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PREFACE

It is with great pleasure that we present the proceedings from the National Conference on Building on Family Strengths: Research and Programs in Support of Children and their Families held in Portland, Oregon from June 1-3, 1995.

We at the Research and Training Center on Family Support and Children's Mental Health wish to express our appreciation to the researchers, service providers, administrators, policy makers, educators and family members who presented their work at the conference and who have allowed us to include it in these proceedings. This conference provided an arena for participants to exchange information about research and innovative programs addressing family issues in children's mental health and related fields. The conference focused on both the substance of research and programs addressing family issues, and the process of those efforts. Examples of substantive concerns include questions about the nature, accessibility, acceptability, and outcome of family support programs, promising approaches to improving the cultural appropriateness of services, and a host of related training concerns. Examination of process issues included the study of family-provider, family-system, and provider-provider collaboration, the development of the life cycle of family organizations, and questions about the emerging practice of paying family members to provide services, among others.

The role of family members as research partners continues to receive particular emphasis at this meeting. As we have studied the challenges that families face in caring for their children with serious emotional disorders and in obtaining appropriate services, the need for families to be more fully involved in the research process has become even more apparent. Again, the challenge of involving families in research provoked many lively discussions.

Our goal for our annual conference is to encourage the conduct and exchange of family-oriented research that is relevant, accessible and useful for family members, service providers, policy-makers, and other non-researchers. The way ahead involves many challenges, because researchers have not traditionally been trained to involve families and others in the design and implementation of research, nor to see them as consumers of research. In addition, most family members, as well as many service providers, policy-makers, and other potential users of research have not been prepared or invited to be engaged in the research process, or to make use of research findings. Consequently, achieving our goal will involve effort and adaptation on the part of all participants. There are attitudinal and language barriers to be addressed in the building of partnerships between researchers, family members, and others, as well as practical and technical difficulties to be overcome in the design and execution of a more open research process. We believe, however, that greater collaboration in the research process will ultimately
pay off in the form of relevant research findings that are used to inform program design, implementation, and evaluation of services for families and children.

We want to thank the researchers and educators at the Research and Training Center on Family Support and Children's Mental Health, the Regional Research Institute on Human Services and the Graduate School of Social Work at Portland State University for their support of the conference and our work in general.

Shad Jessen, Rae Anne Lafrenz, and Kaye Exo have taken major responsibility for preparing these proceedings. For the conference itself, special thanks to Nancy Koroloff, Director of Research; Pauline Jivanjee, Chair of the Conference Committee; Kaye Exo, our new Conference Coordinator; and Rae Anne Lafrenz and Shad Jessen for their assistance with a multitude of arrangements. Thanks also to all Research and Training Center staff for their support and help with conference preparation: James Mason, Director of Training; Bev Stephens, Family Information Coordinator; Harold Briggs, Solla Carrock, Lyn Gordon, Iris Garvilles, Paul Koren, Marilyn McManus, Denise Schmit, Denise Stüntzner-Gibson, and Tracy Williams-Murphy.

We appreciate the support of President of Portland State University, Judith Ramaley, as well as the support of James Ward, Dean of the School of Social Work, and William Feyerherm, Associate Director of the Regional Research Institute on Human Services and Associate Vice Provost for Research and Sponsored Projects. Regional Research Institute staff who assisted with the conference included Diane Mikkelson and Debi Elliot.

Our National Advisory Committee, led by Mary Hoyt, continues to encourage all of our efforts. Once again, we are pleased to thank Committee members for their commitment in helping us to meet our goals, including the goal of an annual research conference.

Finally, we thank our partners in the federal government. Gary DeCarolis, William Quinlan, and Diane Sondheimer of the Center for Mental Health Services, and Roseann Rafferty of the National Institute on Disability and Rehabilitation Research for their support.

Barbara J. Friesen, Ph.D.
Director, 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 for 1994-99 by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. The current grant supports activities that complement the work of the Research and Training Center from 1984-94.

The Center’s activities focus on improving services to families whose children have mental, emotional or behavioral disorders through a set of related research and training programs. Research efforts are clustered around four themes:

1. *Family Participation in Services.* This cluster of four projects is organized to study ways that family members can contribute to the planning and implementation of the program of services for their own child. A special focus of the work of this cluster is on issues of empowerment, including ways of measuring empowerment and ways of increasing empowerment.

2. *Family Participation at the Policy Level.* Projects in this cluster examine issues, constraints and innovative practices related to the participation of parents of children with serious emotional disabilities on decision-making bodies that plan, evaluate and coordinate services. Special emphasis is on ways of involving families of color at the policy-making level.

3. *Families and Out-of-Home Care.* In this cluster research projects are related to services that are provided to children who cannot live at home and on the relationship of the family to this type of program. There are two major concentrations in this cluster. The first is on family support and the role family support plays in helping children stay at home. The second focus is on out-of-home treatment resources and the contribution that family members can make to the effectiveness of treatment when their child is not living at home.

4. *Evaluation of Statewide Family Networks.* This project involves an evaluation of 28 statewide family support networks funded in September 1993 by the Center for Mental Health Services. Already underway, the national evaluation examines aspects of family support, system change and infrastructure development across projects.
5. *Interventions in Professional Education*. Projects in this area are designed to increase service providers’ knowledge and skills regarding state-of-the-art practice in children’s mental health. In collaboration with the Federation of Families, project staff will develop a process and set of strategies that family groups can use to open communication with faculty about training issues. Another project will develop and test family-centered curricula for regular and special education teachers.

Center staff includes faculty at the Graduate School of Social Work, research associates and assistants, students and support personnel. The Center is part of the Regional Research Institute for Human Services of the Graduate School of Social Work.
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Section III
Conference Agenda
SECTION I
Key and Plenary Presentations
Barbara Friesen: This conference, which is called *Building on Family Strengths*, as you know, focuses on research and innovative programs that address family issues in children's mental health and other fields.

Ten years ago we couldn't have had this conference because we didn't know anything much about family perspectives (nobody had asked); we didn't really have any research that looked at the system through the eyes of families; we didn't know very much about what families who had children with serious emotional problems needed. So, it would have been very difficult to have this conference.

Another reason it would have been difficult to have this conference is because one of the features of this conference and one of its goals is to have service providers and family members and researchers talking to each other and exchanging information. And ten years ago, we wouldn't have known where to find the nearly one-third and one-half of the participants here who are family members. I think that research about family issues is beginning to come of age, and I'm very excited by the response to this conference and by the program that we have put together. We had, unfortunately, many more submissions of abstracts, people wanted to do more presentations than we could use, and we turned down many very good ones. And it is very exciting that there is enough going on that we have lots of choice.

If you look inside the agenda, you'll see that the goals of the conference are really to provide a place where we can look at state-of-the-art research findings and issues in the area of family support and family-centered service, to create a forum for the exchange of information, and to highlight family participation in the research process and the usefulness of research for family members. We want your feedback as we move through the conference. How well are we accomplishing those goals? We really do welcome and want your input.

The Research and Training Center on Family Support and Children's Mental Health is a part of the Regional Research Institute, which is a part of the Graduate School of Social
Work, which is a part of Portland State University. So we operate as a part of a very large organization, and it is my pleasure to introduce to you James H. Ward, who is the Dean of the Graduate School of Social Work. He will give you a welcome from the School of Social Work.

James Ward: Thank you very much. It is indeed a great pleasure to extend to you a very warm welcome to Portland State University and the Graduate School of Social Work. And later on you will be welcomed, I'm sure, to the Regional Research Institute and of course the Research and Training Center as well. I've looked through the program and it is excellent. "Building on Family Strengths" is a remarkable title at this juncture in our history. I can't think of anything more important than the family and the more we can strengthen the family, the more I think we're going to strengthen society. I commend you for traveling all across the country to Portland, but I want you to know that in coming you not only came to receive an excellent program worked out and followed through by Barbara Friesen and others working with her; you also have some excellent weather that the same group planned especially for you. So my challenge to you is to get as much out of this program as you can, but also take some time to go out and smell the roses and breath the fresh air. I want to thank you very much for coming. I want you to feel that this is your home away from home and I hope that you will have an interesting and exciting conference. Again, welcome.

Barbara Friesen: The Regional Research Institute for Human Services is our geographic and also spiritual home, and I'm very pleased to introduce to you Bill Feyerherm, who is the Director of the Regional Research Institute. He's the person we turn to when we need help with a variety of clients and actually we needed him to do that for some issues having to do with this conference. So I'm very pleased to introduce to you Bill Feyerherm.

Bill Feyerherm: With an introduction like that, I'm wondering what kind of help Barbara needs next. It's a good thing that Dean Ward was between the two of us in terms of an introduction after Barbara's remarks. If Barbara said, you know, we don't do it alone, I felt like saying those of you who know Barbara ask yourselves whether she can do it alone or not. She's very capable.

One of the things that I want to do is to not only welcome you to the Regional Research Institute, but also draw your attention to what I think is a unique facet of this particular conference and, actually other conferences that the Research and Training Center has put on. You have among you a mix of individuals: practitioners, researchers, family members; some of you are all three in one. In reflecting upon that mix, I'm kind of torn or irritated, if you will, at the contrast with other conferences that I go to.
I participate in the National Coalition for Juvenile Justice. One of the things that you would expect is a similar mix in that group and, in fact, in our national meetings we take pride in the fact that we bring in what we call youth members. In juvenile justice it makes sense to bring in youth members. We bring in people who are parents of kids in the juvenile justice system and we give them special name tags that are color-coded that tell everyone which group they belong to, and we have separate sessions for each group because they have unique agendas. And so they might meet once in a while and they all know which group they belong to and they interact accordingly. You, on the other hand, are a collective set of people who are interested in family strengths. You bring each of your specialties, your special perspectives, but not only should you enjoy the weather, not only should you enjoy the presentations, but you should enjoy the interaction with one another, with people of different perspectives about the same common concern. And that really is a thread that cuts through much of the work of the Research and Training Center, that cuts through much of the work of the Regional Research Institute, a convenient place where people from multiple perspectives can come together to look at common issues and problems.

With that, I welcome you. Thank you.

**Barbara Friesen:** Barbara Huff, who is the Executive Director of the Federation of Families for Children's Mental Health, which is a national family advocacy and support organization, I think very well remembers the time when we didn't have any family members at meetings. Then we had special sessions for family members, so it hasn't been that long, Bill. Please welcome Barbara Huff.

**Barbara Huff:** I brought my own fan club with me up here. Thank you, Boston. First of all, I just want to say a couple of quick remarks. I have been in Portland many times and I've never seen bad weather, so I've decided that you just don't want us all moving here and you tell us you have bad weather. You tell us all about this rain that we never see when we come, and I guess we're glad of that.

First of all, I would like to thank Barbara and her staff for planning this wonderful conference. Knowing what it is like to plan conferences, we give lots of kudos to people who do that kind of planning so we'd like to say thank you to Barbara, and most of all I would like to say thank you to the families who are here. Taking time out of very busy schedules, making childcare arrangements, trying to find money, I mean all the things you do to try to make a trip like this. My congratulations to the number of family members that we have in this audience.
I would like to introduce the Federation staff. First of all, I'd like to just quickly say, and I think it's important to do this because not only are they what holds up this national organization and certainly supports me and my work in the Federation as well, but I think it is important for you all to see the growth here in the Federation. This staff is made up of families who have children with serious emotional and behavioral problems, so obviously we're all in and out of crisis all the time, just like many of you are in this audience. So let's see who we have in this room with us at the moment. First of all, is Mary Telesford here? Maybe not, that's a face I did not see. I know Trina Osher is here. Trina, you want to stand up? Yes. Carol Obrochta, are you in the room at the moment? Carol Obrochta, very good. Paul Cazzola, as many of you may know, had open heart surgery not long ago and has just been released from the hospital and so one person who is very instrumental in all of our lives is not with us at the moment. Pedro Briones is home holding up the fort and with a student who is working with us this summer as well. I don't know if Illiana Hernandez is here from Miami; she is on contract with the Federation. And also Scott Bryant-Comstock, who I know is not here; he is at home in North Carolina.

So with that introduction of our staff, I wanted to quickly say a couple of things, and one or two of these things you've heard me say before but I think it's worth reiterating. I first of all want to tell you that the benefactors of research are our children and our families. So it is most important for you all to begin to understand that as best you can and let me tell you, from a layman's point of view, it has not always been easy. So I would encourage you to ask lots of questions. Don't think a question is too silly to ask when you are in workshop sessions. It is very important that you begin to get a handle on research questions and all the lingo that researchers use. So I would encourage you to ask lots of questions while you are here, and know that the Federation is available if you need to sort it out later, to give us a call and any of our staff members will help you the best way we can to understand us.

So knowing that we are the beneficiaries of research, it makes much sense to me that we are involved at all levels of research, and you've heard me say this before and you'll hear me say it again that we need to be involved in the planning for research and the implementation of research and the evaluation of research, and I will continue to say that very strongly. And the last thing I want to say (and many of you have heard me say this) is that we should all ask this question when people want to do research. And the question being, “what will the benefits be for my child and family that this particular research question is being asked?” I think it is important that we continue to think about that, that research continues to be a benefit to all of us. So with that, I would say again to Barbara, thank you for having us here, and thank you for you all being here as well with us from the University, and it's always great to have you here. Thanks.
Barbara Friesen: One of the things you'll find in your packet, if you haven't uncovered it, are two glossaries. One is a glossary that has acronyms and definitions in it that may be of interest, and we also have provided a research glossary that has in it some definitions of terms. Barbara Huff encouraged you to ask lots of questions and we encourage you to ask lots of questions but also to be patient. We have asked our presenters to try to be as clear and as “non-jargon” as possible. We also ask the rest of the audience, the people who aren't presenting, to be patient and also to ask lots of questions.

Terry Cross is the Executive Director of what used to be the Northwest Indian Child Welfare Association, and is now the National Indian Child Welfare Association. This is a group that started in 1983, twelve years ago, around issues having to do with the implementation of the Indian Child Welfare Act. Terry Cross is a friend. Terry Cross is someone who is really the architect of the cultural competence continuum and, along with others, is the author of a monograph on cultural competence that many of you may be aware of. Terry used to be my neighbor. We literally shared a wall that didn't have a ceiling there so I like to think of it as a kind of semi-permeable membrane. You know, we got a little research and training center and Northwest Indian Child Welfare Association kind of went back and forth in the airway across the ceiling. Terry and his group have moved. They have been so successful that they have moved out of our building and into much more elegant offices, and we miss him sorely. We invited Terry to introduce Karl Dennis today because Terry is a friend of Karl's, he's a friend of ours, and I think that Terry's work also really embodies the notion of building on family strengths.

Terry Cross: That’s the the best introduction to an introduction that I've ever gotten, so thanks, Barbara. In our Indian culture, the family really is the core. Tribes are nothing more than collections of families and we have organized many of our tribes into clans, but without the family and without those relationships there would be no tribal culture. And so, it really is in our minds, the strength of the family, the well being of the family, the ability of the family to work together and to heal itself is really the crux of helping, and that's really what we are trying to do in Indian country throughout social services. But also, through a healing process that involves our relatives and our children. And I was reminded of a story that I heard just the other day when I was out doing some training, and it is about this separation that occurs between family and the professional community, and the story goes something like this. The family goes into a mental health clinic to get some help with a child and they arrive ten minutes early for their appointment, and the evaluator marks down "anxious." The next family comes in for an appointment and they are ten minutes late for their appointment and the evaluator talks to
them and says, "resistant." The next family comes in right on time for their appointment, talks to the evaluator and walks out, and the evaluator marks down "compulsive."

We are taught in human services to look for pathology. That's what we're challenged to do. And, unfortunately, that very aspect of our teaching gets us in trouble when it comes to finding strengths, and people heal out of their strengths, not out of their weaknesses. One of the people in this country who has had a tremendous impact on getting us to look at people's strengths, to get us to look at service models that get away from the idea of pathology is Karl Dennis. I have had the pleasure of working with Karl for several years, of hearing his philosophy, and of hearing him talk about his services. He really exemplifies a movement away from pathologizing everything to really trying to find the strengths and find partnerships with people.

Karl is the Executive Director of Kaleidoscope in Chicago and a pioneer in WrapAround services and intensive family services at home; one of the first people to really talk about working with families in their own home, and a role model throughout the country, a lecturer and a consultant. I know he is on the lecture and consultant circuit because every town I go to he has either been there just before me or is just coming after me. We have a lot of fun setting up the audiences for each other around the country. He is also a pioneer in providing foster care for HIV-positive infants and one of the first in the country to do that kind of program. He is one of the first in the country to establish a "no decline, no punitive" discharge policy in treating children. Right down the line you can see the thinking. The family orientation, looking at the community, looking at the strengths and building that, and before Karl gets up here, I want to tell just one little Karl story. It is about another example of this whole notion.

Several years ago, Karl had to relocate his agency in Chicago, and had to find a place for that agency to be. Now Karl's agency deals with a lot of teens, a lot of young people. And Chicago is a town that has some pretty rigid boundaries between where teens and other groups will allow each other to go. So one of the considerations in siting the agency was where do we put an agency where we want all kids free to come to but where there are gang boundaries and lines that people can't cross. Well, how do you find that out? His board said: Hire a consultant to figure that out and a siting consultant. Guess where Karl went? He went to his clients. He found a group of kids who knew the city and knew those boundaries and could draw those lines and help the agency site it. But he had the audacity to ask the board to pay them as consultants at the same rate, which they did, and which I think is just a great story of how you take values and you put them into action to make things work. So, without further ado, I present to you, Karl Dennis.

**Karl Dennis:** First, I want to thank Terry. Terry has been a good friend for many years.
I'm a little disappointed in him today though, he doesn't have any turquoise on. I'm wearing more turquoise than Terry is.

Today, I wanted to start out by talking about two things that I'm really celebrating today. The first thing is that when I was in college, I got called in and I sat down and I was told that they didn't think I would ever amount to much. I didn't seem to be able to stay on target; I seemed to move from one thing to another, and my advisor suggested to me that one thing that he was really sure of is that I would never, never be able to hold a job for any length of time. And today is my 20th year anniversary with Kaleidoscope. I wish I could find him. Another thing that I am celebrating is that it is really wonderful to be here and to see people who I have worked with, who I've cried with, who I've schemed with over the years, and to see all of you in one room and not stuck away somewhere in Idaho or somewhere in Georgia, but to see all of you together.

I tend to measure things in different ways sometimes, you know. When I go out and do presentations, I want to know why no one ever sits in the front row. That not true of parents. You guys have come a long way in the last ten years where you sat in the back or stood in the back, and now you take up the whole front row any time you go anywhere and I can celebrate that.

Over the last few years, I've traveled over 600,000 miles on United Airlines and I've been a lot of places and I have had an opportunity to learn a lot, and most of what I've learned, I've learned from parents and from people who have shared their experiences and shared their stories with me. And it has helped me a great deal to help me to formulate my own philosophy and my thinking. A lot of times I get extremely discouraged, but I get discouraged because things seem to be moving so slow. And then when I stop to think about it awhile, I go back and I remember 15 years ago or 20 years ago and I remember in reality how far we have really come, and I think that one of our issues has always been that we tend to be impatient, that we tend to think that we can get systems to change and we can get some paradigm shift in thinking by next June. And I think that what we are looking at here is the long, hard row that we're going to have to hoe in order to make this work. This is a long-term process but the successes that we see, the little successes, whether success for the family or whether success for the kids, or whether success in a pocket somewhere in the country where we see change really happening. I think that we are really seeing that.

I had gotten to the point where I thought I heard every question that could ever be asked of me. I was in California last year and after we did two days of training, a young man stood up in the back and he said, "You know, there's one thing that we didn't get out of this training on WrapAround." And I said to him, "What's that?" He said, "Well, you
didn't tell us why we should change. What's wrong with the way that we have been doing things? Isn't it working?" The night before, public radio came on with a startling piece of evaluation. They suggested that, in California, 80% of all the adults in the correctional facilities are graduates of the juvenile justice system; they are also child welfare and had no help in the special education systems. Now, you people in California will have to forgive me, but I know that California is a little weirder than most of the rest of the states in the union. But I'm convinced that if we looked at any state, that we would see similar figures and similar statistics, and I think a lot of that has to do with how we have funded services and how we look at services in what I feel is an unrealistic way. We tend to want to cut off services for people at age 18 or age 19, and the reality of life is that people need the support and they need the help a lot longer than age 18. Maybe we'll get a chance to talk about that a little later.

But I want to share some of the things that I've seen change around the country and why I'm optimistic. Our people in mental health probably won't like this, but it is my opinion that 15 years ago we provided very little services for children in mental health systems. Kids could get services in a hospital or they could go to an outpatient clinic if they had the resources in order to get there. That has changed so much in the past 15 years. We see foster care programs running out of mental health, we see independent living services, we see a tremendous push toward family preservation and in-home services.

Now, of course, there is a little cynical side of me as well, and that cynical side of me says it is not just because that we are all humane and we have moved in that direction. But we know that the type of services that we're talking about in the community are more cost-effective, not just more humane, but more cost-effective. I've looked at hospitals around the country and I watched the spiraling cost of hospitalization. I like to keep track of the most expensive system that I've seen. You people from Pennsylvania, you win. Western Psych charges $2,000 a day and I call that robbery without a gun. I mean the gangs that I work with in Chicago wouldn't even tolerate that kind of theft from anyone. But because the hospitals have been so expensive, what we have seen happening across the country is that even the for-profit hospitals have looked at doing things in a different way, and they are moving out into the community in wonderful ways. And those communities who have adopted another process, like Stark County in Ohio, who can brag that they have reduced their dependency on hospitalization over the last 18 months by 98%, they have found another way to provide services to their families and children. So we see mental health moving toward the community.

When we look at juvenile justice, the average cost of keeping a kid in what I call the junior jail in this country is $38,000 a year. That ranges from about $16,000 a year all the way up to $96,000 a year and that dubious honor is shared by Rhode Island. Anybody in
here from Rhode Island? See, they could afford to send a few people after spending that kind of money. But juvenile justice systems around the country are now saying that they can't afford that because there have been no increases in their budget. It costs between $150,000 and $170,000 to build a new junior jail cell. So, in juvenile justice, we see them start to move out into the community. They've got monitoring programs, bracelet programs, anything that will allow them to provide services to people and not spend those kind of dollars. So we are encouraged by that in juvenile justice.

When we look at child welfare, an example would be in the State of Illinois. Four years ago, we had 34,000 kids in substitute care. Today we've got 45,000 kids in substitute care and that's just in four years. And the budgets have not increased to support that increase. So, in Illinois, where we used to depend on sending kids as far away from us as we possibly could (you know you can tell how difficult a kid is by how far they start to try to send him. You know, if a kid is in California from Illinois, that's a real desperate individual). But we can't afford to do that any more, and so where we used to see kids passing each other on trains going from state to state, child welfare systems are now saying we need to keep kids at home and we need to do a better job of it.

Then we look at special education. You know, I was one of those people who used to feel that most of the kids who are placed in residential placement in this country are placed there through child welfare or through mental health, but the reality is that in excess of 50% of them wind up in residential placement through special education. And I think the reason for that is pretty simple. I think that in most states there was always an incentive to place kids and that incentive was that if a local school district could make a case for the placement of a child, then the state would pick up, if not all of the payment, certainly part of it. So the incentive there was not to keep people but to move people away. Now, in every state that I've been in when I had an opportunity to talk with people in special education, the special education directors are all basically saying the same thing. They are saying if local school systems are going to place children, they are going to have to pay 100% cost of that freight. And so what we see in education now is movement toward inclusion, toward keeping people in their own communities, and we see some wonderful examples of that around the country. Farrell School in Pennsylvania brags that they haven't suspended anyone from school in over two years because they have been able to bring in the other services and other systems right into the school system. Mansfield, Ohio has the same brag. I haven't visited either one of those places personally, but that's what I hear from people that I trust. Caring Communities in St. Louis, there's another example of how communities are coming to the school system and are able to provide the services.

Probably the thing that I'm most proud of is what I've seen happen with parent
organizations. And as I watch parent organizations grow from doing just advocacy to becoming active participants and I can look to people like Jerry and Creasa Reed, who are in Kansas, and actually providing services for people and managing (and nobody knows yet how you did that, Jerry), but managing to get them to be able to bill that to Medicaid so they can get paid to do it. Or Sue Smith, who is down in Atlanta. She and Norman are probably down there busy putting their services together. They are getting ready to start to provide treatment foster care, independent living, and in-home services. As a parent organization, they got tired of the service providers in their community, so they're going to do it themselves.

And so I'm very proud of those movements that we have seen, and I really am encouraged by that, as I'm encouraged by the number of people that I see here.

I want to talk a little bit about the thing that I love the most, WrapAround. Unfortunately, though, I'm really getting kind of sick of the word. I'm really sorry, I should have come up with something a lot longer and something that wasn't so catchy, because all of a sudden we hear all these strange things being said about WrapAround. I'm constantly bombarded by people who want to show me their WrapAround program, and I keep trying to explain to people over and over again that WrapAround is not a program, it is a process. And it is a process we use simply to try to help families maintain their children and to help them by providing services for them. It is as simple as that. And it is not new. The other thing that is very frightening to me is that people have started calling me the grandfather of WrapAround. That is not funny! WrapAround is an evolutionary process that is incredibly old, and we see its roots in every culture. Most of us have all heard the African proverb that it takes a whole village to take care of a child. And I would suggest to you that that's how communities attempt their WrapAround. Among the Lakota Indians in the Dakotas, at one point, they had four people who would be honored, the shirt-wearers. And it was the responsibility of those four people to make sure that everyone in the tribe was fed, that they were clothed, and that they had shelter. And they couldn't eat, or wear clothes, or go inside until all of the people in the tribe were taken care of. And that's how communities attempt to provide services on an unconditional care basis to the people that they are privileged to provide services for.

I can't leave out the medical community because psychiatrists, other than Ira Lourie, who is my buddy and I'm not allowed to talk about, always know exactly what happened, when it happened, and why it happened. I was in Canada and I was talking to a psychiatrist and he moved his pipe from one side of his mouth to the other and he said to me, "Karl, WrapAround services started at the turn of the century." And I said, "Yes. Can you tell me about it." And he said, "Yes, there was a small community in Belgium and they started to discover that they didn't have resources for their families and for their
children, so they did what small communities tend to do, they had a town meeting. The
town meeting lasted for four days, and at the end of those four days they had come to the
conclusion that it was their responsibility to provide care for all of the people in that
community. Not to send children and send families to other villages or to other
provinces, but to provide care for them in their own community. And they went a little
further, because they agreed that if, for example, there was a family who was homeless
and needed housing and there was someone else in the community that had spare rooms
in their house, then it was that person's responsibility to take them into their home. And
if that person refused to do so, then they would be the people who were asked to leave the
community, not the people who were in need of help and in need of services.” And so
that's a community's attempt at unconditional care. So if anybody ever calls me the
grandfather of WrapAround services again, I will get very, very upset with you, because I
know I’m old, but I'm not over 100 yet.

For us at Kaleidoscope, it started in the mid-70's and it started very simply. It started
simply with an attitude that children are best served with their own families. And
because we were all parents ourselves, we also believed that it was our responsibility to
care for our own children, regardless of their condition. And if we were going to feel that
same way about our own families, shouldn't we feel the same way about the families that
we were privileged to provide services for. And so that translated for us into a
philosophy of unconditional care, that we would run services on a no-decline basis and
that we would never, ever throw anyone out of our services, regardless of whatever their
behavior was. I can never conceive of throwing one of my children out of my family, so
why would I run a service where I would throw people out of that particular service?

And so we started that in the mid-70's, at a time when the State of Illinois had 1,000 kids
in out-of-state placement and they were bringing those kids back. So when the state
found out that we would provide services for whoever was referred to us, of course we
wound up with those children who were considered to be the most difficult and the
hardest to serve. Children who my friend Bill Underwood likes to refer to as “children
who have severe reputations,” which I think is a much better phrase and a better way of
describing the people that we provide services for. Children who any professional from
any county who heard the first name of that child would start to tremble immediately in
anticipation of having to provide services for, and they would not be trembling with
elation. But we learned very early that if we provided the services to those families that
they asked us for and told us they needed and we did that, then we could keep a lot of
those kids at home with their own families. It became as simple as that.
So the real thing that I want to say to you today is, as we look at WrapAround as a process, is that it is really simple. As I go around the country now, I'm starting to see where it has become so complicated that I don't even recognize it sometimes because some people have to complicate things in order to make it work for them. This is a simple process, this is what you do with your own family; and I think that's why it works. I think it also works because morally it's correct and morally it's right, and I think that's what we all believe and that's what we all need to be doing but we have drifted off in different categorical ways that I think haven't helped us. And I think that's why we have all of those kids, all of those young adults in the California penal system who have come through all of our wonderful systems in this country unsuccessfully.

I'm going to take questions a little later. One of the things with me, though, you have to remember, those of you who know me, is never ask me a two-part question because I'm not bright enough to remember the second part of that, and please, no acronyms because as we move around the country and every time I sit down at a table with someone and they hit me with 10 or 12 acronyms and I really don't understand what the hell they are talking about, and I'm really too chicken most of the time to ask them to explain over and over again what those acronyms are. So as you ask those questions, please give me a break and stay away from the acronyms if you can, because, for some people, it is difficult.

I want to spend some time talking about what we feel and what we've learned are the elements of WrapAround. What are the things that are most important and ought to make this process work. As I said earlier, this is an evolutionary process. Some of the things that we thought were important when we first started it, we learned that we needed to expand. We went into Alaska in 1985 and helped with the Alaska Youth Initiative, and we pulled inter-agency teams together at a state level and at a community level to help to make the decisions and to help to make the red tape disappear so that we could provide services for families and children. What we did primarily was pull all of the human service people together, from education, from child welfare, from mental health, from whatever system was prevalent in that community, and we pulled them together and we had them come together to help to make decisions. Unfortunately, initially, we did not include parents in the process. That was a big mistake. That was really a big mistake.

The second mistake that I think that we made, and was just as important, was that we failed to include what we call the “movers and the shakers” of the community in the process. We didn't get the cultural leaders, we didn't get the business leaders. We didn't get those people involved in the process that owned that particular community, and as a result, in Alaska, I think that as great a process as it was, that we kind of wound up with a parallel system and in some ways it has not infused itself into the entire system. They are
moving in that direction. So we learned to involve those people. Now involving people from the business community in human services in the Initiative is a little different. But we have gotten some really strange benefits out of it. We sat down in one community with a community team that was forming and they had their business people there and their cultural leaders there and no one knew how it was going to go, and then the human service people started to stand up and they started to explain what it was that they did and what they didn't do. And they talk about how categorical their services were and how difficult these changes would be...

[Sentence deleted from the transcript, paraphrased for clarification - Ed.]

... and they explained to him (business leader) very patiently why that couldn't be done. And when they got through and sat down, he stood up and he scratched his head and he said, "You know, maybe if you guys can't do it, maybe we have the wrong people running these agencies." It got very, very quiet in the room and then the people from human services started to stand up and started to talk about how they possibly could work together and how they could make it work. And so it becomes very, very important to have those business leaders involved. If you're going to move a community system away from placing kids in the hospitals and residential programs, the community has to be part of that process, because that's where your protection is going to come from.

Also, as we look at the federal government and we look at the moves that are being made for us in this country, there is a suggestion in my mind, at least, that we may be taking a backwards step, and we may be dependent upon the states themselves, without those federal entitlements in a couple of years, to provide whatever financial services that we need. And it is going to be very important then to have on board those people in the community who can help you to make those decisions, and who can say well, this works. How do I know it works? Because I've seen this kid and I've seen this family, and I've seen it work for them, and so let's try this and let's continue with this process.

Now, I'm accused of saying a lot of times that interagency collaboration is an unnatural act between unconsenting adults, and basically I still feel that way, but I feel that way for a different reason. I used to think that it was all about turf issues, and I've now come to the conclusion that it is unfortunate but we don't cross-train people in our systems. If you get an MSW in social work, no one ever explains to you what a mental health professional does or what a special education person does or what a juvenile justice person does. We're very categorical. And so we've become so categorical that we get narrow and we tend to see things only in one way. John VanDenBerg, who is certainly one of my best friends and certainly won't mind me saying this, always says that he wishes he had back in his hands the first 90 treatment plans that he ever wrote. Because
he is a family therapist, and so, for every one of those treatment plans, he knew that people needed family therapy. If you are a hammer, you see the world as a nail. When we come together then and we sit down, we are usually convinced that whatever system or whatever services that we provide are the most important services and those are the services that we need to continue with. We have learned, though, that it is imperative that we bring all of these people together from these different systems because they all have different resources, and if we share those resources, maybe we don't need as much money to provide services as we think we do.

A few years ago we went into Missouri for the CASSP project and the teams had already been assembled in Missouri and they were simply told: You are to bring the two most difficult situations that you have, whether it's a kid or whether it's a family, and you are to bring those to the table and we'll bring some people in and they can sit down and they can start to work with you around those issues, and whatever they come up with, don't worry about it, we'll pay for it. A blank check. They gave Karl a blank check. I've never had one of those; I was overjoyed. So we went in and we sat down and in two days I was extremely disappointed because I couldn't spend any money. All of the resources and all of the services already existed in those communities.

In one small rural community they had this one kid who had been the Antichrist. They were convinced that the devil had sent him just to destroy their community, but as we sat down with him, what we came to believe was that it wasn't that the child was the problem, it was that the community was a problem in terms of the resources that they had to provide for this child and his family. And so when we sat down it became very, very clear immediately to some of the people that this child was certainly in need of mental health services. Well, they didn't have a mental health professional in that community. So what we were able to do was to talk to people in the educational system who were convinced that they had some other children who were in need of mental health services into keeping the school open a couple of hours in the evening. They would then serve this kid and they could serve three or four other children and that would pay enough money to have a mental health professional drive in twice a week in order to provide the services.

Our next issue became that this kid evidently had to have almost round-the-clock supervision and they didn't have a process for providing that. Well, the first thing that we found was that the kid had an uncle that he seemed to get along with pretty good. That uncle was out of work, and so we were able to get the uncle to come in and spend some time providing services for and working with his nephew. It just wasn't enough, though, so we went to the child welfare people and what they had was a homemaker's contract. And we said: “Why don't you corrupt that a little bit and why don't you hire someone
through that homemaker's contract so that they can come in and provide some of the services?" Still hadn't spent any money.

