In the service testing protocol adapted for North Carolina, a stratified sample of 12 children is initially drawn from each site to constitute the cases that will be intensively examined in service testing. In the three-day process, service testers recruited from other sites or agencies are paired with “shadows” (staff members or stakeholders from the local site), who are then trained on the use of the protocol. Each service tester-shadow dyad then reviews case records and conducts interviews of caregivers, children (if old enough and with the consent of legal guardians), service providers, and informal resources. Upon completion of their case
reviews and interviews, each pair scores indicators in tandem using a six-point scale (1 = grossly unacceptable, 2 = substantially unacceptable, 3 = partially unacceptable, 4 = minimally acceptable, 5 = substantially acceptable, 6 = optimally acceptable). Scores are submitted to an evaluator and analyzed in the last evening of service testing. On the third day, individual case summaries are presented to the program director and case managers. Aggregate findings are then given to the community on the same day or at the closest meeting date of the Community Collaborative.

We assessed system development for NC FACES by comparing percentages found acceptable (scored 4 and above) on each system performance indicator for cases that were reviewed in 1997 (N = 48) with the percentages that were acceptable for cases reviewed in 2002 (N = 45).

**Individual Outcomes**

The national evaluation tracked child and family outcomes through interviews of caregivers and children 11 years and older that were conducted at baseline and every six months thereafter over a maximum period of three years. To examine individual outcomes, we drew upon data on school performance and clinical symptoms collected through the national evaluation. We chose school detentions and problem behaviors (based on caregiver reports for the six months preceding interviews) as our dependent variables as these are the outcomes that are most likely to place the child at risk for out-of-home placements. We used T-scores on Total Problem Behaviors as measured by the Child Behavior Checklist to assess clinical symptomatology (1991). Our study samples consisted of children who had complete data on relevant indicators for the baseline and 12-month periods.

**RESULTS**

**Service Testing**

Table 1 compares results on service performance between the first and last service testing events. The changes were most substantial for indicators that were scored lowest at baseline. The service plan indicator (having a unified cross agency service plan built on identified strengths, needs, and preferences) was acceptable for only 29 percent of the cases reviewed in 1997; it became acceptable for 58 percent in 2002. The indicator for services related to successful transitions was acceptable for 30 percent in 1997. In 2002, the indicator was acceptable for 61 percent. Substantial improvements were also seen for child and family participation, functional assessment, and service coordination - indicators that reflected the principles incorporated in the statewide implementation of the program. Declines in service system performance occurred for urgent response capability (crisis planning), resource availability, and service team functioning. For the last indicator, service teams had to be functioning and intact in the past three months and stable in their composition in the next three months.

| Table 1. Comparison of System Performance Indicators’ between 1997 and 2002: All Sites |
|--------------------------------|-----|-----|
| Indicator                      | 1997| 2002|
| Child/Family Participation      | 52.0| 83.0|
| Service Team                   | 65.0| 62.0|
| Functional Assessment           | 45.0| 64.0|
| Long-term View                  | 33.0| 34.0|
| Service Plan                   | 29.0| 58.0|
| Resource Availability           | 71.0| 65.0|
| Plan Implementation             | 40.0| 55.0|
| Mix, Match, Fit                | 50.0| 67.0|
| Caregiver Supports             | 66.0| 69.0|
| Urgent Response Capability      | 79.0| 51.0|
| Service Coordination            | 47.0| 68.0|
| Successful Transitions          | 30.0| 61.0|
| Effective Results               | 56.0| 57.0|
| Monitoring/Modification         | 52.0| 61.0|

1Percent of cases reviewed that were found acceptable (scored 4 or higher)
Table 2. Percentages Suspended at Intake and 12 Months

<table>
<thead>
<tr>
<th></th>
<th>Intake</th>
<th>12 Months</th>
<th>N</th>
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<tbody>
<tr>
<td>All years</td>
<td>56.0</td>
<td>41.4</td>
<td>186</td>
</tr>
<tr>
<td>Years 1 and 2</td>
<td>56.9</td>
<td>50.8</td>
<td>65</td>
</tr>
<tr>
<td>Years 3 and 4</td>
<td>56.2</td>
<td>36.4</td>
<td>121</td>
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months to be scored as minimally acceptable. Supports given by the caregiver to the child, consideration of a long-term view in the service plan, and effectiveness of services remained basically unchanged between the two time periods.

**Individual Outcomes**

School suspensions declined and total problem behaviors decreased one year after enrollment into the grant, regardless of when the child entered the program. But the rates of improvement were better among those who enrolled later as compared to those who enrolled earlier. More than half (56.5%) of all children for whom data were available at both baseline and one year had been suspended at intake. The percentage fell by 15 percent at 12 months (Table 2).

Among those enrolled in Years 1 and 2, the percentages of suspension fell from 57 percent at intake to 51 percent while among those enrolled in Years 3 and 4, the percentages decreased from 56 percent to 36 percent (Table 2). The same pattern is evident for total problem behaviors. About 85 percent of children were in the clinical range for total problem behaviors at intake. The figure decreased to 66 percent at one year regardless of time of enrollment for services. The reductions were 15 percent for those enrolled earlier and 20 percent for those enrolled later (Table 3).

**DISCUSSION AND CONCLUSION**

Children enrolled in System of Care in the last two years of the grant had better outcomes for problem behaviors compared with those enrolled in the early years. As System of Care becomes more developed in its implementation, the rates at which children improve also increases, highlighting the value of conducting a cohort analysis to demonstrate the effects of the program.

The most marked changes in service system performance occurred in those indicators that were rated lowest at baseline, demonstrating the value of providing immediate evaluation results to the appropriate audience. Unique to service testing is the immediacy with which results are given and the audience to whom the presentation is made. The three-day process culminates in a major community event where aggregate results on system level performance and child and family outcomes drawn from the national evaluation are given to an audience of family members and their advocates, service providers, agency officials, and other stakeholders, including legislators. The improvements shown in system performance and outcomes indicate that changes in service delivery were made in the directions suggested by baseline data. For instance, the Guilford site intensified training in Child and Family Team meeting facilitation and plan development for their service providers.

System of Care does not take place in a vacuum, but is affected by the sociopolitical context in which it is developed. Thus, substantial improvements occurred in indicators that reflected statewide support for principles such as child and family participation, strengths-based training, and inter-agency collaboration. However, declines were also seen in some indicators that may have been due, at least in part, to budgetary constraints experienced by the state along with other states in the nation.

The results on system performance further identified gaps in services. The long-term view indicator was...
acceptable for only one-third of the cases reviewed at baseline and remained so in the last year of the grant. Because of the complex challenges of children faced by children in the program, the tendency has been to focus on the control of immediate problem behaviors rather than on long-term results. There is a need for the System of Care family to more purposefully and deliberately plan for the future of children with serious emotional disorders.

Finally, System of Care is incremental in its development. In the last year of the grant, despite state support and the energy and commitment of families and other stakeholders, the percentages of cases reviewed that were found acceptable were still at relatively low levels for all service performance with the exception of child and family participation. All of this speaks to the long-term nature of System of Care development. This is a twenty to thirty year political and systemic process during which incremental changes will occur and will need to be consistently supported before the “tipping point” is reached and System of Care becomes the norm.

REFERENCES


Renewing Hope: Childhood Bipolar Resources, Information, & Experiences

Studies indicate that one percent of people in the United States, or approximately 2.5 million people, have bipolar disorder. Historically this diagnosis has been provided for adults struggling with illnesses characterized by severe mood swings that alternate from deep depression to the extreme highs of mania. The bipolar diagnosis has only recently begun to be more frequently assigned in childhood, after many years of investigations clarifying the differences in symptoms observed between children and adults. Many children and their families have experienced inaccurate diagnosis and numerous negative outcomes before obtaining the assistance they deserve. These outcomes have included suicide, school failure, hospitalizations, legal difficulties, violence, and social isolation, leading to the view that bipolar is a life threatening condition when undiagnosed and untreated.

The diagnosis of childhood bipolar is especially complex, as parents of children with bipolar can chronicle in vivid detail. Parents’ capacity to advocate for their child and family can be seriously impacted by a lack of easily accessible information specifically addressing the needs of children with affective disorders. Fortunately, some specific books and information are now available for parents, children, and professionals in the journey to understand, advocate, educate, and strive for healing through appropriate care for children with bipolar disorders.

DIAGNOSIS OF CHILDHOOD BIPOLAR DISORDER

One aspects of the presentation was a discussion of resources focused on advocacy for early diagnosis. Early, accurate diagnosis can improve educational
outcomes, decrease isolation, and enhance the parenting experience for the child and the family. National resources explored and shared with participants included up to date information on international research trends. Differential diagnostic clues included helped to clarify bipolar from other disorders such as confounding symptoms with a diagnosis of attention deficit disorder and/or attachment disorder. These relationships between a variety of mental health concerns and bipolar illness are highlighted since medications utilized for one diagnosis may be less than helpful or damaging for another.

Schools play an important role in the provision of diagnostic and intervention services to children with mental health disorders. Historically school personnel have sought with frustration to identify acceptable educational approaches to support mental health services. Struggling in isolation has not produced optimal results. Children with bipolar disorders present exceptional challenges in the school setting. Sharing information and experiences with school personnel in helpful collaborative roles between families and other service providers augments the child’s educational success.

Bipolar disorders are biological, caused by the way individuals’ brains and nervous systems regulate their behavior. Studies indicate bipolar disorders run in families, although the exact genetic mechanism remains under study (Waltz, 2000). In adults, the illness usually presents as a pattern of mood swings from the “highs” of mania to the “lows” of depression. Each phase commonly lasts for several weeks, with periods of wellness between periods of higher or lower mood (Papolos & Papolos, 2002).

Until recently, childhood diagnosis rarely occurred due to concerns a bipolar label would stigmatize children. Children rarely fit the recognizable adult patterns of mood swings and tend to cycle rapidly between high and low moods with few discernible periods of wellness (Papolos & Papolos, 2002). Co-occurring disorders can exist in children with bipolar disorders, notably Attention Deficit/ Hyperactivity Disorder (ADHD) and Reactive Attachment Disorder (RAD). Recent recommendations advised ruling out bipolar before instituting medication treatment for other disorders such as depression or ADHD to safeguard the child’s brain.

Brain-imaging technologies (computer tomography, magnetic resonance imagery, and single photon emission computed tomography) that show variations in the structure and function of the brain are a promising diagnostic tool for children with bipolar disorders. As these technologies are being refined, specific diagnostic criteria for childhood bipolar disorder are being formulated (Waltz 2000). In addition, parents are their children's closest observers, and parental input is essential to correct early diagnoses.

Left untreated, bipolar disorders in children can lead to social isolation, school failure, substance abuse, legal difficulties, violence, and even suicide (Lynn, 2000). Understandably, bipolar disorder is viewed as a life threatening condition when undiagnosed and untreated. As recently as September 2003, researchers released brain scans confirming extremes in emotion caused damage in the brain. Fortunately, medications and other interventions can help children with bipolar disorder. Many resources are increasingly available to family members attempting to support a loved one with a bipolar illness, including books and other publications, websites, and family-focused organizations.

BIPOLAR SYMPTOMS IN CHILDREN

Childhood bipolar symptoms differ from those of adults with children rapidly cycling. Instead of moving from a manic state to a depressive state several times a year, as adults do, children often move back and forth within a week and sometimes hit numerous high and low points within a single day (Papolos & Papolos, 2002). When in a manic or hypo-manic state, children rarely exhibit elation or euphoria and tend to be hyperactive, irritable, oppositional, inflexible, and given to explosive rages. During tantrums, which can last for hours, family members and pets can be
threatened or hurt, and objects can be damaged or destroyed.

Other markers of children with bipolar disorders are impulsivity, impaired judgment, inattention, distractibility, sleep issues, and suicidal thinking. Fascination with knives and fire, prone to dangerous behavior, and cruelty to animals may occur. Torturous dreams, vivid hallucinations, and morbid fantasies live in their minds and fill dreams. Their reactions to these unsettling phenomena can include magical thinking, fears of the devil, and the creation of staying-safe rituals (Lynn, 2000).

A variety of other emotional disturbances, neurological problems, and medical illnesses can look like bipolar disorders, or can co-occur with bipolar disorders, in children (Waltz, 2000). These include ADHD, Oppositional Defiant Disorder, Conduct Disorder, Asperger’s Syndrome, Reactive Attachment Disorder, and Tourette’s Syndrome. For this reason, diagnosis of childhood bipolar disorders is a process of elimination or differential diagnosis, which simply means finding the correct medical label by systematically eliminating other labels. Misdiagnosis raises concern since medications indicated for one condition can be contra-indicated for bipolar disorders, causing escalation of bipolar symptoms and additional risk to the child’s brain.

FAMILY STRESSORS & WELLNESS

The presence of a child with bipolar disorder in a family increases stress, fear, and denial for the entire family (Lynn, 2000). Until the disorder is defined and accepted, neither the child nor the family may make sustainable progress. Parents often feel shame and guilt about how they tolerate a child’s tyrannical behavior, and about how abnormal their family life has become (Lynn, 2000). Family life is unpredictable, and they find themselves constantly waiting for the worst to happen. Family members are often subject to criticism and social stigma from others. Parents must develop exceptional parenting skills and concentrate on what works for their particular child while persistently pursuing medical and mental health assistance that works.

The key to effective parenting of a child with a bipolar disorder is to be a constant presence for the child, without tolerating the child’s abuse (Lynn, 2000). A child’s rage needs to be skillfully managed, not accepted. Avoiding counterproductive arguments with the child, empathetically recognizing the misery behind their child’s behavior, and helping their child understand the symptoms productively improves life. Medications prescribed by professionals can be of great benefit to the child, but parents can also investigate other wellness strategies such as naturopathic treatment, nutrition, and sleep improvement. Perhaps the greatest challenge for parents and family members is acceptance of the limitations faced by the child with a bipolar diagnosis during periods of instability (Lynn, 2000). In order for the family to function well for the child and as a unit, they must first grieve the loss of the illusion that love is enough to make the child normal.

FAMILY ADVOCACY

In the face of a stressful and often confusing situation, families must find the strength to take responsibility for their own well being, to be informed about bipolar brain chemistry, and to research medications and other interventions available to assist their child. Working together they develop a self-care plan for the whole family including the formation of a resource team, including extended family members, friends, therapists, teachers, and respite workers willing to step in to help when needed. The parents maintain careful records of medications used and treatments tried by their child, whether or not they were successful. Persistence is key, along with never allowing professionals to blame a child’s problems on the family. Laws are in place to protect the rights of families, and legal advice may be sought when needed.

Parents need to be aware of their child’s rights in the school system. Federal laws specifically mandate that all children receive “free appropriate public education” regardless of disability. Parents must use these laws to put supports in place for their child in the school setting. Responsible parents “educate the educators”. They communicate with the child’s school about
diagnosis, and bring in experts to help advocate for the child. They also share information about their child’s strengths and needs in team meetings, ask pertinent questions, and monitor their child’s school progress to ensure that established goals and procedures are being implemented.

TREATMENT OF CHILDHOOD BIPOLAR DISORDER

Therapy goals for a child with bipolar illness can include discussing the nature of the illness and treatment options, identifying personal mood swing triggers, developing methods to prevent or shorten mood swings, and identifying and stopping detrimental thought patterns. In addition, therapy can be useful in coping with problem symptoms and medication side effects, and improving a child’s behavior at home, in school, or in the community. For older children, therapy can be instrumental in supporting positive lifestyle changes, such as overcoming an addiction and maintaining sobriety. Therapy can also play a key role in helping a child develop the personal strengths, resilience, and self-esteem necessary to counter the detrimental social and personal effects of bipolar disorder.