It was at that point that we went to the local university and we talked the university into using interns as part of this process, so we got some more people into the mix that were interns to help to provide some services. So we went out of there without providing any additional dollars because all the services existed in the community. And in most of the communities that we have been in, the services are there, they are just held by different categorical services. If you come into a system through mental health and there is an issue of a diagnosis, that will only entitle you to the resources of mental health, not to the resources of child welfare, not to the resources of special education. If you come in through education, there's an issue around a learning disability, maybe, which will entitle you to the resources of special education but not to the rest of the services. But if we start to blend those services together and we pull those services together, we have a wealth of resources that we can use in order to provide services. So that's why we believe it is imperative that we pull these different systems together in order to help and in order to serve people.

It is also important for us to understand that if you leave anyone out of the mix, you've lost already; you just don't know it. If mental health and child welfare and a private provider get together with a family and they put this wonderful plan together and then they go down marching down to the school with the plan, then the school people are going to get a little upset about it because no one called them to be part of that decision-making process. People who have to do some of the work need to be part of that decision-making process, and if they're not, then you've lost. And I'm not jumping on education with that; I think that is true of all services and systems, including private providers, who want to be part of the decision-making process.

Another important thing is that we get to learn so much about what we are doing and the people that we serve when we can pull all of these different disciplines and minds together as part of the process. I met this wonderful parent in New Mexico this year. (One of the things we talk about when we are putting child and family teams together is getting 4 to 8 people who know the family best, that the family would pick out and bring as part of the process.) I walked in the room and I wanted to turn around and walk out the door. They had a child and family team and they had 18 people on the child and family team. Eighteen people. And I said "Oh my God, I'm going to have a migraine before I leave this session." But each and every one of those people were important to that family, and it was imperative that they be involved. Four of the children out of the six have been hospitalized at one time or another and for some strange reason they never went into the same hospital. The children went to three different schools and so we had the people
there from three different schools. The people from the hospitals had one opinion of the children; the people from the school said, “Well, we don't run into those problems.” The people who provided the services to the family were doing it in a vacuum without involving the people from the hospital or the people from the school, and they were doing a pretty good job. One of the greatest interventions that I've ever heard was suggested by the people in the hospital because they were suggested in a vacuum; that suggestion was that the 16-year-old had an imaginary friend. I assumed from talking to him that it was an imaginary friend, I assumed that the people in the hospital thought there were some real strong clinical implications here, so they said to his mom: “This is what we'll use as an intervention. Any time he feels like he's starting to talk to his imaginary friend, then he is to go and sit down in the chair by himself and he is to concentrate on the fact that he doesn't have an imaginary friend.” It's not a bad intervention. Unfortunately, the thing that the people at the hospital didn't know, that mom and the six kids lived in two rooms, and when the kid sat down to do his concentration, then the other kids would go around him, like this, trying to break his concentration. So it was not an appropriate intervention simply because they had not pulled all of those people together at one time to sit down to try to figure out what it was that they could do. So it is imperative that we bring people together.

This conference talks about services being family-focused. Services have to be family-focused. Children do not exist in a vacuum. Some of my friends who work in hospitals and residential programs and run good services are always telling me about the same kid. They always tell me about this kid who came in and was in bad shape and they worked 12 months with him and they put him together and he was really in good shape, and then they sent him home and in 6 months he came back into that facility and he was in worse shape than he was the first time he came in. It is unfortunate that a lot of people in our business seem to think that what happened to them was that there was something awfully wrong with the family and that's what happened to that kid. But it's not common sense to me to assume that you can take someone into a structured program for 12 months, surrounded by 14 people, then send him home to a family and don't provide any support to him at all and expect things to happen. Or if you do provide support to him, plug in 6 to 8 weeks of service and expect a miracle to happen. Or 3 months of services and expect a miracle to happen. We have to learn how to provide services that families need, and we have to learn how to provide it in a timely way for them; this is imperative. We can no longer look at capitations for services. There are some people who may only need 3 months of service, but there are some people who may need 6 years of service. If you have one of those kids who bounces off walls, then you need a lot more help than 6 weeks of service. And we have to learn how to provide services to the entire family, whatever mom needs, whatever dad needs, whatever the kids need, and as we have looked over the last few years at the sibling panels and we listen to siblings, whatever those siblings need.
Now to me that's a real common sense issue.

There's only two of us; there's me and my brother. I'm the good kid. Even my brother would probably say that. If someone came into my house and started taking my brother to movies and started taking my brother to recreational parks and doing real nice things for him and didn't do it for me, well there's only two things that I would be able to do. One is, I'd have to start to get rough myself so they would do it for me, or I'd have to sabotage that plan for my brother. So to me it is just common sense that when we provide services, we need to look at providing services to the entire family.

It is also important for people to understand that you family members know your family the best. You know what your kids need, you know what your families need, so you have to be part of that decision-making process, and you have to be in control of that process. Should I repeat that? You have to be in control of the process. It's your family, it's your decisions. It's not my family, it's your family, and we have to learn how to listen to you, and do what it is you think is important. And that's so simple to me. That’s the way I work with my family. If I go to a doctor and I don't like what he says, then I go find another doctor. I just move until I find someone that I'm compatible with who can work well with me as part of this process. It's really interesting that some of the things that we know, that make so much sense, that we have to go out and do research about it so that we can confirm what it is that we already know.

John Whitbeck up in Washington got tired of listening to us talk all the time about what families told us they needed and what was important to families, so he decided that we would do this research project. It wasn't a five-year project, which made me very happy. But what John simply did was that he went to the states of Washington, Ohio and New Jersey and simply asked people in the public system: “Give me the names of 300 families that have been successful.” From each of those states, he randomly selected 100. And then he went and he simply asked them, “what made it work for you?”

These are the four things that he came up with most often. The first was Access. He said that when people came, they did not come with a prepared treatment plan for families. They came with a list of options and then the family and the worker sat down together to decide what was most important. They said that they had a Voice. They felt that at every juncture of the planning, that they were consulted as to what was important and asked what they needed. Which meant that if I went in and I sat down with a family and we made this wonderful plan and then I went back to the office and I scratched my head and said, "You know, what we promised to do here, all of a sudden we can't do it. So we'll do this instead." They didn't do that. They called the family back and said, "Hey, we can't do that. These are some of the other options that we have to replace that. How do you
feel about that?" The third was Ownership. The families felt that they had ownership of the process, that it was their plan. So one of the things that I like to do when I work with families is just to hold up whatever material it is when we get finished and ask people “Whose plan is this?” If they say it's your plan or if they say it's mental health's plan, or education plan, you have failed to provide people with a sense of ownership about the services. The fourth thing that is just as important to me is Consistency, and they said that they got tired of seeing strange and different people come into their home, especially when they were in crisis. Now, it's common sense to me that the last thing I'd ever want to see when my family is in crisis is a stranger. I want to see people I can trust. I want to see people that I've got a relationship with.

And so that is a wonderful piece of research that we can use that suggests and tells us what we already know. But it's a nice piece of paper that we can trot out, and it's important to have those certainly for those people who doubt that these processes work.

Services have to be unconditional. We have to make a commitment to serve whoever needs services and never, ever, under any circumstances, do we give up. Instead of changing people from placement to placement and from system to system, we just change the services to meet their needs. So the people wind up being cared for by the same people, not by new people. Show me ten people who have been in our system for at least 18 or 19 placements, and I'll find a statement in there somewhere that says that they are resistant to treatment. Because if you keep moving people from placement to placement, if you change their peers and people that they trust, the adults that they trust, and you change those therapeutic people that they come to depend on, and you keep moving them, it is a real sign of pathology if they still trust people - if they're not resistant to service. So it is imperative then that we change the services as opposed to changing the people.

Now, I think that it is important also to realize that no matter how many assessments we do or how many skills that we think we have, the reality is that we never really know who's going to make it or who's not going to make it, and so we need to give everyone an opportunity to make it.

One of our treatment foster parents at Kaleidoscope was, in 1984, the first person in the State of Illinois to work with an adolescent with AIDS, and some of you have heard part of this story before. Rudy had the most horrendous background of any child that I had ever worked with. He had been on the streets since he was 11 years of age. He had been on the streets since he was 11 years of age. He came from a very, very bad situation where his family just didn't take care of Rudy. So Rudy became a prostitute at 12, and Rudy ran the streets. I didn't meet Rudy until he was 16 years of age, and when I met Rudy, we put him in Delores Samuels' foster home and Rudy was there two days and he ran, and we found him and we brought him back, and he was gone two more days, and we just kept at it until we finally got him to the point where
Rudy would call when he was on the run. And next, we were able to get him to stay home sometimes. And after that, he kind of settled in.

And then Rudy wound up going to the hospital for an operation and some enterprising person decided that they would test him for AIDS. Why was that? They didn't ask Rudy. They didn't have a protocol that would tell him what to do if he tested positive; they just tested him. And so when they tested Rudy, Rudy did test positive. People reacted incredibly bad. They put his food out on trays, and slid it in because they wouldn't come into the room. Some of the people in the hospital refused to take his blood. One of the staff told another adolescent in our services that Rudy had AIDS and if you went near him that it would kill you. But never once with all of the people moving around him, did anyone suggest to Rudy that this was horrible news that he had received and what we need to do is to sit down and spend some time with you around counseling. People pulled away from him. Not his foster mother! I called up Delores and I said, "Delores, bad news. Rudy has AIDS." And she said, "Well, what do I do about this; do I just burn all his clothes and stuff and get him new clothes? What do I do?" It never, ever occurred to her to throw Rudy out of the home. I was at the hospital, and Rudy lived with AIDS a lot longer than most. I was at the hospital visiting Rudy the day before he died and as I walked out of the hospital, parked in a no-parking zone was one of my ex-clients. He was sitting behind the wheel and I played social worker, and I walked up and I said, "Cedric, why are you parked in a no-parking zone?" And Cedric says, "Because this is where mama told me to stay." Delores had called him up and told him that it was the responsibility of everyone who had lived in her home to help to provide care for Rudy, and he needed to come and take her to the hospital and he needed to visit Rudy. Delores had managed to get everyone in her family system involved in that process.

Last week we were notified that Delores Samuels had won the Foster-Family-Based Treatment Association's "Foster Parent of the Year" award. But it was her commitment to unconditional care. Once you get involved in that as a process, it just never really occurs to you to give up on people. You learn how to become creative, you learn how to do things in a different way, but giving up is not one of the options that you can use. So that commitment has to be unconditional. If we can't provide that service, then I think we need to get out of the business and go sell used cars or something and let people who are willing to provide that kind of service do it.

Services need to be community-based, and this is where I part company with a number of people. I just don't believe in residential care. I believe that residential care has been developed as a system and for the system and not for the people that we serve. I have never met a kid that, if we didn't have the right resources, we couldn't provide services for him in the community, and we couldn't provide those services in a community for a child.
in a cheaper way as well, rather than placing kids in a residential program.

One of the young men that we provided services for at age 13 was taken out of the Cabrini Green housing project by a well-meaning person who saw that he was charming, saw he was intelligent, and saw that he had a future. And it's kind of dangerous in Cabrini Green, so she decided that she would save him, and she sent him to this wonderful residential program in northern Illinois. It is a wonderful residential program; there's no doubt about that. It was in an upper middle class community. Vincent did very well there. He finished high school in a suburban school, made a lot of friends, learned about the resources in that community, but at age 18, that service was ended and it was time for him to come back into the city because he could not afford to live in that community. It was also unfortunate that the particular service that he was sent to believed that you don't let kids contact their families for the first two months, so that they can fit into the milieu of that particular service. And Vincent’s family did not understand that. They thought they had lost him and they moved away. And so Vincent came back into the community with no family and with no friends. The one thing that Vincent had going for him was that he was 6'3" and weighed 225 pounds. It was the year that I really wanted to beat Father Smith in basketball because he had been creaming our agency for five years. I had a lot of little guys this tall, Vincent was very tall, and I thought that if Vincent could play basketball, then maybe I'd beat Father Smith. I walk up to Vincent and I asked Vincent, I said, "Vincent, do you like sports?" And Vincent looked me in the eye and he says, "I love sports, Karl, and I'm good." Oh, I could see that trophy. And as I started to walk away, it occurred to me maybe I ought to ask Vincent what his favorite sport was because it might be football. So I turned to Vincent and I said, "Vincent, what's your favorite sport?" And Vincent looked at me and he said, "Karl, I really like fencing and polo."

Now they took this African American youth, took him away from his family, away from his community, and they taught him how to appreciate fencing and polo. I mean, it was like taking a kid out of an incredibly rural area and putting him in the inner city. He didn't know that if he wore his hat on one side of his head he could get killed. But more importantly, his family and resources were gone.

So I don't believe that we need to place kids in residential programs. I believe we need to keep kids in their own communities with their own families and with resources that they're going to have to use when they grow up. Let us not forget that the federal government says that the average age when kids leave home for the last time and stop getting money from their parents today is 27. Wait, I shouldn't say that, I should check the room first and make sure there's no children in here because we don't want to set up their parents. But for that reason we feel that it is imperative then that we keep kids in
their own community with their families because they're going to keep coming back and forth.

We believe that the services need to be individualized. Every time I say that I think about Christina, a parent in Pennsylvania who always talks about the fact that one size does not fit all. And one size does not fit all. I'm a parent. I've raised three children. And as any parent knows that raises more than one kid, the children are not the same and you can't use the same discipline on them. My daughter who is the oldest, and she's the family historian, recently pointed out to me that my youngest son, Dwayne, was the first person in our family who had ever voted Republican since Reconstruction. What was scary about that was that he was proud of it. And I started to think about Dwayne when he was a little kid and the interventions that we used on Dwayne. All I ever had to do was to say to Dwayne, "Dwayne, if you don't stop, I'm going to make you stand in the corner for an hour." Dwayne would go to pieces. He would do anything to keep from going in that corner, because, like a lot of Republicans, Dwayne had no imagination (laughter), so if you put him in a corner, every minute was like an hour to him, so he would go to pieces. That was a good intervention for him.

His brother, Tony, though, was very much like a Democrat; he had a lot of imagination and no policy. I could put Tony in the corner and Tony said, "Okay, Dad." And he'd bounce right into the corner. I would go back an hour later and he would look at me and say, "Is my time up?" Because he would sit there and daydream for the whole hour. It was not an appropriate intervention for Tony. For Dwayne, yes, but not for Tony.

And there's a tendency for us to want to try to use the same interventions on everyone. We like behavior mod and we like level systems and we like forcing people into those kinds of systems and services and we don't individualize the services. I have never really understood why we feel that it is necessary to put all of the people who have the same issues together. We like putting all the fire setters in one place together. And we wonder what they're teaching each other. Or worse than that, we'll put all the sex offenders in the same place together. We need to learn to individualize services. Meet people where they are, look at the stress of those people, and provide the services accordingly, and don't depend on old tried and true methods. We have to become creative. We have to be able to look at everyone as an individual.

We believe that the services need to be strengths-based. We really have to take the time to look at the strengths of people and to learn what it is that they do very well and to base services on those.

Some of you who were at the WrapAround conference in Chicago a couple of years ago
may or may not remember Tyrone. Tyrone was on the video tape and Tyrone and Carol came up and introduced the keynote speaker. Tyrone's children have AIDS, Tyrone has AIDS, and Carol has AIDS. Tyrone came to our attention after the Department of Children and Family Services took Tyrone's and Carol's baby away from them. They were living in an abandoned building. They were both drug addicts who would do just about anything for drugs, and they were not doing very well. And we were told pretty basically that we needed to take care of this child, but, you know, don't even worry about the family. I mean, they're throw-aways. But I believe that a family is the best environment for someone, and even if they can't be the caretakers, at least they can have contact and they can provide services and help. And we see it as our responsibility to go out and help them. That's the unconditional care philosophy; no matter how well things are working for people, or how things are not working for people.

So we went out and we started to work with Tyrone and Carol and it was a long haul. Tyrone went to jail that first year we were working with him and we were there the day that he got out of jail, but Tyrone started to pull it together and we started to see these incredible things in him. He is one of the most articulate people I have ever met in my life. He came in and he painted pictures for all of the nursery. We didn't know he had that skill. He got down on his knees and he played with other kids, and I believe that he is the best person that I have ever seen in my life among kids. And we watched Tyrone grow. And we watched Carol grow.

Today, Tyrone is an AIDS counselor in Chicago, and when you walk down the street with Tyrone, you think he is the king of the neighborhood, the way people come out and the way people appreciate him and the way people respect him. That's the philosophy. We didn't know whether he was going to make it or not, but given the opportunity and if people are willing to stick with people, it has been our experience, in most cases, that they will pull it together.

We looked at Tyrone's strengths, and we kept saying over and over again to Tyrone what those strengths were. David got a chance to meet him a couple of weeks ago when he was in Chicago. Is he the king of the neighborhood, David?

The other person, and this is the old story, is Yvette. Yvette had 16 placements. Yvette had solid scar tissue on both of her wrists. She had made 13 suicide attempts. She had made her 13th in her program and they threw her out of the program when she made the 13th suicide attempt, which was a real strange one to us because that's what she did. You need to be able to do a little reframing sometimes. I don't believe that there is anyone in the world so incompetent that they would try to kill themselves 13 times and fail. So evidently she was trying to tell us something. So as Yvette sat down in front of us, we
did what we call a strengths-based assessment. You know, you can find assessments out there, but for us it's really pretty simple. You know, what I tell staff is kind of remember those two blind dates that you went on. The first blind date that you went on, you decided instantly that you didn't like that person, and you were not really interested in what they liked or what they didn't like or anything about them, all you wanted to do was to get away from them. But that second person that you went out with, you said, "Oh! This one may work." And so you started to manipulate your way in by asking them things like, "Well, what do you like, and what do you like to do?" "Well, I like to do that, and I like
to do this." You set up a relationship and you set up a rapport with people and you learn about them, and that's what a strengths-based assessment is in my opinion.

The first thing that we asked Yvette was, "Yvette, did you ever work with anyone you liked? Or thought did you any good?" And Yvette said, "Yep, there was this psychologist. His name was Joe Benaziack and we worked together and things were really going great." And I said, "Well, how long did you work together?" "Just six months." And I said, "Oh. Well, how come you stopped working with him?" "Well, they moved me to another program." And then we break up those therapeutic relationships every time we move kids from placement to placement.

So we put down Joe's name, and I asked, "Yvette, anything you really like to do, or anything you do well?" And Yvette said, "Yep, I'm a hell of a cartoonist." And I said, "You got any cartoons with you?" She reached in this bag and she pulled out this cartoon. It was in a plastic bag. I call that 'child welfare luggage,' because that's the way we move kids from placement to placement. And she held up this cartoon, and it wasn't the greatest cartoon in the world, but I said to Yvette, I said, "Look, I'd like you to paint one of your cartoons like that for me in a good size and we'll hang it up on the wall out in front, and I'll pay you to do so. And she mumbled, "Yep, $10 or $15." And I said, "No, I'll pay you $250." She got so excited. She had been in the system all her life. She had never had $100 in her hand in her life and here was an idiot that was going to pay her $250 to paint a cartoon. So she said, "Yeah, I'll paint it." So we started her painting that picture. We got in touch with Joe Benaziack, got him agree to see her twice a month, and to continue to see her for two years. Found her an apartment a half a block away from where Joe worked, and surrounded her with staff. At the end of the first week, the staff came in, and they were a little agitated, and they said, "Karl, you're really blowing it with this kid. She can't make it out in the streets. This kid is too weird." And I said, "Well, what's the matter?" And they said, "Well, she gets up in the morning, singing every morning, and the first thing she does is she makes her bed, and if there is a wrinkle in that bed, she tears it apart and she makes it again. And then she sweeps the floor 2 or 3 times. She gets everything up off the floor. She scrubs the sink twice. She's got all of her clothes lined up by color and all of her shoes lined up." And so I said, "Well, what's the problem?" And then it occurred to me that the staff were pretty much like my own kids. They thought cleaning up after yourself was deviant behavior. But that was Yvette’s strength.

And so we went out and found a motel owner that would be willing to take Yvette on as a maid trainee because she liked to clean and she tended to do that well. So things were going along pretty good, and we started to pull staff away so we only had one staff person with her now.
She finished the picture. She brought the picture in. I looked at the picture and I said, "Oh my God, I've got to hang this up." So I called a friend of mine who came and charged me $300 to mat and frame the picture. It started to look pretty good after that. My second-in-command, Olivia, came in and she looked at it and said, "This is a wonderful picture. I want to enter this in a contest." And I looked at Olivia like she had lost her mind, but she entered it and the thing won third prize. So I said to Yvette, I said, "Yvette, this is really pretty good." I'm a believer now. I said, "You know, we're going to have an open house in a couple of months and I'd like to use this as a cover for our open house invitations. Can I use it?" And she thought for a minute and she looked at me and she said, "Sure, Karl, for $250." She is now a capitalist. So I agreed to pay the $250, and the night we had the open house here is Yvette. We got her two dozen roses, we got her a long white dress, and she is standing by this picture and she is pointing to this picture like she is Picasso or someone, explaining all the inner meanings to anybody that would come by.

Well, her mom shows up, and we had been looking for her mom and could not find her. Her mom lived a lot of states away, but her mom came back because Yvette's sister was graduating from medical school, and the two of them showed up at the agency. The sister was an idiot. The first thing out of her mouth was, "This is a wonderful place. If I was crazy, I wouldn't mind being here." And she said that in front of Yvette. This is the day we knew that Yvette was going to go for her wrists. But instead, Yvette took her mom, she showed her mom the picture, talked about winning the contest, talked about all the money she had rooked out of me, talked about working with Joe Benaziack, talked about her job. Yvette has never made another suicide attempt again. Because the services that we developed for her were based on her strengths. We looked out for the pathology, but we based it on her strengths, which is one of the things that we love to do in human services is that we love to raise people's self-esteem. And the way that we usually do that is by calling them a lot of names like seriously emotionally disturbed or talking about their families as dysfunctional, and that's really guaranteed to help to raise someone's self esteem. So I don't even allow my staff to use those phrases. I tell them I will kill them if they use those phrases.

Services need to be culturally competent. Now there's no way in the world I'm going to stand up and talk about cultural competence with James Mason and Terry Cross in the room. But I'll tell you a couple of little stories that I don't think they've heard. Now, my grandmother, and I can only say this because my grandmother is no longer alive. My grandmother was the most culturally incompetent person that I had ever met in my life. And the reason that I can say it is because I believe that I am standing in Portland and if my grandmother was alive and heard me say this, she would slap me all the way from...
Chicago. She believed in using her hands, and they were the fastest hands that I had ever seen in my life. Now she would take a bullet for me, but there was certain things that I was not allowed to do, and one of them was to talk about her. Now, my grandmother believed that there were only two kinds of people in the world; there were Methodists and there were other people. Now, she never said that there was anything wrong with the other people, but she constantly bombarded us all the time with the virtues of Methodists. So much so, that when I got married and my brother got married, I married a Methodist girl. I got a bigger wedding present than my brother because he didn't marry a Methodist girl.

So subtly, we internalize this and that's what we tend to do, that we tend to take our own value systems and we project those on other people. I was in a state that has coal mines, and I was working with this team of people and this social worker kept saying over and over again that there's an issue of neglect here because these people don't give these kids breakfast in the morning. What we discovered was that they had been three generations in the coal mines working from 11:00 p.m. to 7:00 a.m. in the morning. They didn't eat breakfast. So I asked her, "Well, are the kids healthy?" "Yeah, the kids are healthy." Then I said, "Well, what's the issue?" "The issue is that everybody should start their day off with breakfast." That was her value and she couldn't leap to another value.

I was in Memphis a little while ago, and, before we did the workshops, they took me to the Cracker Barrel. You know, we don't have those in the inner city. You may not have them out here; it's a nice little country restaurant and they got a little country store in front of it, and you've got to be careful because you'll trip over rocking chairs going in the door. And then they serve breakfast and they serve lunch and dinner in there. Well, I went in with these people from Memphis and we sat down and we started to order. They ordered pork chops, grits, pancakes. When these people got through ordering, they had a steeple on their plate like this of food. I had never seen so much food. Jerry would understand this. There was so much food on their plate that I couldn't even eat. It gave me indigestion just watching them eat all that food. Well, we left and we were walking across the street and it occurred to me that if there was a 6-year-old boy who lived in that community, and it's one of those kids that bounces off walls and was also non-verbal, and they decided to send him to Chicago, I'd put him in one of my yuppie foster homes that believed that one stick of bacon had enough cholesterol to kill you, and this kid would start bouncing off the walls and we'd be trying to figure out what the hell was going on, and he would just be hungry because he had a different eating pattern than we were used to. I won't say a lot about that, only that it is important that we learn to value diversity in people and learn to celebrate it.
Services need to be cost-effective. If you provide services in the community and you provide WrapAround services, then there are three times or three different situations where this might not apply. The first one is that, in no states where we have started this process, have we decided what we'll go and do is we won't get the most difficult kids, we'll get some kid somewhere down the line a little bit and we'll kind of get our toe wet a little bit until we figure out how to do this. But if you say to people that you are going to use the same dollars to provide services for people in the community, then you are not going to be able to make it cost-effective. Eventually you will, but at first, it will cost you a few more dollars.

The other thing is what we call over-wrap. And that's when you get really terrified and you surround someone with 10 or 15 people, as opposed to one or two, or the one that they may need. And people usually work their way out of that in a year or so.

If I need to find a job for someone, who's the best person to find that job? A social worker or someone at the Rotary Club? Someone at the Rotary Club because they have those contacts. And so we have to learn to use those free services in the community. I was in Cheyenne, Wyoming and I said that, and this little social worker afterwards said, "You mean I should go out and ask people in the community?" And I said, "Yeah." I went back three months later and she had found 39 free services in the community. She found people who were willing to fix people's cars if they needed it. I learned a long time ago, if you ask people for money they'll run like hell, but if you ask people to provide some of the things that they normally provide, then they'll be of assistance. So, she found dinners for people. When families needed activities together, she found bowling. She found people haircuts. She found people who were willing to come in and babysit free for some of the kids. And so it is imperative that we use those services, and when we don't use those services, then we wind up spending more money than we need to spend. The rule is: never pay for anything that you can get for free. Not because you're cheap, but that's the way you work your way out a job.

If you meet the needs of the family, then this process is usually successful. I've never seen anyone who can put one of these plans together and make it work the first time. They need to be adjusted from time to time and we need to reach back and always remember that someone has to keep that philosophy of unconditional care, and we keep changing it. Just keep changing the plan.

John Burchard, who is up in the University of Vermont, says that in all of the research that he has done, the one thing that stands out the most is that when the services don't work, the WrapAround services don't work for a child and family, then he can usually point to the fact that the adults who had a responsibility for providing that service seem to
be arguing and don't seem to be getting along. There's an old African proverb that says, when elephants fight, the grass suffers.

Services need to be outcome-driven. I want to talk a little bit about research and then we'll open it up to questions. I have never really understood why people like to have me around who are researchers because up until four or five years ago, I cared less than anything about research. And the reason that I cared less than anything about it was that when I got through reading it I never knew what I had. I came to the conclusion that only researchers really understood the research.

The other thing that was very clear to me was that it took five years to get anything back. Now I believe that services need to be evolving, so if it takes three years to do a research project, it's nice to know what I was doing three years ago, but you can believe that I'm going to be doing something different now. So I need research that can give back to me the information I need in a timely way so I can adjust my services to fit that need.

The other thing was I just didn't really care about raising anybody's self esteem. I didn't care about these subjective things that you see, you know. All I wanted to know was that if there was a kid who was truant from school 30 days last year and he was only truant from school 6 days this year, then I must be moving in the right direction. I wanted the objective things that I could use to tell me whether or not the services that I was using were moving in the right direction. If a kid was hospitalized 30 days last year, how many days this year?

Now, the one problem I think that we have with our research process, and this was pointed out to me by one of my staff, is that we're pathology-driven in our research approach. And when we do use strengths, we use opposites. You know, instead of saying a kid was truant from school, we say a kid attended school. We don't use strengths like, a kid got a date, those things that normally happen in the progression of a kid's life. We don't include those in the process. So my charge to researchers is to go out and develop research projects that are objective, that talk about people's strengths as opposed to the pathology, and that I can get back in less than a year. That's what I need in order to run my services. It's also nice to take that kind of information, certainly if it's been written in words that have less than four syllables in them, to a legislator, so that a legislator will understand what it is that we're talking about and what we've been successful with or what we haven't been successful with. I also want to know how much money I've saved. And I also want to know how many jobs I've created in the community.

Okay, why don't we take some questions. Those are basically the elements of
WrapAround, and only three people went to sleep, so I feel it worked out okay. Yes, ma'am.

**Conference Participant:** My daughter had an episode in February; later she was getting suicidal again and my mental health services had just started going to a WrapAround program. We were the first family in our area to apply for emergency assistance. So when we finally met with who was going to be the support person, they said she hadn't finished her training yet, so she wasn't available. Meanwhile, my daughter was continuing to go downhill and I could only get an appointment with the mental health service agency every two or three weeks. But yet they were telling me they really cannot recommend hospitalization and I know that everyone is all for keeping children at home, but sometimes severe mental illness can destroy families like a bomb. My question is, we sent our daughter to the hospital because we had no other resources. We came back and they said we had the person trained, but it will cost you 50% of the cost and she's $80/hr. We also were told that our mental health costs for therapists was $84/hr., which we couldn't afford. So we struggled with finding any WrapAround resources that would help our family. So I would like to know, do we have any other choice or other states besides placing your child in a residential treatment program over a year because you can't qualify for Medicaid which is the only way you can get aid or any kind of financial assistance? Are there other areas of the state that have programs that help families who are middle income but whose insurance is depleted and you have no way to pay for their services?

**Karl Dennis:** You hit on a hard one. You're asking about four questions there, and I asked you to do them one at a time because I'm not very bright.

**Conference Participant:** What state has a model where middle-class families are served by WrapAround programs?

**Karl Dennis:** Most of the states that have individual care grants, you can usually work those middle class families too, but they are limited. The issue here from what I'm hearing, and I'm not going to presume to say whether or not your child needed to be hospitalized or not, but what I'm hearing from you is that the system basically wasn't in place. Those elements that I talked about that needed to be there in order to provide WrapAround were not there. You didn't seem to be part of that decision-making process for one thing, and what they did was they piece-mealed something together. That's why. When I started out, I said I wished that there had been another phrase that we had used besides WrapAround, because what has happened now is all kinds of crazy stuff is being described as being WrapAround. WrapAround is within an agency that is family focused, that is individualized, that is strengths-based, and if it doesn't have those elements and unconditional care elements to it, then it's not WrapAround. It might be something that is
good, but it's not WrapAround. So that's my first answer to you.
I don't know what state you're in and I don't know whether or not that is working. I know that Barbara Friesen and them have dedicated a lot of their last years to trying to get people to understand that people do not have to go broke and wind up in the child welfare system before they get services. I guess there is a lot of stuff that is moving in that direction. A lot of us have learned to manipulate systems in order to get the services that we need to get. If I had a child, for example, that was under the age of 16 years of age that seemed to have those severe issues, then education might be one of the ways that I might want to approach it and I might want to go that way. But one of the things that is important is to find those advocates, find those people from your state that are in this room who have learned how to manipulate the system. Those are the brightest people in human services that I know. And if you spend some time talking to them, they'll tell you how to manipulate that system to get services for you.

**Conference Participant:** When our state legislature met, they cut emergency assistance funds which was the only existing program to help middle class families with mental health care.

**Karl Dennis:** Well, we have an education process here. See, they didn't save any money by putting your child in the hospital. And I'm thinking it might have cost them more money than if they would have provided services for him in the community. And so that is part of that education process. That’s why these advocate groups, these parent advocate groups are so important, because you guys put so much pressure on legislators now that they are learning that that's not the direction they need to go in.

**Conference Participant:** It cost thousands of dollars to send our daughter to the hospital for two weeks. She learned how to mutilate herself, which she wasn't doing before, and she came back and her friends wouldn't touch her with a 10-foot pole. Obviously hospitalization, you're right, if it’s at all possible, you shouldn’t hospitalize a child. A family can only absorb so much stress.

**Karl Dennis:** You know, it seems to me that what you did was appropriate. The issue, though, is that the services just weren't there for your child. It's a failure of the system there. If all of the services would have been in place and they would have provided services to you and your family, and then you would have came and you would have said, “I still can't deal with it; the kid needs to be hospitalized,” then I would have to go along with your decision on that. But it's just been my experience that when we can plug in the right services and enough services, that doesn't become necessary.

**Conference Participant:** Would you find it more effective if each community agency mandated individual service plans for each family?
**Karl Dennis:** Well, I mean, that's nice, but I don't think that gets the job done. I mean we have mandated, permanency planning in child welfare, we got IEPs mandated in education, and I don't think that's the issue here. I think it's a training issue. It's the issue around training people that there are other ways to do things. I really don't get upset with people who do things the same way they've been doing them for 30 years if they don't have any options or if no one has exposed them to anything else. And I think that's the real issue that we are working with. So, I mean, you can do it. You can mandate it, but I don't think it works. Who's from California? California just tried to do WrapAround legislation. It was the worst piece of legislation that I'd ever seen. I got a chance to see it when they first started. It had all the elements of WrapAround; it was three or four pages long. By the time they finished with it, it was 20 pages long and half the elements were missing. So you can't always mandate. What you want to try to do is change the way people think about things.

**Conference Participant:** I just have to say how privileged I am to be here, by a strange coincidence of fate. We relocated from Florida to Georgia. My daughter was diagnosed as bipolar and we'd been dealing with this since she was 2 ½ years old. I've seen the system change and I know how hard it was for us to fight for her at 2 ½, when we didn't have a diagnosis and didn't know what was going on. And we had treatment since then; she's soon going to be 17 and we've seen the most progress with the agency in Georgia, which seems to have a lot of what you're doing. It's very family focused and we've really gotten further there in six months than we have in all these years. Thank you.

**Karl Dennis:** That's great. Here come some of those weird California people.

**Conference Participant:** Okay, how would you convince agencies within a collaborative to include parents in decision-making and planning when they say they have a culpable and adversarial relationship with the parents?

**Karl Dennis:** I guess if I was from California, I'd get my hands on Jennifer's letter. Have you seen Jennifer's letter, the letter she wrote? I'll see if I can remember. I was out in California and Jennifer told me this story of how she was going to sit down as an advocate at a county level and this clinician said to her that he really didn't think that families needed to be part of the decision-making process about other people's children and stuff. What he said the reason was was that they certainly didn't have the background and they didn't have the experience to do so. What Jennifer asked him was, did he have any children, and he said, "Yes." And to ask him, did he love his kids, and he said, "Well, of course I do." And she says, "When there's something that they can't do, do you get upset?" And he says, "Yes." "Have you taken care of your children all of your life?" And he says, "Yes." She says, "How would you like to be in a situation where your kid is
so out of it, you can't take care of him? And then you have to give up custody of that child to go to some other place? And, from year to year, you continue to struggle with that. And then after a number of years, finally your child comes home.” And she says, “Well, I've had a lot of experiences, and I hope that you never have those experiences, but I think that between your degrees and your education and my experience, maybe we can both come together and we can maybe move some mountains.” And so those emotional appeals that come from parents to legislators and to clinicians are those things that I think do the best job. And I'll be glad to share that letter with you. That’s the thing that I love about parents. You guys say it so much better than anyone else. Yes, ma'am?

**Conference Participant:** (inaudible question)

**Karl Dennis:** One of the people that I really like and appreciate is Mike Renfro, who ran adult mental health in Alaska and has now been promoted to run all of mental health services in Alaska, Mike went out and trained parents to be the facilitators, parents and friends of adults in the system, so that they became the facilitators for WrapAround. He had this pot of money that he was going to pay them with, and they refused to take the money because they thought it was a privilege and an honor to be able to help to provide that service. So I think that you're right, and I think that this whole idea of cross-training has to happen. Because it is true that people who work in social services don't really know about the resources of mental health and vice versa and education as well. The other charge that I would give to people in universities is some of these people who train - - have them do things that I can use. I need to have people who are trained to go out in the community to provide in-home services and who understand these concepts. I almost run my own university in order to train people, and I think that time would be better spent if I was having those people provide services and they were trained when they came in.

I think the research is really promising. I think the research that is being done and the WrapAround and community-based services pretty much support the things that I've said. Al Duchnowski has been involved in stuff in South Florida, John Burchard at Vermont, Jody Lubrecht and the stuff that she did in Idaho. So we're starting to get the materials that we need. See, we never had materials that suggested that the other stuff worked.

Well, let me thank you very much for listening to me. Thank you.
Title: Plenary Session: Implications of Research Advances in Children’s Mental Health

Presenter: Peter Jensen

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Barbara Friesen: It gives me great pleasure to introduce to you Carolyn Sanger, who is the Chair of the National Alliance for the Mentally Ill Child and Adolescent Network. Please welcome Carolyn Sanger.

Carolyn Sanger: Barbara, thank you. When I opened my program yesterday and saw my name in print and I hadn't returned the call to Barbara until Tuesday morning when I got back from overseas, I said, "Wow, what a phenomenal printing company that could get that done in less than 48 hours." But I'm glad that she knew that I would be very honored by this opportunity to be in front of all of you. I'm going to follow Barbara's lead for one moment, if I could, and make an announcement prior to what I really wanted to share with all of you. I've heard it twice this morning and I need to make sure that I clarify it to the entire group; many of you have heard that the National Alliance for the Mentally Ill has undergone significant changes in terms of its councils and networks. Does that mean that the Children and Adolescents Network within NAMI will no longer continue to exist? What does it mean? What I really would like to announce to all of you is that what it means is that NAMI has recognized that the issues of families dealing with children and adolescents who are mentally ill, seriously emotionally disturbed, whatever terminology it is that we'd like to use, must be a priority for NAMI as a whole. And so, it does mean that, although 12 networks or councils have been eliminated, the ways in which the staff and the finances can now be redeployed will permit the issues of children and adolescents to have a full-time staff person devoted to these things, and we are very excited about it, so if you hear that we're disappearing, we're not.

Whatever terminology any of us use, whether it is emotional and behavioral disturbance, serious emotional disturbance, mental illness, it is an equal opportunity oppressor. As too many of us who are parents in this room know, our children's lives can be devastated no matter what the circumstances of our lives. We may live in urban Detroit, we may live in suburban Broward County, we may live in rural Urbano, Maryland. We may have six children or we may only have one. We may have been relocated six times in the past 10
years because of business or we may have lived for 17 years in the same house with as much stability as we know how to bring to our family. We may be small business owners, we may be corporate attorneys, we may be school bus drivers. But the onset of a mental illness in one of our children affects each of us with the same feelings. First, I think, comes disbelief, then anger, desperation, frustration, and guilt is surely a part of it. Whether our child is diagnosed at 2 1/2, as we heard a mother mention yesterday, or at 5, when my son had his first major depressive episode, or when an award-achieving 19-year-old, who seems to have nothing but a perfect future in front of her, explodes with the onset of schizophrenia in the middle of sophomore year at Stanford.

Parents need contact, all of you who are parents know this, with others who have already walked that walk and weathered the system. And I happen to have, at a very critical time in my life, been welcomed by parents who have already been down that path within the National Alliance for the Mentally Ill Children and Adolescents Network, which is a grassroots organization composed of family and friends of children and adolescents who suffer from severe and persistent, no-fault brain diseases. It has provided me with a network of parents who have also walked in my shoes. It has provided me with a constant barrage of concrete data about new advances in psychopharmacology, based on discoveries that only new imaging techniques of the past 10 years have made possible in the brain. It has introduced me to the equally dedicated parents involved in the Federation of Families for Children's Mental Health, and it was this involvement that propelled me into the midst of all of you in the audience who are the committed professionals, who want to achieve for our children non-categorical, collaborative, community-based systems of unconditional care for our children and to keep us connected as parents, even when residential treatment may be our child's only immediate option. I am therefore very pleased to be here on behalf of NAMI today and to tell you how thrilled we are to be with you.

It is the advances in imaging and the work of the Child and Adolescent Disorders Research Branch of NIMH to which I literally feel I owe my son's life and therefore I'm particularly honored to be on the podium at the time that Dr. Jensen is here. And I would like to read an excerpt to him of a poem written by a father in Omaha, Nebraska named Peter Cunningham. It was not written about a child who is mentally ill, but I think the message it conveys is just the same, and I think every one of you will see your feelings contained in it, and I will read just a small part of it:

"This is our son. This is your patient. This is our life. This is your work. This is the creation of our love. This is your problem to solve. This is our only son, Paul. This is one of your many patients. We conceived him, nursed him in our hopes and dreams long before he came here. If we could solve his problems, we
would. If we could will order into the chaos of his brain, exchange our lives for his, release him from his suffering, go back before the nightmare began, we would. We need you. We respect you. We appreciate you and everything that NIMH does." (I put that in.)

"We are so incredibly vulnerable as parents, and we depend on you, but that does not mean that we accept you as infallible, nor does it mean that we give up our responsibility for Paul to you. What we need is to have all our power and all your power working together to give him the very best we can give him. Never forget, we are experts too. We are parents, experts in love. Please help us to do for our son what you would do for yours."

And I thank you.

**Barbara Friesen:** It's my pleasure to introduce to you Barry Kast, who if we had a Commission of Mental Health, he would be called a Commissioner. Many people in many states have Commissioners of Mental Health. Barry is our big cheese, and he's the Administrator of the Oregon Mental Health and Developmental Disabilities Services Division. Barry and I have known each other since we were both very young. I wanted him to do this introduction today because Barry is someone who has really helped to make the Mental Health Division a family-friendlier place and who also, I know, values the contribution that research can make to the development and evaluation of good services.

**Barry Kast:** Thank you, Barbara. States which have commissions have them because the legislatures wanted, in some sense, to remove the mental health director from the Governor's direct authority, but I must say, in this state, it is a pleasure to work for John Kitzhaber, who is a friend of yours as well as my boss. I know that there are a number of Oregonians here today and I'm glad to see that. For those of you who are from out of state, on behalf of the Governor and the people of Oregon, I welcome you here.

The nation has really reached a pretty critical point in setting up its national priorities, and if you read the newspaper every day, you can see what a perilous time we live in for a variety of interest groups and constituencies. We are now half-way through the Decade of the Brain. The decade I would note brought on by advocacy for families in the National Alliance for the Mentally Ill, and which has brought us really some major advances in the epidemiology of mental illness and mental disorders, their neurology, pharmacology and rehabilitation. And I know, having worked in this field now for 20 years, that we're getting better at what we do, we understand what we're doing, and a lot of that understanding and progress has come about because we have the knowledge we
need to make things work. That doesn't happen by accident. New knowledge comes as a result of research which is itself on a tide of investment, which must be sustained over time. And the national debate about the federal deficit and the future of federal budgets is putting a lot of that investment in peril.

Senator Hatfield, one of our two senators from Oregon, noted on the floor of the Senate a couple of weeks ago that there was a billion dollars in cuts in the medical research agenda for the next five years, and he noted at the same time that there was about an equal increase in research in nuclear weapons development, even though we're in an environment in which nuclear weapons are rapidly becoming diminished in their role in defense. And partly because of Senator Hatfield's advocacy, I think some of those cuts will be reversed.

Here in Portland, the Oregon Health Sciences University receives more than 80 million dollars a year in federal medical research, and we have substantial investments also at Portland State University. I personally have been involved in two major efforts, one to research the effect of the Partner's Project, and the other the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) mandate under Medicaid. We have a good partnership with the Portland State Regional Research Institute and the Research and Training Center.

For those of us who are in service agencies, or who administer budgets that provide services for families, we have to ask what all of this research really means. What do things like positive admission tomography, serotonin uptake inhibitors, ventricle size and so forth mean to us anyway? One hopes that the results of these efforts bring to us better treatment, better outcomes, and, for families, increased hope. And so I would say without any question in my mind, it is new knowledge that liberates us from superstition and gives us the tools we need to move forward.

It is for these reasons that I take pleasure in introducing Peter Jensen to you. Dr. Jensen is the Chief of the Child and Adolescent Disorders Research Branch, Division of Clinical and Treatment Research at the National Institute of Mental Health. These positions come with even more syllables than the name of my agency, which is the Mental Health and Developmental Disability Services Division, but they really capture the breadth, I think, of the responsibilities involved.
Dr. Jensen graduated from Brigham Young University, received his medical training at George Washington University Medical School, did his general psychiatric training at Letterman Army Medical Center in San Francisco, and afterwards, completed his military at Eisenhower Army Medical Center in Georgia, and the Walter Reed Army Institute of Research in Washington where he held a variety of positions, including the Chief of Child Adolescent and Family Psychiatry Clinical Services. He joined NIMH in 1989 as a research psychiatrist just prior to appointment to his present position as Chief of the Child and Adolescent Disorders Research Branch in the Public Health Service. To a distinguished career as a clinician, researcher, and administrator, he adds his academic appointment as a Clinical Professor of Psychiatry with the Uniform Services University of Health Sciences. He is an epidemiologist and has done research in Attention Deficit Disorder.

This career is a frame within which one can see his commitment to excellence and to bridging the gap between the world of research and the world of service. The linkage between what happens in the academy and in the research laboratory and the practice arena have long been critical to those of us in Oregon. This is why we have been developing our bond with both the Oregon Health Sciences University and Portland State University over many, many years. I take some pride in being on the edge of the faculty at both of those institutions and having my own social work degree from Portland State University, and having seen the University's social work school and its various components really improving and moving into the forefront during my career.

This linkage between the academic and the service arena is a model that we, in Oregon, think is applicable elsewhere in the country, and in partnership with the American Psychiatric Association and the Pew Charitable Trust, we've been working hard to help other states learn what we have learned and bring about this partnership in their part of the country.

I would also add that Dr. Jensen is friendly to families, and this is the paramount reason he joins us today. It is noteworthy that Dr. Jensen was the keynote speaker at the first annual meeting of the Federation of Families for Children's Mental Health in 1989. At that meeting, he called for a partnership between professionals and families and suggested that professionals have much to learn from family members, from you. And finally, he directly addressed the long-standing grievance that families rightfully bring to us in the practice community, that they have been blamed for the illness of their children. He has stated that it is totally inappropriate to do so, especially since the causes of many of the emotional disorders are largely unknown. So the challenge is to find an answer to those questions, what causes these illnesses, and how can they be treated effectively. And I can think of no one who better deserves to address a group such as this because he is doing
more than anyone to find the answers to these questions that will lift the burden from families and bring new hope for children with serious emotional disturbances. And he will discuss with us today the implications of research advances in children's mental health. Please join me in welcoming Dr. Jensen to Portland.

Peter Jensen: Thank you very much, Barry. I'm very touched by your comments and also very impressed with your sense of history, to know what I said back in '89, that's terrific. Someone was taking good notes. As you can tell, I'm from the government because I have lots of slides and I have a wrinkled blue suit. It was very difficult to pack because I had to come from Florida where I was for another meeting, and so I had to dress from warm to cold, knowing the Seattle weather... or the Portland weather. You see, I'm from Seattle and I love the Northwest. And so actually my various comments are very kind, but my real true greatest expertise really comes from the fact that I'm a father of five and a scout master, at least a former scout master. I got smart and cut out. It was a lot of work. My wife and I joke about this in terms of parenting. I have to say I really learned most of my child psychiatry in the home. I really learned most of it, I think, from my wife and she was actually an only child and I was one of eight, and so we were a very unusual combination. So we ended up having five children, splitting the difference. Four and a half kids, so to speak. One of them is a little smaller than the other.

But it's taught me a lot. She brought to the marriage an enormous amount of patience and compassion and ability to be with each of the children on a one-to-one basis. And myself, coming from a large family, I brought skills of crowd control, so when we have to move as a group or a troop, then that's my job. But I have learned an enormous amount from her and as much as I value and have benefitted from my training, I had to unlearn a lot of my training for some of the very reasons that Barry commented on in terms of earlier models. I won't tell you how old I am, but I'm older than you think I am, I'll tell you that. I trained under older models of mental illness and causes that really were parental blame models, and so I had to do a lot of unlearning, and it was an enormously beneficial and terrific experience for me, but has not been an easy one. It made me somewhat impassioned about trying to teach other psychiatrists and psychologists, mental health workers and social workers, and others to really understand the implications of these new models for understanding mental illness and working, as Barry said, with families and parents as partners on behalf of their children.

So I'm going to talk a little bit today about some of the models and some of the exciting findings that have shaped the last five years or so, and how it's informing our understanding of childhood mental illness and where we see the future going.

I think just several years ago we were very excited with President Clinton and Hillary
Clinton and Tipper Gore’s position concerning the emotional and mental disorders. And all of the excitement and promise that I think their public positions and their advocacy for this area seemed to be dashed, in terms of our hopes, when health care reform was unable to be passed last year. But on the positive side, I would note, that both houses of Congress and all of the major plans that got up to the point where they were being staffed in various committees had included a parity for children's mental health services, as well as a fair amount of coverage for the adult mental illnesses. So children did very well and there was, I think, a common political will to address the needs of children in health care reform. And, as you all know, it mired down for a variety of other reasons.

Now how did this come about? I think Barry noted some of the issues. The last several years in the Decade of the Brain has been a time of great excitement and we are rethinking. All of our major news magazines have carried articles that have talked about some of the major new findings that are helping us understand how the brain works, and the relationship between brain functioning and mental illness. Even the managed care industry has gotten onto the wagon using this as an advertisement, if you will, or saying, well, they have the best and the greatest in terms of neurosciences. So there has been, I think, a growing appreciation and understanding that mental illnesses, to understand them truly we have to understand the brain and how the brain works.

Now, I'm not going to be reductionistic here today and we're going to come back to this in a few minutes; it doesn't mean that the host of environmental influences and social factors aren't important. They are, as you'll see, I hope, by my comments, that we have to address these issues in their complexity.

Despite the advances we have made in the neurosciences, particularly in the adult mental disorders areas, I think everybody here knows and is very aware of the fact that attitudes still have a long way to go. While perhaps the attitudes of some policymakers have shifted somewhat, these findings reflect a survey done by one of the regional mental health associations looking at attitudes about mental illness that were perceived in the public. And in this particular survey, 71% of the population sampled felt that mental illnesses were due to some kind of emotional weakness. Almost two-thirds to bad parenting. A third had to do with religious causes and really should be treated by repentance, that it was a lack of will. Only a minority had accepted that mental illnesses have an important biological component that needs to be addressed as a part of a comprehensive treatment plan. Or that they were incurable. The epidemiologic catchment area study, a major epidemiologic study across the U.S. has indicated that 20% of U.S. adults in a given year suffer from some form of emotional and mental disorders. A survey done just recently, with somewhat improved methods, has suggested that the rate is even higher. Some of these illnesses are transient, very much like a respiratory
illness. You can have the flu and you can get over it, but you had the flu. And in the same way, there are emotional and behavioral disorders that may come and go, and there are some that are persistent or recurrent and severe. I'm not going to try to draw distinctions between those at this point today, but perhaps we'll have a chance to come back to that.

In terms of treatments, attitudes about using medications or treatments for mental illnesses are probably of some concern, and we'll talk a little bit later about our medication treatments for children that perhaps in some sense are scary, but the alternatives right now in terms of where our research is and the lack of knowledge in some areas is even scarier, and the need for research in this area is profound. But the general public's attitudes about treating things like depression, over in the far right side of the slide you can see, that the attitudes of the public in terms of taking medication, for anxiety and depression for example, people are very concerned about that and would be very reluctant to do that.

So our attitudes about our treatments even are of some concern and we need to think carefully about. I have a bumper sticker. I love my bumper sticker, and it says, "Honk, if you're on lithium." I get more honks. It's a tremendous bumper sticker; in fact, if anyone wants one, I'll give you one of these bumper stickers. It's from the National Depressive and Manic Depressive Association. Wonderful bumper sticker. I never know if I'm getting the honks because of the bumper sticker or because of the way I drive. I prefer to think it's the bumper sticker, but it's actually been a tremendous experience. I get honks from police cars. It's great. And, in my own way, I'm trying to do my part to destigmatize and, if you will, normalize our understanding that the brain affects behavior. And I'm trying, if you will, to come out of the closet on these issues and we all need to; we need to stand up with courage when someone says something either stigmatizing, or despairing, or uninformed. We have to stand up and be unafraid of the words, to call mental illnesses as mental illnesses, as no-fault disorders that require treatment and compassion.

I want to talk about some of the findings that have shaped these changes in attitudes. As Barry said, there have been major new advances, and Carolyn Sanger also mentioned, in our imaging technologies. We've learned to distinguish things that 100 years ago were not possible in terms of either brain structure or function. The early neural anatomists could not tell the difference between the brain of a person with schizophrenia, when they would look at these things under slides or do autopsies after someone had died, versus a person who did not have schizophrenia. This is just one of the new imaging technologies that does not rely on radiation actually and taken from two identical twins. On the right side, you can see the slightly larger ventricles and the increased size in ventricles reflect
actual loss of brain tissue. Now, only in the last two years, are we understanding where that brain tissue loss is coming from. But we didn't know where to look 100 years ago, or 50 years ago, or 10 years ago, but now we know there are places where the cells are smaller, they haven't moved to the right location, but they should have moved in persons who don't have schizophrenia, and even persons perhaps at risk for schizophrenia, there might be critical triggers at the point of the onset of the illness related to these very subtle but real differences in brain structure.

So, not just structure, but also these imaging technologies are leading us to see how the brain functions, how it's working actually, whether we're talking about normal functioning. There's a whole host of innovative challenge tests where you can actually ask people to do certain math tasks or rhyming tasks, or listening or hearing tasks, and then you can see the areas of the brain that are activated. These become very useful challenge paradigms because very often in the resting state, in the unchallenged state, you won't find the differences between a person who has a major mental illness and a person without. And so often it requires these little challenge paradigms, these tests that evoke an area of the brain to function or display its difficulty functioning.

So, not just normal but also in functioning in terms of mental disorders. On this slide, the bright yellow area on the upper right corner reflects activity of the brain. Regional cerebral blood flow. Lots of blood flowing to this area of the brain in the person without schizophrenia versus the person with schizophrenia on the right below, you see a much darker area. We call that hypofrontality. The frontal areas of the brain aren't activated under challenge tests like they should be activated in the normal functioning stage. So, imaging technology is showing us what the locations are. Some of these imaging technologies have gotten even much more precise. This is using a PET imaging, positron emission tomography, where we can take a radioactively labeled glucose molecule or oxygen molecule and the person is under either a challenged or a resting state, it can vary; we can see then how the brain is metabolizing either that oxygen, burning up the oxygen or using the glucose, so you can see, under certain conditions, areas of activity. Here you can see on the right the person with obsessive-compulsive disorder, the great areas of activity in what we call the prefrontal cortex, the singulet, and some of the areas of the frontal part of the brain that are related to obsessive-compulsive disorder. Things that you can't see, like with an x-ray, things that often you cannot see, at least we haven't historically for most of these conditions, been able to see with any kind of slide of a histology where you actually do a preparation and you look at the cells under a microscope. So those are not visible through those kind of means but clearly it's not working the way it's supposed to.

Okay, panic disorder, an example; this is using another technology altogether. A new one also that doesn't rely on radiation and it actually picks up certain aspects of water
metabolism and what you can see in this person is an area of the parietal cortex really
lighting up in a person who's in the midst of a panic attack. When the panic attack goes
away, those white spots which are hot, burning; it's like, if you will, an emotional seizure
would be a way of thinking of it, those white spots cool down. So, you can see that these
have really provided dramatic visual kinds of representations of the difficulties in
functioning in the brain of a person with an emotional or mental disorder.

Now, what's gotten very exciting in the last few years is that we're showing that these
states in the brain function change as the result of treatment. This is a person with
depression, in terms of brain glucose metabolism before and after treatment. Not just
depression; here's another one with obsessive-compulsive disorder. The top left and
bottom left slides refer to a person with obsessive-compulsive disorder prior to drug
treatment, and the bottom left one is after drug treatment. And you can't tell this very
well in this particular slide, but when these data were analyzed, what they basically
showed was there were significant reductions and, in this case, the red is the hot spots, the
red is where it's really active, and there was significant reductions as a function of
medication treatment pre- and post-medication in these areas. Now, what ought to
intrigue you is the right side. That's showing the same effects of behavioral treatment.
Now, I want to think about what that means. Now, behavioral treatment had similar
reductions in the areas of hot spot on the upper right side, moving down to the lower right

More and more, we have understood and are understanding that these dichotomies, when
someone says, "Oh, it's all biological" or "It's behavioral," these are truly false
dichotomies. We don't know how to separate what's biologic and what's behavior,
because all behavior has a biologic substrate. Now, if anyone finds that interesting or
provocative, I'll say it again, because I'd love to argue it with you: all behavior has a
biologic substrate. All emotions have a biologic substrate. That doesn't mean that we
want to reduce people to neurons and molecules. What that means, if we want to
understand some of the basic components of how emotions and behaviors work, and how
they can be problematic under given conditions or become a disorder, we need to
understand the biology and the interaction between that (underline biology) and the
environment. Because we can change environmental parameters and change the way the
brain is functioning. Now, that's a very important concept and ought to be a concept of
great hope for treatment because it means our treatments very much have to integrate both
of those components. So, basically, the brain is the organ of the mind. The brain
generates the mind. I'm not going to get into the soul and the spirit. That's another
lecture for someone with better credentials than mine, higher credentials than mine. So,
I'm not saying that there isn't a soul and a spirit. Let's stay out of that. But I am saying
that all behavior and all emotions are generated in the brain. Mental disorders are brain
dysfunctions and they show up in behavior. Disorders of emotion, disorders of mood, feeling, behavior, development.
Now, I wasn't taught this in my training and even now I think there may be some programs, psychiatry and psychology and social work programs where these concepts are not being taught. I think that's a major problem, and I think we need to make sure that our training programs understand that we cannot dichotomize the human being into pure psychology or pure biology. It can't be done. And the researchers who more and more are going deeper and deeper into understanding these things find that the brain unfolds in the context of the environment. The environment molds and shapes the brain's development, and it lays down patterns of thinking and mood and behavior over time. And that again is the promise of treatment and rehabilitation as well.

Okay, so what about kids? How do all these things apply to kids? Well, five years ago the National Institute of Mental Health, after actually meeting with advocacy groups, nationally, if you will, on the second leg for children of the decade of the brain, met with the National Alliance for the Mentally Ill, the Child and Adolescent Network, National Mental Health Association, and the Federation of Families for Children’s Mental Health. All of the major professional associations came together and were asked to review a document that had been prepared by the Institute of Medicine concerning the sorry state of research on children's mental health and mental illness. And what that document concluded was that it indeed was a sorry state and a whole coordinated effort, a whole plan across a variety of research areas was going to be needed if we were going to address the problems and take the possible advances in research and some of these technologies I mentioned and apply them to children. And so it outlined in a blueprint a host of programs that were needed for us to advance the field of understanding child and adolescent mental illness and mental health.

Now, it's interesting because, at the same time, adult researchers have become more and more aware that if they want to understand adult disorders, they had to look back at children too. What you see in this particular slide is the findings from the national Epidemiologic Catchment Area study or the ECA study. This was a study of some 20,000 adults across the U.S., all 18 and older, that looked at these adults and asked them who had various kinds of mental disorders and what the age of onset of those conditions were. On the far left basically you have 0-4 age. So going along from left to the right, you have increasing age, and what these ages are are ages of onset for a particular illness. So the big peak you see there, the dotted line of the big peak, is a peak of onset of age 5 to 9. So, what this slide shows you is adults who indicate in their adult lifetime that they had a major mental illness, in this case, phobias, were asked: when did this begin? And what we found was the major onset for the phobias was age 5 to 9 for adults. Now, these are all adults, 20,000 adults, and of these 20,000 a certain number had phobias. And so the dotted line is females, girls, or adult women who are reporting back to when they had the onset. The same thing for males. The solid line is males, and so you see the big peak
is 5 to 9 and then 10 to 14 is the one over to the right. And so you see, really the major onset is prior to puberty and in the early adolescent years for adult onset of phobia.

How about some of the other conditions? Depression; similar. Peak ages of onset in the teen years. So, where is it beginning? For girls, or in this case, adult women, where did their depressions begin? They began in their teen years.

And so, the same interesting findings have been demonstrated now for schizophrenia, bipolar disorder, and obsessive-compulsive disorder, as well as Tourette's syndrome. So if an investigator wants to learn about any of these conditions, they know they're going to have to start studying children if they are really going to unlock some of the puzzles surrounding these conditions.

So, you can see, not just was there a lack of research in the child area and we needed to do something, but the adult investigators said, "We need to understand how the person develops over time and what are the triggers that set these things in motion."

Now, the reason I show you this somewhat confusing slide is I want to give you a feel for the complexity of the brain and the brain development. What you have at the very top of this slide is the outer surface of the brain. Going down is kind of the deeper layers of the cortex. So going from the outer aspects of the brain to kind of the inner aspects of the first major layers. And so these little squiggly lines are basically neurons. I'm trying to give you a sense of this.

Now, we know that within the brain there's well over several billion neurons and the current estimates are that there are probably about $10^{18}$ numbers of connections. $10^{18}$ is unfathomable. You cannot think of that. That's a billion, basically. In terms of the numbers of connections in the brain, that's more than we've charted in terms of stars. And that's in a single human brain. How does the brain develop? Well, it's fascinating, because in the first eight days of life, basically in the embryo, there's a flattening out of the embryo and up towards the front of the embryo, something develops called the neural plate and it kind of flattens out and then begins to roll over and it forms what we call a neural tube; the beginning of the spinal cord, beginning parts of the ventricles of the brain. What happens? Well, in the next 21 days from about Day 10 to Day 31, the brain begins sending out, growing from the inside out, little tentacles or little kind of guidewires, and the most advanced areas of the brain kind of piggyback and climb over each other, so that the most complex areas of the brain going from inside out occur the latest. And they start in the center and they move to the outside. And as they do this, they are establishing many, many horizontal connections. The amazing thing, given this complexity, is that the brain develops at all in the right place. I mean, all the complex
signals to get where they're supposed to go and establishing this multiplicity of signals or connections all over, it's truly phenomenal.

What happens in the next one to two years of life is what we call pruning. Based on early environmental inputs, certain areas of the brain become triggered and wired and used. Those that don't get used, get pruned back, they die off because they are not needed. So, for example, a child is born with cataracts. If he or she doesn't get vision in the first few months of life, he will be blind. Not because of his eyes, but because of his cortex. So it's because the environment is stimulating those neuropathways and telling them, "You're going to be needed, you're necessary." And so it's sending a signal out. It's priming them to be used and needed, and the environment then begins organizing the brain and this very complex, going from inner to outer, sequence with the most complex functions moving to the surface, the very top surface last, and dragging their tail with them, making connections along the way.

So what does this have to do with children? The emphasis on development and brain development and the interaction of the environment and the brain is a very important one, and what you see here or what you don't see very well here is actually an environment for a rat. Now this is the rat's equivalent of Disneyworld. This is a wonderful environment for the rat. This is a very stimulating, enriched environment.

Well, what are the early effects of such kinds of environments on the brain as the brain is developing? Here is an environment for a rat that's not so stimulating. This is a cage, basically four walls, he or she doesn't get to interact with peers, there's no chance for novelty, for exploration. So, there's a rat over here on top of the red Minnie Mouse, or whoever that is, and then you've got a rat up top and then you have a couple of rats over there behind Donald Duck. So this is a wonderful environment, you know, we should be so lucky. Now this is an environment not nearly as enriched. What are the effects of this kind of stimulation? Can you stimulate, if you knew the child was vulnerable for the development of autism or schizophrenia, could you stimulate through certain carefully designed tasks, areas of the brain to promote alternative brain developmental pathways where there may have been some lesion in the way the brain developed in the first several months in the womb? And could you make up for that?

Here, rats running a treadmill. What is the effect on brain development of simply exercising the cerebellum, not just exercising the muscles, but if your muscles are moving, part of your brain is moving or functioning. It's active. What's the effect of that? Well, the effect of that, and this is work by Bill Greenough, a terrific researcher up in the Midwest. And this shows, for example, these are some specially prepared slides of neurons showing you the cell body, the axon, the long part of the neuron, these little
shorter filaments that connect to the other ones called dendrites. What Bill Greenough’s work is showing is that the effects of stimulating the brain, whether we're talking about the axions and neurons, the cells themselves, whether we're talking about capillaries, the blood flow to those areas of the brain, has an effect. So that, over time, if you compare the rats who are in this very enriched environment, and that's what EC stands for, versus say a standard environment versus a deprived environment, what you basically find is that the cells are much larger. There are bigger neurons in these enriched environments where they have been stimulated and exercised, they have more connections to other neurons. They've got a lot of work to do. It's like a little mini-computer that's got connections. It's a little way station and it's doing some work.

And so there's more connections for a given cell and the cells themselves, there's fewer per cubic millimeter but they're bigger cells, they're kind of bigger way stations. He's demonstrated that this, we call it plasticity, this ability of the brain to take environmental inputs and be shaped by environment, this plasticity, is a function of age. And so, as the animal in this case ages, you find that the ability, as it gets older, to generate new capillaries as you are stimulating the part of the brain is somewhat less, or the ability to generate more synapses or more connections also drops off.

It's interesting because we have noted in a number of studies that persons who have learned multiple languages are more protected when they have had strokes that affect the language area of the brain. Is it because they have greater capillary profusion in these areas? Is it because greater numbers of the area of the brain have been recruited so they've sprouted into additional areas and it has used up more of the neural capacity? Very possible. And so there may be some human analogs for this as well.

So what does this have to do with children? Well, it's very interesting. We are funding an investigator who is studying autism at UCLA. He's been doing research for the past 20 years on a very intensive behavioral program. And what his early studies showed, and they were widely disputed, and we'll have to see how his replication comes out, but what he showed was very, very intensive behavioral training programs for children with autism, randomly assigned to standard treatment versus what you'd normally get in the school system versus this very intensive 40-hour a week behavioral program greatly increased the number of children who had normal IQs, who had been mainstreamed into the regular educational setting, and had, later, more successful young adult outcomes. Very provocative work, and we're just funding now a three-site replication of this study. But there's animal research that suggests now that you can stimulate areas of the brain to make up for differences, and a behavioral training program is exactly what you're doing. Whether it be for obsessive compulsive disorder or potentially, as hopefully we'll find out in the next several years with some better replications, for disorders such as autism and
possibly other conditions as well.
Now, for children and adolescents, these new technologies have been terrific because we're able to find new technologies that are not invasive. Some of these imaging technologies don't involve radiation. We may have to even adapt some of our technologies, and this is a case of using a special EEG technology by Richard Davison, also in the midwest, studying the brain activity patterns. So finding ways to adapt these things to children is actually something we've been doing for the last several years with some success, understanding which children might be vulnerable for the development of depression as a function of the way the right side versus the left side of the brain works, under certain conditions of stimulation or activity. What does that have to do with family genetics and other things? And are there things you can do in those environments that will either bring it out or protect those children?

Now, also in the area of children and adolescents, we're really seeing a new generation of imaging studies, and this is one of the first ones that came out about four or five years ago. Alan Zametkin, in the New England Journal of Medicine, studied adults with attention deficit disorder, and he compared them with adults who did not have attention deficit disorder. And these adults with attention deficit disorder had ADHD as children and they also now had children with ADHD. So the first studies couldn't be done on children because of concerns about the radiation exposure; now he's actually found some ways to greatly reduce that, so the radiation exposure a child now gets is basically the same radiation exposure you get living on the planet for one year and there's not a great deal at sea level. So we're not talking huge levels of radiation, so the technologies have come a good distance and the risk is negligible. But what his studies showed was that in the instance of ADHD, the areas of the brain in the pre-frontal cortex in the person with ADHD are underactive. This one on the left is the more normally functioning, more normal active brain, and so persons with ADHD had less brain activity in the areas that mediate attention. Now he's gone on and done some other work with adolescents showing some related findings, showing that the severity of the ADHD symptoms, whether it be impulsivity or hyperactivity or inattention, the severity of those symptoms is related to decreased activity in similar frontal brain and brain regions. So, again, this is exciting work and these technologies have helped us understand what parents knew all along when they said, "Well, it's all in your head." Well, that's right, it is all in your head.

Okay, you know the whole issue of diagnosis and the whole issue of labeling a child is an important one and I think we've come some distance, but I would like to engage this group here. I think we're all on the same sheet of music, but if we're not, let me argue with you a little. In the process of understanding that a label, while it can be problematic, can also be the only way to get the child the necessary services and in the long run it can be and should be destigmatizing. And we understand that these are, as Carolyn said, no-fault disorders. These are no-fault disorders and we have to accept and understand, and
greet the label with some understanding and acceptance. To say, "Well, it's just a mild behavioral problem," and not want to use the labels, I think in the long run hurts our work. We have to be willing to say these are disorders of brain functioning that affect either emotions or behavior or development, or all three sometimes. Or thinking.