Parents play an important role in their child’s treatment process. When choosing a therapist, look for a person with a good knowledge of the interaction between brain chemistry and environment who targets interventions to specific problems, is creative with solutions, has good information about community resources, and uses the contributions of other professionals. Parents provide the therapist clear and comprehensive information about family history and the child’s symptoms and behaviors. They remain available to the therapist throughout the treatment process, and never hesitate to seek a second opinion if it does not appear the therapeutic relationship is working well for their child.

Therapy can happen at home, as parents share activities such as playing or listening to music, reading, non-competitive sports, collecting (rocks, stamps, cards), cooking, drawing, caring for a pet or garden, or community “helping” (charity marathons, food banks, cleaning public areas) with their child (Waltz 2000).

FOOD AND BIPOLAR DISORDERS

A growing body of research indicates that children with bipolar and affect disorders are helped by certain foods and supplements, and stressed by other foods and substances (Somer, 1999). In general, whole grains, fresh fruits and vegetables, turkey, fish, nuts, and water are of benefit. In addition, a moderate-dose daily multiple vitamin is recommended. Foods and substances to avoid include caffeine products, sugar, hydrogenated vegetable oils, alcohol, tobacco, and choline (egg yolks, wheat germ, liver, and peanuts). Milk is also on the “hot list” for food allergies, along with chocolate, corn, eggs, fish, nuts, oranges, peanuts, peas, shellfish, soybeans, strawberries, tomatoes, and wheat.

A complex carbohydrate/low protein snack shortly before bedtime improves the quality of sleep (Somer, 1999). Proteins in meat, legumes, tofu, soy and whey appear to increase alertness and stabilize memory, while certain fats aid in general neural integrity. Magnesium can improve energy level, and can reduce insomnia, sensitivity to noise, anxiety, and mood swings. While simple carbohydrates (sugars) can provide quick energy, they can cause sluggishness. Sugar, caffeine, and stress have repeatedly proven to be a poor mix. Foods rich in vitamin B-6 (bananas, avocados, fish, baked potatoes, brown rice, peas, tomatoes, spinach), turkey, and fiber are also known to reduce stress.

Always consult with a child’s pediatrician before trying any dietary plan. Natural food stores are good sources of information about nutritional supplements. Although expensive, naturopathic physicians are excellent resources for allergy/sensitivity testing and dietary planning.

SUMMARY

Parents are the experts on their child’s situation. Even though it can sometimes be a daunting task, the entire family will benefit if parents play a key role in their child’s home, school, social, and therapy experiences,
and become themselves students of the developing resources on bipolar disorders. While the parents’ role is vital, caring professionals and concerned friends provide important resources in the child’s care team. Networks of support are critical as parents make ongoing decisions about the settings and services that will best serve their child.

Collaborative efforts between presenters and participants explored this serious medical condition in an interest group session following the formal presentation. These joint efforts attempt to encourage an optimistic perspective regarding this often misunderstood disorder. The presentation team included a young adult with bipolar, a parent of a child with bipolar, and the adult daughter of a deceased bipolar parent. Handouts highlighted national resources, suggested potentially helpful services, and discussed participant personal experiences encouraging parents, service providers, and researchers to persist in building a knowledge base for improved outcomes.

REFERENCES


Is Caregiver Participation in Service Planning Related to Child Outcomes?

INTRODUCTION

There is little consistency among researchers regarding a uniform conceptual definition of caregiver participation and involvement in children’s mental health services (Curtis & Singh, 1996). (The terms participation and involvement are used interchangeably here.) This consistency is lacking even in educational research (Baker & Soden, 1998), the discipline with the largest number of studies on caregiver participation. Traditional research in children’s mental health has loosely defined caregiver participation in a number of ways, including caregiver compliance with services such as family therapy or parent training (Aebi, 1998; Ainsworth & Cowan, 1996; Kazdin, 1997) or amount of contact or visitation with a child receiving out-of-home treatment (Baker, Blacher, & Pfeiffer, 1996). A small amount of research has also focused on more non-traditional roles for caregivers. These include viewing caregivers as treatment providers who informally volunteer services such as case management and service coordination, and examining caregiver participation more globally by looking at family members as advocates and policymakers (Friesen & Stephens, 1998).

As the conceptual definition of caregiver participation is inconsistent, vague, or absent within and across disciplines, not surprisingly, the operational definition of participation is also inconsistent. Participation has been operationalized as caseworker and case record information on the number of times a child in out-of-home treatment was visited by their parent (Cantos & Gries, 1997), parent’s perceptions of their involvement in planning
and/or treatment (Curtis & Singh, 1996; Wilson, 1999), and parent attendance at therapy and trainings (Aeby, 1998).

The specific caregiver role of participation in planning treatment and services has received some attention due to team-based planning processes such as wraparound (Epstein et al., 2003). However, there are few methodologically sound studies which examine the effectiveness of wraparound (Bickman, Smith, Lambert, & Andrade, 2003), and we found none that specifically examine the relationship between caregiver participation in planning services with child functioning.

This study expands the scant literature on the caregiver role of participation in treatment and service planning. We propose that the quality of participation is an important influence on youth functioning. We also examine the various child, caregiver, and family characteristics that may be related to high quality participation. In our view, high quality caregiver participation consists of the following characteristics: 1) Decision-making and authority is shared between the caregiver, service provider, and administrators; 2) Service providers, administrators, and caregivers must take on new and innovative roles—this includes transforming from the roles of service provider as ‘expert’ and the family as ‘client’ to an equal partnership; 3) Caregivers feel empowered; 4) There is a working level of trust among caregivers, service providers, and administrators. Our hypothesis is that high quality caregiver participation in service planning will lead to higher quality services and increased caregiver investment in treatment, which will lead to improvements in youth functioning.

METHOD
Families qualified for the evaluation if their child (5 to 17.5 years old) needed services in mental health and another service system (school, juvenile justice, child welfare, etc.), had a disability that was expected to last for more than one year, and had a Global Assessment of Functioning score below 50. Randomly selected caregivers and youth (11 to 18 years old) were interviewed after intake, and followed every six months for up to three years.

To measure child functioning for this analysis, we used three measures: 1) the caregiver-reported Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, Doucette-Gates, & Liao, 1999), 2) the Child Behavior Checklist (CBCL), and 3) the youth self-report version of the CBCL, aptly titled the Youth Self Report (YSR; Achenbach, McConaughy, & Howell, 1987). These were completed at baseline and 6 month follow-up.

Six months after intake, caregivers completed a five-item version of the Family Participation Measure (FPM) (Friesen & Pullmann, 2001). The FPM measures caregiver participation in planning services and treatment; in this study, we asked caregivers to identify the service that best met their family’s needs and rate their participation in this service. This study used five items of the FPM: 1) Were your ideas valued in planning this service for your child? 2) Were your family’s values and culture taken into account when planning for your child? 3) Did you agree with the service planning for your child? 4) Were the needs/circumstances of your family considered in this planning?, and 5) Were you able to influence planning for this treatment or service? Caregivers and youth only completed the measure if they reported that they had received mental health services or supports during the previous six months.

RESULTS
Fifty-three participants stated that they had received no services between intake and six-month follow-up. In most cases, this was because the family did not return for services or was discharged after the first few sessions. These participants were excluded from the analysis, leaving a sample size of 175.

Participants
Participants were 175 caregivers and 78 youth. Youth were 61% male and had an average age of 12.2 (SD = 3.3). Youth were 87.9% Caucasian, 7.3% Hispanic, 6.3% American Indian, 4.5% African American, and 1% Asian (numbers add to more than 100% because
multiple race/ethnicities could be endorsed). Most youth were in the custody of their biological mother only (50.3%), or two parents with at least one biological (24.3%). Caregiver respondents were mostly biological parents (75.1%), 94% female, with an average age of 39.9 (SD = 8.8). The mean range of family income was $15,000-19,999.

**Services received**

Caregivers reported that their family or child received individual therapy (78%), medication (66%), case management (40%), wraparound (27%), family therapy (18%), group counseling (11%), and smaller numbers of other services.

**Participation scores**

Six months after intake, high levels of participation were reported; on a scale of 1 to 4, caregivers rated a mean score of 3.5. The distribution was negatively skewed (skewness = -1.6), so for analysis we divided caregivers into two groups that we named high-quality participation (HQP; score greater than 3) and low-quality participation (LQP; score of 3 or below). After this grouping, 73.1% (n = 128) of the sample was in the high-quality participation group.

**Caregiver characteristics and participation**

Several analyses were run examining possible relationships between caregiver characteristics and participation. Using the dichotomous independent variable of high/low quality participation, several t-tests were run with caregiver age, level of education, adequacy of transportation, adequacy of social support network, and caregiver strain as dependent variables. Two chi-square tests were run using caregiver's relationship to the child (birth parent, foster parent, extended family member, etc.) and gender as the dependent variables. None of the tests were significant (p > .05), revealing no relationships between caregiver variables and participation.

**Child characteristics and participation**

Similarly, several Analysis of Variances (ANOVAs) were run using the dichotomous independent variable of participation and the dependent variables of child age, number of living situations during the previous 6 months, grade level, CBCL total problem score and subscales, BERS total score and subscales, CAFAS total score and subscales, Global Assessment of Functioning, and the YSR total problem score and subscales. Several chi-squares were also run featuring the dependent variables of race/ethnicity, gender, previous service usage, previous suicide attempts, self-reported criminal or aggressive behavior, current attendance in school, special education status, school detention, Individualized Education Plan status, juvenile justice detention, use of medication, ever been arrested, and lived in any restrictive setting during the previous 6 months. Most of these analyses were not significant (p > .05).

A few of the ANOVAs and chi-square tests were significant (see Table 1). HQP caregivers were significantly more likely to report at intake that their child was on psychotropic medication, and less likely to report that their child had been in a group home, shelter, or residential treatment at any time in the previous 6 months. Caregivers with high-quality participation scores at six month follow up were also more likely to report that their child had more problems in functioning at intake on several measures, including the CAFAS total score, the CAFAS community subscale, the CAFAS moods/emotions subscale, the CAFAS school subscale. HQPs were more likely to have youth that rated themselves as having more problems on the YSR externalizing subscale.

**Family characteristics and participation**

Several ANOVAs and chi-square tests were run examining the relationship between participation and family income, number of children in household, number of adults in household, family resources, and caregiver and youth ratings of family functioning from the Family Assessment Device (FAD; Miller, Bishop, Epstein, & Keitner, 1985). There were no significant relationships.
Table 1
**Significant Relationships between Child Characteristics and Participation**

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Low part. mean / %</th>
<th>High part. mean / %</th>
<th>$F_{\chi^2}$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAFAS Total problems</td>
<td>173</td>
<td>115</td>
<td>133</td>
<td>4.3</td>
<td>.04</td>
</tr>
<tr>
<td>CAFAS Community</td>
<td>173</td>
<td>6.4</td>
<td>12.1</td>
<td>6.5</td>
<td>.011</td>
</tr>
<tr>
<td>CAFAS Mood/emotions</td>
<td>173</td>
<td>19.3</td>
<td>23.1</td>
<td>6.2</td>
<td>.014</td>
</tr>
<tr>
<td>CAFAS School</td>
<td>173</td>
<td>21.1</td>
<td>24.8</td>
<td>4.9</td>
<td>.028</td>
</tr>
<tr>
<td>YSR Externalizing</td>
<td>88</td>
<td>59</td>
<td>64</td>
<td>4.1</td>
<td>.046</td>
</tr>
<tr>
<td>Psychotropic medication at intake</td>
<td>173</td>
<td>35%</td>
<td>63%</td>
<td>10.9</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Lived in group home, shelter, or residential treatment intake to 6 months</td>
<td>173</td>
<td>15.2%</td>
<td>5.5%</td>
<td>4.3</td>
<td>.037</td>
</tr>
</tbody>
</table>

Table 2
**Significant Relationships between Satisfaction and Participation**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Low part. mean / %</th>
<th>High part. mean / %</th>
<th>$F$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall satisfaction</td>
<td>3.1</td>
<td>4.0</td>
<td>21.1</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Satisfaction with provider’s respect for beliefs about mental health</td>
<td>3.6</td>
<td>4.2</td>
<td>11.7</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Satisfaction with provider’s understanding of cultural traditions</td>
<td>3.5</td>
<td>4.2</td>
<td>12.8</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Satisfaction with provider’s ability to find strength-based services</td>
<td>3.2</td>
<td>4.0</td>
<td>19.6</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Satisfaction with level of involvement in planning</td>
<td>3.2</td>
<td>4.1</td>
<td>22.6</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Satisfaction with number of times asked to participate in meetings</td>
<td>3.2</td>
<td>4.1</td>
<td>19.0</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Satisfaction with child’s progress</td>
<td>3.3</td>
<td>3.8</td>
<td>6.4</td>
<td>.012</td>
</tr>
</tbody>
</table>

Table 3
**Means and Standard Deviations for Repeated Measures Analysis**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Participation</th>
<th>Baseline = M (SD) = 6 month = M (SD) = follow-up = M (SD) =</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAFAS</td>
<td>Low</td>
<td>114 (54)</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>133 (48)</td>
</tr>
<tr>
<td>CBCL</td>
<td>Low</td>
<td>71 (11)</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>74 (9)</td>
</tr>
<tr>
<td>YSR</td>
<td>Low</td>
<td>58 (10)</td>
</tr>
<tr>
<td></td>
<td>High</td>
<td>64 (9)</td>
</tr>
</tbody>
</table>
Satisfaction and participation

Several ANOVAs were run using the dichotomous measure of participation at six month follow up as the independent variable and several caregiver rankings of satisfaction at six month follow up as the dependent variable. All of these were statistically significant, with HQPs more likely to rate themselves as satisfied (see Table 2).

Changes in functioning and participation

Three repeated-measures ANOVAs examining change over time were run using CAFAS, CBCL, and YSR total problem scores as dependent variables and blocked on the dichotomous measure of participation.

For the CAFAS total score, the within-subject main effect (baseline to six months) was significant: overall, youth’s functioning scores improved over time, $F(1, 167) = 20, p < .001$. The within-by-between subjects interaction was also significant: from baseline to six month follow-up, those in the high-quality participation group reported that their youth improved more than those in the low-quality participation group, $F(1, 167) = 4.7, p = .032$.

For the CBCL total score, the within-subject main effect was significant: overall, youth’s functioning scores improved over time, $F(1, 161) = 21.6, p < .001$. There was no significant interaction: high participators did not report that their child’s functioning changed differently than low participators. For the YSR total score, there was not a significant main effect or interaction.

CONCLUSION/SUMMARY

This analysis found that caregivers’ reports of their feelings on participation were not related to family demographics, including education, income, and age. Caregivers of all types felt like they had quality participation in planning their child’s treatment. High-quality participators had youth with more problems at intake, were more satisfied with the services they received and, according to one measure of youth functioning (the CAFAS total score) high-quality participators had youth that improved at a faster rate than low participators. On the other two measures (the CBCL total problem score and the YSR total problem score), youth functioning improved at the same rate for those in the high and low-quality participation groups.

This study is limited in several ways. First, the participation groups were naturally occurring and the measures were almost entirely caregiver self-report. Because of these two interrelated issues, the participation groups may not have been fully comparable; some evidence supports this. Although they did not differ on most demographic measures, caregivers in the HQP group were more likely to report that their child had more problems with functioning at intake. Second, the participation distribution was skewed towards high-quality participation. This may have been due to the fact that the participation measure was the last of a very lengthy (up to two hours long) interview process and participants were exhausted. Third, there were a large number of caregivers that reported receiving no services from intake to six months—53 (23%) of the 228 possible. Most of these participants probably received a small amount of services and, had we been able to complete the participation measure with them, may have altered the participation distribution.

Regardless of these limitations, these findings provide some support for the argument that high-quality participation is associated with improved services and treatment. Additionally, caregivers can feel like they are participating in planning their child’s treatment regardless of their socioeconomic status and other family obligations.

REFERENCES


Employment: What Parents Say About Their Work-Related Experiences

The Common Ground? Families and Employers project has three primary objectives, including: (1) to understand and describe how parents’ employment is affected when caring for a child with a mental health disorder; (2) to identify strategies used by parents to manage employment and family responsibilities; and (3) to identify workplace policies that support employees who are caring for children with special mental health needs. Parents caring for children with mental health disabilities experience unique challenges to integrating employment and family responsibilities. Prior research indicates that parents of children with mental health disabilities report a dearth of community resources, such as child care and education, forcing them to seek flexibility to meet their child’s needs through employment adjustments (Rosenzweig, Brennan, & Ogilvie, 2002). However, factors such as workplace culture or organizational size and sector (Secret, 2000), may have an impact on whether parents achieve the level of employment flexibility they require to meet the care needs of their child.

The concepts of work-life fit, flexibility, and family-friendly workplace underpin the research conducted. Work-life fit refers to the degree to which employed parents realize the various components of their unique adaptive strategies for dealing with the interface between work and family (Barnett, 1998). Fit can be understood as a process—the decisions and tasks undertaken to achieve fit—and as an outcome—the degree to which the parent finds a fit in his or her work-life (Rosenzweig, Brennan, & Ogilvie, 2002). Flexibility is defined as the freedom to adapt working times and place to respond to family needs (Lewis,
Each family seeks a fit in their work-life through flexibility in some part of the work/family/child care system (Emlen, 1997). However, parents of children with disabilities may be reluctant to ask for flexibility (Lewis, Kagan, & Heaton, 2000), realizing that the attitudes of line managers are instrumental in the implementation of flexibility in the workplace (Lewis, 1997).

METHODS

The Parent Employment Experiences Survey (N=349) was designed to gather information about work/life integration as experienced by parents caring for children with emotional or behavioral disorders. The survey, posted on the Research and Training Center on Family Support and Children’s Mental Health (RTC) website, included thirty questions about work/life barriers and strategies. Eligible respondents were self-identified parents of children with emotional or behavioral disabilities who are employed, seeking employment or unemployed by choice to care for their child in the home. Participants were recruited through national family support organizations, two national conferences, and RTC National Advisory Committee members.

The following questions are the focus of this presentation; (1) Are parental disclosure of a child’s mental health status to a supervisor, and perceived supervisor support, related to work-life fit? (2) Are parental disclosure of a child’s mental health status to co-workers and perceived co-worker support related to work-life fit? (3) Are parental disclosure of a child’s mental health status to a supervisor and perceived supervisor support related to flexibility? (4) Are parental disclosure of a child’s mental health status to co-workers and perceived co-worker support related to flexibility? and (5) Are supervisor support, co-worker support and flexibility related to family friendliness in the workplace?

RESULTS

A total of 322 women (94%) and 27 men responded to our survey. The majority of respondents were European-American (83%). The second largest respondent group was African-American (10%), while the remaining respondents represented fewer than 5% of Asian, American Indian, or Hispanic descent. Respondents’ ages ranged from 22-73 years old, with a mean age of 43. Most of the respondents were college educated: 34% reported they had “some college”; 25% had a college degree; and 27% had some graduate study or a graduate degree. Sixty percent of the respondents worked full-time, 21% worked part-time, and 19% reported that they were unemployed. The median income range was $30,000-34,999. The majority of the sample was married or partnered (61%). Most of the sample included biological parents (80%) or adoptive parents (13%). There was a total representation of 766 children, with a mean of 2.2 children per family. The average age of the children was 12. Sixty percent of the total number of children had an emotional or behavioral disability; most of these (73%) were boys.

Seventeen percent of the sample reported that they are currently unemployed to care with their child with a mental health disability, while 11% were unable to find work due to caregiving responsibilities. Twenty-seven percent of the parents reported that at some time their employment had been terminated because of work disruptions due to care responsibilities and 48% had quit work at some time to care for their child with a mental health disability.

Support from supervisors and co-workers are critical factors for parents in achieving greater work-life fit. Parents in the sample reported high levels of support in the workplace. Over 80% of respondents rated their supervisors and co-workers as “very supportive” or “supportive.” This high level of support appears to be a strongly related to disclosure of the child’s mental health status to supervisors and co-workers.

A majority of parents (80%) disclosed information about their child’s mental health status to their supervisors and co-workers. Using multiple regression analysis, results indicate that support from supervisors ($p < .05$) and co-workers ($p < .01$) are significant predictors of work-life fit. The overall model, included supervisor support, disclosure to supervisor, co-
worker support, and disclosure to co-worker, was significant and predicted over 13% of the variance in work-life fit (F=8.407, \(p < .001\)).

Respondent parents reported high levels of flexibility in their current jobs to meet family responsibilities. Forty-nine percent of the participants reported “some flexibility,” and 38% indicated that they had “a lot of flexibility” to take care of family concerns during working hours. Most parents report that their supervisors are the key brokers of flexibility in the workplace. One parent noted, “I had an established working relationship with my supervisor and the management of the firm. It is a give and take relationship with flexibility and understanding during times of crisis and when things even out, I attempt to give back 150 percent.” Results of a multiple regression analysis was significant, predicting 31% of the total variance in flexibility using supervisor support, supervisor disclosure, co-worker support and co-worker disclosure (F=23.243, \(p < .001\)). Supervisor support uniquely contributed to the overall prediction of flexibility (\(p < .001\)).

In a similar pattern as the flexibility ratings, parents reported that their workplaces were family-friendly. Forty-two percent of the respondents evaluated the family-friendliness of their organization as “excellent,” and 31% as “good.” Supervisor support, co-worker support, and flexibility are the essential ingredients of family-friendly organizations. Another parent explained, “The strategy I now have is to find an employer who is family friendly. I work for an airline and it provides me with great flexibility. I am able to trade shifts with other people to accommodate my needs. I also communicate more with my supervisor.” Multiple regression analysis including the variables of supervisor support, flexibility, and co-worker support in the model accounted for 59% of the variance in family-friendliness (F=101.306, \(p < .001\)). Supervisor support (\(p < .001\)), flexibility (\(p < .001\)), and co-worker support (\(p < .01\)) each uniquely contributed to the overall prediction of family friendliness.

CONCLUSIONS

Parents are finding ways to integrate work and family responsibilities. Finding a family-friendly workplace means having a supervisor and coworkers who offer support when family care concerns must be addressed during hours dedicated to employment tasks. A closer examination of the factors associated with disclosure and how support is negotiated with supervisors and co-workers is needed to gain a deeper understanding of work-life fit.

Unfortunately, despite the support received in the family-friendly workplace, the majority of parents are not satisfied with work-life fit. Support from the workplace, while necessary for work-life fit, does not appear to be sufficient for parents with care responsibilities for children with mental health disabilities. For work/life integration to be satisfactory, additional sources of family support within communities must be identified.

REFERENCES


Family Support for the Whole Family: Handbook for Child and Youth Programs

BACKGROUND

The Oregon Family Support Network (OFSN), a family-run organization affiliated with the Federation of Families for Children's Mental Health, has developed support groups for parents. In the process of doing so, we've discovered that providing free, safe and interesting programs for children and youth is key to supporting parent involvement. The Handbook for Child and Youth Programs was developed to support the youth and child-care staff and the organization's leadership in providing these essential components of successful family support. It provides philosophy, options, policies, procedures, sample forms, approaches to serving children and youth successfully, activities and projects to use in child and youth groups and tips for problem solving. The Handbook was distributed at the conference session in print and CD formats and included the following contents:

1. Why Child and Youth Programs for a Family Support Organization
2. Policies Procedures: How to put together programs that build on the strengths of the children, the youth, the parents and the organization
3. Individual Child/Youth Needs
4. Sample Forms
5. Program Activities: Plans, Workbooks, Patterns, etc. For Children and Youth
6. Additional Information

Some key components of the Handbook include the “what” and “why” of child and youth programs that operate concurrently with and in support of parent...
support groups. A second key component, included in this summary, is how child and youth providers can work with parents to address the individual needs of participating children and youth with proactive planning to prevent “crisis” situations.

**REASONS TO HAVE CHILD CARE AND YOUTH OPTIONS CONCURRENT WITH PARENT SUPPORT GROUPS AND OTHER EVENTS**

Parents have plenty to say about why this is a good idea. For example:

“I don’t have child care options for the very reasons I would be unable to come to the support group, if it were not provided: the challenging behavior of my child limits options and resources.”

“Families don’t have financial resources for child care.”

“Child-care makes it possible for both parents to come”

“I want a program for my child that is fun and positive. The child’s time is of value.”

By prioritizing child care the organization models the value that all children are important. Also, planned programs can be a developmental and learning opportunity for the children. Some other possible benefits of, and opportunities offered by, concurrent youth activities are that they provide

- a social opportunity;
- an opportunity for siblings to come together;
- an opportunity for children with various behavioral and emotional disorders to meet others who share commonalities and differences;
- an opportunity to belong to a group;
- a welcoming space—“This group is the only place our whole family belongs, or the only place we really feel welcome”; and
- a family-centered space—families can begin to “own” the group, rather than the group becoming just another place parents go without the children, or a place the family goes and feels somewhat unwelcome or “special.”

Also, youth activities are helpful because

- children who are not ready to be separated from their parents may use the group as a first step in independence, as parents are close by.
- parents can relax and participate, knowing their child is safe and nearby. This is especially true for children whose behavior is high risk.
- they are like respite care—“These group meetings are the only break I get!”

**CHILD AND YOUTH PROGRAM OPTIONS**

The workshop provides a range of options to consider in starting up and running a child and youth program:

- Reimburse parents for child care costs.
- Develop a contract with a local day care program to provide childcare during the meeting.
- Have parents take turns providing childcare on site, during the meeting.
- Run the children’s program in a space near to the group provided by volunteers, managed by the parent organization.
- Provide childcare in a space near to the group provided by paid staff of a host agency (family center, school, church, etc.).
- Have the parent organization manage the children’s program of planned, varied activities provided by staff and volunteers in space near to parents meeting.
- Use coordinated planning. Examples:
  1. Parent group is planned to meet at the same time and place a special program is offered to the children (swimming, crafts, sports, and movies).
  2. Parents meet at mental health facility concurrently with group therapy for children or teens.
  3. Parents meet at the same time children and have an individualized behavior skills service provided by the mental health agency.
• Parent meetings held at a time when there is not a childcare need (during school hours, when children are in a recreation program or respite services.)

ADDRESSING INDIVIDUAL CHILD NEEDS: WORKING WITH PARENTS

In providing activities, programs and support to each individual child, there is usually a need to respond to challenges and difficulties that come up with a child or a young person. Planning, problem solving, and solution seeking in a family support organization needs to always be in collaboration with the parent and youth, and usually with the involved child as well. Some, but not all, children who have various mental health, behavioral, or emotional needs will be especially vulnerable to factors that caregivers can be completely unaware of. Some examples of these vulnerabilities include:

• All kinds of changes: routine, place, schedule, etc.
• Transitions: moving, adding a new family member, changing schools
• Environmental factors: temperature, smells, lights, sounds
• Staffing: new staff, staff leaving, staff moods or illness
• Internal factors: emotions, headaches, pain, hunger, thirst
• Interactions: getting in trouble earlier in the day, friend is angry, fight with sibling, hurt feelings
• External factors: the weather, air quality, darkness, national disaster
• Confusion: having heard or understood only part of an instruction, an explanation, or a news story.

Sometimes these factors are called “triggers.” Our own behaviors might be a trigger. Something we do could be a distressing factor resulting in behavior that is not successful. In one instance, a caregiver wore a certain perfume that was an irritant to a child. Whenever the caregiver came close, the child moved quickly away. Neither one knew what was really occurring but they both interpreted the situation in their own way. The caregiver viewed the child as “not liking me or respecting me, darting away from me at every opportunity.” The child thought “I don’t like her” and “I want to get away from her.” When the mom was called to help, she knew her child had sensitivity to scents; she knew right away that this scent was an especially irritating one for her child. A solution was reached by the caregiver’s agreeing not wear the perfume again. A discussion with the child provided an opportunity for self-awareness to develop and the child was encouraged to consider and identify irritating smells and then to talk to the person about it. This child may have experienced the scent as painful, much stronger than most of us would experience and intolerable. The behavior was an automatic self-protective response that was misunderstood by both the caregiver and the child.

Some things to keep in mind when problem solving with families, children, and youth include the following:

• Children want to be successful (in school, in programs, with friends, with adults, in doing tasks, and in the world). When it seems like they don’t want to be successful, it is likely that they have lost hope that they can be. It will seem like they don’t care.
• What is known collectively (by the child or youth, parent, care-giver, friends and others) may shed light on the source of the difficulty. Behavior comes from somewhere; it is purposeful, even if it can be mysterious and hard to figure out. Often with careful listening, the child or young person will tell a good listener the source of their behavior, and in the telling will discover something about themselves.
• TRY SOMETHING. Make a plan, communicate the plan with whoever will be a part of it, give it a try, then ask, “Is it working?” If not, TRY ANOTHER WAY.
• Most settings for children do not provide an opportunity for them to discover their “triggers”
in a positive, constructive way. In programs for children and youth, we have the opportunity to do so, and therefore, to provide valuable self-awareness and coping skills than can be practiced in many other settings.

Key elements of addressing the needs of an individual child or youth include:

- Listening
- Communicating
- Collaborating
- Making a plan and trying it
- Assessing success
- Celebrating success
- Try Another Way, until a success is found
- Communicate, communicate, communicate
- Celebrate, celebrate, celebrate!!!!

For more information about our experience with developing and running concurrent child and youth activities with parent support group meetings, please contact us at our statewide office:

Oregon Family Support Network
15544 So. Clackamas River Drive
Oregon City, OR 97045
1 (800) 323-8521
Fax (503) 656-5442
OFSN@Open.org
http://www.ofsn.org/
Family Participation in Evaluation: How to Make it Work

In recent years, the use of participatory approaches in research and evaluation has gained momentum. Participatory approaches are believed to lead to studies that are more relevant to the needs of families. Ultimately, a goal of participatory approaches is to produce findings that will be used to improve services for families (Osher, van Kammen, & Zaro, 2001). The National Institute on Disability and Rehabilitation Research (NIDRR) has adopted a list of advantages of participatory action research, formulated by Turnbull, Friesen, and Ramirez (1998):

1. Increased relevance of research to the concerns of family members;
2. Increased rigor of research;
3. Increased benefit to researchers in minimizing logistical problems;
4. Increased utilization of research by families; and
5. Enhanced empowerment of researchers, families and other stakeholders (p.178).