Okay, this is a study of depression. Depression is just a stage and all kids grow out of it, right? Wrong. Marika Kovacs did one of the first studies nearly seven years ago. She has followed these children forward, but in one of her first reports, she showed that children met criteria, adult criteria, for a major depressive disorder. This was controversial. You shouldn't call a child depressed or with major depression. And when she first started this work, she had all the child psychiatrists and child psychologists and social workers; she just frightened them all off because they didn't want to label the kids. She said, "Well, wait a second. Let's use the adult criteria, and let's test it." Well, what she found was that, in actual fact, three-quarters of children, that's your 72% up there in that top bar, after a major depression, went on to develop another episode of major depression in the next five years. That figure in the next 10 years that she has followed forward approaches 90%. Are these children just in a stage? Well, a third of them went on to develop, over time, bipolar disorder. Over a third, anxiety disorders and conduct disorders. These are significant conditions. Understanding the longitudinal course, and being willing to use the label to get these children services and then to intervene, has to be done. We have to greet that as our friend. We're worried about labeling. The labeling is an issue, but the bigger issue is the stigma, and that's where we should focus. Not to back-pedal and not use the terms. We have to use the terms.

If we're willing to kind of take that step, we're willing where we have identified a child who actually has a condition and who is at risk gives us a chance to intervene. One of the things that Marika is doing now, in terms of brain development and functioning, one of the ways that we're thinking about depression, for example, is that a depression scars the brain. It's like, if you will, if you have a big grass field in your backyard and you go out and you send your scout troop walking through that grass field on one path and they beat the grass down in one area, well the next scout comes by the next day and he's going to walk where the next scout walked. Well, pretty soon you're going to have a path that goes in one way, that was the choice of that first person. The grass doesn't grow as well, it stays beaten down, more people continue to use it. In the same way, kind of like a seizure, we've learned that events in the brain lay down a pattern or a tendency to follow the same path again. It's like a little scar.

And so the issue of prevention of a major depression or when you identify a child at risk to prevent a major depression which you may then also prevent a bipolar episode down the road, is an area of a great deal of excitement right now and potential research. And
what this slide shows is that these children, for example, who most of them began in Marika's work with mild depressions, mild dysphoria... You see those little blue dips, the littlest ones that just barely go below the line, versus a big dip, a major depression and this is kind of over time, then another major depression or similar occurrence, and then notice now the blue dips are getting closer together. They are starting to occur with more frequency to where actually they become, if you will, a cycle in the brain. So this is the level of current theory that has actually support both in the animal research and some suggestive work now in human research. And it's a real concern to investigators because we are now aware that we don't want to put an adult or a child at risk by under-treating for a perpetual cycle of recurring problems that really had to do with failing to aggressively treat those first few episodes. And so, again, the brain is a developing sensitive organism, and it's unfolding in the context of the environment, as well as the things that happened to it directly, and it generates new cycles and new patterns within itself. It's like the heart has a pacemaker. The brain has its own cycles as well.

Well, what about treatment for children right now? This is material that was prepared for the President's Health Care Reform Task Force. We're really talking about efficacy of our treatments for adult disorders, and we have very little that has been done in the area of schizophrenia in children. But actually, I can comment briefly on all five of these on the left.

Way over in the far right you have angioplasty and atherectomy, and that's just to give you some comparison, some of the big expensive cardiovascular kinds of procedures and how effective they are versus how effective our treatments for major mental disorders are. We're doing pretty well if you look at the cost of those procedures and how effective our procedures are. We really only have one study, one significant study of early onset schizophrenia and that is showing some very promising work that clozapine, or Clozaril, works for early onset childhood schizophrenia. The real issue is, it's a very rare condition and probably misdiagnosed, but when it is well diagnosed, Clozaril works. Haldol doesn't for this early onset schizophrenia. Or at least, Clozaril is more effective.

Panic disorder, we're just starting studies in this area in the child and adolescent area, and I can't comment.

Bipolar, we have a three-site study underway that's looking at the efficacy of lithium, and we hope to know a little bit more about that in the next few years.

We've had several studies now in obsessive-compulsive disorder (OCD) and we've now shown that medications do work for OCD in children and adolescents. They are effective.
Now there is good reason to think that behavioral treatments are effective as well, if we extrapolate downward from the adult information, but all those studies haven't been done.

Just tomorrow, and I guess I'm going to break the news to you first. For major depression, we have our first-ever clinical trial that's demonstrated efficacy of an anti-depressant for children and adolescents. So we've had four or five years of investigators failing to find any medications that work for major depression in children and adolescents. And tomorrow one of our investigators is announcing the results of this new drug. One of the new classes of anti-depressants indeed is effective for adolescents with major depression, and there are some differences in that study and the way it was conducted that perhaps helps us understand why they got effective results where others haven't.

So, we're making some headway in a number of these areas. I didn't put up ADHD because I'm going to tell you about that in a minute. The bigger point that I would like to make is, if you think about a child being an unfolding developing organism in the context of a family, of the school, of a peer network, and you think about the brain being sensitive to all of those environmental influences but being on its own trajectory as well, being malleable, but it's got a course, and that course is partly shaped by history, partly shaped by the present. That if we're going to provide effective treatments for children and adolescents, we have to make sure we have provided research-based, demonstrated treatments and a compassionate caring and effective system of care. Both things are necessary, and so we don't want to be in a situation where we're only arguing for compassionate systems of care without efficacious treatments embedded in those systems of care. So don't leave those two things, you want those both moving simultaneously. Effective treatments. Research-demonstrated treatments in appropriate systems of care.

I'm going to close with a description of where we are going now, what we are doing that is maybe going to have an impact on you and your children's lives, for those of you who have children with a major mental disorder or those of you who are delivering services. And we have right now, within NIMH, a number of major initiatives going on and I'm pleased to say some of the most visible and exciting initiatives are in the area of children. In fact, two of our three major multi-site studies are with children.

First thing I want to mention is issues of pediatric pharmacology. Linda Reilly, on behalf of the Research and Training Center from Oregon here, recently came to a conference we had in D.C. on the issues of using medications in children and evidence for efficacy and safety in children. And, as Linda said to me before the meeting, it was scary because the idea of research for children is scary. But scarier still is the fact that these medications are widely used without research evidence for safety and efficacy. And so, because of
these issues, we have embarked on a major initiative to really expand appropriate research on when should medications be used, are they safe, and are they effective. Now, I have been touched and moved at times to hear parents tell me the story of their own particular child.

And one friend of mine has a wonderful family, a wonderful woman who has two sons and I was the scout master for her two boys. One of these, or both of these boys, went on to develop one bipolar disorder and one schizo-affective disorder. And they are on major significant medications now, and what her son said to her four or five months ago, he said, "Mom, what are these things going to do to me? Is there a problem in me taking these? I know I feel better." And so this child went from being regressed and hallucinating and having just very unusual thoughts and feelings and ideas and unable to leave his room to function and doing straight A's back in school. And so he said, "What's this going to do to me?" And it tore at her heart strings for good reason because she couldn't answer the question. And she had the same worries. But now if someone had said to her, you shouldn't use these medications because we don't know if they're safe or effective, well I think that would be outrageous to tell the parent and physician they shouldn't use these medications because safety and efficacy hadn't been demonstrated. That would be the worst of all worlds is to legislate it away, because this has helped this child. Much better to advance the cause of research, to make sure that when parents make that decision with their child, with their physician, they have the fund of information to make those decisions at their fingertips.

So, we've started now a major initiative in this area where we're working with the National Institutes of Child Health and Human Development, the Neurology Institute. In the meeting I just left we spent a full day again working on this initiative. We had, I have to say with some excitement, a lot of members of the pharmaceutical industry now who have been shying away from this area because they're afraid of liability. We raised a lot of issues saying that they have to do it. And FDA now has a mandate where they can probably require them to do it if they don't. So, they know they have to begin studying safety in children because they're used anyway and parents need this information upon which to make reasonable decisions.

One of the other major initiatives we have going on is a six-site study of Attention Deficit Hyperactivity Disorder. This is the most common condition with children and adolescents; it comprises a lion's share of the referrals in the school system, in the mental health system, and is associated with pronounced problems in the long run in young adulthood, in adolescent adjustment. And so, given my earlier slides, you shouldn't be surprised to know that this study we've pressed forward and are now designing has major components that we're bringing together: medication and a very powerful psychological
intervention. We're putting them together, and we're comparing, because we think that's probably the best way. We don't know. We think it is. It makes good sense. We're comparing that over 14 months with the best possible medication you can use. We're comparing that with the very powerful psychosocial intervention that doesn't use medication. We're following these families very carefully because if a child starts to have significant problems, then we have to add in the other treatment. We don't want to get a child in that position but we need to know what's most effective, and some families don't want a child on medication, so we need to see if the psychosocial treatments work. For some families, the psychosocial treatments may not be appropriate or may not be necessary. We need to know that as well.

So we're comparing those three treatments over 14 months and following families out for two years to treatment as usual. We've recruited almost 600 families, so this would be the largest treatment study that NIMH has ever conducted with children or adults. So this will be a very important study. One-fourth of the families are assigned back to their primary care provider. We call that assessment and referral. We're going to follow them in the health care system, which is not great. We all know that. We're going to see if they get the care that their own system provides that is not this complex, integrated, very carefully followed, what's the difference and how it works best for families, versus a very intensive psychosocial, versus the best medication we can do, versus putting both the medication and the psychosocial treatments together. So this study, I expect, will set the treatment standard for ADHD for the next decade. We're very excited about it and we should in the next one and a half to two years be having results from this that will have an enormous, if it's successful, impact, particularly if we find that these intensive treatments make a difference compared to this standard, run-of-the-mill health care system that is out there. And if any of these bottom three treatments are more effective than care as usual, that has implications for our health care delivery system as well, so we designed this in the context of health care reform.

The other major study that we're doing, that some of you may have heard about, is called the UNOCAP Study, and this is a study of some 20,000 children. These will be five sites, including four geographic sites that are local, one at UCLA, one in St. Louis, one in Baltimore, and one at Duke, and then a nationally representative site. And so it will be a total of about some 20,000 children, and we'll be following these children, it is expected, at least two years. And what are we doing? Well, UNOCAP stands for Services Use, Need, Outcomes, and Costs in Child and Adolescent Populations. So, we're going to try to see who's getting mental health services. What kinds of services are being delivered in the various sectors and, again, this has great implications for reforming various health care systems. How do people get into the health care system? What are the barriers to care? How do families or children fall between the cracks of the various systems? How
is care integrated or, too often, not integrated, among the various sectors that are involved in delivering mental health services? How are they organized? How are they reimbursed? Issues of looking at family involvement, family participation with models of true collaboration. How much of these are a part of our systems or not a part of our systems, and how do those kinds of things affect the outcomes and satisfaction? What are the impacts and burdens on families in terms of the burden of mental illness in a given child? And, again, what about children who don't get in the system, who need care but don't get in? And why are children not getting in? What are some of the risk factors that might be opportunities for prevention as we understand how these disorders unfold? What is the mismatch between service need and actually what they're getting? And I think most of us would suggest that there is an enormous mismatch. And then what happens to these children over time if they don't get the care that they need? And what is the impact on the family over time with our unintegrated and somewhat disparate systems of care that often don't take the families in as partners in this process?

Barbara Huff, from the Federation for Families, actually came and consulted with the UNOCAP group, as did Laurie Flynn from the National Alliance for the Mentally Ill. They came and both consulted with the collaborators and tried to bring to the collaborators a family perspective and some of the critical questions we should be pressing forward. One of the points that Barbara made, in particular, was that we really need to make sure that we can address the issue of costs. What do these things cost? To go back to the legislatures or to the Congress and say, "This is what is needed and this is what it's going to cost, and this is what it's going to cost if you don't provide it." Those kinds of costs are very critical for these policy kinds of decisions.

In truth, I think we should not despair; although there was a setback last year, I do think that times have changed and times of crisis are also truly times of opportunity, and if we're going to see now in a Republican-controlled Congress a whole new wave of block grants and, in the long run, cutbacks in services, you have to remember, we have to remember these things are cyclical. The problems aren't going to go away; needs will be addressed. They have to be addressed. But that depends on us and it depends on us working together and advocating effectively. So, there are opportunities here.

Change will come. It will come. But it also has to affect not just our systems, but our providers. One of the things we are very interested in is retraining the older generation of psychiatrists and psychologists, social workers and nurses, others out there who are providing care with these old models and they haven't really taken up the challenge of the new systems. And I think that even though we are having to shed some of our old clothes, I think even people like Freud would have been very happy about this. I think I've overstayed my welcome. Thank you very much.
Plenary Luncheon: Family-Centered Culturally Competent Systems of Care

Presenter: Velva Spriggs
Affiliation: Center for Mental Health Services Planning and Systems Development 5600 Fishers Lane, Room 11C-17 Rockville, MD 20857

Presenter: Janice Hutchinson
Affiliation: Child, Youth Services Administration Commission on Mental Health Services 2700 Martin Luther King Avenue, SW Washington, D.C. 20032

James Mason: Today we're going to have a keynote luncheon speech by two people from Washington, D.C., Velva Spriggs and Dr. Janice Hutchinson. But to start, another person who has been very dear to our Center has been Linda Reilly of the Oregon Family Support Network. And so, we're going to have Linda Reilly introduce Velva Spriggs.

Linda Reilly: Well, it's truly a pleasure for me to be able to introduce our next speaker, Velva Spriggs, who's here with us this afternoon from Washington, D.C. She has a truly impressive professional background. She earned her master's degree in social work from the University of Pennsylvania in 1969 and has been working in service-oriented positions ever since. She started with the Mental Health Association of Prince George's County, and she worked as an officer in the Peace Corps for five years. Then she went to the U.S. Department of Education, and from there to the U.S. Department of Housing and Urban Development for about six years. Presently, she serves as the Director of System Planning and Development (also known as the Child and Adolescent Service System Program, or CASSP) for the Child, Adolescent and Family Branch of the Center for Mental Health Services in Washington, D.C.

But as a fellow parent and a fellow family member, I know Velva best as the parent of a 17-year-old son who has a dual diagnosis of SED and learning disabilities. Her special interest in children's mental health issues comes out of her personal struggles with his disability. Her experience has led to support and advocacy for other families in her area and to founding the Washington, D.C. Family Advocacy and Support Association. From
advocacy at that local level, she became active at the national level with the Federation of Families for Children's Mental Health, including serving on the Board of Directors as their treasurer, and receiving the Federation's very first "Claiming Children" award.

Velva continues to be a tremendous resource to families by her personal example and by providing ongoing support to parents from a mom who's really been there. Please join me in welcoming Velva Spriggs.

**Velva Spriggs:** Well, thank you. You know, it's really quite something else to hear others talk about your experience. And I must say that I feel very privileged and very proud to have been associated with this movement, and I do recall when the Federation of Families for Children's Mental Health began in the Washington, D.C. area. I remember all of the enthusiasm and all of the risks that people were taking, all of the excitement, and it just really does my heart good to look around this room and see how much we've grown, and how we are bound and determined to go forward in spite of everything, Newt Gingrich included.

I want to extend to you greetings from the Center for Mental Health Services, the Child, Adolescent and Family Branch. And I also want to give recognition to those parents and professionals in the Washington, D.C. area who have helped to enlighten me on this topic of parent-professional partnerships. Specifically, I'd like to acknowledge the presence of four members of the Family Advocacy and Support Association who are here and I'd like to see them stand because they existed before the Federation.

And in an effort to be culturally sensitive to at least one other group, I'd like to say “Bienvenidos a los representantes de las comunidades Latinas.” Welcome to everybody.

This is truly a reaffirming moment for me to be able to share my views and perhaps to hear yours on the value of parent and service provider collaboration, and to do so in the context of the significance of race and culture in our society. For those of you who are just beginning to explore the workability of this partnership idea, I applaud your interest and assure you as I would if you were at my favorite watering hole, come on in, the water's fine. You'll discover, just as you do when you put your toes into the water for the first time, testing for the level of risk and comfort, that it's a little cool but as you begin to immerse parts of your body little by little you become acclimated, more comfortable, and then boastfully ask others to join you. So will be your experience of immersion into the depths of parents and professionals for family and service provider partnerships.

You may be a little uncertain about the benefits at first, but you'll soon discover that the outcome for the children you parent and serve will be enormously worthwhile, not
necessarily easy, but very worthwhile. And for those of you who have been involved in this process for some time, as I have, you can attest to the benefits as well as the bumps and lumps that you encounter along the way. There are often issues of trust and questions to be overcome in the partnership, but there is also the potential for openness, joint sharing of information in the child's and family's best interest.

My son's school counselor and I sometimes talk daily. I'm not always pleased about that, but we do. Our conversations go something like this: "Your son's doing better today at school, but he nearly stormed out of the history class." "I'm not surprised," I say, "because of a very unsettling matter that arose at home before he went to school. Could you tell me what precipitated the outburst in class and how you handled it?" I say. And the discussion continues until we're both satisfied that we've explored our concerns and attempted to resolve them for that day. Believe me, it has taken a year to get to this point of teamwork and mutual respect for our joint expertise: hers as psychologist and mine as a mom who knows this child best of all.

In another situation, I was not so lucky; the principal accused my husband and me of trying to take over her school, because we were not willing for her to be the only expert, the sole discussant and decision-maker in our child's school life. So my husband and I, out of frustration, were so confrontational in those days that we too said things that did not facilitate dialogue.

So there were many lessons to be learned by us all. Yes, it was difficult, but I think the key was tenacity. Sticking to it. Not giving up. Being flexible. Not being stymied by the paternalism. Learning to respect each other eventually. And recognizing that it's better to deal with a child or adolescent as a whole person, not just the part that the teacher deals with, or the parent sees, or the psychiatrist responds to. When we all get together to assess what's going on, we all gain broader knowledge and understanding from a holistic view. So in my view, it is absolutely essential. There is just too much to be gained as a result of coming together around the issues that concern our children.

In collecting my thoughts about today's talk, I considered both historical and present-day experience in an examination of the topic, "Parent-Professional Collaboration." It is as though I am looking at the field of children's mental health in kaleidoscopic movement, ever-changing and yet reflecting patterns that repeat themselves again and again and again.

We all remember, for example, the days when parent blaming, a useless, alienating practice, was pervasive among practitioners in the mental health and education disciplines. Their formal education and training reinforced a common societal belief that
families caused their children's mental and emotional disorders. The National Alliance for the Mentally Ill and the Federation of Families for Children's Mental Health, along with their many friends in the professional community, have fought vigorously in recent years to counter this belief, and yet, in many places, the belief and practice of blaming persists. So we have our jobs cut out for us still in this area. We remember when parents considered themselves blameworthy as they sought an explanation for the causes of their children's emotional disorder.

But, most happily, we have begun to abandon the concepts of blame and broad sweeping statements about family dysfunction to the junk heap of well-intentioned theories and practices gone awry. And in their place we welcome a more enlightened view that takes emotional disturbance in children out of the dungeons of our mental health services history with the recognition that we all have a role to play collectively, cross-culturally, cross-racially in the amelioration of our children's emotional health and our society's response to it.

This is a joint effort. We call it collaboration. And even though many of us can only talk the talk, although some few of us are beginning to walk the walk, at least it has become politically correct to embrace the values on which the concept of parent-professional partnership is based. And some of those are that the provider and family members working as a team should work as a team with mutual respect, empathy, information sharing, and decision-making responsibilities. Another is eliminating blame as an operating dynamic and viewing all participants including family members as having strengths, expertise, intelligence, motivation, feelings, and other resources that are instrumental to problem solving. And what about the elimination of language barriers, either in the cases where practitioners use words that are not familiar to parents or in the cases where people come in speaking a different language, having an interpreter there, or finding some way to cross that communication gap. Or when we involve deaf parents, knowing the importance of having an interpreter. All of this goes a long way in bringing people together in a positive force to work towards the benefit of our children.

These principles or values sound easy enough to accomplish but we all know they are not easy to implement. There are challenges, many challenges, and numerous barriers, and let me name a few of those. The stigma associated with children who have emotional disorders and their families is certainly a major one. Blaming, discussed earlier, which focuses on intervention or "fixing" the parent rather than on the child and family as tools of intervention. How about paternalism, a marginalizing tool that disempowers and supports discussions around status differences in the relationship. These things are utterly useless and should be abandoned.
There is also the situation involving parents and providers whose prior negative experiences with each other may get in the way of their being able to collaborate effectively. Agency policies that do not support collaboration with professionals outside of the mental health system or with families. And, of course, there is one that you know all too well here in Oregon, the government policy that requires families to relinquish custody to obtain services, and the list simply goes on. But if you superimpose now, if you superimpose on all of this the racial and cultural issues that can divert or abort opportunities for partnership building, you simply exacerbate the situation. Clearly, these are areas that must be acknowledged and attended to in a competent manner. The issues of race and culture often inspire stereotypical thinking, and I know I'm talking to the choir, but I just have to say it anyway. The issues of race and culture often inspire stereotypical thinking, fear, nostalgia, feelings of inferiority and superiority, benign patronizing and useless intervention. How else do we end up with a disproportionate number of black children and Hispanic children and Native American children in the criminal justice system when they in fact should be in the mental health system and that's where they belong?

Now let me place my remarks in their proper historical context. We have come to this time and place where race and culture are an essential part of the discussion on children's mental health, because race and culture have always been a part of America's human landscape, its sociopolitical existence, and its economic force in the world. Thus, it stands to reason that race and culture also impact our formulations of mental health policy, professional training goals and standards, service delivery, evaluation, research and, indeed, our discussions and activities related to parent-professional collaboration.

Out of the concerns with race and culture that are vehicles to determine privilege, opportunity, and access to the best of America's institutions, racism has emerged as a system to restrict privilege, opportunity, and access. And contrary to popular belief, it is not dead. It is not dead. And, it is also not color-blind. Racism is ingrained in our way of thinking and both overtly and subtly affects us all. Of course, it is uncomfortable to discuss because of the pain it causes, the resentment and anger it conjures up, the negative energy expended, and the impotence that we often feel in response to it because sometimes we're just not real clear about what to do about it.

So we've coined a more acceptable term. How about cultural diversity? Where we acknowledge an appreciation for ethnic and cultural differences in everyone. Now, it's a perfectly good term, and I encourage its use in proper context, but it does not take the place of nor eliminate the need to discuss racism in our society, because racism, different from cultural diversity, is tied to issues of power and resource distribution.
This nation, ostensibly governed by egalitarian principles which incorporate values of rugged individualism, personal liberty, free enterprise and the supremacy of white over black, and other associated coloring, has used race to the detriment of millions to mete out privileges, opportunities, and advantages of all kinds. This is a simple, undeniable, historical fact which has shaped the legacy of human relations in America and it has served as the force behind cultural destructiveness, cultural incapacity, cultural blindness, and all of those areas that we talk about in cultural competence. Well, I guess we all know that. The question is, what are we going to do about it?

I know that we refer to this as the "R" word, at least I've heard people recently refer to it as the "R" word, as if its use is no longer necessary, fashionable, or politically correct. In other words, been there, done that, slayed that dragon. Next? Well, I get concerned because I know there is yet much to do, especially during these times when we are being forced to manage fewer resources, of generating more conflict and competition, and our politicians whom I consider irresponsible, are tying these issues to race and culture in order to perpetuate the alienation and the fear that we may have or feel or experience among one another. But we know the real deal. We know that we can overcome this. We know that we must, if we are to have a future and if our children are to survive, and if our children with this SED diagnosis are to be able to participate in this society as all other people so that we enhance everything that we produce for the benefit of everyone; then we have no choice. We must overcome this. We have to find solutions, and I'm really, really very serious about that.

In spite of all of that, I do remain encouraged because I know there are many brave souls in this audience who are willing to say the legacy of racism ends with me, white, black, Hispanic, Native American. I know my Hawaiian brothers and sisters are out there too, Asians, all of us. We're willing to say that this ends with me.

You are the ones who must risk challenging mental health policymakers to ensure that they incorporate culturally competent concepts and principles in service planning. You are the ones who must risk challenging professionals and service delivery, who structure treatment plans, service plans based on stereotypes, mythology and just plain ignorance. You are the ones who would risk much with challenging family members, even, who devalue the contributions of other family members on the basis of racial or cultural differences.

As I think about what we can do, I'm going to be rather general about it, but I think this is something that certainly requires the thoughts and the work of all of us. I know that there is no situation where only the parent is involved with the child, or only the teacher, or only the psychiatrist. We have to talk to each other, identify strategies to work together
as a team of experts with mutual respect. We have to rid ourselves of this albatross that
tells us that there is all of this elitism out here attached to people simply because they've
gone to school and gotten degrees and that they may in fact know more than somebody
else, or whatever they have to say, or whatever they think has more credibility or more
status. All of us, all of us are experts in the management of what happens to our children,
and we need to approach this with that point of view.

We need to make the parent-professional partnership model a part of the curriculum of
every person being trained to work with our children: doctors, teachers, social workers,
psychiatrists, whomever it is. The things that I have shared today, which I firmly believe,
I feel strongly need to be a part of the curriculum, and having worked at the School of
Social Work at the University of Maryland for seven years, I am absolutely convinced of
that.

Parents, get on advisory boards and policymaking boards affecting our children and let us
all come together in a spirit of communalism so that we learn from each other and we see
our children and our families as belonging to all of us, because I contend that we must not
compartmentalize this thing so that I talk about my child and then your child and
somebody else's child, but we talk about our children. All of these children belong to all
of us, and then we can walk in lockstep fashion and no one can break us down with these
barriers of stigma and racism and all of the other things that I have mentioned that divide
people. And I guarantee, I am willing to risk it; we will have a better world. We can do
it. We have risen above many, many obstacles in our history and there is no reason why
we cannot rise above this. Thank you.

**James Mason:** Thank you, Velva, very much. Very inspiring words. Now I have the
honor and opportunity, rare honor and opportunity to introduce a very dear friend of mine
who I've known for the past seven or eight years. I met her about five or six years ago in
the District of Columbia, got with her again in South Carolina, and just got to hang out
with her earlier this year. What's really impressive is her commitment, caring, passion,
concern for children's families that stands out above everything else that she does and she
is. I walked away tremendously impressed and awed many times and she's become for
me, and I hope will become for you, a mentor or role model, an inspiration.

Today we were talking about how I would introduce her, and she wanted me to be kind of
small and modest and what have you; in fact, she gave my Dean a bad time about me, so I
told her I'd get her back. She is the Administrator for Children and Youth Services
Administration in the District of Columbia, which is a full-time serious, meaningful job.
She is also the Medical Director for the same organization, and for me that's kind of like
two jobs. I believe in hard work most of the time, but two jobs and the volunteer work
that she does, the other areas of concern, AIDS awareness, pregnancy prevention, violence, domestic violence, just a very impressive powerful person.

So without a whole lot of further ado, and without embarrassing my friend and colleague and inspiration much further, I would like to bring to the podium and have you help me give her a very warm welcome, Dr. Janice Hutchinson.

**Janice Hutchinson:** Well, good afternoon. I know you see a lot of Washington, D.C. on the news, but I want you to know that Velva Spriggs is the best part of Washington that you don't see.

Well, last week, I was at the APA, that's the American Psychiatric Association, meeting down in Miami and I was talking to my peers down there about some of our kid issues in the District and HIV, and that was nice and pleasant, but this is just so much more special to me to be here with so many of you who are actually real families and real parents. It just makes such a difference.

I came here to Portland yesterday for the first time in my life even though I went to college here on the west coast, and I was thinking about what a lovely city this was. It reminded me of before I moved to Washington, D.C. I used to go to Washington, D.C. and think, "Oh, what a lovely city Washington is." Well, I've been living in Washington now for about seven years and so I have seen a side of Washington that is often covered by racism.

I'm going to share with you today, particularly, two programs that we have in the District that we're very proud of, but before I do that I wanted to put into context what these programs are and to more explicitly describe to you what you don't see when you come into Washington, D.C.

As most of you know, the Casey Foundation conducts a survey every other year of the social and economic conditions of our children. They call it the the Kids Count, and they look at social and economic conditions in 50 states plus the District of Columbia so there are 51 areas in the survey. Let me tell you where the District falls in some of the most serious areas.

The percent of low birthweight babies in the District is 51st. Infant mortality rate in the District is 51st. The child death rate in the District ranks at 51st. Number of births to unmarried teens in the District is 51st. Juvenile violent crime, arrest rate in the District is 51st. Percent of teens not attending school and not working, ages 16 through 19, in the District is 49th. The teen violent deaths in the District is 51st. The percent of children in
poverty in the District is 50th. The percent of families with children headed by a single parent in the District is 51st. What is not included in this study is that the District, up until last year, had the highest homicide rate in the country. I understand, in 1994, the homicide in the District dropped 7%, so the District is currently third in the country. The District also unfortunately has the highest incidence of HIV infection among its teenage population, more than double than that of the next closest county.

Now, needless to say, there is a lot of trouble in the District. There are many problems and challenges to raising children in the District, and that's not to say that it is impossible. The District also has one of the few 1,600 scores on the SAT this year; she was a young lady who attends a D.C. public high school.

The kids are smart and they are strong and, with proper support, will do just fine. Kids need families and sometimes families need families. One of the most distressing things for myself as a mental health person is to have a child tell me in the course of an interview that they have been molested or violated in some way, and that they have told a parent, a teacher, a nurse, a doctor, and that person has not done anything about it. Also distressing to me in the position in which I sit, is to have a parent call me and tell me, "You are the fifth or sixth person I have talked to. I need help for my kid and I can't find it anywhere."

Some of us in the District have decided that we have got to be a lot more efficient and move a lot faster to help our kids and our families. The scientific evidence is there. What Dr. Jensen presented to you this morning is really just the tip of the iceberg. There is good scientific data that indicates that the child who is traumatized, who is unrecognized, whose distress is unrelieved, is the child who is most likely to be in trouble later on. So if we can't stop the trauma, we can't make life what it might need to be for that kid early on, for whatever the reason, we have to at least be there to interrupt that cycle and bring relief as soon as possible. And that's what I hope to talk to you about in a few minutes here today.

This is a program developed by people like Hope Hill and Nancy Weir, a youth trauma team. There is one other team like this that I know about in the nation and it is in New Haven, Connecticut. By day, we're called the Mobile Crisis Team. Any child who is in distress in the District who cannot come into our child psychiatry emergency room may call us and we will take two or three or four of our staff, whatever's necessary, out to see to that child in a state of distress. That means that last year, for example, when a child was attacked by a pit bull, a three-year-old, and the pit bull had literally scalped this child, we were there within 15 minutes. And we were there not to just minister to the child, but also to provide services to those other three or four kids who were standing around
watching, and to reassure the mother that she was not a bad person because she wasn't there when this happened to her kid.

Two or three years ago, some children were shot in a swimming pool in the District, shot by another teenager, as a matter of fact. Once again, we were there very quickly to provide crisis debriefing and counseling services to those children who were also there and who were not shot. We actually went door to door in that neighborhood offering our services and we went to the hospital to see about those kids and families.

Now, by nighttime at 6:00, it's like Cinderella. We become the Youth Trauma Team. We join with the metropolitan police department in the District and we take a van out about 8:00 or 9:00 every evening in the two highest crime areas in the District. And our point and purpose is to provide crisis debriefing and counseling services to those children and families who are victims of and witnesses to violence.

The last time that I rode with the team, we were called to a scene in which a young man was shot. He was shot several times and the police had taken off his clothes, so he was lying in the street completely exposed. Our team was available to come and say to the police, "Would you please cover this fellow up? This is extremely damaging for these children and parents who witness this. Cover him up. Move him away from the incident." Then we were able to also intermingle with those children and families, offering on-site crisis counseling and debriefing, as well as providing them information about linkages and other resources. We also provide follow-up for those children and their families because we understand that trauma unfolds itself over time.

This video is from an evening newsclip in D.C.; I’ll show you just a few minutes of what we do.

VIDEO PRESENTATION

Janice Hutchinson: The team responds to homicides, stabbings, shootings, child abuse episodes, as well as scenes of domestic violence. One night as we were riding around one of these areas, we came upon a situation in which a teenage boy had hit his teenage girlfriend and we were able to stop and talk to those kids right after this happened and actually involve the boy's family in addressing the incident.

The faster you can be there when there is trouble, the better it is for the kids and the family. The homicide rate in the District, as I said previously, has dropped 7% in 1994. Now, people like to say that's because the police are arresting more people, and I'm sure
that is a very important and critical factor, however, some of us like to think that it is because of this kind of effort also, that we do make a difference.

Now, one of the things that I didn't say when I was running through the laundry list of various problems and issues in the District was how many children we are seeing who are sexually violated. We have 10-year-olds on our inpatient unit who have gonorrhea of the throat, we have 14-year-olds who have chlamydia of the rectum. I was recently reviewing the medical chart on an HIV-positive kid, a little girl who's 14, and she has had herpes, gonorrhea, syphilis, chlamydia, and a couple of other things. She is a child who has been molested. And since we've done such a poor job of addressing the problem of sexual abuse of our children, it has begun to spill on to the streets, so that now teenage prostitution is like an open-air market.

In Los Angeles, there is a program called "Children of the Night." And in New York City, there is another program and I think it is called "Paul and Mary." To address the problem of teenage prostitution in the District we have developed a program called "Helping Individual Prostitutes Survive" (HIPS). It is another outreach program.

We believe in children's mental health that says we have to be where the kids and the families are. They are not in our offices, they are not at the desk, they are not up on the wall. They are out in the streets. So, that's where we have to be. On Friday and Saturday nights there are areas of downtown D.C. that look like rush hour and it is because of prostitution traffic. This is not a minority activity. This is not a low-income activity. This is a very middle-class, upper-middle-class supported activity. You cannot get through certain downtown streets in the District after midnight because of all of the traffic and traffic consisting of people, of fellows picking up young girls, and sometimes boys, to sexually abuse them.

The HIPS program goes out every Friday and Saturday night. We have a van, our trusty van. Sometimes we combine with the Youth Trauma Team, but always on Friday and Saturday nights from about 9:00 p.m. until about 4:00 a.m. because the kids are out until about 6:00 a.m. Usually there are two or three of us in the van who will go out riding through these prostitution strips, talking to these kids as best we can. And what do we do exactly? The driver of the van is herself an ex-prostitute.