Family involvement in children’s mental health research and evaluation has received support from a variety of government agencies. NIDRR now encourages grantees to use participatory action research to involve families and consumers. Since 1993, system of care projects funded by the Center for Mental Health Services’ Comprehensive Community Mental Health Services for Children and Their Families Program have been required to involve family members as participants in the evaluation of the projects. In addition, the Surgeon General’s Report on Mental Health (U.S. Department of Health and Human Services, 1999), the National Action Agenda on Children’s Mental Health (U.S. Department of Health and Human Services, 2001) and the President’s
National New Freedom Commission on Mental Health (New Freedom Commission on Mental Health Subcommittee on Consumer Issues, 2003) have promoted family and consumer involvement in the research and evaluation of children’s mental health services.

These developments have presented family members with opportunities to work on teams that are evaluating the services their children are receiving. Evaluation teams at system of care grant communities around the country employ family members on their teams in different capacities. Involving family members on evaluation teams has led to the development of new family-evaluator partnerships in systems of care, requiring evaluators to collaborate with family members in all aspects of the evaluation of services. Team members have reported a number of benefits of involving family members on evaluation and research teams. For example, system of care team members have reported that family members are more likely to gain the trust of research participants and to get accurate information from them (Osher & Telesford, 1996). In addition, family members have assisted in the design of user-friendly formats for findings, which facilitate the dissemination of results to wider audiences, especially other family members (Vander Stoep, Williams, Jones, Green, & Trupin, 1999).

In addition to these benefits, there are also challenges to family participation in evaluation teams. While more evaluators are now beginning to work with family members on evaluation teams, few have prior experience working with these family members in this capacity. Many evaluators have been traditionally trained to maintain control of the research process and distance themselves from the “subjects,” those who are being researched (Sohng, 1992). However, in these family-evaluator teams, evaluators interact with family members as partners in the evaluation process. Without adequate training, the participatory approach can present challenges to evaluators. There are also challenges related to the lack of organizational supports for family participation in evaluation teams.

This presentation discussed findings from a qualitative study of evaluators’ perspectives on collaboration with family members on evaluation teams. The purpose of the study was to gain understanding of the challenges facing evaluators and family evaluators working together and to identify effective strategies for building collaborative relationships in evaluation teams. Our presentation reported on evaluators’ descriptions of challenges to collaboration and the strategies they reported using to address them. A family member employed by Clark County, Washington’s system of care evaluation team described examples of the barriers the team has faced and the strategies they used to address them.

**METHOD AND SAMPLE**

To find out evaluators’ perspectives about working with family members on evaluation teams, we developed a qualitative survey. Open-ended questions were designed to provide understanding of the challenges facing evaluators and family members working together and effective strategies for collaboration. We identified evaluators through nominations by key informants and snowball sampling and conducted telephone or face-to-face interviews with them.

We asked evaluators questions about the roles that family evaluators have played on their evaluation teams, their training to work with family evaluators, the challenges they have faced, and the strategies they have used to overcome these challenges. The interviews were audio-taped, transcribed, and analyzed qualitatively using a grounded theory approach (Glaser & Strauss, 1967). Members of the team developed a coding scheme and independently coded the data, compared the coded sections of the interviews and negotiated the categorization of the data. The data was categorized according to themes, these themes were synthesized, and examples were identified to illustrate the themes.

Results are based on interviews with 20 evaluators from different parts of the U.S., most of whom were involved in the evaluations of systems of care funded by the Center for Mental Health Services’
Comprehensive Community Mental Health Services for Children and Their Families Program. Fourteen evaluators reported that they had Ph.D.’s, two were Ph.D. candidates, and four held Masters degrees. Sixteen were female and four were male, with a mean age of 41.4 (SD = 11.2, range 28-66). These evaluators reported working in the field of children's mental health for an average of 13.8 years (SD = 7.4, range 3-30) and 70 percent said they had some level of experience as a family member of a person with mental health needs or a consumer of mental health services.

RESULTS

Evaluators were asked how well their training had prepared them for collaboration with family members. Fifty-five percent of the evaluators reported that they were trained to maintain distance from research participants. Most evaluators reported that partnering with stakeholders on research and evaluation teams was not discussed in their academic training. In response to a question about how they learned to work with family members, 70 percent of the evaluators reported that they learned by doing the work. One evaluator said that what helped her to do the work was, “learning by doing…learning from others around here who are trying a lot of the same things.”

Family members were described as being involved in a variety of evaluation activities, including:

- helping with the development of projects,
- developing instruments/surveys,
- collecting data,
- training other family evaluators,
- participating in the decision making,
- assisting with analysis of data,
- assisting with the interpretation of results
- presenting data, and
- helping with dissemination of results.

In response to a question about challenges in their work with family evaluators, evaluators described several difficulties. The primary challenges described were recruitment and hiring difficulties; payment of adequate salaries; concerns about the impact of family members on research rigor; stakeholders’ lack of appreciation for family evaluators’ roles; and the tension between advocacy and research. Respondents also discussed the strategies developed to address these challenges. Examples of the challenges and some of the strategies used to address them are summarized below.

**Difficulty recruiting and hiring family members without relevant academic training**

Some evaluators reported that it was difficult to hire family evaluators who did not have a degree due to hiring policies based on academic qualifications. Strategies that evaluators reported using were creating a job classification specifically for family members and hiring family members as consultants. The Clark County family evaluator reported that the team initially addressed this problem by hiring a family member as a consultant through a contract with a family support organization. This organization did not have to adhere to the restrictive policies regarding hiring and pay that constrained the university-based research team. Subsequently, she was paid via a personal services contract with the university. Later, when she had gained experience on the job, she was hired as a university-based research assistant.

**Paying family members adequate salaries**

Several evaluators mentioned their inability to pay family evaluators salaries that were appropriate to the complexity of the work. As one evaluator commented, “We say on one hand that we value families as much as the work of professionals, but we never pay them as much… it’s hard to pay them what they are worth.”

To address this challenge, evaluators reported developing contracts to pay family evaluators based on their skills and expertise, rather than based on academic qualifications. One evaluator reported that she had worked to get the family evaluators a pay increase based on their skills and expertise rather than degrees.
Concerns about the effects of family evaluators on the rigor of the research. Some evaluators reported stakeholders’ concerns about the impact of family members with personal experience of receiving mental health services on the rigor of the research. They described community partners’ fears that family participation on the evaluation team would compromise the quality of the research. A few respondents mentioned their initial fears that it would be difficult for family evaluators to maintain objectivity. In response, a number of evaluators commented that they had learned that obtaining objectivity is not really possible. One evaluator said, “I think that I was a little less flexible about [objectivity] than I am now, realizing that sometimes that fuzziness of boundaries actually benefits us researchers in a lot of ways.” The Clark County family evaluator said that it had been necessary to continually emphasize the benefits of having family members on the research team to community stakeholders, while also encouraging objectivity. Evaluators reported that research rigor can be maintained through frequent open discussions in team meetings, training, sporadic supervision of interviews, and thorough verification of data. They suggested that these activities are especially important in the early stages of research.

Community stakeholders’ lack of appreciation for family evaluators’ roles

Several respondents reported that community stakeholders, especially service providers, did not value the family member role on evaluation teams. Evaluators talked about the challenge of gaining respect for the family members as real members of the evaluation team. In some cases, respondents informed us that family members gained respect over time by demonstrating that they could do high quality work. Some evaluators reported educating stakeholders about the valuable contributions of family evaluators. One evaluator described helping community stakeholders to appreciate family members’ roles by demonstrating that family participation improved the retention of participants and quality of findings. The Clark County family evaluator described the team’s efforts to gain respect for her role, including “professionalizing” the family evaluator role, mutual education, and naming everyone on the team as team members, regardless of status. She reported that the team demonstrated the importance of family members as core members of the evaluation team by ensuring that they attend meetings, participate in presentations, and are involved in interpretation of findings and writing reports.

Tension between advocacy and research rigor

Several evaluators mentioned challenges related to family evaluators’ desire to use preliminary data for advocacy. One respondent reported that a family evaluator became frustrated at seeing the data but not being able to use it. She said that she had talked with this family member to help her to accept the slower pace of change with research. Evaluators said that open communication about the tension between research and advocacy was helpful in dealing with this challenge. For example, one evaluator stated, “The other thing, I think, is the ability to negotiate things, like the advocacy and research issue. The willingness, we realize that we have to talk about this and we have to hash it out.”

CONCLUSION

According to participants in this study, family members play a variety of roles on evaluation teams at systems of care around the nation. Most respondents of this study reported that they had not received training on how to work with family members. Evaluators reported encountering a number of challenges in their work with family evaluators and they described strategies to overcome them. Next steps in the research agenda are to expand our understanding by exploring family evaluators’ perspectives. We will examine evaluators’ training needs related to collaboration and develop training materials to improve family-evaluator collaboration.
REFERENCES


Identifying and Building on Strengths of Children with Serious Emotional Disturbances

ABSTRACT

This presentation reviewed findings of a study completed by the lead presenter on collaborative methods of identifying strengths of children challenged by serious emotional disorders. The children in this study had a high level of exposure to mental illness, domestic violence and substance abuse in their biological families and were living with family members or foster families in the community. These children were at continuing risk of placement outside of their homes and communities due to serious emotional and behavioral problems.

The focus of the research was to study agreement and difference between parents and professionals in assessment of strengths by the parent and professional. This study explores data collected from families of children with serious emotional disorders receiving community-based wraparound services supported by the mental health services program for children funded by the Center for Mental Health Services, Substance Abuse and Mental Health Administration (Taylor, 2002b).

Eighty-five children were assessed by the parent and professional using the Behavioral and Emotional Rating Scale (BERS), the Achenbach Child Behavior Checklist (CBCL), and the Child and Adolescent Functioning Scale (CAFAS) at admission to the community-based program. It was found that families provided significant and unique information regarding their children. An analysis of the strengths scores revealed significant differences in the assessment of strengths by the parent and professional raters in domains of intrapersonal strengths, affective strengths.
and family involvement. The findings support the use of the strengths measure by multiple informants to provide unique information regarding the child’s strengths and functioning (Taylor, 2002a).

BACKGROUND

Mental and emotional disorders in children and adolescents touch at least one in ten children and just one in five of those children receives treatment, as documented in the recent report on Mental Health by the United States Surgeon General (U.S. Department of Health and Human Services, 1999). Mental health care available to families challenged to care for their children with serious emotional disturbances has been historically fragmented, restrictive, and categorical (Knitzer, 1982). Many families do not have access to the right level of treatment for their children in the community, this lack of sufficient services can exacerbate the development of more severe disorders. Mental health treatment and services provided to these children and their families must be better coordinated and integrated with other elements of the health care, education, and social service system to better support families in providing care in the home and community.

Social workers and other helping professionals have relied on a deficit-based approach to practice, emphasizing classifying pathology over identifying strengths. This study explores practice methods aimed at increasing positive expectations for these children and their families by increasing involvement of both families and professionals in assessing strengths of the child. In this presentation, the author of the study identified key practice constructs of the wraparound model and how these constructs were explored through the use of standardized instruments. The Behavioral and Emotional Rating Scale (BERS; Epstein & Sharma, 1998) was used to identify strengths and to identify areas of agreement and difference between professionals and family members in providing care in the home and community.

RESEARCH METHODS

The study presented explored strengths-based practice constructs through an analysis of measurements of functioning, behavior, and strengths of the child from two perspectives. The focus of the study was to evaluate the identification of strengths by the parent and professional. A goal of the practice model in the program where the data was collected was to increase family participation in assessment. Concordance between family and professional assessments of strengths as well as investigation of behavioral and functional assessments from the perspective of the parent and the professional were analyzed to investigate the constructs.

The Behavioral and Emotional Rating Scale (BERS) is used in this study to examine the level of strengths identification as well as the level of concordance between the parents’ and professionals’ assessments of strengths. The BERS is an empirically derived scale assessed to be valid and reliable to identify strengths across the domains of Interpersonal Strength (IS), Family Involvement (FI), Intrapersonal Strength (IaS), School Functioning (SF) and Affective Strength (AS) (Epstein & Sharma, 1998). The BERS strengths assessment was completed by both the therapist and parent during the assessment period allowing a statistical analysis of differences in strengths identification from the perspectives of the therapist and the family and comparison with national norms reported by Epstein & Sharma (1998). Traditional measures of behavioral problems and difficulties in daily functioning were also investigated and reported in the original research, but were not a focus of this presentation (Taylor, 2002).

RESEARCH QUESTIONS AND FINDINGS

The BERS was scored and compared to national norms reported by Epstein & Sharma (1998) for children with emotional and behavioral disorders. The mean scores for therapists and families were at or
above the 50th percentile compared to these national norms (Table 1).

To analyze the differences in therapists’ and parents’ strengths scores, a repeated measures analysis of variance (ANOVA) was used to examine differences in mean standard strength scores, primarily to examine rater by subscale interactions, as illustrated in Figure 1. There was significant main effect due to Rater \( df \ (1, 84) = 12.36, p = .001 \) across all scales. Parent raters had significantly higher ratings of strengths compared to therapists on all scales. Scale main effects were significant \( df \ (4, 336) = 7.49, p = .000 \) supporting the discriminant validity of the subscales. The mean scores of Family Involvement (FI) and Affective Strengths (AS) generally were the highest of the overall combined ratings and the School Functioning Subscale (SF) the lowest. The Rater x Scale interaction effect was significant \( df \ (4, 336) = 6.93, p = .000 \) (see Figure 1). The difference between therapists and parents was greatest on the Intrapersonal Strength (IaS) and Affective Strength (AS) subscales. The smallest difference was on the School Functioning (SF) subscale.

**Figure 1.**
Rater by scale interaction effects.

### Table 1

<table>
<thead>
<tr>
<th>Subscale</th>
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<th>( SD )</th>
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</table>

Note: Higher Scores represent higher ratings of strengths.

\( N = 85 \), Normative mean = 10; \( SD = 3 \).

Percentile compared to EBD Sample \( N = 861 \) as reported by Epstein and Sharma (1998).
Post hoc pairwise comparisons were also completed using the $t$ test for independent means. Parents’ and therapists’ scores on the same subscales, when compared, indicated a significant difference on the Intrapersonal Strength (IaS) scores [$\text{Mean Difference} = 1.39, SD = 3.46, t(84) = 3.70, p = .000$]. There was also a significant difference on the Affective Strength (AS) scores between parents’ and therapists’ scores [$\text{Mean Difference} = 1.67, SD = 3.20, t(84) = 4.80, p = .000$]. There was also a difference on the Family Involvement (FI) scale approaching significance [$\text{Mean Difference} = .59, SD = 2.68, t(84) = 2.02, p = .046$]. These significant findings of difference on subscales ratings support the value of multiple raters in assessing strengths and the importance of examining the rater by subscale differences (see Table 2).

### Table 2. BERS Subscale Score Mean Difference Between Parent and Therapist Ratings

<table>
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<th>Source</th>
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<th>$t$</th>
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<td>.406</td>
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<td>3.20</td>
<td>4.806</td>
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</table>

NOTE: Mean difference compares mean scores on BERS Subscales from 85 pairs at baseline data collection.

**CONCLUSIONS AND IMPLICATIONS FOR PRACTICE**

The analysis of measurements of strengths from multiple perspectives supports including parent voice in assessment of their children using empirically tested instruments. The data supports an expectation that families will bring unique information to the assessment process and challenges a bias that families stressed by children with emotional and behavioral problems may not identify strengths at the level observed by professional helpers. These findings further support the utility of the BERS instrument, particularly the strengths domains scores, to provide additional perspectives from multiple raters also found by Friedman, Leone, & Friedman in their study comparing parents’ and teachers’ assessment of strengths (1999).

This application of a strengths assessment was supported by the use of the strengths-assessment instrument. Differences were seen between families and professionals in assessing strengths both in comparison to the national norms and in relation to each other. Parents consistently reported a higher level of strengths across all domains. Sharing assessment data collected from this instrument facilitated communication about strengths, needs, and improvements and enhanced participation of both the youth and their family, according to family members in the program where the data was collected. The study provides additional data supporting the use of multiple sources of strengths and is proposed as method to increase family and youth participation in both assessment and planning.

The BERS was developed to measure the strengths that all children possess with the assumption that children can be motivated by the manner in which significant adults respond to them. This study investigated a use of the strengths assessment, involving both the family and professional completing the BERS scale. When adults important to the child emphasize strengths, this may lead to more active engagement in appropriate activities and pro-social behaviors on the part of children or youth. These results support the importance of the multiple perspectives in assessing the child’s strengths, as parent and professionals bring significantly different perspectives.

Analysis of the BERS scores from parents and professionals revealed significant differences in the subscales related to Intrapersonal Strengths, Affective Strengths and Family Involvement. While the
difference in the Family Involvement score may be accounted for by more observation time by the parents, differences in assessment of Intrapersonal Strengths and Affective Strengths are significant findings. These findings support the importance of incorporating the family’s perspective during the assessment and not relying on the professional as the sole expert in domains of emotional and mental functioning. The results support the perspective of family members asserting their input needs to be heard and heeded, and challenges assumptions that professionals possess privileged insights in the affective domains. The data provides an opportunity for both professionals and parents to explore differences in perceptions and to increase the level of discourse about areas of agreement and difference.

A strengths perspective shared by parents and professionals serves to instill hope and create a context for the family and community to sustain that hope for positive outcomes (Modrcin, 1999). Identification of strengths and the full involvement of the youth and their family in developing a plan of care are viewed as critical variables to success of a wraparound plan for children and adolescents (Franz, 2000). The results of this study extend these observations through empirical research findings. Through comparison of the strengths domains scores, an opportunity for deeper communication between families and professionals about observed strengths is increased. Exploration of concordance and differences in assessments between families and professionals expands the discourse, increasing opportunities to recognize and build on strengths of the child.

Sharing assessment data enacts an approach recommended by family researchers and advocates in which the family’s input is sought and valued at all levels. This practice enacts a paradigm shift from the traditional view of the mental health professional as the expert, with power differentially weighted to the professional and often denied to the family (DeChillo, Koren & Mezera, 1996; McAmmon, Spencer, & Friesen, 2001). Families and professionals are interdependent in completing assessments and planning care on behalf of children with SED; listening to families is critical to developing genuine mutuality and shifting from a traditional stance of power and authority to one of mutual agreement, rapport and effectiveness (Collins & Collins, 1990; Heflinger & Bickman, 1996). This study provides empirical support for increasing the influence of a parent perspective in assessment of both strengths and problems, and may provide a method for program administrators to assure that direct service providers have included families in assessment, and that identification of strengths is included as an essential component of that assessment (Simpson, Koroloff, Friesen & Gac, 1999).

The transaction between families and professionals involves a simultaneous and inseparable operation of the person-environment system. It directly impacts the child and is potentiated through active participation by family members in treatment planning and decision-making (Heflinger & Bickman, 1996). Inclusion of families in assessment and treatment planning, focusing on strengths, and providing flexible and effective services and supports to children in lieu of institutional care are critical practice principles needed to sustain improved services to children and families. These findings support use of multi-source measurement and intentional communication about the results into the day-to-day practice of agencies and professionals providing services to children with the highest needs.

The methods and findings of this study fulfill a primary aim of the presentation today, to share methods of implementing strengths-based assessment and promote full inclusion of families. Studying concordance and differences in perceptions of parents and professionals validates the unique contributions of families in the assessment process. Identification of strengths and building on these strengths through participation of the family are important methods to improve practice and support community and home-based care for children with serious emotional disorders.
REFERENCES


INTRODUCTION

Drug use is a serious problem among juvenile detainees, with an average of 60% of detained adolescents testing positive for an illegal substance in 2002 (Arrestee Drug Abuse Monitoring Program, 2003). Unfortunately, most juvenile justice systems are unprepared or ill equipped to either treat or collaborate with other community service agencies to address the complex needs of these youth. One approach to this multi-faceted problem is the Reclaiming Futures (2002) initiative, whose purpose is to build community solutions to substance abuse and delinquency by reinventing the way courts; police, detention facilities and communities address the needs of substance-abusing juvenile offenders. Our two-part presentation highlighted activities of a Reclaiming Futures site in Montgomery County, Ohio (RF-MCO). The first half of the presentation described the use of the Wilder Collaboration Factors Inventory to assess and monitor the health and function of a coalition of youth-involved agencies. The second half of the presentation discussed the development of focus groups and initial findings regarding youth and family experiences with the local juvenile justice and substance abuse treatment systems, as well as their support networks.

COMMUNITY COALITIONS

Building workable community solutions between and within systems is complex and full of challenges, particularly in the early stages of the change process. Community coalitions provide one way for individuals and organizations to work together to achieve...
common goals and promote systems change (Butterfoss, Goodman & Wandersman, 1993). Coalitions offer many advantages, such as providing a diversity of opinions and a wider range of available services, reducing service duplication, and improving communication, cooperation, and trust between agencies (Winer & Ray, 1994). Unfortunately, coalitions often experience a number of challenges including inadequate focus; uninvolved membership, poor leadership, bureaucratic constraints; differences in agency cultures, turf and resource struggles, incompatible staff roles; and differing norms, values and expectations. In order to develop and maintain the viability of coalitions as change agents, coalition members must continually monitor and assess their progress to address and overcome such challenges.

The RF-MCO coalition, composed of key representatives from a variety of youth-involved agencies, has adopted the *Wilder Collaboration Factors Inventory* (Mattessich, Murray-Close & Monsey, 2001) as a user-friendly tool to assess the strengths, weaknesses, and overall quality of its internal functioning. This 40-item instrument allows coalitions to monitor their strengths and weaknesses across six categories – membership characteristics, purpose, communication, environment, process and structure, and resources. Our presentation demonstrated the instrument’s utility as a routine pulse-check of the coalition’s direction and function by presenting sample baseline vs. Time 2 *Wilder Inventory* results (see PowerPoint presentation of the same title to view sample results). Findings can provide an early warning system of coalition dysfunction without fixing blame on individual members. Results can also affirm progress and provide motivation to the group. Scoring and interpretation guidelines are provided, as well as discussion on how to utilize questionnaire feedback to improve coalition functioning.

**YOUTH & FAMILY FEEDBACK—FOCUS GROUPS**

Building workable community solutions between and within systems also requires a joint partnership between professionals, communities, and the youth and families who stand to benefit from system changes. All too often, however, change efforts and their resulting policies and programs are not based on the needs of youth and families. Instead, they are based on the needs of the system. While such change may provide some short-term solutions for youth and families, system change dictated by system needs is unlikely to produce change that is relevant or sustainable.

The youth and families impacted by proposed changes are the experts on their experiences with systems and know what solutions work best for them. Listening to these experiences, and using that knowledge to shape change initiatives leads to the development of policies and programs that are: 1) relevant because they address the unique concerns, experiences, and strengths of youth and families; and; 2) sustainable because policies and programs are more likely to endure over time when they are based on the expressed needs and strengths of these individuals.

One way to listen to youth and family experiences is through focus groups. As an information-gathering tool and means of community participation, focus groups have considerable potential for providing the stories and perceptions that can greatly enrich the process of understanding the experiences of communities (Hancock & Minkler, 1999). RF-MCO began the ongoing process of listening to youth and families by conducting focus groups with those involved in the local juvenile justice and substance abuse treatment systems. The purposes of these focus groups were twofold: First to document youth and family perceptions of, and experiences with, the juvenile justice and treatment systems; and; second to gain a better understanding of their support networks.

RF-MCO focus groups were a collaborative effort that involved the active participation of local coalition partners in both the development and implementation of the groups. Coalition partners helped create focus group questions, recruit youth and family participants, and conduct the groups. Between December 2002 and January 2003, the coalition conducted a total of 13 focus groups. Overall, 51 youth and 51 parents/
guardians participated in the groups. The majority of youth and parent/guardian participants were African-American females. Participants were recruited from the following organizations: 1) juvenile drug court and probation services; 2) a local prevention program; 3) a local church, and; 4) a substance abuse treatment program for women with children.

Each focus group was conducted by two coalition members—one asked questions and the other took notes. Each group was also tape-recorded and transcribed. To analyze the findings, a codebook was developed by reviewing all transcripts and compiling a list of themes and sub-themes that emerged from focus group questions and youth/parent conversations. A researcher from outside the project then reviewed a sample of transcripts, along with the codebook, to ensure the codebook captured the important themes. After this review step, similar themes were combined, and additional themes added, to create the final codebook. With the codebook complete, each transcript was coded to uncover the experiences of youth and families around the identified themes. An outside researcher also coded a sample of transcripts with the final codebook to ensure coding was consistent across different coders.

Focus group findings presented at the conference included four primary themes: 1) The Voices of Youth; 2) The Voices of Parents; 3) Social Support; and 4) Natural Helping. The Voices of Youth revolved around four major areas. The first area focused on the negative perceptions many community members have of youth involved in the juvenile justice system. Youth feel others judge them based solely on the choices they have made, but feel those decisions do not define who they truly are. As one youth stated,

_They need to watch the way they talk to people 'cause they be just talkin' to you like you just, you a piece of trash...tellin' you ain't gonna be nothin' in your life._

Youth also talked about the lack of attention and care they receive from adults in the system. They feel adults are only interested in them when they get in trouble,

_You know, it's all about the probation officer, all about they care...my probation officer if I go in and talk to him, he's just doin’ his job. It ain't like he's there, really actually caring what I do. So it's like well, if you don't care then why should I even put anything, any effort into this if you don't care?_

Finally, youth expressed a desire for activities that are developmentally appropriate, teach them something, and connect them with other youth going through similar experiences,

_...the classes, they ain't helpin’ me...talk about how we can go out here and better ourselves, like get a job, stay in school, you know what I'm sayin?_

The Voices of Parents were very similar to the ideas expressed by youth participants. Parents also wanted more pro-social activities available to youth, as well as the opportunity for youth to talk to other people who have experienced similar situations. One parent suggested,

_How 'bout a program that has somebody who has experienced it, telling their life story of what has happened to them and what they overcome and how, you know, what they did to become straight. And it's somebody that's gone through, that has hit rock bottom and then come back up. They need to experience and hear stories._

Parents also discussed their support needs. Overall, parents do not feel they have the support they need as it relates to having a child involved in the juvenile justice system and want more avenues to talk about their experiences and receive advice and feedback.

The final two themes, Social Support and Natural Helping, revealed information about the support networks of youth and families and the potential benefits of a Natural Helping program that could provide additional support to them during their juvenile justice and substance abuse treatment experiences. While the focus groups revealed that youth and families do have people they can turn to for different kinds of support, the levels and types of support varied across participants, making a Natural Helper program a potentially important means of...
enhancing the support networks of youth and families. When asked about such a program, participants provided specific feedback about: 1) who natural helpers are; 2) who should receive them; 3) what they should do; and 4) why they are important. Participants described natural helpers as caring people they can rely on; people who share similar interests, and;

a group of dedicated people who is willing to stay in this for the long run and willing to support and help this person all the way through.

Participants also felt, however, that youth and families should play an active role in determining whether they need a natural helper in their lives. In terms of roles, participants believed that natural helpers should provide: 1) support and encouragement; 2) guidance and help to keep youth focused on a positive path and; 3) reminders for things like court and treatment appointments. Finally, participants discussed the importance of natural helpers for those youth and families who need additional support. As one youth stated,

I think that program would be good because it’s giving kids the opportunity to really have positive things they’re doin’ instead of seein’ all the negativity and stuff goin’ on. And bein’ around it, just bein’ around a positive person who don’t put theyself out there like that.

The experiences uncovered during these focus groups have a variety of implications for agencies working with youth and families involved in the juvenile justice and substance abuse treatment systems. First, a negative focus on youth and family problems in both systems influence staff perceptions of, and interactions with youth and families. Shifting from a problem focus to one that also embraces and encourages the strengths, assets, and abilities of youth and families is one way to address this issue. Second, it is important to develop more pro-social, developmentally appropriate opportunities for youth to think critically about their lives and build/use their skills to make positive contributions to their communities. Along these same lines, it may be helpful to provide youth with the opportunity to interact with other youth who have been challenged by similar circumstances. Third, it is important to develop support programs for parents who have a child involved in the juvenile justice and treatment systems so they have the opportunity to express their frustrations and concerns and receive advice and feedback from people who understand their experiences. Finally, feedback regarding a Natural Helper program provided insight into: 1) assessment strategies needed to identify strengths and gaps in support networks so that appropriate youth and families are referred to the program; 2) recruitment and screening strategies; and 3) development of a variety of support enhancements to match the unique needs and strengths of youth and families.

REFERENCES


The Context of Services for Effective Individualized Service/Support Planning: Assessing the Necessary Agency and System Support for Wraparound

Collaborative multidisciplinary teams that include family members and youth as equal partners have become an increasingly popular mechanism for creating and implementing service plans for individual children with complex needs and their families. In children's mental health, these teams are known as Individualized Service/Support Planning (ISP) teams or wraparound teams. Consistently delivering high quality wraparound throughout a system of care has been challenging, however (Farmer, 2000; Walker, Koroloff, & Schutte, 2003). At the team level, it is clear that the practice of wraparound is complex and difficult. What is more, practical experience has shown that teams require extensive support both from their agencies and from the system of care if high quality wraparound is to be achieved and sustained (Malekoff, 2000). But this necessary level of support is difficult to achieve. It appears that people at the organization and system level are often not aware of the spectrum of supports that is necessary if wraparound is to be effective. But even when they are aware, they may still find it difficult to put the necessary supports into place, since organizations and systems face many pressures and competing priorities (McGinty, McCammon, & Koeppen, 2001).

The presentation focused on describing the results of a research project that was designed to address three questions:

1. What does it take for wraparound teams to be
2. If teams are to be effective in this way, what supports do they need from the organizations that collaborate to provide wraparound?

3. What supports do these organizations—and the teams—need from the systems of care within which they are embedded?

METHOD

Our research strategy included several sources of information and data. We began with a literature review focusing on (a) research on effectiveness in teams that are similar to wraparound teams (i.e. teams that undertake complex planning tasks, define their own goals, include members with diverse perspectives, and so on); (b) elements of organizational context that promote or impede effective teamwork; and (c) research directly related to collaborative family-provider teamwork in child- and family-serving systems and agencies. We then collected data during semi-structured interviews, conducted in person or by telephone, with stakeholders in the wraparound team process. We interviewed a total of 55 people with high levels of experience in wraparound at the team, organization, and/or system levels. Included in this number were interviews with 28 team members who had been nominated as experts in wraparound practice either by their programs (with the programs themselves having been recognized nationally as exemplary) or by wraparound trainers or researchers with experience in a variety of communities around the nation. In addition to these experts, we also interviewed seven experienced team members (including five caregivers and one youth); one trainer; twelve directors of wraparound programs; five system-level administrators from the county, regional, or state level; and two researchers with a national perspective on wraparound teams. Our interviewees included seven African Americans, two Latinos and three Native Americans.