Sometimes we talk about things like cultural competency and we are too narrow in our vision. Culture does not refer just to race and ethnic group and religion and nationality. It also refers to targeting groups of activity. There is a whole different culture among teenage prostitutes, if you will. And so, the driver of the van who, as I said, is a former prostitute herself will drive us down the street, and she takes an approach I would have
never particularly thought of, she yells out the window, "Hey, girlfriend, how you doing? You need some coffee? You need some hot chocolate? You need some condoms? You need some conversation? You need a place to stay? Would you like to go back to school?" This is how the conversation begins to go over several weeks. And eventually, "Would you like to get away from that guy, that pimp that keeps you tied up like this?"

We have got to rethink our definitions of family. Because what we are seeing and offering to those kids on the street, we offer in a loving and caring way unconditionally, and we are acting as family substitutes for kids who are out of their homes, many of them very abused, very neglected and very abandoned. So on Friday and Saturday night, we become their family. We are their resource. We have left our kids on the street to the drug dealers, to the drug cultures. We need not leave our sexually abused kids again on the streets to the pimps and johns. Let me show you a little bit of what we do.

The next tape, please.

**VIDEO PRESENTATION**

**Janice Hutchinson:** This is an excellent tape. It was developed by a graduate student at American University. Let me just say that what you will see on this tape is what some people do not necessarily expect, and yet, you see young, white teenagers on the streets.

I had a dispute with a councilman in the District because we took him out one night on the HIPS van and he complained that there were a lot of kids on the streets who were from other areas, who were from the midwest, who were from Canada, etc., etc. Now, this is someone who has children himself and he decided to defund this program. We have to lose this idea, as Velva said earlier, that “is it my kid or it is your kid;” they are our kids. And any of us who sends our children anywhere in the world expects that the parents there, that the adults there, will be responsible caretakers for our kids. That's why we send our kids every year, thousands of them, away to other campuses and colleges, to towns around America, and to Europe and other places abroad. We expect that the adults are going to be responsible for our kids, no matter what they look like and no matter that their biological family is not there. When we can stop making these kinds of artificial separations, we will do better.

HIPS is also an example of the difference between being where the kid is and being in your office. Our hotline last year received about 300 phone calls. We actually tabulated over 2,000 personal contacts with teenage prostitutes on the streets. That's the difference it makes when you get up out of your office and go out to where the kid is.
I can say more, but I'm going to stop now. Let me just remind you of what we all know and that is the buck stops here. Thank you.
Title: Plenary Panel: Positive Examples of Researcher-Family Collaboration

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Panelist: Yvette Nazario
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James Mason: Good morning. In keeping with the theme of the conference, we figured this would be a real neat opportunity to highlight some of the research activities that are being conducted around the country. In particular, what we were looking for were examples where researchers and parents and family members were coming together to conduct research that was relevant, meaningful to families and children. And I was able to secure the participation of several people who I have known for several years around the country and have great respect for, but also I would be remiss if I didn't acknowledge that, within the audience, there are a number of other examples that need to be highlighted. So I apologize in advance to those of you who should be up here on the panel.

With us today is Mary Telesford, as many of you know, with the Federation of Families. Mary's been kind of a buddy and mentor and colleague of mine for 11 years now. To her right, Susan Tager, who has been involved in our projects. To her right, Phil Leaf, from Johns Hopkins, another real popular and important person in the area of children's mental health. Mary Evans, a friend out of the New York State Office of Mental Health. Yvette Nazario, who works for a project out of New York, Children's Emergency Homebased Services. And to her right, Valerie King, also out of the City of New York.

The important thing that I think we all need to keep in mind is that there is so little known about families, the roles that families can play with respect to research. Over the last 10 years or so, the Portland Research and Training Center, as well as Georgetown and Florida, have looked at ways that family members and parents can be involved in delivery of services, the refinement of the service delivery system. But in the last years, there have been some real neat opportunities for parents and researchers, and even service providers, to collaborate and conduct research that was going to be very, very critical. We may hear our panelists talk about such areas as research design, the type of instrumentation measures that could be used, the data collection process, the data analysis process, and perhaps most important, how the research would be disseminated in ways that could be useable to various people like professionals, researchers, academicians, service providers, but also so that it was useful to parents and family members.

I'm going to turn the mike over to Mary who, unfortunately, has only about 10 minutes to talk a bit about her experiences as a professional and as a parent conducting research. Please welcome my panel and, in particular, welcome Mary Telesford.
Mary Telesford: Thanks, James. As James said, I have worked for the Federation of Families for Children's Mental Health on the Mental Health Initiative for Urban Children, an initiative sponsored by the Casey Foundation. I guess most of you have heard an explanation of the Federation and the Mental Health Initiative, so I'm going to use my 10 minutes to talk about the topic rather than give you a history of all that stuff. But if anybody wants to know the history of the Federation or about the Mental Health Initiative even more, feel free afterwards to ask me.

One of the things in working with the families in the Casey sites, and the sites are in Richmond, Virginia; Boston, Massachusetts; Miami, Florida; and Houston, Texas: the initiative is geared to assisting families and working in assisting reform, a process of reform using mental health as an access point. And I know that sounds really strange because it was strange to me, and I can only tell you it took me a while to understand what it really meant until I was really working in it. So again, I'll give you more information about it if you'd seek it later.

But what we really want to talk about are what are some of the best practices that researchers can engage in in working with families, especially families of color. Those families which I predominantly work with. One of the things that families tell me and I think makes a lot of sense is, if you are a researcher, you need to get the full picture before you try to talk about the individual child, which means a child does not come here by herself. She is part of a family. She is part of community. So you need to get the whole picture of what really goes on in order to understand what's going on with the child or family or even a community. And you get the whole picture by being culturally sensitive, coming to the situation with valueless eyes. Meaning that you don't try to impose your own value structure and beliefs on maybe another community that does not hold the same. Also, in coming to an environment that is different than yours or one that you fear going into, for whatever reasons (and those are many so we won't list them), it is helpful to you as a researcher to identify someone in that community that can give you access to people that you want to talk to. And this makes a lot of sense, because if you don't, many times the results and answers that you get are not really those that are going to be most beneficial in putting together whatever you're trying to do.

And another thing that researchers should try to do in working with families is explain the project in language that the families can understand. To go in with the jargon that researchers usually use and evaluators and assessors, many times the families won't ask the questions because they can't even begin to understand how to pose the question, except to say, "What the heck are you talking about?" And then they are sometimes very reluctant to do that. So you think you're explaining it and you're not. So what I suggest you do is, before you go, find a family member of someone else or even your kid. You
know, when my children were like in the fourth and fifth grade, if I was determined, I used literacy training; if I was determined to work with people who were having problems with reading or whatever, I tested it on my children. So if they were able to do it, then I figured that maybe this would be something helpful for people who were having difficulty reading. So I always suggest that you test your presentation on people who are most like those that you are going to work with to see if they understand it.

Another thing, you need to talk about the risks and the benefits of being involved in this type of whatever research you are doing, especially if there is a treatment involved. What is the benefit to the person who is receiving the treatment? What's necessary in the family to ensure that the benefit is maximized?

And thirdly, is there a risk? No one wants to go into something blindly and find out later on that there are risk factors that they would probably not want to be involved in had they known what your project was all about.

Another issue is confidentiality. Assure that there is some way of maintaining the confidentiality of all the results and findings that you get. Many times people are not forthcoming, nor should they be, if they don't feel that what they say is being taken in confidence and being disseminated and reproduced in such a way that a finger will not be pointed at them.

Another issue, and this is a particularly sore one for me, because many times in the communities that I've worked, people go in, researchers go in and surveyors and they ask a lot of questions and there's this underlying threat. They'll say, "I'm from HHS," and it implies that if you don't cooperate with me then perhaps you're going to get a reprisal of some sort. Maybe somebody is going to come and visit you when you don't want them to, or they'll look into your assistance or your public assistance or some other things, so I want to really stress that people should freely be involved in research. Not just because of their situation or because they are a captive audience.

And then I guess the last barometer is talking about how you approach people or whatever. I always use the barometer of myself. If I would not want it for myself or my family then I don't expect anybody else should want it either. So that's the bottom line to that.

Moving quickly to something else that I think is important, that we have learned in working with the Casey sites, is the whole idea of strength-based models of evaluation and assessment and all kinds of things. First of all, as I said to you, most of the communities, all of the communities in which I work in the Casey sites are
"disadvantaged" communities, and they were chosen because of that. So you have all of the negative descriptions and we don't need to go through those, we know what they are. Because of that, many times it is assumed that there is nothing positive or there are no strengths in these communities, and that is a big mistake. And I believe that if we are really serious researchers and other people who are working to benefit families and children, if we are really serious about bringing about positive outcomes for our families and children in these communities, that we need to really look at the strengths. We need to build models that will allow us to not only understand the strengths of the community but to replicate behaviors molded on those strengths in other individuals and communities to improve and maximize outcomes for children and families.

Last but not least, what can families really do in terms of strength-based models and definition and design? First, they can give you access. Second, they can give you information. And third, you can give back to this community, which it deserves, something that will benefit them. Opportunity to learn and grow and replicate behaviors of strength that will make their community and your life as a researcher a lot more relevant and real, and I'll stop there. Thank you.

Susan Tager: Hi, I'm Susan Tager. I'm from Baltimore, Maryland, and I work for the Families Involved Together there, and through that I work for the East Baltimore Mental Health Partnership setting up their family support network. I am the mother of an 18-year-old son who has bipolar and various and sundry other diagnoses, and he has been ill all of his life and has been through all levels of service. I have actually been working with the East Baltimore Partnership before it was the East Baltimore Partnership, and Dr. Phil Leaf, who is sitting to my right. He actually invited me to be on an advisory committee for the City of Baltimore to look at child and youth planning, which eventually became the advisory board to the East Baltimore Partnership. I took the job to set up the family support network and have been very, very happy to do that. I have really, really loved my job.

I was originally a little bit concerned about the fact that I knew that probably 97% of the people that I would be working with would be African-American and obviously I'm not African-American. And we talked a lot about cultural competency. And I looked at the things that I have in common with the families, with folks that I'm going to be working with. Well, I'm a Baltimore native. I went to public schools in Baltimore, the same as probably most of the people that I'm going to be working with. My kids, my one son who does not have special needs, is in Baltimore city public schools and my other son was in Baltimore city public schools. And I'm very familiar with the neighborhood where I'll be working. And I have not felt any problem with the differences that we have. I would hope that the families have not felt that either. I have felt very welcome and open, but of
course the main thing that we have in common is that we are family members of children who have mental illness, and that is a culture that we share that transcends the racial questions or background that I was concerned about.

The Partnership has been extremely family-friendly, I think, from the beginning, from even its inception. One of the things that Dr. Leaf, Phil, did in writing the proposal was, he went around and he interviewed people, interviewed families in their homes and talked to them about what it was that they thought that they needed for their children. And I went with him on two of those interviews and then he and I sat in the car out in front of Johns Hopkins Hospital, and we talked about what I thought I needed for my son. When I read the proposal, I could see those things in what I had said, what the other family members had said, right in that proposal. I mean, he had listened. It wasn't just lip service. Oh, I'm going to do an interview, I'm going to write this down, and then I'm going to put down what I think. No. It was what families really said that they wanted. And you can see that in the way the Partnership has been set up, that there's such a respect for families from the executive director, from the coordinator of the research, the resource coordinator to the case managers, the school-based clinicians. There's just a respect for families and a real respect for what it is that families think that they need.

And part of my job is to attend all meetings. I was told at one time, I heard that certain people were excused, and I said, "Am I excused?" And I was told, "No, you're never excused." Because my job is to really be there and to represent the family point of view. And I guess there were times, particularly in the beginning of the project when the word "dysfunctional" would come up, and I'd, you know, take great umbrage. I don't hear that word any more. And it wasn't very often, because I think that it kind of comes from that very beginning of listening to what families wanted, to putting it in a proposal, to putting those ideas into practice that has made it so that the Partnership truly is family- and child-focused. It's not a matter of professionals thinking of what they think. You know, we know we can tell you what you need. No, it's listening and giving that respect. I feel like a colleague. I feel like people respect me and respect my opinions and experience as family member, and that's welcomed, and it's really looked for, for advice from my colleagues and the school-based clinicians and the resource unit.

Soon, my job is going to end. I'm not quite sure how soon. But part of my job is to find a family member who is receiving family services and to train that person to take my job. I don't think it's going to be that hard, though, to train somebody to do my job because the training comes from living the life. It really does, because the job is really supporting people and helping staff members to be family-aware, and I don't think that that's going to take a lot of training. There are so many family members that I talk to who really will be able to do the job. It's going to be a problem choosing the one, not finding, you know.
It's not that they're not out there, because they are.

I'd like to introduce a couple of people to you, if that's okay. Elaine Folks and Shirley Henderson are here with us and they are family members from The East Baltimore Partnership, and Angela Lloyd, who is also a family member on our Family Advisory Committee, which is made up of mothers of children who have mental illness. They help me to think of what are the things that we need to do with our support groups and our education and the newsletter, and so that is all made up of family members. And I thank you very much.

**Philip Leaf:** Morning. Before we get started, I wonder if all the parents would stand up for a minute. I was worried about that. Usually I'm not all that concerned about presenting either what we're doing or the researcher things because I know most of the people in the room are going to be researchers and they probably don't know what's going on anyway, and if I just tell them I'm from Johns Hopkins and I have nice slides, it will sound good and they'll go away impressed. But I think clearly given the room is filled with people that actually know what's going on, know how systems or services are or are not working, that know what the gaps are, I'm not going to sort of try to tell you what we've found. But what I'd like to try to tell you a little bit about is the perspective that we're trying to take. Some of it was conveyed by Susan. In any research area, you really need to understand what it is you're trying to do research on and the people you are trying to do research with. If you're talking about children who have serious emotional problems, you really need to understand the needs of the children, of the families that they live with, and the service systems that they're in.

Part of the philosophy of the program at East Baltimore Mental Health Partnership is that it takes a village to raise a child, and that has two important perspectives. One is, we often, as researchers, focus very narrowly. We focus on psychiatric disorders even though we like to talk about strengths being really important; we very rarely do research measuring strengths looking at what's going on. But we also focus on, categorize this is how we're going to describe children and how we're going to describe the family. And the reality is that if it takes the entire community to support the family, support the children, then understanding where some of the problems are, they're really community problems and they're essentially the ways we have structured our schools, the ways that other things have evolved, and unless we really take a much more systemic approach, both in terms of doing research and who to involve in the research and solutions, we're really not going to have very good pictures of what's going on.

I should confess, I only moved to Baltimore about four years ago. The project has been going on about two years. Much of the work that the project was built on was going on
for six or seven years, so I can't claim credit either for the success of the project or even getting it going, but what Baltimore had been able to do with the families, the political leaders, and church groups, had been able to come together to really be thinking about the problems that existed in the community and to sit around tables and try to talk about their solutions. I think some of these are the results of our program and I think its success has been the ability within Baltimore, and I'm not saying Baltimore is unique, but I think one of the things was being able to get the state-level people, community-level people, academics and family members talking about what do they see as some of the problems and what do they see as some of the solutions. Grants can't necessarily come out without anybody knowing about it; we actually had been meeting for about nine months before the request for proposals for the grant from the Center for Mental Health Services came out, and the whole purpose of that meeting was to talk about where do family members, where do providers see are some of the gaps and could we brainstorm about some of the solutions. And it was very interesting the kind of issues that came up, the kind of solutions that came up really were things that everybody was able to agree on, and then we were able to sort of come together with these solutions.

So I think a perspective, both in terms of thinking about how to do research and what it needs to be on, is having this broad picture, and we've expanded to some extent in terms of needing to include families. The people who are involved with our children, people in schools, people in social service agencies, have found enormous strength in our particular community. And in the churches, the church groups in terms of the resources, the members of the congregations were able to be involved in and to work with families. So those are some of the things that we wind up doing. And so besides being sort of just a theme, when we think about research in this area, you really need to think about the broader picture.

Clearly, one of the things that many of us are interested in is how to move the 87% of the dollars from the 2% of the kids. And as researchers, we spend lots of time describing that. But what we were able to do and gain from the parents is to understand the processes and why is it that we can't get services to kids until they're really enormously in need, and until families are almost dropping children off at emergency rooms and saying, "I just can't take this anymore." And not just families. We found an enormous number of foster parents who are dropping off their kids. So given the system couldn't take care of it. One of the things I think that researchers have an interest in is that families and community people are really important within their own communities in understanding the structures and the processes that really have led to this situation. A number of us are working in programs that have common principles, and so one is that the system of care needs to be child-centered and family-focused. Here, both in the State of Maryland and in our local planning board, we actually have institutionalized this in terms of the goals of these
different sectors, but from a research perspective, if you're really funding child-centered and family-focused services, we don't really have good ways to study that. We need to work with parents, work with families to develop questions that really reflect what that means from the family's perspective.

We also have talked about the system of care being community based with local services as well as management and decision-making responsibility resting at the community level. I'm really fortunate to be working in a community where there are a lot of good community people. I think one of the reasons we were able to get our recent empowerment zone is because of the local community leaders. How to move things to being community-based doesn't mean that the professionals in the community are running the service system. It's the people that are living in those communities who need to really have control over the schools, social service systems, and the mental health service systems.

One of the things that we're working on in Baltimore City, and this is with the mayor, with the political structures, and with the governor, is how to do that from a research perspective. One of the things that we need to do is monitor this, and this is the thing that the families and groups are involved in. Are these service systems moving, are they just changing? Are the families really getting more control over what is going on in these communities? Having come up with some of those ways of easily assessing those things, so that in your community, you would know over a couple of years if things are getting better or worse from the community control issues. Then we really take this to heart in our program. We're really not trying to work with the professionals; we're really trying to work with the parents. Parents really are responsible for their children, their children's participation in the community. In our neighborhood there is often really very little opportunity for the children to participate, when we have schools that aren't really working very well. We need to engage the parents and other community leaders who have other interests in children to really be able to work at a community level to improve the general community structure.

Looking at it from the other perspective, the other thing that we've really spent a lot of time doing research on is the whole issue of out-of-home placements. I think, as researchers, we've got to focus on what's going on with children in moving kids out of home. The reality is, we really need to be looking at the whole process or we're really never going to be able to be putting together these systems that prevent unnecessary removal of children from their homes. But one of the things that parents have talked about constantly is how their children were expelled from school several times and it's almost only after the kids have been kicked out of school several times that you can even mobilize serious resources. We talk to the schools who say, "Well, yeah, you can get rid of a kid, but you're going to be getting somebody else's kid back in because we're getting
kids referred in," and unless we are able to work again with the institutions and communities, these aren't just family issues. These are really the ways that our infrastructure, our churches are structured, our schools are structured; we're really never going to be able to have a good continuum of care, a good continuum of services. So I think the real strength is both in our research site and in trying to frame the question. The researcher has certain skills and a lot of idiosyncratic ways of manipulating data, but the more successful researchers are able to come up with questions and figure out how to answer those questions.

Those are the same skills that people in business have, and they are the same skills that parents have, that people living in the community have, in terms of how do you get by on a day-to-day, how do you make your community better. And so, I think I'd like to say that research isn’t a four-letter word. Probably researchers are, if this wasn’t this company, I would say dysfunctional and disadvantaged; disadvantaged in that most researchers and most research that is submitted isn't funded. Most researchers aren't able to put together projects that work very well. And I think that working with parents, working with people who really know what it is that's being studied, will contribute enormously to the researcher's ability to look good. Certainly I was able to collate information from lots of people in Baltimore City, to take pieces of projects that are working really well, and put them in a proposal. But our project and our grant should never have come together without having talked to the parents and the families in the community. And I think that, for people who are trying to develop services as well as trying to develop research projects that are going to explain what's going on, families clearly are the key resource and to some extent, rather than thinking about how can we train families and work with families to get engaged with researchers, we really need to figure out how do we get to the researchers and really get them to understand that it's in their best interests. That they're going to do better research. They're going to finally start to understand what it is that they're looking at; but they're only going to be able to do that by really working with the parents. And it's not just talking to them at the end of the interview, but really involving them in the entire process of defining what the questions are, defining how you go about answering those questions, and most importantly, when the data is in, figuring out what to do with that, and for the next study. But now researchers also like to have impact on how they can work with families and other people in the community, to take the information and then use it in a way so that the community gets better and the lives of our children and families get better.

**Mary Evans:** Hi, I'm Mary Evans, I work at the New York State Office of Mental Health. What I am supposed to be doing there is to try to develop policy and program relevant to research that will make a difference for the citizens of New York who are seeking services.
One of the things that came up about five years ago was that the National Institute of Mental Health and now the Center for Mental Health Services had made available grants of money for doing what they call research demonstration grants in which you could either start up a program or enhance a program and then study the outcomes that are associated with that program. Our group got together and wrote one such grant and, shortly after that, got funded; we turned around and wrote another grant because I was really passionately devoted to the idea of trying to understand the outcomes that are associated with crisis services that we were offering in the Bronx, New York, and the intent of in-home services that were available there.

Now as you look at me, you can understand why my boss laughed when I told him that I intended to go to the Bronx to do this work. He says, "Well, Mary, that's really nice. It sounds like an interesting idea, but you're going to blend right in with that population down there in the Bronx." Because I am, as James Mason would say probably, a white lady, and my mom would love to hear you say that I'm a lady because she was always hoping for that. But that's absolutely correct.

And so the other thing that you would need to know about me in terms of my cultural incompetence, I suppose, is that I have no children and never have had any children. And estudio español, but that does not make me culturally competent. So, therefore, I needed to get folks involved with me in this project that would ensure that what we were learning in this project was going to be useful for the folks that we were engaging in the research with us.

And so, we did a number of things as we were preparing this grant. First of all, we had working with us on our first project that we got funded, parents who had raised a child who had a serious emotional disturbance. I asked Ginny Wood if she would engage with us in helping us put together this second grant to help me understand what it is like to have a child that's in crisis, to have a family that is in crisis, and try to seek services, and the frustrations that are involved in it and how you know when there has been a successful outcome from your own perspective.

The next thing that I did is that I went down to the Bronx, and I started making home visits with the folks that were going in with the intent of in-home services so that I could see and feel and smell and taste and really get involved in what it is like to receive these kinds of services in the Bronx. What the problems are, what the frustrations of those parents were, to try to understand from a better perspective the kinds of services or program enhancements that we might want to bring to the program that we were developing in the Bronx.
We also put together a management group for the grant once the grant got funded and in that management group we had a lot of the bureaucrats from the health hospitals corporation and from the local psychiatric center and from the Bronx borough office and the New York City Office of Mental Health, but we also put on there Ros Moore from the Parent Resource Center in the Bronx, and then Wanda Green, a parent who was working with the Parent Resource Center. And so we began to develop some relationships with folks down in the Bronx who could help us. We partnered also with the Hispanic Research Center down in the Bronx. The Hispanic Research Center was helping us to develop instrumentation that would be culturally relevant for the population that we would be studying. And to do so, we pilot-tested all of our instrumentation. The Parent Resource Center and some of the folks who were living in the Bronx helped us by getting us parents that we could pilot-test some of the instrumentation on to try and get some sense about whether or not it was relevant, it was family-friendly, it was understandable to them, and also if there were other things that they really thought that we should try and measure with the study that we were doing.

As we developed the project and got the project funded, we also began to understand that even though we had done these things to try and ensure a culturally competent program and a culturally competent evaluation, one of the things that was really important to us was that we didn't have a very good understanding of the direct experience of the parents who were receiving services in the Bronx, and that we thought the best way of really getting some handle on that experience was to send the parent with our interviewers into the home when we were doing data collections. And therefore we asked the parents to identify for us some parents that could help us with our next data collection. To help us get some understanding of what parents' experiences really were as they have received the services and were continuing to struggle with the issues and problems on a daily basis. So Yvette Nazario joined us in going into the homes, and I'm going to let Yvette talk about what her experiences were.

**Yvette Nazario:** Good morning and “Buenos dias.” At the Parent Resource Center, I noticed that going inside and telling the parents that I have a son and a daughter with mental emotional problems, it’s a good feeling. It's not just going inside and saying a professional is coming in there, oh, your son needs this or your son needs that, but when they see them in talking to me and doing the interviews and I tell the parents that I do have two kids, they feel good. More often, they feel like they could ask all the questions. And the kids know me. When I told one of the kids that I went to that my son has emotional problems, he told me how he's doing and he felt so good when I told him that my son is doing wonderful, and you’re doing good too. He said, "Well, how he does, what do you talk to him...?" and asking so many questions. It's a good feeling for the
I'm one of the parents that was against medication. My two kids are on medication and it's doing wonderful for my kids. And doing this is getting me more support in helping my family and helping other parents that have kids with emotional needs. Parents feel more relaxed talking to another parent that knows what's going on, that they're not alone, because there's been times when I've been crying and in tears when I was lost. If it wasn't for the parent support group, that they're out there, the Parents Resource Center, research, and all the support that I got, because in the Bronx we are a family and we work together.

And, it's like I didn't know my daughter had emotional problems. I just found out about it recently, and it's helped me out so much knowing so much information and meeting other people that we could talk and we could relate to, and tell them that if one of your doctors tells you that your son needs medication and they don't tell you why, keep on asking. Because some medications they will do harm, but not all of them. You have to know why they need the medication. And parents, they won't even ask because they are afraid, because they could be labeled things, like ADD. You don't know what that is, I don't know what that is. And you're explaining to them going inside this interview, and making people feel so good. I've been going to all kinds of races: Spanish, black, everything, and it's like they feel good. My Spanish, I have a Spanish and English accent, and they feel good. “Oh, she knows what's going on.” I'm from the Bronx, and everybody knows. “Oh, she knows what's going on; she's talking for real.” And they feel good about it because, when we were growing up, everything was secret; you couldn't say, “I guess you're having a problem with your daughter.” Oh, don't say that, because again it's like that's the biggest thing, the biggest gossip there is; but now in these days, it's out there. We got to help. We just got to keep on with the power of love, keep on talking. If you think this is not right, don't give up; just keep on because these kids are going to make it. And I'm going to fight it and I'm going to keep on for these kids.

People, you're not alone, because I was; you're not alone and we all together can work this. And the kids are going to make it. They're going to be professionals too. They ain't going to be behind. And the kids on medication, it works. It depends on what good it works. And the families that I've been going to, they are so helpful, and we could talk and I play with the kids. They love my ring. They play with the ring while we're doing the interview, they love my ring. And they ask me so many questions, that it's a good feeling. It's not just a professional going inside there alone. But when you go in with another parent, and that parent has been there, you give them so much support, they're not alone no more. They're not alone, and it's like, I love it. I like what I'm doing. I'm getting more help for myself and my family. I can communicate with my family, with other people, and tell them that we could all get together and go out. We do so many...
things with the Parent Resource Center and the research, that we can go out with them and the kids will feel good, being with everybody that's been there. And all these kids, they run around, they talk too much, but hey that's the way they can talk. Now, my kid could talk. Now, people will look at you; “Oh, he's talking so much, why can't you discipline? That kid needs discipline.” It's not that. You don't know what's going on. But when we're all together, we can help each other. One hand washes another, and we are working on it and it is wonderful and I love what I'm doing. And I'm going to make this short, thank you for listening.

**Valerie King:** That was wonderful, Yvette, just wonderful. I'm Valerie King and I'm with Citizens Committee for Children, and I would just like to tell you a little bit about the Citizens Committee for Children in New York City and the research project that we're doing that includes parents as full partners in our research.

CCC, Citizens Committee for Children, is an advocacy agency in New York City and we advocate for all needs of families and children. Our mission is a better life for children and families in New York City. We advocate in the area of health, education, housing, juvenile justice, child welfare, and mental health, and I'm the mental health consultant at CCC. We're a citizen volunteer organization. All of our projects are developed from our citizen volunteer group.

The research project that we're doing looks basically at the full continuum of mental health services for children in New York City. We've looked at different facilities throughout all five boroughs, and we are concerned about the gaps in care. What we have in New York City is something we call a kidlock, after gridlock. I have the feeling from my experience here in Portland that you don't have much gridlock here in Portland, but we have a lot of it in New York City. And what kidlock means in New York City is that children are having difficulty accessing beds in inpatient and residential treatment facilities and there are long waiting lists at many of these community mental health centers. What we are doing is looking at the length of stay at inpatient residential treatment facilities and at the ability of the community, the school and home-based programs to provide services for these children.

Well, how do we go about this? We did this basically by asking: who's the research for? Is the research just for professionals or for providers, for our mental health legislators? The research is for the children and families, so in order to design the research project, I felt and convinced our members at CCC that we had to go and talk with children and families, and have children and families included in the research project. We were able to do that and we got a lot of positive support. We must recognize the parent support groups throughout the five boroughs in New York City for having supported this research.
We included parents and older youth in the design of the research project. We trained parents as interviewers when we went on our site visits. We trained parents to be involved in all parts of the study and as guest speakers. Parents came to our monthly meetings and shared with us their experience. We also interviewed 20 parents so far, and it's ongoing, to tell us their story, to put a human face on the research project, and it really has made a difference. As I said, it was difficult in the beginning to convince some of our board members who were like some of the dinosaurs that we saw in Peter Jensen's last slide who were saying, "I'm not so sure I like the way things are going," but basically I said; "Who is the research for? We have to include families and allow them to tell their story and allow them to take part in this research project.” Some of the psychiatrists who are volunteer participants said, "Well, that's okay, Valerie; maybe after we collect our data, you can go and talk to a few parents." And I said, "No, that won't work, we won't do it that way. We have to include parents from the very beginning.” Some of the parents who I invited to join us said, "Well, I'm not so sure about being in a work group and meeting once a month with psychiatrists, psychologists and social workers because I have to see enough of them when I go for my appointment." But they found that I said to the professionals in the group, “We have to park the professional hat outside the door, when we come in to work on the study, we're all here together as full partners in the study and we have to cooperate and collaborate as partners.”

I've given out some of my buttons and magnets and a tote bag full of CCC reports to Barbara Friesen, so that if you would like to get some information about Citizens Committee for Children and would like to read some of our previously published reports on mental health services, you can contact her and she'll give them to you. Also, there were some handouts that looked like this with a CCC on the top and you might have seen some of the drawings. By the way, all of the drawings in our published reports are done by children at an arts program in Brooklyn, New York.

But back to having parents involved. As I said, parent resource groups in each of the boroughs and I have had the honor of getting to know the citywide parent advocate and getting to know many of the parents in these resource parent support groups, and it really has enriched the study, it has really enhanced my work and it's broadened my experiences, and Yvette, you are not alone. As long as I'm at CCC you will have a voice at CCC to articulate the needs of children and families in the mental health system. Thank you.

Mary Telesford: We’d like to open the floor to questions from the audience to any of the panelists.
**Conference Participant:** Hi. Can you hear me? I went to many, many of these things and all I hear is research, whatever, whatever, and all this money that all these people get. And then I hear all these volunteers, all these mothers, all these parents, but I never hear anything... then I hear we're partners, let's join together. But then, let's volunteer. But all these professionals have a full-time job. But the parents that we're supposed to be helping, that live below the poverty level, I don't hear anyone that's got a full-time job that's making as much as that person that took all this information, put it into this proposal or this grant, and I guess I'm just waiting to hear someone say what else do these parents get besides taking their information and putting it into, and getting this grant... that's it.

**Yvette Nazario:** Hello; okay, I started as a volunteer but I'm not now. Okay, I could make a little bit more, but I'm not a volunteer. I do work part-time and I could provide for what I'm making.

**Susan Tager:** I don’t live below poverty level; I work full-time and the person who will take my job will work full time. Okay, but the person that takes my job is coming from the project and will be paid in a full-time position. That's one, okay, that's one.

**Conference Participant:** I think what you are saying, if I understand correctly what you're saying, is that parents are asked to participate in a lot of things and they are never paid. If the bottom line is, do you get paid? The answer is no, you don't get paid. And I think that's one of the concerns; we write grants and talk about research and what we're going to do, that we don't assume the parents are automatically going to just give of their time, energy, and information and not get something for it, because not only is it, if you have $90,000 and the people that you are partnering with get nothing, we know that's not a partnership. At least that's what you're saying. You know, partners mean equal in some way, and that's something that we really have to look at, and I think researchers really need to hear that, and that when they are writing their grants, because they write grants and have line items, that they put that line item in there to pay parents for their participation as partners. Is that what you were saying? Thank you.

**Conference Participant:** Speaking as a parent, you don't get paid, but the services that you receive sometimes are so much of a help so we don't matter about the money. When you're doing this research, the parents are going in, they don't know about the line of services that are available, so where we are connected with the services, that's more than enough because we're being helped. Because you're being overwhelmed with the psychiatric, the medication. You have to pay for all of this whether it's insurance, or medical assistance. When you get hooked up into these partnerships, you get free counseling, you get all types of services provided for you and your family. So that right
there compensates a lot for the money. You don't actually need the money once you start receiving the services because it's a great help for receiving the services.

Valerie King: There is something I would like to respond to because I know I use the word "volunteer" quite frequently and that is because our agency, Citizens Committee for Children, is an entire volunteer agency with the exception of a very small staff. There are only five staff. We have almost 150 or 200 volunteers. These are citizen volunteers. Some of our volunteers are from the mental health professions, grandparents who are interested in just giving their time to make a better life for children, and parents who are interested. It's all on their initiation, to some degree, to become a part of the process. I have found that the work that I do, that parents will come up to me and say, "We really enjoyed this, we've learned a lot in working with you." And I find that very, very helpful, and my response to them is “I'm learning from you as well.” It really is a partnership in that sense, in that we're teaching each other as we go along the way.

Conference Participant: I have a question. Piggybacking on this issue of economics and research and talking about reform. Are any of your projects looking at reforming the way research dollars are being spent since parents' and so-called volunteers' expertise and professionalism and skills are being used? And can we look forward to some kind of report at one of these conferences where we will be partners? I feel we need to be careful about the words we are using, volunteer and partners. Let's be real, we're in America, and partnership means equality, so they say, and behind that, if you don't have dollar signs, green which is the color that everybody likes, we do not get anywhere. So I'm really looking for reform of research that involves families and parents because we do have skills and we do have expertise. Without us, there will be no research. That's my question.

James Mason: I think in response to the question, the preceding question, one of the things that we've learned at the Research and Training Center here in Portland with respect to parents being involved in research are two critical dimensions that have to be considered. One is the budget. I mean, we talked about line items. We have to be prepared to create line items where we can compensate parents for such things as their time, for their expertise, lodging, per diem, for special childcare needs and things of that nature, and if that isn't advocated for or built into the research design and the proposal process itself, you may be kind of shooting yourself in the foot inadvertently and turning parents off in the long run, because there will be that sense of exploitation.

The other thing that kind of goes along with organizational culture is that often, if we don't pay someone for their advice, for their consultation, we may not take it very seriously. When we bring a consultant into town and we pay that person handsomely, we
tend to try to utilize that information to the fullest degree. So another reason for trying to suggest ways to compensate parents for their time and their expertise is that if we don't, we will trivialize their information and we won't value it as much as when we pay people. Often good advice, if it's not purchased, won't be utilized. Those are some of the things that are reflected in some of our more recent products that come through the Portland Research and Training Center.

The other thing that gets in the way with respect to compensating parents is the whole policy issue. We've had trouble compensating parents by virtue of our bureaucratic procedures where we don’t have a social security number, we don’t have a precedent. So, again, as you begin to think of involving parents, I think you want to be real careful about that. You need to look for creative ways to create line items to compensate them for their time, and you also want to look for policy barriers, which, even when you have the money there to pay, there may be a political impediment to doing something.

So the questions that you're raising are very germane, and I think, from the standpoint of conducting research and involving parents, we're still pretty much in our infancy stage. Before we get to you, there's a hand in the back.

**Conference Participant:** I want to say that everybody up there almost said that they reach out to the churches and the community leaders, but nobody's hitting the core of the problems because they do not reach out to the people that are not in those social settings. So therefore, not reaching out to those people is not getting a true diagnosis of what the issues are and how are you going to start working on that; also in that paradigm shift, I mean how do services for the undiagnosed get paid for? You know, this is supposed to be prevention and intervention and nothing happens until a child gets a diagnosis, and these are one of the issues that we are also looking at. And as for parent volunteerism, there is too much collaboration without coordination and especially on the parents' side. And then the barriers of what the research calls for when you're coming out and reaching to the community. All they do is look at the guidelines of what that research is and not really listen to what the community needs are, so the interpretation of what the answer is is sometimes not there because you missed those vital points, because you only have a viewpoint that is very narrow. And when people are saying, "My family's in crisis," and they're talking about something that's not indicated that was in the research, they don't look at that as something important. But those parts are the core of the problems that create families that have multiple issues.

**Conference Participant:** I'd like to make an addition to two comments. One, Deborah mentioned that research and programs are touching on people who have already been diagnosed. My whole issue is the kids in the street. Where I come from, children are getting shot down in the parks. People coming out of church are just getting sprayed with
bullets and falling on the sidewalk. The kids on the corner are not being addressed at all. I have not heard them addressed since I've been in Oregon. That's one of my issues. The other one is about parents getting paid or not getting paid, and some parents are getting services. Some parents need services. I don't need services. That's why I'm here because I was so blessed to raise 10 children without needing services that I thought I should give and I want to give, but I can't give and live without pay.

**Conference Participant:** Can I just add one thing to what she was saying? I'm a case manager and I work with Children's Hospital Early Intervention. Those services are already there. Medicaid, practically all of our cases and our department survives off of Mass Health, which pays for those services. You are in the United States and you're entitled to those services. So don't be grateful for them. Even if you don't work. For all of those people who get Mass Health, Medicaid, and everything else, their parents have worked or their forefathers have worked, and they've taken our taxes just like everybody else.

**James Mason:** Please thank the panel for me and the people that brought up the comments. Thank you.
SECTION II
Summaries of Paper and Panel Presentations
Increasingly, families of children with serious emotional and behavioral disorders want to make mental health services more responsive to their needs. One important way to help create change is through program evaluation -- the collection and study of information to improve service programs. This presentation shows how one family-centered program, Project Connect, has included families in evaluating its program and learned ways to improve.

Project Connect, a service of the Massachusetts Society for the Prevention of Cruelty to Children (MSPCC), is designed to develop, implement, and monitor interagency treatment plans for children and adolescents who have serious emotional disturbances (SED). The mission of Project Connect is to provide the coordination and creation of services necessary to keep children in their own homes, their own schools, and their own
communities. In addition to other strategies, Project Connect utilizes both Parent Partners -- experienced parents of children with emotional disturbances -- and Interagency Service Teams to provide crucial support and coordination. Project Connect’s philosophy embraces the core values of the Child and Adolescent Service System Program (CASSP), invites parents to be equal partners in the treatment planning process and focuses on the strengths in families and children. It is funded through a grant from the Massachusetts Department of Mental Health and covers 26 cities and towns south and west of Boston.

The experience of I.V. McKenzie, the mother of an eight year old boy with Attention Deficit Hyperactivity Disorder (ADHD) and associated emotional disturbance and behavior disorder, provides insight on how Project Connect works in partnership with parents. The family was referred to Project Connect following an inpatient hospitalization of their son, but was exhausted at that point. They were reluctant to become involved with yet another person or agency and tell their story over again. However, the fact that the Parent Partner from Project Connect had been "down the same road" helped to make the initial meeting very comfortable. At their meetings with the Parent Partner and later the Interagency Team, they were made to feel like active partners rather than simply service recipients. Their input was used in the development of the service plan, and the focus on family strengths resulted in a plan with services to support all family members. Services included use of a behavioral specialist, respite care, and a sibling support group as well as after school and therapeutic recreation programs for their son. The parents were still the primary decision makers throughout, and felt no loss of control over their son's life.

To develop their evaluation methods, Project Connect worked closely with the Technical Assistance (TA) Center for the Evaluation of Children's Mental Health Systems. The TA Center is a federally-funded program at the Judge Baker Children's Center in Boston that aims to promote evaluation of systems of care for children.

Focus group: One strategy was to convene focus groups to learn about families' experience of Project Connect and identify areas in which services could better fit families' needs. The parent focus groups also provided feedback to help shape the caregiver questionnaire discussed below. The groups were conducted by a consultant from the Technical Assistance Center who solicited information from the parents through a series of open-ended questions. The fifteen parents attending identified respect from the service system and increasing the self-esteem of their children as important goals. The single change parents most wanted was better understanding and acceptance of their children who had emotional disorders from extended family, particularly grandparents. Other goals were cooperation, understanding, and support among nuclear family members. The most critical services to help them meet their goals were therapeutic
recreation programs, respite care programs, flexible funding streams, and after-school programs. An unexpected outcome of the groups was to provide a forum for parents to network with each other and to start forming natural support systems. I.V. McKenzie attended the focus group, and found that parents were not just routinely being asked for feedback, but were being involved in a larger way to help shape a program that was still changing.

**Caregiver questionnaire:** A brief questionnaire was also developed to assess parents' or other caregivers' satisfaction with Project Connect. Parents in the focus group provided feedback on the questionnaire to help make it more sensitive to parents' interests. Questions concerned: 1) the process by which services were provided (e.g., were parents treated with respect and dignity); and 2) family outcomes of Project Connect, such as increased knowledge about obtaining services, help to stabilize children at home and improved coordination of services. Additional questions asked whether children's behavior had changed while involved with Project Connect. These questions addressed, for example, children's need for hospitalization, aggressive/assaultive behavior, and mood/behavior changes.

Four and five-point Likert scale questions that ranged from very dissatisfied to very satisfied were used. Scales ranged from 1 (greatly deteriorated) to 5 (greatly improved) on children's behavior items. Volunteers from the community conducted a telephone survey of 34 parents or other caregivers who were served during Project Connect's first year.

Data analysis of the instrument revealed that questions could be combined into three internally consistent scales measuring Satisfaction with Process, Satisfaction with Family Outcomes and Child Behavior (all Cronbach alphas exceeding .80). On average, parents were satisfied with process (mean = 3.5 out of 4), and with family outcomes (mean = 4.1 out of 5). Parents, however, reported no change, on average, in child behavior (mean=2.5 out of 5).

Additionally, parents who attended educational forums were more satisfied than those that did not (t(28.04)=2.78, p=.01), and parents differed in level of satisfaction depending on which regional support team worked with them (F(3,27)=2.81, p=.058).

One respondent to the survey was I.V. McKenzie, who found it thorough but consumer-friendly, and felt more respected and empowered because of the survey. She felt that the questions on Satisfaction with Process and Satisfaction with Family Outcomes were meaningful and useful, but that questions on Child Behavior were not realistic because of the seriousness of children's difficulties and the short-term nature of the program.
Discussion: Project Connect is a good example of how a new, small program can successfully include family members in program evaluation to help improve services. The focus group provided an expanded vision of families' needs. The questionnaire, designed in consultation with parents, provided evidence of parents' satisfaction with services, identified specific areas of strength and weakness, and raised questions for further investigation about the impact on children. The difference between reports of family outcomes and child behavior must be interpreted in light of the seriousness of children’s difficulties and short-term nature of the program.

From the results of both the focus group and the survey, Project Connect has modified its program to make it more responsive to parents. The program changes included replacing an interagency team member who made parents feel inferior; changing the room design in one meeting location to create a more inclusive, supportive atmosphere; developing a more flexible policy regarding closing cases; and including extended family, particularly grandparents, as part of the planning process. One of the easiest but most symbolically significant changes that Project Connect made was to invite professionals to the treatment planning meetings on behalf of the parents. This minor change helped create an atmosphere in which the meeting is the parent’s and people are invited to support the parent. The most difficult change has been to get grandparents involved due to the lack of information that they have about the issue and the reluctance of some parents to ask for their help.

Because of their in-depth knowledge of their children and their stake in service programs, families have an important role to play in every facet of program evaluation. Historically, however, family involvement has generally been limited to providing information. In the future, this could be a "growth area" for families, who could partner with professionals to help shape the design and use of program evaluation.
The New Hope Unit at Southeast Louisiana State Hospital is a family-centered brief-stay adolescent unit. Located in Mandeville, LA., the program employs the family-centered approach from admission to discharge in treatment of adolescent patients. This presentation encompasses a short introduction to the Unit, followed by a discussion of the origin and mission of New Hope. Map and slides illustrate patient demographics and the catchment area of south Louisiana where most patients reside. The New Hope Unit compares metaphorically with gumbo, a stew originating in southern Louisiana. Special ingredients go into gumbos and the New Hope treatment program - varying from recipe to recipe and from family to family.

Staff of the New Hope Unit has embarked on a program evaluation, using a questionnaire to assess post-discharge adjustments as measured by parental perception of symptom remission. This evaluation compares parental rating of symptom remission with level of parental participation in the New Hope program. Discussion includes problems related to follow through on this endeavor.

Psychiatric inpatient service, both by definition and treatment strategy, is changing. Currently, symptom remission is the focus of inpatient settings. At New Hope, programmatic design and operation address these dilemmas and strategies. From admission, the New Hope team brings the patient's family into the treatment process. This
involves integration of staff, patient, and family and continues through subsequent interactions. A case presentation illustrates how family involvement directs focus of treatment from behavioral problems at admission to systemic restructuring by discharge.

Other vignettes from coed psychotherapy group and multi-family group illustrate ingredients of the New Hope gumbo. Patients bring family focus to group issues. Multi-family targets family support, preparation for discharge, and re-integration with the wider community. As metaphorically compared to a Calder mobile, family involvement is crucial to establishing a healthier equilibrium for patient and parents.
One of the criticisms concerning research on family preservation and other family intervention programs is that outcomes are often measured only from the perspective of the service system (e.g. placement) or of the service provider (eg. worker ratings of family change). This session reported on a study of family preservation and family-centered services that asked families to rate themselves at the beginning of services and again six weeks later. The six-week rating was at the termination of family preservation services and at the mid-point of family-centered services. The findings, from a master's thesis by Laurie (Armbrust) Arndorfer completed at the University of Iowa, were introduced by Kristi Nelson, supervisor of the research, and discussed by Thomas Wright, a therapist from Intensive Family Services in Portland, and Marjorie Pace, a family member, both of whom participated in a similar study in Portland.

The Iowa study included 21 families who received crisis intervention services paralleling the Homebuilders program and 18 families who received longer term (four to six months) family-centered services between September 1992 and February 1993. Three instruments were used to assess family functioning and case outcome: the Family Risk Scales (FRS) (Magura, Moses, & Jones, 1987) and the Family Systems Change Scale (FSCS) (Nelson & Landsman, 1992) completed by the worker and the Index of Family Relations (IFR) completed by the family (Hudson, 1982).

Despite differences in the populations and service approaches in the two programs, one surprising similarity was noted. At the six-week point, families in both groups rated themselves as having significantly more problems than at the outset of services; workers noted significant improvement on both the FRS and FSCS. The majority of families were also rated by the workers as improved on the 12 items in the FSCS.
Further analysis revealed that families who rated themselves as having few concerns at intake rated themselves as having moderate to severe problems six weeks later and some families who rated themselves as having moderate problems increased their ratings to severe. Since it is unlikely (although possible) that services caused families to get worse, an alternative explanation is that families became more aware of or more willing to discuss problems. Clinically this is a positive result, indicating that families had moved from a pre-contemplative stage (Prochaska & DiClemente, 1992) to more readiness to recognize and address issues and concerns. This is an important change especially if the family has not voluntarily sought services. This result is less desirable, however, from a research point of view since two-thirds of the families seemed to have gotten worse and only 10 percent improved. This raises important issues when evaluating brief intervention programs since such results would be interpreted as indicating that the program was not effective.

Both discussants agreed that families in crisis and workers trying to assist them have a difficult time giving priority to research and completing lengthy research instruments. In Ms. Pace's experience, things did get a lot worse before they started to get better and it was likely that this change would be reflected in the research instruments. To get a true picture of family change, it is important to contact the families for follow-up interviews several months after the termination of services.
Families who have children with emotional or behavioral disabilities face multiple and complex challenges in their daily lives. Even though parents shoulder the ultimate responsibility for assuring that the needs of both their child with a disability and their family are met, only recently has the professional establishment asked for parent input about what types of support are effective in making life better for their child and family. This report presented preliminary results of a study conducted with 100 parents in Oregon who have children with a wide range of emotional or behavioral disabilities. Survey research methods were used to explore parent perceptions of the effectiveness of the informal and formal support their families received.

Results indicated that, while parents perceived as helpful both informal and formal support, informal support was generally perceived as the most helpful. There was strong evidence that parents relied on family members the most and friends the second most when they needed someone to talk to about their concerns and challenges they faced raising their child with an emotional or behavioral disability. In addition, while parent-run support groups were rated as very helpful sources of support for families, only 35 parents reported participating in these groups. One recommendation is that parent-run support groups and advocacy organizations be viewed by professionals as important sources of support to families, and therefore be nurtured, encouraged, and be considered partners in providing comprehensive services to children and families.

Preliminary analysis of data regarding family service coordination revealed moderately strong relationships between receipt of functions of service coordination and parent perceptions of success in getting the help they needed and satisfaction with family quality of life. In addition, although families were generally receiving assistance from more than one professional, over one-fourth of parents surveyed were receiving none of the functions of service coordination and a total of fifteen families were receiving at least four of the five functions (i.e. assessment, service plan development, linkage, monitoring, and advocacy) described in the literature as important to effective child-centered and family-focused service delivery. Only 7 of the 100 parents surveyed
reported they were receiving the 5 critical functions in addition to assistance to learn how to access services more independently and to communicate effectively with professionals (i.e. self-advocacy).

Initial exploration of the relationship between receipt of service coordination and child and family outcomes suggested that further research is needed to clarify appropriate child and youth outcomes based upon input from these children and their families. Recommendations for future research include the development and implementation of research efforts, using both qualitative and quantitative methods, to allow parallel study of the microlevel and macrolevel factors which may influence effective service coordination. One result of these efforts would be the development of an operational definition of family service coordination which could be systematically evaluated for its effectiveness.

A second recommendation is that small-scale efforts which systematically incorporate informal and formal sources of support into the process of assessing, developing service plans, and implementing service delivery be developed and evaluated to establish their efficacy and cost effectiveness. Finally, results of this study suggest that parents of children with emotional or behavioral disabilities be involved in the development and implementation of interprofessional training at the pre-service and in-service levels to provide professionals with an in-depth understanding of the diverse needs of this population and an understanding of the parents and families who are ultimately responsible for meeting the complex needs of their children with disabilities, while maintaining the well-being of their families.
Transforming how professionals, schools, and agencies interact with families is critical to current strategies for improving educational, mental health, and community outcomes for children and their families. The importance of families as service providers was recognized during the development of the modern children's mental health movement in the 1980's, and was embodied in principles of care and cultural competence. These principles were operationalized in the 1990's, as the family movement grew (particularly the Federation of Families for Children's Mental Health and its affiliates). Principles were further conceptualized between 1990 and 1994, as over one thousand diverse individuals from families, schools, Head Start centers, mental health programs, and children's services helped to develop and to validate the National Agenda for Achieving Better Results for Children and Youth with Serious Emotional Disturbance (U.S. Dept. of Education, September, 1994).

Although transforming the way in which families are viewed and treated has become a fundamental tenet of many human services and educational initiatives, problems remain at the operational level. Professionals often complain that families do not respond to them or respect their knowledge. Families still complain about being ignored or marginalized. These are not rare occurrences. Site visits to and reports from many programs suggest that service approaches remain agency-focused and "parent unfriendly."

Recasting relations between families and other service providers is central to achieving all 7 National Agenda targets to: (1) expand positive learning opportunities and results; (2) strengthen school and community capacity; (3) value and address diversity; (4) collaborate with families; (5) promote appropriate assessment; (6) provide ongoing skill development and support; and (7) create comprehensive and collaborative systems.

The evolution of the language of Target 4 of the National Agenda reflects the importance of collaborating with families. The initial label for the proposed target was "support families." After feedback from a national teleconference was evaluated, the language was refined to providing "family friendly service." The validation of the National Agenda, which included extensive stakeholder outreach and seven focus groups, led to the final
language of the target: "To foster collaborations that fully include family members on the team of service providers that implements family focused services to improve educational outcomes. Services should be open, helpful, culturally competent, accessible to families, and school-as well as community-based." (p. 11)

Changes amounted to more than simple "wordsmithing." Language and metaphors reflect what we believe, and they structure how individuals interact, as well as how interventions are implemented (Ryan, 1969; Osher & Kane, 1993). For example, there is a difference between getting families on "your team" and sharing decision-making as partners. Team members support what you do, partners share decision-making and risk-taking. Similarly, there is a difference between viewing a service provider as a "case manager" and as "service coordinator" or "facilitator." People are more than "cases." The team manager implies a greater level of authority than facilitator or even coordinator. Language and metaphors do more than structure relationships. As Hibbits (1994) suggests, "...as an aspect of our mentality's deep structure, our metaphors can reveal a great deal about us, both as individuals and as members of a broader culture" (p. 235). Transforming the relationship between families and other service providers depends upon examining and reframing what Hobbs (1983) called institutional metaphors. This, in turn, depends upon analyzing the conceptual and social underpinnings of the language that we use.

Target 4 of the National Agenda provides a case in point. Obviously, support for families (the focus of the first wording) is central to almost any intervention. Similarly, the ease with which families access services (the focus of the second wording) is central to the effectiveness of support. Nonetheless, family voice and authority -- both in the case of individual interventions and in the case of policy -- are central to defining the support needed and in delineating how that support can be made accessible to families. "Wrap-around" services look different when they are defined by agencies and professionals working without the meaningful participation of families. In the words of the National Agenda's fourth target, "...the object is to reorient family-school interactions to build a partnership in which service planning reflects the input of families' goals, knowledge, culture, and, in some cases, need for additional services" (p. 11).

No partnership, however, is easy. Partnership challenges a century of hierarchical and culturally insensitive professional/family relationships and a century and a half of "family blaming." In addition, professionals, unlike families, have a status interest in their authority and expertise (Miller & Riessman, 1968; Berlin, 1969; Bledstein, 1976; Ehrenrich & English, 1979). In fact, professionals frequently maintain their status by employing mystifying language that may confuse, demean, or put off consumers (e.g., the medical language of "co-morbidity" as opposed to "co-occurrence"). The historic pattern of professional/client relations has been characterized as "disabling help" (McKnight,
1977) in which active professionals use their knowledge to "fix" passive clients (Goffman, 1961) who are only viewed in terms of deficits. This pattern is reinforced by agency-directed planning and by administrative regulations that often reflect the political lobbying of professional organizations (Lubove, 1965).

Hard to develop in all cases, partnership is particularly problematic in the so-called helping professions (Rothman, 1980; Levine & Levine, 1992), with three primary factors to consider. First, these professions have roots (Lubove, 1965; Rothman, 1980; Gordon, 1994) in a set of assumptions that Craven (1994) described in the following manner: "Normal children, raised in good, sound, white, Anglo-Saxon, Protestant homes, would grow up to be good citizens and contributors to the nation's economic progress" (p. 29). Second, professional socialization in these fields builds on a paradigm that Ryan defined as victim blaming: "...a process of identification (carried out, to be sure, in the most kindly, philanthropic, and intellectual manner) whereby the victim of social problems is identified as strange, different" and the cause of his or her problems. Finally, the organizational models in which these professions have been organized have been characterized by what Manheim (1936) called bureaucratic conservatism -- "...the fundamental tendency of all bureaucratic thought is to turn all problems of politics into problems of administration" (p.118). These three factors have buttressed what can be called three tendencies that have framed relations between families and other service providers: (1) viewing families as the root of their child's problems; (2) ignoring the social factors (e.g., racism and poverty) that contribute to poor outcomes; and (3) transforming political critiques and family input into managerial problems.

The Center for Mental Health Services' Child and Adolescent Service System Program (frequently referred to as CASSP) and the family movement have started change. Families (e.g., The Federation of Families' Family Leadership Initiative) have educated professionals regarding the benefits of collaborating with and effectively including families. As a result, more and more professionals have started to view family members as central to their own interventions. Some of these professionals, in fact, have started to avoid the language of dysfunction. Others have developed approaches that are family focused. Although they may view the agency and professional expertise as resources of solution, they still focus planning around the needs and strengths of families.

Promising as they are, these changes are fragile ones. Alone, they will not transform the relations between families and other service providers or sustain new relationships. There is a difference between adopting a principle and operationalizing (or internalizing) it. Taylor and Bogden (1992) have analyzed how institutions transform language to manage the gap between goals and practice. In addition, the development of child and family focused approaches is threatened by the way in which managed care may be
implemented. A century of experience suggests that bureaucracies mediate how professionals deal with clients. Professionals in bureaucratic systems find it hard to relate to clients in an egalitarian manner (Blau, 1973). Moreover, they use their control over scarce resources to discipline clients (Wilensky & Lebeaux, 1958), isolate them from each other (Cloward & Piven, 1965), and control the expenditure of scarce resources (Lipsky, 1979). Meaningful changes require the development of family and youth directed approaches in which family members actively participate in the identification of problems, definition of issues, determination of action, and evaluation of process and outcomes -- both at the individual and policy level. If this is not done, it is likely that service providers will define "wrap-around" and "systems of care" in an agency-oriented manner, selecting services from an existing array of services and providing services in a manner that reflects the needs of agencies.

Transforming the relationship between professionals, agencies, and families hinges on four important aspects of progressive change. First, the family movement must continue to gain strength. Second, family members -- particularly poor and working-class families and families of color -- must gain a meaningful voice in the development and evaluation of policy. Third, attention must be paid to the extent to which the traditional professionally oriented, agency-directed, deficit-focused paradigm is routinized in the day to day realities of agencies and in the language that many service providers choose to or are mandated to use. Finally, those who want change must identify and analyze both the barriers to as well as opportunities for meaningful collaboration between families and other service providers. If these developments do not take place, family focused approaches are likely to deteriorate into agency-directed ones. If these changes do take place, family and youth-directed approaches will frame collaboration and help realize the vision that underlies the National Agenda: "A reorientation and national preparedness to foster the emotional development and adjustment of children and youth with or at risk of developing serious emotional disturbance, as the critical foundation for realizing their potential at school, work, and in the community" (p. 3).

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Significant progress has been made in developing child and family services grounded in a family strengths based philosophy (e.g., Stroul, 1993); however, to date, programs are only just beginning to incorporate the family strengths, family based perspective into program evaluation research design and methodology. If we are to maintain our commitment to empowering families from a strengths based perspective and to expand the opportunities for enhanced parent-professional collaboration, we must develop innovative collaborative research methodologies which consider families as full participants in all aspects of ongoing program evaluation research. This presentation describes one project, undertaken in the State of Maine, to involve parents as researchers in collaborative action research. Collaborative action research suggests that "each group represented in the process shared in the planning, implementation, and analysis of the research and that each contributes different expertise and a unique perspective" (Oja & Smulynam, 1989; p. 1). Collaborative action research represents an attempt to empower people proactively, and to study research problems which arise out of a community, rather than through the eyes of the researcher. In collaborative action research, parents and researchers work together to set common goals and mutually plan the research design, collect and analyze data, and report results. Collaboration assumes that researchers and parents will communicate frequently and openly throughout the process to avoid possible conflicting perceptions and assumptions which result from their different positions in the field. The pilot study we will describe is our effort to enact collaborative action research.

This pilot study grew out of an ongoing program evaluation of a new intensive child case management program in the state of Maine. The intensive child case management services are part of a continuum of child and adolescent mental health services developed and implemented by the Maine Department of Mental Health and Mental Retardation. Six agencies were awarded four year contracts with the Department of Mental Health to provide intensive child case management services. Three of the agencies are community mental health centers, and three are private, non-profit child and family services agencies.
There are a total of 13 child case managers employed throughout these six agencies (state population: 1.2 million people), with each case manager expected to carry a caseload of 15 families with children with severe emotional and behavioral disabilities. Previous evaluation efforts in Maine focused on child case managers' perceptions regarding their work roles and activities, and assessing the degree to which case management services were family strengths based (Werrbach, 1994; in press). In addition, a review of child case management records was also conducted in order to characterize the children and families served by the program, to examine how child case managers spend their time, and to articulate the relationship between child and family characteristics and child case managers' work activities (Werrbach & Harrod, 1995). Finally, we were also interested in understanding parents' perceptions regarding their involvement and satisfaction with intensive child case management services. We proposed a collaborative research model whereby parents were active participants in all aspects of the evaluation of parent satisfaction with intensive child case management services. We want to emphasize several important points about this pilot project: (1) This is a small pilot study - we are only funded for $5,000. Money is nice, but you don't have to have a lot of it! (2) We are trying to accomplish the project in an incremental fashion by using this model in one region of the state, and then replicating our efforts in other regions; and, above all, (3) We wanted to develop and refine family strengths based research methodology that was "family friendly" and could be used by the families themselves.

First, we conducted two focus groups with parents of children with serious emotional and behavioral disabilities (who received case management services) in order to obtain parents' recommendations regarding the conduct of family strengths based research, and to recruit for parent-researchers. What did we find? (1) Parents want evaluation research that doesn't exclusively focus on family "dysfunction" and problems; (2) Parents feel blamed and judged by professionals already - they don't want to be evaluated from a "problem focus;" (3) Parents want researchers to spend more time with them - "Come to our houses and spend some time with us in order to more accurately observe our family and child situation;" (4) Parents believe that there is "no accountability" in the system for child outcomes. Parents want evaluation of service providers to stress accountability and be responsive to families and children. They want an "accountable" system - ongoing assessment, quality assurance and evaluation; and, (5) Parents want more collaboration among providers and parents - this includes researchers. Parents want to participate in the evaluation process through periodic updates, ongoing participation in focus groups and participation in the data collection.

Next, we recruited parent-researchers from participants in the focus groups. Due to budget constraints on the project, only one parent was able to get paid and work on the
project. The parent-researcher kept a notebook of her experiences, feelings, and thoughts as she participated in this project.

Based on thematic analysis of the focus groups' discourse, we developed a semi-structured interview aimed at discovering parental satisfaction with the intensive child case management services. The interview consisted of open-ended questions related to characteristics of the child and family, parental satisfaction with the system of care, service needs and barriers, and history of service use. We spent time assessing the interview format in order to ensure that the interview was strengths based and family/child focused. The interview takes about 1-2 hours to administer. We taped the interviews and transcribed the notes. We worked in teams for the purpose of conducting interviews. The evaluator did the initial interview with the parent-researcher observing. Next, the parent-researcher completed two interviews as the lead interviewer, with the evaluator as the observer. After each interview, we processed how the interview was conducted, what could be changed, and what was working well. We completed a total of four interviews.

What have we learned so far from the families we have interviewed? (1) Families find great satisfaction with a case manager who does not take over, causing the family to be totally dependent on them, but rather offers suggestions and service options to help the family find out what it is that works best for them. A model of family empowerment was most useful; (2) Families are pleased when they do not receive criticism but instead are given unconditional acceptance from their case manager, being applauded for what the family feels are their successes; (3) Families appreciate and benefit from a case manager who encourages a family to ask questions and does not perceive them as a nuisance when they do so. Case managers should give families adequate information to ensure the best possible communication between them; (4) Families also appreciate a case manager who perceives the family as individuals who are part of the same whole. Much consideration of other family members' needs must be taken into account if the child for whom case management services are being provided, is to succeed within her or his own home; (5) Families want and expect a case manager to advocate with them on a consistent basis with the schools, their communities, and local and state government - and not remain in the background simply hoping that change will magically come about. They want their case managers to be knowledgeable about services and to make a strong stand that will directly affect the creation and availability of child and adolescent mental health services.
Title: Issues Concerning Lengths of Stay for Children in Psychiatric and Residential Facilities in New York City: The Viewpoint from Families and Youth

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An estimated 202,400 youngsters in New York City need some form of mental health service, yet citywide estimates project that fewer than 11,393 children each week actually get the services they need. In addition, children who are currently receiving mental health services are encountering barriers to appropriate levels of care. The problem is "kid lock," overcrowding in inpatient and residential facilities and waiting lists at day treatment, outpatient, and therapeutic home based services. The experience of children and families varies from service guidelines due to changing mental health policies, and a fiscal climate that requires mental health providers to do more with less.

Citizens' Committee for Children (CCC), a not-for-profit children's advocacy agency in New York City, is engaged in a two year grant funded study to examine the scope and severity of the situation, from referral and admission to discharge and aftercare. CCC has conducted an extensive survey of a representative sample of inpatient psychiatric and residential mental health facilities throughout the five boroughs of New York City. We interviewed administrators and clinicians on site visits to these facilities and preliminary findings indicate that there are limited options for children with serious emotional disturbance. Many of these children, after achieving some stability or treatment goals, deteriorate while waiting for treatment beds or treatment slots that are in short supply, at all levels of care.

Our unprecedented study includes the viewpoints of participating parents, youth, and mental health advocates regarding mental health services to children and families. We invited parents and youth to participate in our study as volunteers in research planning, being site visitors for data collection, and as guest speakers in our study task force meetings. In addition, we developed an informal interview format for parents and youth participating in the mental health system to become respondents in our study, to express their experiences and provide anecdotal case illustrations to the study's findings and recommendations. Our interviewers were trained professional and citizen volunteers committed to improving the lives of children and families.
The study is particularly timely, given the context of national trends to reform health care services and the development of more community oriented, school, and home based mental health services. The study explores the continuum of mental health services available for children with serious emotional disorders, with the goal of providing recommendations to mental health policy makers, service providers, and, most importantly, sharing information with participating families and youth to improve the delivery of mental health services.
Title: Respite for Children Receiving Short-term In-home Psychiatric Emergency Services: Lessons from the Data

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Each year numerous children, adolescents, and their caregivers seek help in psychiatric emergency settings. Although the mental health field lacks standardized approaches to treat these children and to support their families (Rosenn, 1984), short-term, intensive, in-home interventions modeled on the Homebuilders program (Fraser, Pecora & Happala, 1991) are being widely disseminated.

In 1987, the New York State Office of Mental Health (NYSOMH) established Home-Based Crisis Intervention (HBCI) as an intensive in-home service option for families. HBCI is modeled on the Homebuilders program, which provides short-term services to families with a child in psychiatric crisis. In 1993, the NYSOMH received a three-year research and demonstration award from the Substance Abuse and Mental Health Services Administration (SM-50357) to study the delivery of in-home crisis services. In this project, two new intensive in-home psychiatric emergency programs for children and their families, an enhanced version of HBCI (HBCI+) and Crisis Case Management (CCM), were implemented and are being compared to the existing HBCI program. In-home and out-of-home respite services are additional supports available to families assigned to the HBCI+ and CCM conditions. This presentation describes the respite services available to parents in the HBCI+ and CCM conditions, summarizes the use of respite in these programs during the first year of the project, identifies the barriers to the use of respite raised during a focus group conducted to increase respite use and the steps implemented to minimize identified barriers, and compares the profiles of children and families who use and do not use respite. Only families who received the full intervention are included in this analysis.

In-Home Respite: For families enrolled in the HBCI+ and CCM programs, in-home respite has been made available on both an emergency and planned basis. In-home respite is provided by providers specifically trained to care for children with emotional disorders. Services to a family are typically provided by the same respite care provider who is selected to match the needs of the child and the family. Given the cultural diversity in the Bronx, English and Spanish speaking respite care providers are available. In-home respite services are also not required to specifically take place within a family's
home. Respite care providers can engage in recreational activities with a child such as going to the zoo, seeing a movie, or taking a trip to the mall. A separate pool of money is available to cover the costs associated with such activities. Additionally, in-home respite services are also available for siblings.

Out-of-Home Respite: Out-of-home respite care is also available to families enrolled in the HBCI+ and CCM programs. In out-of-home respite, a child is taken into the home of a trained individual or family. Out-of-home respite providers were hired and trained by a private agency licensed by NYS to provide such service. Given the short-term nature of the intervention in this project, out-of-home respite stays are limited to three days per occasion but there is no limit on the number of instances in which it may be used. As is the case with in-home respite, out-of-home respite is available on both an emergency and planned basis. Respite is also provided by the same respite individual/family, to the extent possible, for families using out-of-home respite on multiple occasions. As possible, respite homes are selected to match the needs of the child and the family and both English and Spanish speaking respite providers are available. Out-of-home respite can also involve extended days that do not require an overnight stay.