RESULTS

Figure 1 [facing page] provides an outline of the conceptual framework that we developed in answer to these questions. The framework describes a series of necessary conditions—conditions that must be met if high quality wraparound is to be achieved and sustained. In the presentation, we provided an introduction to the framework and to the three assessment tools we have developed to help people gauge the extent to which these conditions are in place in their local implementation.

As can be seen from the figure, the number of necessary conditions is quite large, and we were unable to discuss each one in detail during the presentation. We have recently produced a full report on our work (Walker, Koroloff & Schutte, 2003), which includes

- Details about our research sources and methods.
- A full description of each of the necessary conditions.
- A summary of the research evidence that provides the rationale for including each condition as necessary.
- Examples of ways that different communities have met each condition.
- The assessments of implementation at the team, organization/agency and system levels.

Three Levels

The conceptual framework organizes the necessary conditions into three levels: team, organization, and system. When we refer to the team level, we mean the caregiver and youth and at least two or three other consistently attending core members who take responsibility for creating and implementing a plan to meet the needs of the family and child with an emotional or behavioral disorder. These team members, whom family members identify as important in their lives, usually include service providers and members of the family's informal and community support networks.
### FIGURE 1: NECESSARY CONDITIONS

<table>
<thead>
<tr>
<th>TEAM LEVEL</th>
<th>ORGANIZATIONAL LEVEL</th>
<th>POLICY AND FUNDING CONTEXT (SYSTEM LEVEL)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Practice model</strong></td>
<td><strong>Practice model</strong></td>
<td><strong>Practice model</strong></td>
</tr>
<tr>
<td>i. Team adheres to a practice model that promotes effective planning and the value base of ISP. Sub-conditions of practice model 1-7</td>
<td>i. Lead agency provides training, supervision and support for a clearly defined practice model. ii. Lead agency demonstrates its commitment to the values of ISP. iii. Partner agencies support the core values underlying the team ISP process.</td>
<td>i. Leaders in the policy and funding context actively support the ISP practice model.</td>
</tr>
<tr>
<td><strong>Collaboration/partnerships</strong></td>
<td><strong>Collaboration/partnerships</strong></td>
<td><strong>Collaboration/partnerships</strong></td>
</tr>
<tr>
<td>i. Appropriate people, prepared to make decisions and commitments, attend meetings and participate collaboratively.</td>
<td>i. Lead and partner agencies collaborate around the plan and the team. ii. Lead agency supports team efforts to get necessary members to attend meetings and participate collaboratively. iii. Partner agencies support their workers as team members and empower them to make decisions.</td>
<td>i. Policy and funding context encourages interagency cooperation around the team and the plan. ii. Leaders in the policy and funding context play a problem-solving role across service boundaries.</td>
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<tr>
<td><strong>Capacity building/staffing</strong></td>
<td><strong>Capacity building/staffing</strong></td>
<td><strong>Capacity building/staffing</strong></td>
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<tr>
<td>i. Team members capably perform their roles on the team.</td>
<td>i. Lead and partner agencies provide working conditions that enable high quality work and reduce burnout.</td>
<td>i. Policy and funding context supports development of the special skills needed for key roles on ISP teams.</td>
</tr>
<tr>
<td><strong>Acquiring services/supports</strong></td>
<td><strong>Acquiring services/supports</strong></td>
<td><strong>Acquiring services/supports</strong></td>
</tr>
<tr>
<td>i. Team is aware of a wide array of services and supports and their effectiveness. ii. Team identifies and develops family-specific natural supports. iii. Team designs and tailor services based on families’ expressed needs.</td>
<td>i. Lead agency has clear policies and makes timely decisions regarding funding for costs required to meet families’ unique needs. ii. Lead agency encourages teams to develop plans based on child/family needs and strengths, rather than service fads or financial pressures. iii. Lead agency demonstrates its commitment to developing culturally competent community and natural services and supports. iv. Lead agency supports teams in effectively including community and natural supports. v. Lead agency demonstrates its commitment to developing an array of effective providers.</td>
<td>i. Policy and funding context grants autonomy and incentives to develop effective services and supports consistent with ISP practice model. ii. Policy and funding context supports fiscal policies that allow the flexibility needed by ISP teams. iii. Policy and funding context actively supports family and youth involvement in decision making.</td>
</tr>
<tr>
<td><strong>Accountability</strong></td>
<td><strong>Accountability</strong></td>
<td><strong>Accountability</strong></td>
</tr>
<tr>
<td>i. Team maintains documentation for continuous improvement and mutual accountability.</td>
<td>i. Lead agency monitors adherence to the practice model, implementation of plans, and cost and effectiveness.</td>
<td>i. Documentation requirements meet the needs of policy makers, funders, and other stakeholders.</td>
</tr>
</tbody>
</table>
At the organizational level, the picture becomes somewhat more complicated. We find it useful to distinguish between two roles that organizations or agencies can play relative to wraparound teams. In the first role, an agency takes the lead in wraparound implementation, and is responsible for hiring, training, and supervising team facilitators. This agency may also provide training for other team members with specialized roles, such as family advocates or resource developers. In the second role, an agency acts as a partner to the team-based wraparound process by contributing services, flexible funds and/or staff who serve as team members.

We think of the system level as the larger service policy and economic context that surrounds the teams and team members’ agencies. Because many communities have not yet developed a system of care we also use the term policy and funding context to refer to this level. Put simply, the policy and funding context includes people and groups at higher levels whose actions and decisions impact wraparound teams and organizations through formal and informal policies, and through decisions about finances. For example, the policy and funding context often includes administrators of child- and family-serving agencies (child welfare, mental health, juvenile justice) at the county, region, or state level. Policies and funding decisions may also be impacted by state and local governing bodies, as well as by other organizations that set policy, monitor or enforce policy, or interpret state or national policies to local service providers.

Five Themes

The conditions are depicted in Figure 1 by the columns and are also organized according to five themes: practice model, collaboration/partnerships, capacity building/staffing, acquiring services/supports, and accountability. At each level—team, organization, and system—stakeholders must engage in activities that meet the necessary conditions. The framework does not attempt to specify exactly how a program or community should meet each condition, only that there should be some structure, mechanism, policy, or process for doing so. For example, in the area of accountability, the framework includes the necessary condition that the organization monitors adherence to the practice model of wraparound (as well as implementation of plans and cost and effectiveness). Since the practice model is built around the value base of wraparound, part of this monitoring must focus on whether or not teams are truly working in ways that promote the values. However, monitoring adherence to the value base can be done in several ways. For example, an organization might ask family members to rate the level of adherence to wraparound values that they experienced in their team meeting, or the organization might ask supervisors to observe team meetings and provide feedback on adherence to the values. Theses are two different activities on the part of stakeholders that satisfy this aspect of the condition. The framework recognizes that it is important that organizations and systems have some flexibility to decide—based on local context and local needs—what sorts of strategies will work best to meet the conditions in their particular community.

DISCUSSION AND IMPLICATIONS

Interrelationships Across Levels

The organization of the framework according to themes also draws attention to the ways that the three levels of activity are interrelated. Failure to recognize the impact of system level actions on the organization, or the effect of organizational decisions on teams, leads to narrow problem definition and ineffective solutions. Staff at all levels can easily end up blaming each other, feeling defensive about their own actions and demoralized. Practical experience has shown that achieving meaningful change at the service delivery level requires extensive support from the organizational level, as well as from the system level. (Clark, Lee, Prange, & McDonald, 1996).

A good example of the impact of one level on another can be found within the collaboration/partnership theme. Support across all three levels is necessary to ensure that key team members will be able to attend meetings. For example, a child welfare worker from a partner agency is told by her supervisor that she
can no longer attend an individual child’s team meetings because she needs to use her time investigating child abuse cases. Her regular presence at team meetings is critical to the team’s ability to make appropriate decisions. This organizational decision is sparked by a recent child death and increased community pressure on the child welfare agency. In a community with low organizational and system support for wraparound, the team facilitator is left to negotiate directly with the child welfare worker or her supervisor to assure some level of involvement in team meetings. If the facilitator is well-respected or has a strong network of friends, he may manage to get the child welfare worker’s supervisor to allow her to attend the next meeting for this specific child. Alternatively, the child welfare worker may begin attending team meetings on her own time. However neither of these solutions changes the general policy that continues to restrict child welfare workers’ involvement in other (and future) teams. In a community with strong organizational and system supports, the team facilitator might enlist the help of a supervisor or program manager who will negotiate directly with the manager of the child welfare agency to work out a different policy that does not restrict workers’ participation on wraparound teams. Further, a strong interagency body at the system level could examine the problem of increased scrutiny of child welfare and can seek ways to resolve this issue that do not undermine the collaboration and partnership that is necessary for wraparound.

Another example comes from the area of acquiring services and supports. One of the key tasks of the wraparound team is to integrate community services and natural supports into the plan. As it turns out, teams are rarely successful in building plans which are not primarily reliant on formal services. Our research indicates that this is in large part due to a lack of support from the organization and system levels. For example, teams require knowledge about specific strategies for attracting and retaining community and natural support people to the team. Ensuring that team members acquire this necessary knowledge is a responsibility at the organizational level. In reality, organizational pressures often work the other way, to encourage teams to develop plans that rely on formal services that have already been contracted. Again, it is the responsibility of organizations to ensure that teams are able to develop plans based on the family’s expressed needs and strengths, rather than on the services that are “on the shelf.” If many teams within a program are successful in integrating community and natural supports into the plan, another problem may well emerge: There may now be more demand for community services and supports than capacity to provide them. This would be the case if a number of teams in a wraparound program suddenly discovered high quality after school program at a local church that combines mentoring, tutoring, and social skills development. The program might have openings for only one or two children. As another example, suppose a team wants to provide caregiver respite by paying the child’s daycare worker to have the child at her home every other weekend. This creative- and potentially highly cost effective- solution is derailed because there is no existing mechanism for certifying or paying a non-traditional respite provider. If plans are to be truly individualized and community based, the organizations that collaborate to provide wraparound must devise strategies for developing community capacity to provide the services and supports that tend to be requested by teams. Developing community capacity and informal supports will also require support from the system level. For example, the policy and funding context must allow organizations the flexibility and autonomy that are necessary if they are to develop the specific services and supports that will be successful within a particular community context.

ASSESSMENTS OF THE ORGANIZATIONAL AND SYSTEM CONTEXT

During the presentation, we presented a series of assessments that we developed as a companion to the conceptual framework. These assessments—for team process, organizational support, and system context—are designed to provide stakeholders with
a structured way of examining the extent to which the necessary conditions for wraparound are present in their local implementation. The assessments are not designed to provide a rating or ranking of the implementation, or to measure change over time. Rather, they are intended for use in discussions of the strengths of the implementation, as well as to help clarify and prioritize areas for further development.

The assessments were designed with an eye towards issues of mutual accountability across the various levels of implementation of wraparound. Traditionally, we think of people at the service delivery level as accountable for the quality of the services that they provide. When programs fail to deliver desired outcomes, the blame is often laid at the provider level. However, as our research has made clear, high quality work in wraparound cannot succeed where the necessary organizational and system level supports are lacking. But how are people at these levels to be held accountable for providing an acceptable level of support? We believe that assessing the extent to which the necessary conditions are in place at the organizational and system levels provide a means for pushing accountability upward as well as downward. The assessment of organizational and system support are tools for this sort of upward accountability. In contrast, the team level checklist can be seen as a more traditional sort of tool, of the type that is used for supervision in a more familiar form of downward accountability. The idea is that a balance of upward and downward accountability actually builds a culture of mutual accountability that encourages focused problem solving over defensive blaming.

REFERENCES


Maximizing Family Participation in the Development and Monitoring of Care Plans: What We Know About What Works

Family Service of Rhode Island has initiated a pilot project to more completely involve families in the planning and monitoring of their services. This pilot, building on and significantly revising an earlier initiative, uses a utilization management process designed to ensure quality services with a family-centered approach. The organization strengthened this process through involvement of family members and through significant changes in the process to make it more “family friendly.” This presentation provided training detailed information about the steps for accomplishing family integration, the lessons learned about that process, and materials that participants could bring back to their agencies.

At the 2002 Building on Family Strengths Conference, Family Service of Rhode Island offered training on a strategy to increase family involvement and ownership in designing, monitoring, and evaluating their own family care plan. Continued analysis of information from family members and staff led to substantial changes in this family involvement initiative.

Several years ago, Family Service of Rhode Island implemented a new utilization management process to ensure the delivery of “best practice” service to its over 400 families. Increasing need for home and community based services and growing outpatient, residential, foster care and adoption programs challenged consistent delivery of quality, family-focused services. This utilization management process serves to mitigate the increasing risk associated with the increasing severity of presenting needs of children and youth. Like many not-for-profit
agencies serving families, our clinical staff are often hired directly from graduate school, paraprofessional case managers are hired with a wide variety of experience and training, and supervisors are often only a bit more seasoned than their staff. The utilization process provides an opportunity for case review, determination of appropriate level of care and service, risk assessment, and staff coaching and training, thus supplementing the supervision provided at the unit level. Each family situation is reviewed at least every 90 days for a minimum of thirty minutes, if work with the family is successful and moving forward as planned. For families identified as having elevated risk or in need of more intensive monitoring and planning, reviews are conducted weekly. This process has greatly increased the ability of the organization to assign resources and services to families most needing them. A two year evaluation of this process has documented staff benefits resulting from the training and coaching time with the senior clinical, medical, and educational staff who constitute the “permanent seats” at each review. In nearly one-half of the family service plan review meetings, changes or additions are made to the services offered.

Even as the organization made the investment in ensuring quality service, there was a recognition that a critical component was missing: the families receiving services. In the fall 1998 *Focal Point*, (McManus, 1998), there was discussion of a plan moving from an expert-driven, professionally-centered approach to a family-centered, team-supported approach. The organization moved to implement a pilot project in which families were identified as part of the team reviewing the care plan and its outcomes, based on a model described in “Children and Youth—The Continuum of Services” in National Peer Technical Assistance Network, (Adams, et al.,1998). The evaluation of that effort, based upon information collected from families, suggested that they found the process valuable and affirming, but quite stressful and intimidating. Staff evaluations supported both the positive value and the associated family stress. Concern was raised about whether the stress and discomfort made family involvement inappropriate for many families already experiencing so much stress.

As a result of this concern, a second pilot has been implemented which makes the process more “family friendly.” The site of the meeting is moved to the family home. Fewer professionals outside of the team are involved. The trappings of documentation are made less obvious. Families are offered more control over the environment and an experience involving mostly professionals already known to family members.

A small number of families completed this pilot program, in part as a result of the criteria used for family selection and in part as a result of the increased commitment of staff time needed for completion. The sample size of completing families was nine. Eight of the families completing the pilot family involvement process also completed data collection at the end of the family utilization management meeting. Of those eight families in which parents responded, seven of the eight rated the experience as “excellent,” and one rated it as “good.” Parent comments centered on the value of parent and family participation in discussion of services, both what had been successful and what needed to be offered. In addition, most families noted that this meeting served as an excellent opportunity to review family progress. All of the responding parents said that they want to participate in this same process again and that they would recommend it to other families receiving service from the organization.