In-Home Respite: It was projected that 3,480 hours of in-home respite would be used during the first year of this project (58 families x 6 weeks x 10 hours per week = 3,480 hours). Examination of the 59 families enrolled in the two study conditions (CCM and HBCI+) with access to in-home respite indicates that 16 families (27%) used this service. These 16 families used 847 hours or 24% of the available in-home respite hours. The number of hours of in-home respite services that families received ranged from 2 to 106 hours, averaging 41 hours.

Out-of-Home Respite: It was projected that 400 days of out-of-home respite would be used during the first year of this project. The same 59 families enrolled in CCM and HBCI+ during the first year also had access to out-of-home respite. Three families (5%) used this service. These 3 families used 11 days or 3% of the available out-of-home respite days. The number of days of out-of-home respite services that families received ranged from 2 to 5 days, averaging 2 days.

During the first year of the study the use of both in-home and out-of-home respite fell below anticipated levels. Over two thirds of the families with access to in-home and out-of-home respite have not used either service. The majority of the families using respite have used in-home services. Only three families have used out-of-home respite.

During the discharge interview, parents whose child was enrolled in one of the two programs with access to respite were asked about their knowledge of these services.
Nearly 62% of the parents remembered being informed about the availability of in-home respite while 59% recalled being told about the availability of out-of-home respite. In excess of one third of the parents were unaware of the availability of both in-home or out-of-home respite.

Additionally because many of the families who had been informed of the availability of respite services had not used them, a focus group was conducted to discuss issues related to the use of respite. Focus group participants included in-home and out-of-home respite providers, HBCI+ and CCM providers, staff from the two hospital intake sites, parents, research staff, and program personnel. In all, 21 individuals with varying perspectives and opinions concerning the use of respite services were convened for a three hour session to identify obstacles preventing the use of respite and to develop strategies for minimizing these obstacles.

Participants identified 37 obstacles limiting the use of respite services. These obstacles were then sorted into like categories by five external raters and the joint proportion matrix was factor analyzed resulting in ten obstacle groupings which is summarized in Table 1. Parents’ and services providers' need for more information was identified as an obstacle limiting the use of respite. Parents who expressed having many unanswered questions about respite and service providers indicated they were not clear about what respite entailed.

It was also acknowledged that respite had a negative connotation and was viewed by parents and service providers as the first step in removing a child from the home. Parents believed that using respite signified they were not doing a good job taking care of their child and service providers expressed reservations about the therapeutic value of respite. Issues involving choice and flexibility were also identified as obstacles. Parents did not feel they were given a role in planning respite service and did not have an opportunity to assess the respite services. It was believed that children could not be matched to respite providers and that respite could not be accessed on an as needed basis. Another obstacle raised during the focus group related to the safety of children using respite. Both parents and service providers expressed concerns about the recruitment, training, and supervision of respite providers.

What actions have been taken to minimize the obstacles limiting the use of respite identified during the focus group? (1) Informational brochures have been developed for both in-home and out-of-home respite services; (2) Respite providers have been placed on retainers to increase program flexibility; (3) Respite providers held an "open house" for service providers; (4) In-home and out-of-home respite coordinators are informed when a
new child is enrolled in the study; and (5) Increased dialogue and awareness has developed between researchers and service providers.

Significant differences were found between respite users and nonusers concerning the number of children in the household and the identified child's age. Families using respite had more children living at home (mean=3.3) compared to nonusers (mean=2.2) and the identified child was younger (mean=10.3 years old) compared to nonusers (mean=13.3 years old). Additionally, families using respite had significantly fewer social supports (mean=74.1) compared to families who did not use respite (mean=89.9).

Although not statistically significant, families using respite services were less likely to have an adult in the household who was employed and the identified child was more likely to be living with neither biological parent.

Table 1: Obstacles to Using Respite

I Information Needs
- Parents have unanswered questions about respite
- Service providers are not clear about what respite services entail

II Providers’ Perceptions about Respite Services
- First step toward removing a child from the home
- Lack of trust in nonmedical interventions

III Coordination Issues
- Need to coordinate the efforts of respite and service providers
- Respite perceived as a separate service

IV Parents’ Perceptions about Respite Services
- Using respite suggests that families are not doing their job
- First step toward removing a child from the home

V Therapeutic Use of Respite
- Do not know how to use respite creatively
- Lack of vision for respite services

VI Choice
- Lack of parental involvement in planning respite services
• Parents do not have an opportunity to evaluate the respite services

VII Delivery
• Lack of effective strategies for introducing respite to families
• Insufficient time in short-term model to introduce respite

VIII Flexibility
• Cannot match child with respite provider
• Lack of flexibility in accessing respite

IX Safety
• Concerns for the safety of the child in respite
• Concerns about how respite workers are recruited, trained, and supervised

X Cultural Issues
• Some cultural groups are less likely to use respite

Title: Challenges Faced by Working Caregivers of Children with Serious Emotional Disorders

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Recent empirical and theoretical scholarship has addressed the difficulty of balancing the demands of employment and family life. A balance becomes particularly difficult to achieve when one of the responsibilities of family life is care for dependent children given by family members who are employed. For employed family caregivers whose children have serious emotional disorders, a lack of support for their caregiving can make
meeting the demands of home and employment very stressful.

The purpose of the presentation was to offer a preliminary conceptualization of six of the major challenges faced by families with workers caring for children with serious emotional disorders.

The first three major challenges were individual and interpersonal: sustaining healthy interpersonal relationships with other family members, co-workers and children; achieving a desired level of job satisfaction and career development; and, managing stress from the competing demands of work, family and caregiving.

The second set of three major challenges identified were in the area of obtaining formal and informal supports: finding adequate child care during working hours; maintaining a level of employment with sufficient income and benefits; and securing support services which will allow working caregivers to engage in full and rewarding work and family lives.
Discussion of the challenges was based on theories of work and family balance in the current literature, empirical research on stresses experienced by employed caregivers, and scholarship addressing issues of support for families having children with serious emotional disorders.

In order to meet the identified challenges, the presentation discussed the Support for Working Caregivers project, a recently funded initiative which has as its purpose the study of families with employed caregivers whose children have severe emotional disorders. The project is designed to (a) identify factors which enhance the ability of employed family members to balance their work and caregiving responsibilities, and (b) to develop a model which will demonstrate the effects of combining natural helping and supportive services for employed caregivers, enabling them to achieve an optimal level of employment and high level of work satisfaction, to meet the financial obligations involved in childcare and mental health treatment of their children, and to lower levels of personal, work, financial, and family stress.

The project was reported to be nearing the end of the first phase: the analysis of patterns of work and family balance found for employed caregivers from the North Carolina Family Caregiving Survey. In subsequent years, the second phase is to be concentrated on building a theoretical model of work and family balance for employed caregivers with children having serious emotional disorders. Finally, the third phase of the project will survey employed family caregivers to test the model and to ascertain the ways in which an optimal work-family balance can be achieved.
Title: Individualized Service Strategies for Improving Outcomes for Children with Emotional/Behavioral Disturbances in Foster Care

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Overview of topic and study: Many children with emotional/behavioral disturbances are adjudicated dependent and languish in the foster care system for years, frequently transferred from one residential placement to another, with little or no progress toward permanency or improved emotional/behavioral adjustment. To address this situation, the Fostering Individualized Assistance Program (FIAP) was developed to provide individualized wraparound supports and services to foster children with emotional/behavioral disturbances and to their families (i.e., foster, biological, and/or adoptive). Outcome findings from a controlled study suggest that the FIAP intervention proved more effective than standard foster care services for this population, particularly as related to decreasing the rate of placement changes and to increasing the likelihood of family reunification or other permanency arrangements.

Target population and program description: The children studied were in foster homes or group shelter care at the start of the study and had, or were at risk of having, emotional/behavioral disturbances. These children, ages 7 - 15 as they entered the study, had been out of their homes for an average of 2.6 years and were changing placements at an average rate of 4 times per year. These children represented the most challenging 10% of the foster care population, having been provided fragmented, categorical, or non-existent mental health and related services typical of the foster care system in this country.

The FIAP goals for its children and families were to stabilize child placement, improve child behavioral and emotional adjustment, and achieve appropriate permanency placements. These goals were facilitated through four clinical components: 1) child and family assessment that addresses individualized strengths and needs; 2) life-domain service planning to support and enhance permanency plans; 3) clinical case management of individualized, wraparound supports and services; and 4) follow-along supports to maintain permanency. At the heart of the FIAP intervention were family specialists who served as family-centered, clinical case managers and home-based counselors,
collaborating with parents and other family members, foster caseworkers, other providers (e.g., teachers, therapists, scout leaders), and foster parents. The family specialists followed and served their children across all settings, wrapping services around them, as needed.

**Research methods and interim findings:** The FIAP intervention was evaluated in a controlled, random-assignment study which compared a sample of at-risk children who received this individualized, wraparound process (FIAP group, n=54) with a comparable sample of children who experienced practices that were standard in the foster care system (SP group, n=78).

The outcome results demonstrated that: 1) FIAP children were significantly less likely to change placements than were those in the SP group; 2) FIAP children were more likely to show a significant initial improvement in emotional/behavioral adjustment, a gain which was matched by the SP children by about the twelfth month of intervention; 3) both groups showed significant levels of improvement in their emotional/behavioral adjustment over time; and 4) FIAP children were significantly more likely than SP children to be in permanency settings with their parents, relatives, adoptive parents, or living on their own. The data also suggested that FIAP children in permanency placements tended to show better emotional/behavioral adjustment than did SP children in permanency placements. Examinations of community adjustment indicators for subsets of children who had any history of runaways or incarceration suggested that the FIAP children showed trends for fewer days in both of these areas. A continuing increase in incarceration days and other deep-end placements by the SP group could ultimately demonstrate the FIAP intervention to be cost effective.

**Implications for children's systems of care:** Through this grant-funded research effort, FIAP has developed and refined an intervention strategy for improving the permanency placements of children who have been out of their homes for extended periods and who are inadequately served in the foster care system. It appears that the power of the FIAP intervention might be strengthened even more through greater use of family systems therapy and better field supervision methods to ensure consistency in the individualized wraparound approach.

FIAP is currently disseminating programmatic and staff training information and technical assistance to improve practices in communities in Florida and in other states. Guidelines for policy reform across child-serving agencies to improve the humaneness and effectiveness of systems serving children at risk and their families are being formulated.
Our society needs to value its children. Systems should not be allowed to contribute to, or exacerbate the emotional/behavioral problems of our abused and neglected children, particularly considering the ever increasing costs of out-of-home placements and incarceration. Rather, we would do well to continue to explore more humane and effective ways of supporting families, to keep them intact and healthy through early intervention, family preservation, early reunification, and adoption efforts.

Note: The Fostering Individualized Assistance Program (FIAP) study, a collaborative research demonstration project between the Florida Mental Health Institute at the University of South Florida and the Florida Health & Rehabilitative Services Department, was funded, in large part, by the Child and Family Support Branch of the National Institute of Mental Health (Grant No. 1-R18-MH47910) and the Child, Adolescent, and Family Branch of the Center for Mental Health Services (Grant No. 9 HD5 SM51328).
As Weiss & Jacobs (1988) and others have noted, program development and theory in family support have far outdistanced efforts to develop evaluations that can adequately reflect the multifaceted nature of family support programs. Further, it is particularly difficult, especially within the context of traditional evaluation paradigms, to develop evaluations that do not in and of themselves violate the principles that family support services are designed to reflect. To this end, the Policy and Evaluation Project at the University of Pittsburgh has been working with local agency directors, family support staff, and parent groups to develop an evaluation methodology that can serve multiple stakeholder purposes, and which is rooted in the general principles of family support service delivery. This paper discusses a value-driven model of evaluation that is being developed to facilitate a partnership-based collaborative evaluation of family support centers.

The assumptions of the evaluation model that we are developing parallel the basic assumptions of family support service delivery, that evaluations, like service programs, should be: (1) collaborative; (2) strengths-based; and (3) flexible, yet goal oriented. We outline below these basic principles and how they relate to family support evaluation. Then we present an overview of evaluation tasks as well as some strategies for performing these tasks that use this family support approach.

**Collaborative:** Family support services strive to create collaboration among numerous different groups of stakeholders, including funders, service providers, program staff, and families. Similarly, family support evaluations must engage all relevant stakeholders and allow them to have a voice in developing the program evaluation. Successful collaboration will provide the foundation to ensure that the evaluation is culturally competent, family friendly, and community-driven. In essence, family support evaluations are done ‘with’ families and programs and not done ‘to’ them.

**Strengths-based:** Just as family support services are based on the assumption that all families have inherent strengths that can be nurtured and developed, this evaluation...
model is based on the assumption that all programs have strengths that can be used to continually increase program effectiveness. The primary question addressed using a family support approach to evaluation is "how can we continue to improve this program by building on its strengths?"

**Flexible/Goal Oriented:** A basic principle of family support services is that they must be responsive to families’ dynamic needs. Evaluations of family support services, likewise, must be able to respond to the ever-changing informational needs of stakeholders. However, just as family support programs are designed to help families achieve their goals, family support evaluations must help programs stay goal-oriented and focused on long-term outcomes.

The family support evaluation model takes these general principles and uses them as a ‘filter’ through which all subsequent evaluation activities are conceptualized and operationalized. The basic tasks involved in implementing the family support evaluation model are: (1) building the collaboration; (2) focusing and planning the evaluation; (3) implementing the evaluation; and (4) using the evaluation for program improvement.

Building the collaboration involves identifying stakeholders, forming a decision-making group to oversee the evaluation, and establishing guidelines for making decisions about the program and its evaluation. Focusing and planning the evaluation involves developing a ‘program working model’ based on agreed-upon program goals and objectives, a prioritized set of evaluation questions, and methods and a timeline for answering these questions. Implementing the evaluation involves beginning to collect information to inform the program working model, and monitoring and reviewing the processes through which this information is gathered. Finally, program improvement involves using the information gathered to address the questions, reformulate the program model, and to guide changes in program activities. Although these tasks overlap considerably with those that would be conducted within the context of a traditional evaluation framework, each is operationalized using the family support principles outlined above. Thus the evaluation becomes both a more useful and appropriate tool for building successful programs as well as serving to promote empowerment and self-sufficiency in those involved in the evaluation.

This approach has several advantages over more traditional evaluation models. First, it increases the match between the evaluation methodology and the service program approach. For example, many of the traditional methodological approaches used by evaluators, such as random assignment to treatment and control groups, lengthy and often unexplained interviews, and detailed enrollment processes are either inappropriate or ill-suited for family support programs.
Second, this approach forces stakeholders to be explicit about the program assumptions, objectives, and goals as well as those of the evaluation. This helps provide a common understanding of the nature of the family support program. Because of the complex and broad goals of family support centers, stakeholders often have widely contrasting views about the intended purpose and expected outcomes of these programs. Utilizing this proposed family support model requires that a collaborative group build a ‘program model’ that explicitly outlines the underlying program assumptions, program goals, and how program activities are linked to these goals. Further, individual programs differ tremendously in terms of their primary focus: for example, pregnancy reduction or delay of subsequent pregnancy might not be a primary goal for a family support program that serves predominantly married couples. But it may be the main goal for a family support program serving teen parents.

Third, this approach is overtly strengths-based. The strengths-based approach has strong implications for the questions the evaluation should be asking--in particular, the evaluation is not asking “did this program work?” (note past tense). The evaluation should be asking questions aimed at program improvement, such as “where is this program strongest, and where can we make it stronger?” and “how can we move the program and its participants forward towards its/their goals?” Because of this strengths-based approach, this family support evaluation model is less threatening to those involved than more traditional evaluation models. Further, evaluation becomes a process that can serve to support program activities by empowering programs and families to ‘take control’ of their own evaluation (e.g., Fetterman, 1993).

The family support evaluation model also brings with it many challenges. First, and arguably foremost, this approach, like any collaborative effort, takes a significant investment of time and energy. This approach involves an ongoing commitment--the evaluation doesn’t ‘start’ and ‘end’ -- it continues, ideally, as long as the program exists. The family support evaluation model also requires certain conditions to work effectively. First, it requires true collaboration, that is, real sharing of decision-making power regarding both the program and the evaluation. True collaboration also relies on mutual respect for a diversity of opinions: funders must value the opinions of families, program staff must value the opinions of funders, families must recognize the needs of policy makers. In fact, it has been our experience that this approach is not likely to be successful if socio-political problems are such that people cannot come to the table as equals. An atmosphere of openness and trust is absolutely critical in order for collaborative program improvement to occur. Finally, it should be recognized that this approach requires innovative, nontraditional approaches to evaluation, which often involve compromising some degree of scientific certainty and methodological rigor.
Title: Improving Child Outcomes Through Parent Participation: CASSP, School Restructuring, and University Collaboration

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In the decade since the publications of *A Nation At Risk* and *Unclaimed Children*, both the school restructuring and service integration movements have emerged in tandem. Each has emphasized transformation of roles, beliefs, and processes to facilitate parent participation in decision-making. Though these attempts to improve outcomes for children have occurred in philosophical and chronological proximity, few have consciously linked them.

In order to examine efficacy of these reforms on child outcomes, the University of South Florida Department of Special Education and the Florida Mental Health Institute's Department of Child and Family Studies' Research and Training Center established a partnership with an ethnically and economically diverse urban-rural middle school north of Tampa. In the past three years, Office of Special Education Programs (OSEP) grants to investigate school restructuring and to develop child and family policy leadership were matched with a Child and Adolescent Service System Program (CASSP) grant to bring university resources to a research-based focus on parent participation in school decision-making.

Data now emerging from the OSEP school restructuring grant highlight the developmental and complementary relationship between increasing parent participation and transforming professional beliefs, roles, and processes. Though parents were represented on the school advisory council which sets goals to improve child academic outcomes, most policy initiatives arose from traditional school leader roles. However, through university involvement, these roles and processes have gradually been challenged, resulting in parent participation in shaping policies such as diminishing out-of-school suspensions which had adverse effects on family resources and child outcomes. Concurrently, efforts to increase parent decision-making in their child's academic and social activities were initially limited to more traditional support group and bake-sale roles. Over time, through the consultation and support of the CASSP grant, school administrators and social service staff have begun to embrace a parent-as-partner, strengths-based philosophy and wrap-around process of assessment and planning for Exceptional Student Education (ESE) children. Additionally, community agencies in this resource-poor county have been engaged as on-site partners in this school-based effort.

These changes in academic, social service, and management processes are only now emerging in the third year of this unique partnership. Though the CASSP grant expires in June 1995, continuation of this effort has been ensured by committing resources from the OSEP Child and Family Policy Leadership grant. This gives the middle school the opportunity to expand application of CASSP philosophy of parent involvement and service integration through developing the wraparound process at feeder elementary
schools. Participation with parents in this process is gradually changing school service staff roles and the professionals' beliefs about families.

Through the faculty advisor, the CASSP coordinator, and the doctoral student responsible to all three grants, this panel presentation told a story of transformation of initial vision and efforts when faced with the harsh realities of how schools and social services customarily view and work with families. Are charismatic leaders necessary to effect change? Can beliefs change before roles are transformed? What strategies are effective when barriers to parent involvement are hidden beneath politically correct rhetoric? The panel compared their experience and data with the audience.
Until 1986, Ohio’s public mental health system was heavily dependent on state institutions for youths in crisis or for those with severe mental disturbances. Mental health leaders chose to close one existing state adolescent psychiatric hospital and replace it with a new entity. The goal was a collaborative, community-based system of care that linked families with local private hospitals and community alternatives. This approach seemed more family-centered and desirable to the mental health leaders. This paper presentation describes the impact of the system on families, youth and mental health services with the conversion from an institutional to a family-oriented model. It also describes the evaluation of the new service system and the characteristics of the youth and treatment services that they received.

Mental health leaders in Ohio created an alternative to the state adolescent psychiatric hospital called Alternatives for Children and Teens (ACT). This new agency received funds that otherwise would have gone to the now-closed state institution. ACT’s mission as a support and advocacy agency was to find appropriate care for youth in crisis or to link the family with community supports to avoid hospitalization. ACT began accepting
cases in 1989 and it continues this role, of contracting with private hospitals and managing the care of youth that have been referred.

The research database for this paper presentation came from the mental health service records for the 282 youth served by ACT in 1989-93. Additional data are from a randomly selected comparison sample of over 500 other youths served in community mental health clinics but not included in the ACT services. The service records include the mental health information system data operated by the Ohio Department of Mental Health, as well as data from Ohio’s 508K system for the identification of youth with severe emotional disturbances. This information was used to answer five questions that address diagnostic and outcome differences for children in home-like environments versus those in substitute care environments.

(1) Did those youth in substitute care present diagnostic differences from those in family environments?

Previous studies have shown that residentially housed children have higher rates of conduct disorder, anxiety, and attention deficit disorder (Silver et al., 1992). Dickson, Heffron, and Parker (1990) found that children in intact homes have more substance abuse problems than other populations.

Our data confirm that children in home settings were more likely to have drug and alcohol problems. Additionally, the children in home settings were more likely to be diagnosed with personality disorders. The children in substitute care environments were more likely to have adjustment disorders than were the children from home settings.

2) What are the characteristics of youth from families versus substitute care environments?

Frank (1980) studied foster children versus traditional families and found that foster children were more likely to have mothers with mental illness and more likely to have severe emotional, economic, and social problems. It was also found that psychosocial problems tended to increase with time spent in a foster environment.

Our data do not indicate such differences. Race, age, gender, duration of the impairment, and global functioning were all similar for the two groups. AFDC and child support accounted for double the amount for those children in a homelike environment, but the primary income sources were the same for both (none, wages, unknown, and parent/relative).
3) Were there differences in the types of treatments that the two groups received?

In our study, we found that children in substitute care situations received significantly more residential care days ($t(550)= 4.09, p<.05$), as well as total hours of care ($t(550)= 4.25, p<.05$), and a more diverse sampling of treatments ($t(550)= 4.02, p<.05$).

4) Did the development of in home case management and family therapy decrease the need for hospital care?

Flomenhaft and Sullivan (1992) found that day hospital supports and family therapies decrease the need for hospitalization independent from both diagnosis and severity of symptoms. Hinckley and Ellis (1985) also report similar outcomes from home-based services. It has also been reported that home-based services lower much of the stigma associated with treatment (Goldfine et al., 1985), and lower recidivism rates (Gordon, Arbuthnot, Gustafson, & McGreen, 1988).

The data show a strong increase in case management and family therapies, while also showing a strong decrease in inpatient hours. While this is not enough to imply a link, there are significant correlations between family and case management therapies and other therapies and significant correlations with diversity (case management vs. diversity, $r=.1610, p<.0001$; family therapy vs. diversity, $r=.1322, p<.001$). This suggests that case management and family therapy consumers receive a diverse selection of therapies (thus possibly avoiding hospitalization).

5) What diagnostic types and ages were most responsive to short-term interventions versus those requiring more care?

It has been found that diagnosis is a much less reliable predictor of hospitalization length of stay than other indices (Cyr & Haley, 1983; Goldstein, Bassuk, Holland, & Zimmer, 1988). Much more predictive is the level of family disruption (Dickson, Heffron, & Parker, 1990) and family status (Jerome, 1986).

Not surprisingly, the diagnoses of personality disorders, major affective disorders, and psychoses all required more long-term interventions. Age had no significant effect after the effect of time in therapy had been partitioned out.

Conclusions: The study seems to agree with much of the past literature. The role of family structure cannot be ignored in the context of treatment. The data has shown a link between family type and diagnosis, length of treatment, and types of treatments. In the future, clinicians should take this very important information into account.
Our research has also shown that children with severe emotional disturbances, such as those in the ACT group, present the outcome patterns of other clinical populations. This is valuable for researchers interested in the external validity of future studies.

The limitations of this study concern the data collection method. Much more conclusive results could have been obtained with a carefully controlled study such as the ones cited in the review of past literature. It was a goal of the authors to show the efficacy of using the dual databases for tracking the mental health system in Ohio and it appears that these can be effective tools for the researcher.
Since 1989, researchers staffing an ongoing component of the Research and Training Center on Family Support and Children’s Mental Health, the Family Caregiving Project, have collected data on the characteristics of caregivers, their children, social support, and stress and coping of family members caring for children with serious emotional disorders (McDonald, Donner, Gregoire, Poertner, & Early, 1993). As part of the data collection process, McDonald and his co-workers surveyed 258 family members, of whom 41% were employed full-time, 14% were employed part-time, and 42% were not employed outside of the home. The family members rated their stress levels as "some" and "moderate" in all areas, with the highest stress ratings going to "home and family". Caregivers reported that they were handling their job responsibilities "very well" but rated their management of time as being more poorly handled.

The presentation reported preliminary results of a secondary analysis of the Family Caregiving Survey data for the caregivers in the sample who were involved with employment outside the home. Presenters explored the level of employment and parenting configuration most identified with positive appraisals of work, highly satisfactory family relationships, satisfaction with caregiving, and lower levels of stress in key areas of family life.

Data for the analyses were obtained from the North Carolina Family Caregiver Survey, which is a comprehensive instrument including: demographic items; an index of the severity of the child's behavioral difficulties (Achenbach, 1981); items on the use of
formal supports (Friesen, 1989); and three stress scales which measure perceived stress, stress generated by responsibilities, and pleasure derived from activities (Press, 1990).

For the secondary analysis, questionnaire items were identified which addressed six aspects of the balance between employment and family responsibilities for the caregivers surveyed: work responsibilities, family responsibilities, financial situation, supportive services used, caregiver characteristics and child characteristics. The research particularly investigated differences between families with different work structures; that is, varying levels of employment and parenting arrangements. Families with different work structures were expected to demonstrate differences in (1) family, child, and caregiver characteristics; (2) financial situations; (3) supportive services used; (4) levels of work stress, satisfaction with handling work responsibilities, and pleasure with work; and (5) levels of family stress, satisfaction with family responsibilities, and pleasure with family. Finally the analysis also addressed the relationship of child emotional and behavioral problems to measures of work and family stress.

A subsample of 184 caregivers was selected for the secondary analysis reported here. To be included in the subsample, a caregiver had to be employed full-time or part-time, or had to have a spouse or partner who was employed full-time outside the home. The caregivers in the study were divided into five different types of work structures: 35 were single parents working full-time, 12 were single parents working part-time, 64 were dual earner parents employed full-time, 22 were dual earner parents with at least one working part-time, and 51 were unemployed caregivers with an employed partner.

The caregivers included in the analysis were mainly young adults (M = 34.7 years), mothers (N = 153, 83%), and European-American (N = 168, 91%). Of the caregivers indicating their education level, 27 (15%) stated that they had not completed high school, 46 (25%) were high school graduates, 86 (47%) had some college or vocational training, and 24 had attained at least a bachelor's degree. The families tended to be large, with the average number of children being 2.6. The youngest children in the families were generally of school age (M = 6.7 years), and oldest children were in the early preteen years (M = 10.5 years). Family incomes were in the lower middle income range, with the most frequently reported annual family income range being $15,000-$24,999 per year. Ninety-eight families reported that they lived in a city, while 30 families lived in rural areas, and the remaining 52 families resided in small towns.

Significant differences were found between families with different work structures in the following characteristics: highest level of caregiver education, age of youngest child, age of oldest child, caregivers’ age, and reported family income. Caregivers from different family structures also differed significantly on their levels of job stress, their level of
pleasure in their work, their use of work as coping, and their personal investment in their job. In terms of family measures, caregivers with different work structures differed in their satisfaction with handling of family responsibilities, their handling of home responsibilities, and their level of pleasure in their primary relationship.

The level of child problem behavior was not related to work stress or work structure, but significantly correlated with reported child stress and family stress. Child competency was negatively correlated with child stress for these working families, but was not related to any other work or family measures.

Families used few formal supports to balance work and family responsibilities, and use of support was not related to family work structure, level of employment or family income.

Participants in the presentation discussion emphasized the difficulty of obtaining employer understanding of the complications of balancing work and family obligations for family caregivers of children with serious emotional disorders. They also discussed the compartmentalization of work and family, which helped them deal with the stress of caring for their children by investing themselves in their work which gave them great satisfaction and some measure of control in their lives.
This brief paper presents a summary of findings from a study of training programs that prepare professionals to function interprofessionally and in interagency settings and to promote family-professional collaboration. Study respondents were the directors or leaders of university or agency-based interprofessional/interdisciplinary education or training programs which were identified through a snowball sampling methodology. Respondents participated in an initial telephone screening interview to determine their appropriateness for inclusion in the study and then in a long telephone interview. Many respondents also submitted printed information about their programs. Findings indicate that a small number of exemplary programs address interprofessional and interagency collaboration and incorporate family members in designing, planning, implementing and evaluating training.

Sixty five professional education and training programs were nominated for inclusion in the survey; 51 were found to meet the criteria for inclusion: interdisciplinary content; teachers/trainers from different professions/disciplines; and an audience (participants) representing different professions/disciplines. Of these, 26 were agency-based training programs and 25 were university professional education programs. The programs identified in the survey represented a wide selection of types of training programs for family-centered practice in the human services.

Collaboration with other agencies, departments or institutions: The survey indicated a high level of collaboration, with 21 out of 26 agency-based programs (81%) and 17 out of 25 university programs (68%) working jointly with other agencies, departments or institutions to plan, design, implement, administer and/or evaluate the program.

Focus: Approximately half of the respondents stated that their training program had a specific focus such as health, mental health, child abuse or drug and alcohol abuse, while the other half had a general focus on family-centered services.
Formalization: Sixteen university programs (64%) were part of an accredited training program. Nineteen agency training programs (73%) were distinct entities within the organization, while the others were seen as one aspect of the ongoing work of the agency. Twenty three university programs (92%) were described as distinct training programs with a specialized focus on interprofessional/interdisciplinary education, in contrast with the remainder which had interprofessional content and methods infused in the curriculum of a general educational program. Formal application procedures were required for applicants to 60% of the university programs. The existence of written curricula and course outlines was taken as an indicator of the formalization of the program: twenty two university programs (88%) and 19 agency-based training programs (73%) had written curricula.

Duration of education/training programs: Most education/training programs identified in the study were of relatively recent duration. Only two university programs and three agency-based programs had been in existence for 20 years or more. The median duration of all programs in the study was 3 - 4 years.

Family and consumer input into the planning, design, implementation, and evaluation of training programs: Family members and consumers were slightly more frequently involved in the design of agency training programs than in university programs. Consumers were involved in the planning, design, implementation and evaluation of 16 university programs (64%), while family members were involved in 13 (52%). Consumers were involved in the planning and implementation of 18 agency programs (69%), while family members were involved in 17 (65%). Consumers were involved in providing training in 15 agency programs and 12 university programs. The extent of consumer and family member involvement was more extensive in agency-based training programs; for example, family members and consumers were on advisory boards, involved in planning, designing, and evaluating programs, and they served as paid trainers.

Types of professionals involved in providing training: The professions most frequently represented among trainers were: social work, in 46 of the total of 51 education/training programs (90%); psychology (73%); nursing (61%); education (47%); and special education (45%). Other professions represented included pediatrics, psychiatry, physical therapy, juvenile justice, home economics and drug alcohol counseling.

Training methods and content: 10 university programs and 7 agency programs offered interdisciplinary content through specialized classes. Interdisciplinary content was integrated throughout the curriculum of five agency programs and four university programs. The remaining programs offered a combination of these 2 approaches.
Respondents were asked to comment on the inclusion of a list of specific topics related to collaboration and family-centered services in their curriculum. 7 university programs had an entire course on interprofessional communication, 6 had a course on interdisciplinary group process and 8 had a course on cultural competence. Of the agency programs, 4 had entire workshops on shared decision making, conflict management, and cultural competence. In most cases, respondents stated that the content was integrated throughout their curriculum or (in the case of universities) addressed in field placements.

Challenges in training program development: All respondents referred to challenges they had encountered in developing their training program, and their responses were categorized into fiscal and resource constraints, administrative challenges and political challenges.

Fiscal and resource constraints: These were the most frequently mentioned by all respondents. The most prevalent resource needs were for more funds, trainers, space and faculty release time. Strategies for addressing these challenges included grant writing, development of collaborative budgets, faculty and trainers volunteering their time, and charging contractors. The outcomes were mixed, with resource constraints a constant struggle for many training programs.

Administrative challenges: Administrative challenges were quite varied, ranging from the abstract "determining the meaning and content of collaboration" to the concrete "deciding who to invite to meetings" and "finding convenient meeting times." Other challenges included finding time for collaboration, sorting out the roles of participants, getting people involved, lack of clear goals and common language, and state requirements for training and licensing. Strategies adopted included increased communication and negotiations with states regarding standards. The outcomes were mainly positive, except for state licensing standards which were an ongoing concern in some states.

Political challenges: Political challenges were less frequently mentioned, but where they occurred they had a serious impact on program development. The most common themes related to power and turf issues, decisions about responsibility, the effects of categorical funding, lack of commitment to family-centered practice, and histories of poor relationships between agencies. The lack of organizational and community structures to promote and support collaboration was also a serious concern. Strategies used to meet these challenges included meetings, discussions and information sharing. Political challenges were ongoing concerns in many programs.

Strengths and benefits of training programs: The most frequently identified program strengths were the value of the holistic approaches adopted, training offered from a
strengths perspective, the focus on under-served populations, and opportunities for developing skills in working with other professions.

**Conclusion and recommendations:** We recommend that professionals be prepared to provide family-centered services through joint training with other professionals in the system of care, with interdisciplinary trainers, including family members. Training materials and practice opportunities should focus on skills for collaboration, both with other professionals and consumers and family members.

A list of family-centered interprofessional education and training programs which participated in the survey, together with names, addresses and telephone numbers of contact persons and brief program summaries may be obtained from the authors. More detailed information is included in the final report of the Interprofessional Education Project, entitled *Interprofessional education for family-centered services: A survey of interprofessional/interdisciplinary programs*. To obtain a copy of the complete report, contact Pauline Jivanjee.
Title: Beliefs of Social Workers, Psychiatrists, and Psychologists about Parents of Children with Emotional and Behavioral Disabilities

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A stratified, random sample selected from professional registers of social workers, psychiatrists, and psychologists was surveyed by mail. At the time of presentation, data collection was not yet complete. Respondents whose views were reported included 341 social workers, 414 psychologists, 138 psychiatrists, and a small number from other disciplines; 440 were female, 366 were male. The survey instrument was a questionnaire recently validated (Johnson, Cournoyer, and Fisher, 1994) eliciting the views of service providers about parents of children with mental, emotional, and behavioral disorders. The instrument comprised five factors (blaming parents, sharing information, validating parents, giving medication to children, and giving parents explicit instructions about how to help their children).