Data was collected from the staff participating in family utilization management meeting process, including clinicians, case managers, and clinical supervisors. Findings included the following:

- All indicated that the family utilization management meetings were far more focused on strengths and building on strengths than the organization internal review process.
- All noted that consumers found it a powerful experience to have senior clinicians and
administrators come to their home to talk about the progress that the family had made and to plan the next steps.

- Several noted that some of the detail and emphasis on oversight could be further eliminated.
- All agreed that this was worth taking the next steps in implementation.
- All believed that the next trial in the pilot should focus on using this model with the most challenging family service situations, particularly focusing on situations in which service delivery seemed to “be stuck.”

One question arose from the focus group discussion of the staff involved in this pilot. It was not clear whether the protocol should include special preparation of the families for the meeting. Some teams had done this and others had not. Given the universally positive response of families involved, the preparation did not appear to shape the perceived value of the experience. Nonetheless, some staff felt that the value of the preparation might emerge only in terms of longer term impact on services and treatment.

As the project enters the third year of activity, we are committed to further explore the value of family preparation and we are focusing on using family utilization management meetings in those situations experiencing the most difficulty. In addition, the sample size for data collection for the coming year is planned to more than double.

This pilot project on maximizing family participation in evaluation of organizational services receives no external funding. It is a reflection of the commitment of this organization, Family Service of Rhode Island, to find ways to empower families to expanded participation in their own service planning. It is representative of the many initiatives focused on improving service quality which emerge within organizations serving clients. Too often, the results of those initiatives go unreported and unnoticed.

**REFERENCES**

Appendix:
Agenda of the 2003 Conference
### Thursday, June 26th

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>8:00-9:30</td>
<td><strong>Registration</strong></td>
<td>Plaza Foyer Plaza Level</td>
</tr>
</tbody>
</table>
| 9:30-11:00   | **Welcome:** Barbara Friesen, James Ward, Mary Kay Tetreault, and Trina Osher  
**Keynote Address,** Now More Than Ever! The Steps That Systems of Care and The Wraparound Process Must Take To Ensure Outcomes  
*Speaker: John VanDenBerg* | Pavilion Ballroom Plaza Level                                      |
| 11:00-11:15  | **Break**                                                             | Plaza Foyer Plaza Level       |
| 11:15-12:15  | **Concurrent Workshops**                                             |                               |
|              | Session 01: *Intervening Early and Often: A Dropout Prevention Project in New Hampshire*  
*Malloy, Muscott, Cormier, Veit* | Broadway I Plaza Level       |
|              | Session 02: *NICWA Track: A Strength-Based Approach for working with American Indian Families*  
*Nelson* | Broadway II Plaza Level       |
|              | Session 03: "And now for something completely the same": Issues and Dilemmas in creating Integrated Services for Multi-problem Children and their Families  
*Paulson* | Broadway III Plaza Level       |
|              | Session 04: *Austin’s Story: One Client’s Journey from Frustration to Empowerment*  
*Cheek, Buhner, Williams, Harris, Harris* | Broadway IV Plaza Level       |
|              | Session 05: *Moving Towards Cultural Competency: Developing Empowering Partnerships with Aboriginal Families with Children in Residential Care*  
*Petrucka, Derbyshire* | Council Suite Third Floor    |
|              | Session 06: *Building a Family Member/Researcher Partnership: From Conceptual Framework to Dissemination*  
*Williams, Boyl, Woolverton* | Forum Suite Third Floor      |
|              | Session 07: *Latino Track: PARENT S T E P P S (Systematic Training Establishment of Parent to Parent Support) For Diverse Populations*  
*Goldfarb, Landry* | Studio Suite Third Floor     |
|              | Session 08: *Techniques for Identifying Needs in Wraparound Planning*  
*Miles* | Salon I Executive Tower      |
|              | Session 09: *Staying Strong: An Emotional Fitness Self Care Program*  
*Levine, Cruz, Miller, Pessin* | Salon II Executive Tower     |
|              | Session 10: *Diversifying Your Group’s Funding Stream: An Introduction to Fund Development*  
*Schewe* | Salon III Executive Tower    |
### Thursday, June 26th

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>1:30-3:20</td>
<td><strong>Concurrent Workshops</strong></td>
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<td></td>
<td><strong>Session 11</strong> Strengthening Families and Achieving Stabilities within</td>
<td>Broadway I Plaza Level</td>
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<td></td>
<td>FRIENDS Family Support Program [Clemente, Olavarria]</td>
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<td><strong>Session 12</strong> NICWA Track: A Native Community Joining Circles of Care</td>
<td>Broadway II Plaza Level</td>
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<td></td>
<td>[Squetimkin-Anquoe, LaPointe, James]</td>
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<td><strong>Session 13</strong> Family Centered Early Intervention: Practice and Research</td>
<td>Broadway III Plaza Level</td>
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<td></td>
<td>[Bowdish, Albright, Bush, Kelly, Kendziora]</td>
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<td><strong>Session 14</strong> What works? Families Speak about Research, Experience and</td>
<td>Broadway IV Plaza Level</td>
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<td><strong>Session 15</strong> Teen Advisory Council's Mental Health / Violence Project</td>
<td>Council Suite Third Floor</td>
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<td><strong>Session 16</strong> Operationalizing the Wraparound Value Base: Keeping It Real</td>
<td>Forum Suite Third Floor</td>
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<td>[Meyers]</td>
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<td><strong>Session 17</strong> Latino Track: Family Culture: The Path to Natural Resiliency</td>
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<td>[Rodriguez, Norman]</td>
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<td></td>
<td><strong>Session 18</strong> Washington County Enhanced First Step To Success/Mental Health Program [Ballard-Turner, Andrew-Miller, LeDrew, Arthur, Souza]</td>
<td>Salon I Executive Tower</td>
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<td><strong>Session 19</strong> Skill-Based Training for Parent Partners working in Wraparound Settings [Miles]</td>
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<td><strong>Session 20</strong> Maximizing Family Participation in the Development and Monitoring of Care Plan - What We Know About What Works [Watson, Mueller]</td>
<td>Salon III Executive Tower</td>
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<tr>
<td>3:20-3:35</td>
<td><strong>Break</strong></td>
<td>Plaza Foyer Plaza Level</td>
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<td>3:35-4:25</td>
<td><strong>Concurrent Workshops</strong></td>
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<td><strong>Session 21</strong> Latino Track: Cultural Competence: Creating a &quot;Roadmap&quot; for Sustainability [Reid-Rose, Neville]</td>
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<td><strong>Session 22</strong> NICWA Track: Using Family strengths to Build a Model Child Abuse and Neglect Data System [Becker-Green]</td>
<td>Broadway II Plaza Level</td>
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<td><strong>Session 23</strong> Developing a Successful Family Resource Center for information and Support [K. Dunning, Blakely]</td>
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<td><strong>Session 24</strong> Family Perceptions of Educational Planning for Children Receiving Mental Health Services [Friesen, Robinson, Jivanjee, Kruzich]</td>
<td>Broadway IV Plaza Level</td>
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**Appendix:** Agenda of the 2003 Conference 191
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<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>Session 27</td>
<td>Maine Adoption Guides: Family Centered Post-Adoption Services [Lahti, Roma, Stephenson, Berz]</td>
<td>Studio Suite Third Floor</td>
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<tr>
<td>Session 28</td>
<td>Wraparound and the Faith-Based Community: A Partnership Made in Heaven! [Moon, VanDenBerg]</td>
<td>Salon I Executive Tower</td>
</tr>
<tr>
<td>3:35-5:25</td>
<td><strong>Concurrent Workshops</strong></td>
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<tr>
<td>Session 29</td>
<td>From Consumer to Employee: The Strengths and Challenges of moving a Parent receiving Wraparound to an Employee helping other Wraparound Families [Rauso, Bibeau, Gottlieb]</td>
<td>Salon II Executive Tower</td>
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<td>4:35-5:25</td>
<td><strong>Concurrent Workshops</strong></td>
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<td>Session 31</td>
<td>Latino Track: Conceptualizing and Assessing Cultural Competence in Systems of Care [Davis, Barraza]</td>
<td>Broadway I Plaza Level</td>
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<tr>
<td>Session 32</td>
<td>Mothers and Daughters Respond to Research Participation [Boothroyd, Best]</td>
<td>Broadway II Plaza Level</td>
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<td>Session 34</td>
<td>Poetry as Therapy for Homeless and Jailed Teens [Gold]</td>
<td>Broadway IV Plaza Level</td>
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<tr>
<td>Session 36</td>
<td>Parent Perceptions' of Service Delivery: A Family/Youth/Professional Collaborative Research Study [Boterf, Casseday]</td>
<td>Forum Suite Third Floor</td>
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<tr>
<td>Session 37</td>
<td>Shifting to a Family-focused Approach in Services Research for Adolescents with Substance Abuse and Co-occurring Disorders [Brannan]</td>
<td>Studio Suite Third Floor</td>
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<tr>
<td>Session 38</td>
<td>Identifying Factors that Influence Youth Violence: A Community Participates [Arbuckle, Frabutt, Shelton, Witherspoon]</td>
<td>Council Suite Third Floor</td>
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<td>5:40-7:00</td>
<td><strong>Special Interest Groups</strong></td>
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<td>International Perspectives on Children’s Mental Health</td>
<td>Broadway I Plaza Level</td>
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<td>Bipolar Disorder in Children</td>
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<td>Welcome for Youth Attendees</td>
<td>Broadway III Plaza Level</td>
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<tr>
<td>7:30-8:45</td>
<td><strong>Brainstorming Session:</strong> Evaluators and Family Member Evaluators</td>
<td>Broadway I Plaza</td>
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<td><em>Jivanjee, Schutte, Robinson</em></td>
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<tr>
<td>8:00-8:45</td>
<td><strong>Registration /Breakfast</strong></td>
<td>Plaza Foyer Plaza</td>
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<tr>
<td>8:45-10:15</td>
<td><strong>Welcome:</strong> Barbara Friesen and Jill Erickson</td>
<td>Pavilion Ballroom</td>
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<td><strong>Research Plenary</strong></td>
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<td></td>
<td>Fidelity and Effectiveness in ISP/Wraparound</td>
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<td><em>Panel: Eric Bruns, Julie Becker, Janet Walker</em></td>
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<tr>
<td>10:15-10:30</td>
<td><strong>Break</strong></td>
<td>Plaza Foyer Plaza</td>
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<td>10:30-12:20</td>
<td><strong>Concurrent Workshops</strong></td>
<td>Broadway Level</td>
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<tr>
<td>Session 39</td>
<td>The Importance of Strength-based Family Involvement for Better Outcomes</td>
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<td><em>Dunning, Dalrymple, Blakely</em></td>
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<td>Session 40</td>
<td>NICWA Track: Family Unity During Tough Times: A Discussion on Strategies for Coping with Crisis</td>
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<td>Session 41</td>
<td>Integrated Care Coordination: Changing the Face of Children's Protection and Safety and Mental Health Systems</td>
<td>Broadway III Plaza</td>
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<td><em>Hascall, Wacker, Lawson, Stone-Haga</em></td>
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<tr>
<td>Session 42</td>
<td>Checking the Pulse: Using Focus Groups and Community Coalitions to Identify Consumer Needs and Plan for System Change</td>
<td>Broadway IV Plaza</td>
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<td><em>VanderWaal, Carr, Washington</em></td>
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<td>Session 43</td>
<td>When Adolescents Know the Rules, They will Succeed</td>
<td>Council Suite Third</td>
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<td><em>Reid-Rose, Harris, Ellington, Morris, Douce, Quintana, Rugh, Johnson, Rugh</em></td>
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<td>Session 44</td>
<td>Maximizing the IEP Process: True Collaboration Between Schools and Families</td>
<td>Forum Suite Third</td>
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<td><em>Peterson, Williams, Williams, McIntyre, Buhner, Smith</em></td>
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<td>Session 45</td>
<td>Social Support Through Metaphor-Enhanced Group Psychoeducation: A Treatment Approach with Nonabusing Parents</td>
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<td><em>Ostis</em></td>
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<tr>
<td>Session 46</td>
<td>The Positive Power of Painful Change: Building Systems of Care in Communities in Partnerships with Families, Systems and Providers</td>
<td>Salon I Executive</td>
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<td><em>Dague, Greenwood, McCombs, Lawson</em></td>
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<td>Session 47</td>
<td>Latino Track: Building on Family Strengths: Community-Based Strategies to Outreach Mexican Families in Rural Florida</td>
<td>Salon II Executive</td>
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<td><em>Hernandez, Contreras, Ramirez, Tooley</em></td>
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<td>Session 48</td>
<td>School-Based Wraparound Teams: A Model for School Participation in Wraparound</td>
<td>Salon III Executive Tower</td>
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Friday, June 27th

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<tr>
<td>12:30-1:30</td>
<td>Lunch</td>
<td>Plaza Foyer</td>
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<td>1:45-2:35</td>
<td><strong>Concurrent Workshops</strong></td>
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<td>Session 49: Latino Track: The Tapestry Program: A Unique Approach to</td>
<td>Broadway I</td>
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<td>Wraparound [Becker]</td>
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<td>Session 50: NICWA Track: Cultural Competency 101 [Nelson]</td>
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<td>Session 51: A Multi-Method Approach to Understanding Collaboration in</td>
<td>Broadway III</td>
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<td>Systems of Care [Evans, Armstrong]</td>
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<td>Session 52: Implementing a Family Intervention Program:</td>
<td>Broadway IV</td>
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<td>Comprehensive Home-Based Services (CHBS) [Herreras]</td>
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<td>Session 53: Parents Empowering Parents</td>
<td>Council Suite</td>
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<td>[King, Critchlow, Payton, Lyons, Redman]</td>
<td>Third Floor</td>
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<td>Session 54: Promoting Child Mental Health with &quot;Bright Futures&quot;</td>
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<td>[Burke, Ogilvie]</td>
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<td>Session 55: Children in Out-of-home Care: The Changing Role of Parents</td>
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<td>[Shireman]</td>
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<td>Session 56: Are Systems of Care and Wraparound Evidence-Based</td>
<td>Salon I</td>
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<td>Practice? [VanDenBerg, Rast, McCombs, Lawson]</td>
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<td>Session 57: Assessing ISP/Wraparound Implementation at the Team,</td>
<td>Salon II</td>
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<td>Organization, and System Levels [Walker, Koroloff, Schutte]</td>
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<td>Session 58: Clackamas County Mental Health System of Care: Effects on</td>
<td>Salon III</td>
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<td>Family Participation and Clinical Outcomes [Ostrogorsky, Friesen,</td>
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<td>McBride, Ivie, Loaiza, McCarthy]</td>
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<td>2:45-3:35</td>
<td><strong>Concurrent Workshops</strong></td>
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<td>Session 59: Latino Track: Conversations with Parents of Severely</td>
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<td>Disabled Children and their Teachers: Lessons Learned</td>
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<td>[Gonzales, Johnson, Sutra]</td>
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<td>Session 60: Is Caregiver Participation in Service Planning Related to</td>
<td>Broadway II</td>
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<td>Child Outcomes? [Pullmann, Savage, Guthrie, Rhodes]</td>
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<td>Session 61: Employment: What Parents Say About Their Work-Related</td>
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<td>Experiences [Rosenzweig, Huffstutter, Burris]</td>
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<td>Session 62: Practical Principles of Communication [D. Dunning, K.</td>
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<td>Session 63: &quot;Thought Auction&quot;: Planning and Producing a Youth Art</td>
<td>Council Suite</td>
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<td>Exhibit: Benefits, Barriers and Unexpected Discoveries</td>
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<td>[Larrabee, O'Connor, Holmes]</td>
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<td>Session 64: From Access to Discharge and Beyond: Developing Principles</td>
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<td>of Family-Centered Practice within a System of Care</td>
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<td>[Greene, Blum, Thiele, Morris, Schubert, Blum, Carroll]</td>
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*Appendix: Agenda of the 2003 Conference*
Friday, June 27th

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<th>Time</th>
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<tr>
<td></td>
<td>Session 65 Outreach Services to African-American Families at Risk of</td>
<td>Studio Suite Third Floor</td>
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<td></td>
<td>Child Neglect [Nelson, Spaulding, Smith, Shellmire]</td>
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<td>Session 66 Measuring Fidelity in Wraparound Implementation [Bruns,</td>
<td>Salon I Executive Tower</td>
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<td>Leverentz-Brady]</td>
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<td>Session 67 Using Research for Evaluation and Advocacy of Custody Issues</td>
<td>Salon II Executive Tower</td>
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<td>in Maryland [K. Friedman, P. Friedman]</td>
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<td>Session 68 Using Flexible Funds to Support Children and Families</td>
<td>Salon III Executive Tower</td>
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<td>Involved in the Child Welfare System: Findings from Oregon’s Title IV-E</td>
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<td>Waiver Evaluation [Lehman, Liang, O’Dell]</td>
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<tr>
<td>4:30-6:30</td>
<td>Poster Session Reception</td>
<td>Pavilion Ballroom Plaza Level</td>
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**Poster Session**

Pavilion Ballroom 4:30-6:30

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**What is a Poster Session?**

"Thought Auction": Planning and Producing a Youth Art Exhibit: Benefits, Barriers and Unexpected Discoveries
Kathy Larrabee, Jenny O’Connor, John Holmes

Multimedia display of artists in action, which includes the process of creating their art and interacting with their “support base” of instructors, family members and staff at NAMI of Multnomah County. ("Thought Auction"-- When your mind betrays you by enslaving your thoughts and auctioning them off. –Nick)

**A New Video Resource: Caring for Babies with Attachment Based Care**
Jackie Kling, Jo Hussey, Nan LeRoy

This video shows the important caregiver skills that promote emotional health in babies. Childcare centers that base their care on attachment principles recognize that it is essential to form attachment bonds between caregivers and babies. In the video, skilled caregivers use daily routines to help form these bonds. Examples include understanding and responding to babies’ cues, providing comfort for babies in distress, and developing ways of communicating in order to meet the babies’ emotional and social needs.

**Building Bridges to Provide More Culturally Competent Services**
Lenora Reid-Rose, Neville Morris

CCSI has adopted a novel and comprehensive approach with a cycle that starts with self assessment, and concludes within evaluation of the consumer’s results. As providers implement programs to become more Culturally Competent, the strength of the effort will be evident in bridging the disparities as identified by the the former Surgeon General.
Building on Strengths of Children and Families through Collaborative Assessment
Michael Taylor, Jan Lacey

A study exploring strengths assessment by parents and professionals using the Behavioral and Emotional Rating Scale (BERS) to assess and build on strengths and enhance collaboration between parent and professional.

Clark County Childcare Resource Team: A Key to Quality Care
Nancy Jambor, Jodi Wall

A Clark County interdisciplinary team provides training and consultation to strengthen the capacity of child care providers in caring for children with challenging behaviors and their families.

Conducting Family Based Prevention Training via a Satellite Distance Education Model
Donald Wagner, Keith King, Peg Elgas, Mark Scroggins

Strategies utilized to develop and broadcast via satellite, an alcohol and drug prevention training program for Head Start staff in Ohio. The evaluation results, training design and activities, and the social marketing strategies used to recruit participants will be displayed.

Deep-End Starters Versus Less Impaired: Dynamics of Change, Program Outcomes, Model Fidelity, and Client Satisfaction
Dan Ellis, Daria Rostovtseva, Miguel Fraguela

Wraparound Sacramento at Stanford Home is serving two distinguishable groups of clients: those admitted with high level of clinical impairment and less impaired. The research analyzes the differences in outcomes dynamics, model fidelity, and client satisfaction for these two groups.

Does Use of a Consumer Progress Note Empower Parents?
Katherine Levine

Preliminary research comparing two similar home based teams serving seriously emotional disturbed children; one team used a consumer progress note in which caregivers could rate staff, the other team did not. Findings in terms of family empowerment are compared.

Evaluation Challenges in a Unique Wraparound Program: Multiple Methods for Prediction of Success and Outcomes
Twylla Abrahamson, Kimberly Tyda, Rommel Guadalupe, Daria Rostovtseva, Miguel Fraguela

A comparison of multiple methods of assessing child and family "success" in a unique Wraparound pilot project. Also examined are the following factors as predictors of success: demographics, risk factors, caregiver involvement, model fidelity, educational information, and behavioral and clinical assessments.

Family and Community Characteristics as Determinants of Young Adults' Anti-social Behavior: National Dynamics
Mohammad Hoque

Family and community dynamics as they relate to antisocial behavior of young adults using the data collected for the National Household Survey on Drug Abuse, 2000.

Family and Service Provider Perspectives on Pathways to Mental Health Care for Children and Youth in Rural and Remote Communities
Katherine Boydell

Results of in-depth qualitative interviews with 30 family members, living in rural and remote communities whose children have been diagnosed with emotional and/or behavioral disorders. Additionally, 30 service providers interviewed to obtain their perspectives.
Family Perceptions of Educational Planning for Children Receiving Mental Health Services
Barbara Friesen, Adjoa Robinson, Pauline Jivanjee, Jean Kruzich

This poster illustrates an approach to measuring caregiver participation in education planning and report on the responses of a national sample of caregivers whose children received mental health treatment while living at home.

Family-Evaluator Collaboration: Effective Strategies
Pauline Jivanjee, Kathryn Schutte, Adjoa Robinson

This Poster presents findings from a study of evaluator perspectives on collaborative evaluation.

Finding a Direction for how to Respond to Tobacco Use Issues in Foster Care: A Research Study
Mona Schatz

An examination how smoking behaviors and tobacco use is responded to by professionals. How this unique risk behavior among some foster children is viewed and responded to by those who have primary responsibility for the child's well-being.

Healing Parents' Past to Nurture Children in the Present
Ross Williams, Cindy Jones, Steve Barney

Frequently we unwittingly sabotage our efforts and the efforts of our clients. Once we are aware of these issues, sometimes minor adjustments in what we are doing can make dramatic improvements in our clients' progress.

Helping Hands Project
Annette Squefimkin-Anquoe, Jennifer LaPointe, Ruth James

The Helping Hands Project, is a three year planning effort to address service delivery among Native American youth who are at-risk and with serious emotional disturbance and their families.

Informed Adolescents Make Better Choices
Lenora Reid-Rose, William Ryan Harris, Anissia Ellington, Robert Rugh, Shemeka Douce, Eleanor Johnson, Neville Morris, Maria Quintana

The Prevention, Access, Self-Empowerment and Support-A Means to Success (P.A.S.S.) Program, is designed to motivate adolescents make informed decisions, thus enhancing their overall odds of having long-term success in life.

Love Makes a Family
Sima Teherani

Love Makes a Family, Inc. works for social change by creating a supportive non-violent environment within our communities while providing a public voice for all families, especially those subjected to social, economic, and legal discrimination due to sexual orientation or gender identity/expression.

Maine Adoption Guides: Family Centered Post-Adoption Services
Michel Lahti, Mary Ellen Roma, Heather Stephenson, Sharon Berz

A four-year longitudinal study of families adopting children with special needs from foster care. After adoption legalization, families are randomly assigned to a clinical case manager who provides family centered services.
Maximizing the IEP Process: True Collaboration Between Schools and Families
Craig Peterson
A strengths-based approach to an IEP meeting; engaging family and creating meaningful educational goals.

Mission-Driven Sustainability: Art Programs for Recreation, Support, and Revenue Generation
Roger Boothroyd, Larry English, Michael Rank, Bonnie Bucco, Aimee Wright, Rhonda Touchton, Eunice Clark, Beth Pecora
This poster session summarizes the program design, implementation, and evaluation of three Recreational Art Programs (RAPs) designed to introduce children with emotional and behavioral problems to the enjoyment of art expression as well as to enhance the local social support system for their families.

Moving Towards Cultural Competency: Developing Empowering Partnerships with Aboriginal Families with Children in Residential Care
Patti Petrucka, Karrie Derbyshire
Ranch Ehrlo Society has increasingly moved towards a model of family inclusion as opposed to what was often viewed in the past as family exclusion in Residential Care. This recent program development focuses on enhancing and building family strengths.

Parent Perceptions' of Service Delivery: Highlighting Key Decision Points in the Collaborative Process
Eloise Boterf, Lyn Casseday
Authentic collaboration between family members and University researchers resulted in a valid study that can be effectively utilized by all stakeholders.

Poetry as Therapy for Homeless and Jailed Teens
Richard Gold
Pongo Publishing is a non-profit writing program for homeless and jailed teens. Through self-expression, the teens become more aware of their emotional issues and feel less ashamed of their suffering.

Premature Hospital Discharge and Related Custody Issues
Philip Friedman, Karen Friedman
Empirical data were collected to examine factors related to families being unwilling or unable to take their children home from a psychiatric hospital. Caretaker complaints lead to threats of abuse and abandonment charges, or advice that families should relinquish custody for better services.

Reclaiming Futures: Communities helping teens overcome drugs, alcohol and crime
Mac Pritchard, Eileen Deck
Reclaiming Futures is a new approach to helping teenagers caught in the cycle of drugs, alcohol and crime. The mission of Reclaiming Futures, a five-year, $21 million initiative of The Robert Wood Johnson Foundation, is to promote new opportunities and standards of care in juvenile justice.
Residential Treatment: Is It Enough for Teen Mothers at Risk for a 'Syndrome of Failure'?
Deidre Winder

Description of service delivery provided by a nonprofit residential treatment facility for teen mothers mandated to residential treatment. Risk factors will be reviewed with case presentations along with participation to discuss program success.

Responsive Teaching: A Parent-Mediated Intervention for Addressing the Socio-Emotional Needs of Young Children
Gerald Mahoney, Frida Perales

A Responsive Teaching curriculum; information about professional training opportunities being offered through the auspices of a national outreach grant funded by the Office of Special Education programs of the United States Department of Education.

Social Support Through Metaphor-Enhanced Group Psychoeducation: A Treatment Approach with Nonabusing Parents
Constance Ostis

While both voluntary and involuntary clients found group psychoeducation helpful, involuntary clients appeared to benefit that most from the snowball effect between recall of metaphors and other study variables including understanding, mastery, social support, change and parental support of children.

Spotlight on Choices
Rebecca Buhner, Shandy Cheek, Kim Williams

Learn how the Technical Assistance Center of Indiana Behavioral Health Choices has taken their experiences from the Dawn Project to support local Indiana communities in creating their own wraparound systems of care.

Staying Strong: An Emotional Fitness Self Care Program
Katherine Levine, Aida Cruz, Yvette Miller

The Staying Strong Program focuses on self care for caregivers including service providers.

The Need for Standardized Assessments in Family Intervention Programs as a Prelude to Outcome Measurement
Catalina Herrerias, Thomas Reid, Kent Kelley

The significance of statewide standardization of both formal and informal assessments as a necessary precursor to the meaningful measurement of intervention outcomes.

Towards Inclusion: Family Centered Care and Cultural Competence at the Alberta Children’s Hospital
Linda Kongnetiman

Explores the different aspects of family-centred care and cultural competence in a pediatric health care hospital.

Use of Service Integration Measures in a Juvenile Justice Project
Pamela Clark

The Central and Eastern Oregon Juvenile Justice Consortium implemented a grant, aimed at reducing substance use and recidivism for juvenile offenders. A service integration measure was used to find parental views of service integration with the youth’s caseworkers and its outcome.
Virtual Residential and Wraparound Services: Providing Intensive In-home Services in the Home and the Community
Lucia Gadney, David Collins, Tasha Walsh, Betty Dixon

Through unique programs such as the GRAY curriculum, the Therapeutic Mentor Program, the Life Skills course, and the 5 Phase System, Providence Service Corporation provides intensive individual and family interventions designed to facilitate improved communication, enhanced family interaction, improved decision making abilities, and interpersonal skills acquisition.

Saturday, June 28th

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<td>8:00-8:45</td>
<td>Registration /Breakfast</td>
<td>Plaza Foyer Plaza Level</td>
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| 8:45-10:15    | **Welcome:** Maureen Breckenridge  
**Early Childhood Plenary,** Promoting Children’s Mental Health in Early Childhood Settings  
**Moderator:** Steffen Saifer  
**Panelists:** Abbey Alkon, Glen Dunlap, Eileen Brennan, Beth Green | Pavilion Ballroom Plaza Level |
| 10:15-10:30   | Break                                                               | Plaza Foyer Plaza Level      |
| 10:30-11:20   | **Concurrent Workshops**                                            |                              |
|               | Session 69  
Tools for Assessing the Mental Health Needs of Infants, Toddlers and Preschool Children  
[Horen, Thompson]                                                                 | Broadway I Plaza Level       |
|               | Session 71  
Responsive Teaching: A Parent-Mediated Intervention for Addressing the Socio-Emotional Needs of Young Children  
[Mahoney, Perales]                                                                 | Broadway III Plaza Level     |
|               | Session 72  
System Level Changes and Child and Family Outcomes: A Report from NC FACES  
[O'Donnell, Witherspoon, Jones, Fernandez, Arbuckle, Rogers, Smitley, Shelton] | Broadway IV Plaza Level      |
|               | Session 73  
Building on Strengths of Children with Serious Emotional Disorders through Collaborative Assessment between Parents and Professionals  
[Taylor, Lacey]                                                                 | Council Suite Third Floor   |
|               | Session 74  
Use of Service Integration Measures in a Juvenile Justice Project  
[Clark]                                                                 | Forum Suite Third Floor     |
|               | Session 75  
Latino Track: Project SUCCEED in Head Start: Findings from a Parent-Teacher Training Program for Helping Children with Challenging Behaviors  
[Saifer, Friesen, Ostrogorsky, Gordon]                                                                 | Studio Suite Third Floor    |
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<th>Time</th>
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<td>Session 77 Clark County Childcare Resource Team: A Key to Quality Care [Jambor, Wall]</td>
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<td>Session 78 Evidence for Effective Preschool Mental Health Program Design: Analysis of National Head Start Survey Data [Green, Everhart, Gettman, Gordon]</td>
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<td>Session 79 Involving Students in the Parent Experience: Using Experiential Methods to Teach System of Care [Claes, Arbuckle, Jones]</td>
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<td>Session 80 Healing Parents’ Past to Nurture Children in the Present [Williams, Jones, Barney]</td>
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<td>Session 81 Family-Evaluator Collaboration: How to Make it Work [Jivanjee, Schutte, Robinson, Pullmann, Savage]</td>
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