Using multiple regression, analysis of variance, and multivariate analysis of variance, the following results were obtained. Professionals who were familiar with 3 or more parent support groups disagreed much more with statements attributing blame to parents for their children's emotional problems (F=5.05, p<.0005); held more validating views of parents (F=4.69, p<.001) and were more likely to believe that professionals should give parents explicit instructions about ways to help their children (F=4.52, p<.001) than those who knew of fewer groups. Workers who had referred more than 10 parents to support groups in the last two years were more likely to think that medication is helpful than those who had referred 4 or fewer (F=2.84, p<.006). Those who had more contacts with parent support groups in the last two years were more in favor of sharing information with parents (F=2.61, p<.01).

With respect to differences between disciplines, differences in blaming attitudes were marked (F=12.7, p<.0000). Low mean scores represent greater blaming, high mean scores represent lesser blaming. Means were 2.20 for social workers, 2.31 for psychologists, and 2.44 for psychiatrists, with differences between each discipline at p<.05 and differences between the most blaming (social workers) and the least blaming (psychiatrists) at p<.0000 on Scheffe tests of multiple comparisons. Psychologists (mean
=.98) believed more strongly than social workers (mean=1.08) that parents should be
given specific instruction on how to help their children (p<.0000). Psychiatrists were
much more in favor of medication (mean=.69) than either social workers (mean=.79) or
psychologists (mean=.79) (F=19.3, p<.0000). Psychologists were more in favor of
sharing information with parents (mean=.99) than were social workers (mean=1.05)
(p<.001).

Respondents who endorsed ego psychological/psychodynamic theoretical models held
more blaming views than the mean (t=2.23, p<.03), as did those endorsing family systems
theoretical models (t=2.10, p<.04). Respondents endorsing a neuropsychological model
were least blaming (t=-3.84, p<.0001), with cognitive-behavioral and existential-
humanistic orientations in between. Cognitive-behaviorally oriented respondents were
most in favor of sharing information with parents (t=1.66, p<.10, whereas those who
favored ego psychological/psychodynamic approaches were most opposed to sharing
information with parents (t=-2.45, p<.01). Cognitive-behavioral professionals were most
in favor of telling parents specific ways to help their children (t=2.56, p<.01) and
existential/humanistic respondents were least in favor (t=-2.13, p<.03). Differences were
assessed with respect to mean values.

These preliminary results will be modified and refined based on the larger data set which
was still incomplete at the time of presentation.
The burgeoning interest in family support and family-centered services has the potential to transform policy and practice with children and families. At the heart of this transformational capability are the explicit values that guide the conceptualization and delivery of family-centered services. These include, for example, values about: families as partners in the development and implementation of services, parents as experts on their children, and strengths-based and culturally sensitive practice. Adherence to these values represents an important, qualitative shift from traditional, system-centered, deficit-oriented services.

The development of new, family-centered service models has led to questions regarding their relative efficacy. For instance, it has become commonplace at professional meetings to hear speakers expound upon the need for research and evaluation data in support of family-centered services. In most instances, both the questions posed and the methodologies advocated represent conventional approaches to inquiry. This occurs both implicitly, as when conventional methodology is presumed, and explicitly, for example, when the ideals of science are touted as the standard for evaluating family-centered services. Even research and evaluation that attempts to involve family members often restricts such involvement to marginal or researcher prescribed-roles such as commenting on measurement tools. This type of involvement retains the assumptions and structure of conventional research (e.g., the researcher in the expert role) while giving the appearance of "family-centeredness."

This lack of congruence between the values and assumptions of conventional research and evaluation and those of family-centered services is questioned infrequently. In part, this is due to the belief that practice and research/evaluation are fundamentally different processes; the latter being a manifestation of "science" which is subject to a different set of principles and values. (These differences are summarized in the table below.) Such a distinction allows researchers and evaluators to maintain control over how knowledge is generated and how it is interpreted. This is inconsistent with a family-centered orientation and hampers progress toward the kind of system change that is the promise of
family-centered services. In contrast, it is the thesis of this paper that research and evaluation are variations of practice. Therefore, the values and beliefs that guide family-centered services should also guide the conduct of research and evaluation. Practice, research and evaluation are fundamentally similar social, "meaning-making" processes. Despite the different purposes that each may claim, they are highly interrelated. Characteristics of family-centered research and evaluation are identified and discussed.

Table: Comparison Between Family-Centered and Conventional Approaches to Research and Evaluation

<table>
<thead>
<tr>
<th>Family-Centered</th>
<th>Conventional</th>
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<tbody>
<tr>
<td>Assumption/value explicit</td>
<td>Assumptions and values not acknowledged or seen as source of bias</td>
</tr>
<tr>
<td>Participatory at all phases</td>
<td>Researcher or system driven</td>
</tr>
<tr>
<td>Contextual - important contexts identified</td>
<td>Acontextual or contexts not acknowledged</td>
</tr>
<tr>
<td>Strengths-based</td>
<td>Deficit-based, “neutral” or researcher identified strengths</td>
</tr>
<tr>
<td>Culturally sensitive</td>
<td>Euro-middle class or assumed to be objective</td>
</tr>
<tr>
<td>Amplifies and validates (legitimates) client’s voice</td>
<td>Amplifies researcher’s voice, validates theory or system’s objective</td>
</tr>
<tr>
<td>Change and benefit oriented</td>
<td>Participants as objects (information generators)</td>
</tr>
<tr>
<td>Critical, challenges status quo</td>
<td>“Objective,” affirms status quo</td>
</tr>
<tr>
<td>Credibility, authenticity</td>
<td>Validity</td>
</tr>
<tr>
<td>Rights/value-based</td>
<td>Data-based</td>
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Witkin, S.
Source: Developing a Family-Centered Approach to Research and Evaluation
Title: Strategies for Involving Families of Color

Presenter: Mary Telesford

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1021 Prince Street
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Presenter: James Mason

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The session was attended by more than 40 participants and included an equal number of parents and professionals. The overview was presented by Mr. Mason. He began by discussing how the terms used to refer to culturally diversity often confuse more than inform. When terminology is unclear, the goals of a specific activity to connect with parents or family members (e.g., recruitment, outreach, or involvement) may miss the mark. After this inadvertent error, the evaluation component of the cultural activity may not have the validity to figure out the outcome of the cultural activity.

Beginning with a clear description of the target population with which one wants to conduct outreach is important. Simply using the terms cultural diversity may be too broad. The Atkinson and Hackett (1988) perspective contained in the book entitled, Counseling Non-Ethnic American Minorities was cited. The authors contended that within the term cultural diversity, the distinction needs to be made between: (a) ethnic cultural groups of color (i.e., African Americans, Asian/Pacific Islander Americans, Native Americans, and Hispanic Americans), and (b) non-ethnic cultural groups (e.g., women, people with disabilities, seniors, gays and lesbians, and religious minorities). Without making such distinctions, the unit of analysis and goals of a given activity are obscured.
Beyond the differences just described, it was also important to consider the differences between specific groups of color and the mainstream population (which also requires better definition), and the differences between and within the specific cultural groups of color. Alluding to Ponterotto & Casas (1991), Sue and Sue (1990), Green (1982), and Ho (1987; 1992) it was acknowledged that barriers to recruitment and approaches to involvement will vary according to cultural group and community context. Without such specificity, as opposed to greater sensitivity developing, new stereotypes may arise.

Within group differences were described that included: income, education, language, religion, age, national origin, social history, gender, service history, regional differences, and cultural identity. These were briefly explained. Within this context, it was noted that diverse parents and family members may use a bicultural perspective. That is, that although they may belong to a diverse culture, they have skills and experiences that allow diverse people to function effectively within mainstream environments. Parents and family members must also be viewed as to their range of experiences; some are quite new to issues concerning parent and family member participation while others possess vast experience. Therefore, viewing parents on a continuum spanning the prospective range of experiences and resulting levels of awareness is important.

Lastly, it was shared that the recruitment issue must be connected with the involvement issue. The recruitment of culturally diverse parents and family members must stem from a value base that understands the important contributions that can emanate from parent and professional alliances. The potential roles for parents were outlined. Examples ranged from case consultation, parent education and support, family or community advocacy, and policy or program development and analysis.
Title: Straight from the Horse's Mouth: Family Members as Providers of Training and Technical Assistance

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Presenter: Debbie Hyatt

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Under a cooperative agreement with the Center for Mental Health Services of the U.S. Department of Health and Human Services, the Washington Business Group on Health has organized a training and technical assistance network for states and communities receiving grants from the Center for Mental Health Services. These grants support the development and implementation of coordinated service delivery systems that closely involve families with a child who has a mental, emotional, or behavioral disorder with the full range of human services providers in their communities. The initiative is intended to significantly increase the scope and quality of comprehensive community-based mental health services for children and adolescents and their families.
The National Resource Network (NRN) provides training, consultation, and ongoing technical support to the twenty-two grantees. Spanning the many different child-serving agencies responsible for children's mental health, the NRN strives to integrate training and technical assistance with service delivery. Each community sets its own training agenda with the network tailoring its support accordingly.

To maintain a strong focus on families as full partners in community-based delivery of mental health services, the Federation of Families for Children's Mental Health is a prominent partner in the National Resource Network. The Federation's Family Leadership Initiative is dedicated to addressing training and technical assistance needs around family issues as well as developing and maintaining a family focus in systems development, service delivery, and outcome evaluation. The project recruits and supports family members to serve as consultants who can provide family centered training and technical assistance to the service system sites.

Today, most policy makers, planners, and service providers in the field of children’s mental health feel comfortable using the rhetoric associated with family/professional collaboration. Nevertheless, because context influences meaning, it is necessary to clarify terms like team, partner, and collaborate. Empathy, the ability to understand through really experiencing a situation from another’s perspective, is key to building the new relationships on which the system of care is predicated.

The Family Leadership Initiative’s Advisory Group has a vision of a comprehensive service system in which family members and parents of children with emotional, behavioral, or mental disorders will be able to communicate what they know and how they feel without the need for, or interference of, jargon, academic credentials, or translation. At the core of this vision is redefining what the system calls a “professional” to be congruent with the context in which the service system is operating. Family members and service providers must ask themselves whether a Ph.D. from Harvard really is more valuable than a Ph.S. from Tremont Street? Communities need to examine and redefine the structure of their service delivery systems. Parents are the base of the tree, neighbors are the branches, and the leaves are the individually designed services.

Families and service providers need to learn how to respect and treat each other in new ways. Both family members and service providers have to get good at WIN/WIN situations. All players in the system of care need to pay attention to language and how the words we use are understood by those working with us. We all know the red flags. It is a two way street.
Family members and parents can teach service providers the skills they have learned in order to manage life with a child who has a mental, emotional or behavioral disorder. Family members can help each other to better communicate with and educate the system. The Family Leadership Initiative is helping families and family organizations to develop these skills.

Systems change sometimes appears overwhelmingly tedious and difficult. But, we can do this. We have to start by giving ourselves permission to change the system.
Attention to family problems, values and relationship patterns nearly always focuses on Euro-American family formations. Native American family concepts and ideals rarely fit the mold, and the family unit as well as individual members rarely receive full benefit from the psychosocial interventions provided. ".. A model of a nuclear family, with a single unit residence pattern, was requisite of all tribes. This imposed family became the primary instrument to 'civilize' (quotes mine) tribal peoples and to obliterate cultural heritages" (Medicine, 1981).

Few human service professionals question whether variants in family structure and relationship patterns exist, let alone that these various formations might suggest better ways of working through problems. Furthermore, many Native American people are not cognitively aware of their own traditional family systems (which they still practice), nor that a culturally congruent family system would have a greater chance of success than a system which is imposed on them and which might be alien to anything they have experienced.

One outstanding example I recall was an Indian man being required to attend "play therapy" with his three children. Most of the time was spent in imaginary play, where he was asked to "eat" plastic hamburgers and sit on child's chairs, go through hoops on his hands and knees, and so forth. In this man's cultural framework, men would not relate with their children in this way. The therapist never understood this fact. Although his primary problem was alcohol abuse, other issues relating to role definition and function were identified. To further complicate the problem, he, too, was unaware of his own cultural patterns, and blamed himself for not being able to meet with the therapist's approval by personally connecting with the activities.

Many factors, destructive to traditional family structures, have impacted Native American families, some historical, some social and some stemming from cultural conflicts.

Historical events include:
1. 1887 - The General Allotment Act - divided reservations into individually-owned parcels. Excess land sold to non-Indians.
2. 1924 - Indian Citizenship
3. 1934 - Indian Reorganization Act - gave tribal authority over land use and resources.
4. 1952 - Relocation Act - Removal of Indian people from reservations to cities for education and skills training.
7. 1978 - Indian Child Welfare Act - provided procedure for Indian children to remain within their own environments.

Social: The most destructive social issue is usually associated with alcohol and addiction. However, there are more relevant factors to consider, which are lost in the immediacy of alcohol-related dysfunction. Among the more debilitating considerations are: (1) The multiple, multi-generational, complex grief directly affecting each American Indian person; and (2) The continuous assault inflicted through earlier educational experiences, depriving countless Indian children of decent parenting models or a positive attitude toward education. Other social issues include lack of employment opportunities and subsequent economic hardship.

Beatrice Medicine is strong on the point that there is no ONE or "THE" Indian family. Some are bi-lateral, some matriarchal, and others patriarchal. There are frequent examples of interdependent relationship patterns, neither dysfunctional nor co-dependent (Medicine, 1981).

In recent research to uncover systems which prevented child sex abuse in the past, this writer received the following information from elders of six different tribes as strengths of the extended family unit:

1. The children were at the core of the extended family constellation, surrounded by their adult relatives and watched over by older siblings.
2. Extended family members were designated roles within the extended family unit, some tribes being very specific, others not being rigid about the nature of relationship patterns, but having awareness of them built in to cultural norms.
3. Prescribed behaviors according to relationships and functions.
4. Specified behaviors of respect, etc.
5. Specific behaviors taught relative to age, sex, and role of the individual.
6. Work and survival highly valued, requiring all people to participate in a collaborative manner - including children, in child-appropriate ways of "helping."
7. Children constantly supervised by usually more than one person.
8. Among many groups, secrecy about offenses against children was not commonly practiced, yet was not "reported" to non-Indian authorities. They were usually dealt with effectively within the extended family unit, where there were nearly always elders and wisdom-keepers.

American Indian families are now being strengthened through their own cultural traditions. The return to traditional ways of relating and living together are having positive results (Berlin, 1987).
Title: Parents Provide Power to the Partnership

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Salt Lake City, UT 44114-4620

What we would like to share with you is a quick overview, outline and suggested activities for a one-day in-service curriculum entitled, "Parents Provide Power to the Partnership." This curriculum was completely planned and designed by parents to teach and assist human service professionals in developing a better understanding of the parent/family/client perspective in the context of service delivery. It was the philosophy of this expert team that providers must experience and relate to the consumer perspective to more effectively partner with parents. Such partnerships could then result in the development of powerful clinical, political, support and advocacy teams that would shape the quality and future of service systems for children and families.

As you may already know, the impetus for the development of this curriculum grew out of the establishment and implementation of a comprehensive system of personnel development for the early intervention program for infants and toddlers with special needs and their families. You may be familiar with the terms P.L. 99-457 or Part H of IDEA, the Individuals with Disabilities Education Act. We, as parents and professionals, came together under that mandate to develop models of partnership and collaboration that satisfied specific requirements of that legislation. But mandated practices soon evolved into gratifying relationships that we not only valued and nurtured, but started to generalize to contexts outside the early intervention arena.

By building awareness and sharing the benefits of parent/professional collaboration, we pioneered the inclusion of parents on, among other groups, advisory boards, service planning teams, legislative coalitions, Congressional staffs, and community councils. Other service systems, political groups and advocacy organizations began to experience the strength of provider/consumer collaboration. Clients and consumers took pride in and enjoyed the advantages of having built programs and systems that were responsive to their needs because they were structured according to their own design.

As human service providers, you often see families at their most vulnerable. We hope to share with you some mechanisms that may make it easier for you and your colleagues to
better understand and relate to these families. In human services it often seems that it is virtually impossible to meet even some, much less all, of the needs of our clients. And it also often seems as if we can never break a cycle of dysfunction or crisis for those who come to us for help. We believe that partnership, rather than treatment or service provision, encourages families to become as invested as we in their progress and their success. As partners you plan, problem solve, make progress, experience set-backs, and celebrate growth together.

We hope this model will inspire you to join with the population you serve to make your program work. If it is a new program, these partnerships lend experience, practicality, and a hands-on perspective to your planning, development, and implementation. If your program is firmly established and enjoys a rich history of service to families and the community, these alliances shed new light on weary policies and routine procedures. These relationships demonstrate and provide the mutual support necessary to anticipate and respond to daily challenges and to enjoy the accomplishments you achieve together.

Clients and providers as powerful partners help each other maintain the energy necessary to prevent personal and professional burnout, articulate and advocate for continued, innovative, and responsive options to help families survive and prosper, and to rise to the long-term challenge of ensuring that every child and family is allowed to experience dignity, opportunity, and self-actualization.
Dissatisfaction with a human services system that is unresponsive, stigmatizing, and ineffective has led to a ferment of experimentation in recent years. Practitioners in many fields, usually working in isolation from each other, have redesigned services and reshaped practice, transforming the relations between professionals and the families and communities they serve. Often, however, services that treat families as full partners with professionals exist on the margins of a larger system that is disempowering, fragmented, deficit-oriented, and focused on crises rather than prevention or support. Funding mechanisms, bureaucratic constraints, and professional attitudes all inhibit the reinvention of larger health and human service systems as empowering and supportive of families, even when parts of those systems are committed to building and strengthening partnerships with families. The panel discussed efforts to move empowerment-based, family-supportive principles from the margins of larger health and human service systems to their center.

The first speaker, Paul Adams, Professor at the Graduate School of Social Work at Portland State University, introduced the session and described how a neighborhood-based interagency collaboration, the Patch Project, used an innovative team as an entering wedge to produce larger and more lasting system change in Linn County, Iowa. This project is now being studied and disseminated nationally as a model of how a public agency can engage in preventive, community-based work in the context of providing child protective services. The second speaker, Kristine Nelson, also a Professor at Portland State University, described how Idaho and Maryland have used the principles of family preservation and family support, often insulated within discrete programs or services, as the basis for statewide reform of their child welfare systems. Robert Cohen,
the third seminar participant, is a Professor of Psychiatry at Virginia Commonwealth University and director of the Commonwealth Institute for Child and Family Studies. He described a community-based psychiatric hospital that is a model of a comprehensive, family-friendly service system for children and adolescents. He presented practical guidelines for making a system family friendly by empowering staff, changing organizational structure and culture, and involving families in overcoming policy, administrative, and professional barriers to full and equal partnership with parents of children with emotional and behavioral disorders.

All three speakers were part of an intensive month-long international symposium at the University of Iowa's Center for Advanced Studies that examined family- and community-based approaches to social problems. Information presented in this session is included in the book that resulted from the seminar, which describes and analyzes innovative community-based programs in social services, employment training, schools, community policing, youth services, and mental health. Paul Adams and Kristine Nelson directed the seminar and edited the book, *Reinventing Human Services: Community- and Family-Centered Practice* (Hawthorne, NY: Aldine de Gruyter, 1995), which also includes chapters on the history of neighborhood-based services, professional roles in the community, and a model for the delivery of human services that integrates individual, family, and community levels of practice and reconceptualizes professional-community relations.
Engaging parents as decision-making partners in ecological strengths enhancement through a wraparound process helps professionals relinquish confusing deficit theories of human experience while individualizing services. This transformation is endangered when wraparound process is understood and applied as a new method in a continuum of services.

When they are grounded in ecological family systems theory and a more malleable, constructivist, world-view, two inter-related constructs maintain fidelity of the wraparound model. Engaging families as decision-making partners is the key construct which is focused through a process of building from strengths across the ecology of the family in the community. From this theoretical basis, these wraparound constructs have the potential to guide us beyond the current confusing array of deficit theories about children and families, as well as to help transform the professional-as-expert model of medically driven categorical services.
European in origin, the United States WrapAround model is emerging from an early developmental stage in which its unique difference and potential have been solely defined through philosophical statements of principle. To continue this approach risks diminishing wraparound to a circumscribed role in a continuum of categorical services, rather than to transform the way we view and work with families in communities.

A critical and potentially crippling paradox is emerging. Engaging parents as decision-making partners in an ecological, strengths-building focus with professionals whose training has been in deficit focused theories and whose experience has been shaped in expert, medically driven, categorical service models is a formidable challenge.

With all the promise it holds for children and families, the integrity and potential of wraparound process is in jeopardy if we continue to guide its development solely through philosophical "commandments of care" like "No Eject, No Reject, No Surrender" and easily misinterpreted principals such as "family-centered, individualized service," "parent involvement," and "strengths focus." But who assesses and makes service decisions, and from what basis are families involved? Are they the locus of pathology, or are they contributors of information to be assessed by expert professionals? Are families collaborators in assessment with professionals who then recommend services, or might they be decision-makers in partnership with professionals, shaping the very nature of services through articulation of their needs?

The author's role as a Children and Adolescent Service System Program (CASSP) Coordinator attempting to transform traditional student services into a WrapAround model at a rural Florida middle school, as well as her experiences as a consultant and evaluator in a $500,000 joint venture to implement a WrapAround model in urban Tampa elementary schools, form the basis for addressing this challenge to the field. Administrative and clinical lessons from these community efforts highlight the importance of grounding the wraparound process in a clearly articulated theoretical framework with congruent training and supervision in community and clinical assessment.

This presentation delineated the theoretical differences between wraparound and traditional models, and heightened the contradiction of approaching the wraparound process as simply a new method of service delivery. It explored what models of training and supervision as well as which managerial processes may be more congruent with this distinctly different approach to working with families, suggesting the critical role families must play as consultants to wraparound development and evaluation.
This workshop was presented by two parents both of whom have children with mental/emotional or behavioral challenges. They combined personal experiences with practical information to present their workshop.

The Family Support Program runs through a statewide organization called Mountain State Parents Children and Adolescent Network. This program is the first parent driven organization in the state of West Virginia and is funded through the Office of Behavioral Health - Children's Mental Health Division.

As with any program, in order to see progress certain barriers had to be broken. Our state is very rural and we do not have public transportation in many of our counties. As a result, transportation was our biggest barrier to overcome. Parents wanted to access services or attend support group meetings but had no way of getting there. We have worked with other parents who have transportation to provide car-pooling along with our Behavioral Health Centers to assist in providing transportation to their clients that want to attend our functions. Another big problem has been respite or daycare for our special needs children. At this time we are working on developing a statewide respite program with plans of receiving a grant to implement it. Until then, we have parents volunteer to watch each other’s children in emergency situations.

After breaking down a few of the barriers that prevented parent involvement, we saw an increase in the number of parents who wanted to become involved. They realized that change wouldn't occur with only one voice; that it would take everyone to make change happen. Parents also realized that it is more comforting to talk to another parent during a time of crisis then to a professional who really does not understand what you are going through. When they started realizing the benefits and that there is no cost involved, our numbers grew.

We offer support by presenting free workshops for parents on their educational rights, how to handle different circumstances, and their rights in general when obtaining services
for their child/children. Many of these workshops were presented through already existing support groups.

Our program is set up to empower parents. By presenting workshops and offering advice on how to handle different situations, we empower them. We also offer much needed support through a toll-free line for parents. They can request information or just call to talk about their problems.

Through our support groups, parents are able to gain knowledge on their child's disability along with ways of coping. We have professionals speak on various topics. Our most popular speaker in the Ohio County group is a therapist who attends our meetings in December of each year to discuss how to handle the holidays. Since the network's inception, we have started quarterly networking sessions. Support groups sponsor a day of networking on a quarterly basis. A different support group plays host each time. This enables the parents to meet with other parents throughout the state who are experiencing similar problems. Ideas are shared and problems are talked about. Carpooling is an important part of ensuring participation. The network pays mileage and daycare expenses incurred to enable parents to attend who otherwise would be unable.

This year we held our first Children's Conference for parents. We offered workshops on Attention Deficit Hyperactivity Disorder, Adolescent Depression, Adaptations for the Classroom, and Fragile X. To ensure parent participation, we offered parent scholarships. For our first conference we had approximately 75 parents. This doesn't sound like many but last year we only had 5 parents attend the WV-Alliance for the Mentally Ill's Children Track during their conference. So we are growing and next year we hope to double that number. Our theme for our 1996 Conference is "Together We Can Make a Difference" and we hope to also involve the professionals.

Through our Network we also received a $100,000 grant to develop and implement a program to offer financial assistance to families who have a child at risk of being removed from the home. We sent out needs assessments to parents throughout the state and chose the Northern Panhandle and the Eastern Panhandle to be pilot sites for the Family Support Program. The Northern Panhandle was chosen because it is more urban and the Eastern Panhandle was chosen because it is more rural. We felt we would have a better chance of receiving future funding if we could show how it helped both the rural and urban areas of our state. We also want to see where the greater need is.

The program was set up with three goals in mind. These goals are: (1) to deter unnecessary out-of-home placement (and/or to make it possible for families to choose to have their member with a disability return home from an out of home placement); (2) to
enhance the caregiving capacity of families; and (3) to take full advantage of all resources available to families including those present within the public and private sectors, in order to assure a full circle of supports around families.

Families must have exhausted all other means before applying for our funds. However, they can apply and at the same time be seeking assistance from other sources. Our program will fund such goods and services as: respite care, child care, health related costs not otherwise covered, equipment and supplies, homemaker services (when your child is hospitalized in an out of area facility), transportation, utility costs, training and technical assistance, and integrated community activities.

There is not much money allocated for this program but we are using it very sparingly and still serving the parents’ needs. Case managers will assist parents in seeking out alternate resources to assist in purchasing goods and services. If other resources are not available, we fund it 100%.

Another service we offer to our parents is our quarterly newsletter "Parent to Parent." It is written by and for parents of children with a mental/emotional or behavioral challenge. Each issue features a parent's story and current issues that face us as parents. We provide legislative updates and other important information that we feel parents need to know.

All of the programs we have discussed enable parents to not only access services they were unable to in the past but also to empower them. We at Mountain State Parents CAN feel that empowerment is very important and work very hard to empower our parents.

Everything we have talked about enables parents to have easy access to services, but most importantly, it helps parents realize "They are Not Alone and Together We CAN Make a Difference."
Definitions:

Community Team: Used as a term to identify a group of stakeholders committed to improving outcomes for children and families. In Illinois, this would typically be a Local Area Network Steering Committee.

Broker Agency(s): The Broker Agency involves the agency or system who takes responsibility for implementing WrapAround services. This can be a non-profit service provider who agrees to provide unconditional care and flexible services for one child or family. It can also be a public system such as the Department of Child and Family Services (DCFS) who is arranging for needs driven services. In some communities, the Broker Agency includes the member organization of the Community Team who takes a leadership role in terms of contracting, training or supervision of services.

Team Facilitator: This term identifies the person or agency responsible for developing the individual child and family team, working with the team to develop a plan and coordinating/managing implementation of the plan. The Team Facilitator role can be filled by a variety of individuals and organizations. These might include the DCFS worker, a private non-profit service provider, a parent partner, advocate, juvenile court probation officer or school social worker. Whoever is ultimately responsible for implementing the plan can be identified as a Team Facilitator.

Child and Family Team: This term identifies the individualized team which is configured for each child and family receiving WrapAround services. It is important to note that
Child and Family Teams are not staffing groups or interagency bodies. For each child or family receiving WrapAround services, a different team must be configured. Child and Family Teams should consist of informal members such as extended family members, neighbors, employers and friends as well as formal members. Formal members would include those service providers such as teachers, social workers, therapists, public health nurses or probation officers.

Plan that Builds on Strengths and is Focused on Normalized Needs: WrapAround services are based on plans which are unique to the individual child and family. In order to ensure that these plans are individualized, WrapAround plans begin with the strengths of the identified child and their family. These strengths have to be different for each child and family receiving WrapAround services. Additionally, WrapAround services are clearly biased in terms of community involvement. A critical step in developing a WrapAround plan involves the identification of normalized needs which are typical for children of the same age, gender, culture and neighborhood.

Creativity: Successful WrapAround initiatives are frequently seen as reliant on creativity. When identifying creativity as a useful commodity, it is helpful to note that this occurs on both a direct service level and an administrative level. In the case of direct services, creativity is often demonstrated through unique plans and problem solving strategies. In administration, creativity in WrapAround service delivery is often demonstrated by breaking down barriers which prohibit the Child and Family Team from implementing plans or arranging for creative fund or resource development packages.

Training: In addition to formal training and orientation regarding the WrapAround process, a key element of successful plan implementation is training. This frequently involves training and skills acquisition strategies for Child and Family Team members in order to increase coping skills with crisis situations as well as providing those people directly involved in supervising the child with skills needed for behavior control. All good WrapAround plans should include a training component designed to increase the likelihood of the child's success.

Unconditional Commitment: Unconditional commitment means that the child and family will not be removed from services regardless of the behaviors they demonstrate. While unconditional commitment is generally implemented by the Child and Family Team, it also has implications for administration involved with any WrapAround initiative. Administrators implement unconditional commitment through assuring that staff are empowered to implement creative action plans and working on flexible resource delivery.
Flexibility in Attitudes and in Funding: Flexibility in terms of WrapAround services encompasses attitudes and funding. Attitudes are frequently demonstrated when systems are able to join in real partnerships with families and communities on behalf of a child. Although it is possible to develop and deliver WrapAround plans without flexible funding, it is difficult to implement WrapAround for many children and families without flexible funding. Early WrapAround pilot projects often included small amounts of flexible funds which were easily accessible to line staff. Recent developments have included building flexibility in funding in that administrators can and do begin to authorize dollar expenditures for unusual purchases.

Team Meetings: WrapAround can suffer from neglect. Team meetings should occur regularly on both a child and family level as well as a community level. If meetings are not held, WrapAround plans often do drift back to a categorical approach. Additionally, the Community Team must meet regularly to ensure that they are identifying areas where direct service staff and families are encountering difficulties in implementation.

Monitoring/Evaluation: The result of WrapAround services should lie in improved outcomes for children and families. It is common for new WrapAround initiatives to mistake the process of creating a team and creating a plan for the result of the efforts. Individuals should identify what works for a particular child and family and continue to do that. Evaluation efforts attached to WrapAround services often include specific child behavioral benchmarks which can be used as a sign of improvement in the quality of life.

Celebrating Successes: Celebrating successes means that efforts to share what works should occur publicly. This allows direct service staff as well as administrators the opportunity to learn from success as well as failure. Additionally, since WrapAround does involve some degree of risk taking, it is helpful if people involved in taking those risks get some sort of public recognition for good work.

Always Working Toward System Change: WrapAround projects rely on top down and grass roots up partnerships in order to change systems. Partnerships between direct service staff and administrative leadership are critical to the success of any WrapAround initiative. System change is a by-product of most WrapAround initiatives. Most direct service staff are interested in having more flexibility in helping the families they work with. Only through trying out new partnerships is this flexibility likely to occur.
Throughout the United States there has been a pervasive sense that parents did not have a voice in the services provided for their children with serious emotional or behavioral disturbances, that the child and family serving system was not meeting their needs and that the costly proliferation of categorical services was not resulting in positive outcomes for their children. In short, parents did not have access to appropriate and effective services. They were not at the table where decisions were being made. They did not have a voice in those decisions. And they did not feel any ownership in the planning or service delivery process.

Over the past decade many states throughout the country have adopted the WrapAround model for their most difficult to serve youth. The model has become a cornerstone of family-centered practices and of family preservation methodology. Yet training in the WrapAround approach has, historically, been geared toward the child serving system at a policy and practitioner level. But if there was to be full integration of the model at the community level, then parents needed to be engaged in a meaningful way, in a leadership rather than service recipient role. And parents have been an effective and forceful catalyst for change within human service systems.

Could Washington state move parent involvement and interagency collaboration to a level of true partnership between systems and parents? Could Washington improve outcomes for children who have chronically fallen between the cracks (or to highly restrictive out-of-state placements): those children with emotional and behavioral difficulties?

In November of 1993, Pierce County, Washington hosted the first WrapAround training for parents as implementors in the country. The four day institute trained parents to function as parent partners with other parents in facilitating the planning process,
developing and coordinating services, in conjunction with the formal service system, as well as their informal support network. And it offered a viable and meaningful role to parents as working team members. The parent to parent support fostered empathy, open communication and a sense of hopefulness. And it began to address the isolation that is so common in families who have a child with particularly challenging behaviors.

The trainers (three parents of children who have been involved with mental health, child welfare, juvenile justice and one professional) provided six months of technical assistance and hands-on training consultation to teams generated through the training. This included semi-monthly technical assistance meetings, facilitation of planning meetings and having at least one parent partner attend all team meetings. This additional support to teams and mentoring of parent partners enhanced local capacity in replicating this project's efforts. And the teams also allowed a point of entrance into local agencies, providing significant impact at the provider/agency level. But the parent-professional partnerships issue was consistently identified as the largest barrier, by parents and professionals alike.

In response, the training team offered six one day workshops for parents and six one day workshops for professionals in *Building More Effective Parent-Professional Partnerships*. This culminated in a joint session for strategic action planning. These workshops were well received by professionals and many of the ideas generated at the joint session are now being implemented in agencies. But the impact on parents was far greater than ever imagined. For the majority of the parents, these workshops were a starting point. But, for some, it was the turning point.

These workshops are now routinely scheduled as a "preface" to all WrapAround training for parents. But the topic is relevant in-and-of-itself, and as a stand-alone training it has generated significant attention. There have been several additional partnership trainings and WrapAround training institutes for parents in Washington state. And Washington is succeeding in providing more effective, family-centered and community based services.
Title: The Efficacy of Family Support in a Regional Model

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A two-year project was funded by the Idaho Council on Developmental Disabilities to implement a five-county regional family support model. The primary purpose of the project was to obtain information regarding the efficacy of family support, consumer satisfaction with the model and a cost analysis. The pilot project was designed to (1) create a support system for families who have children with disabilities that is responsive, timely and flexible; (2) use existing social networks, and community resources as much as possible; and (3) provide assistance to families to prevent crises, rather than respond to crisis situations.

Family support staff were guided by these principles of family support: (1) to recognize and respect the unique individual needs, strengths and cultural values of each family; (2) to build on a relationship of respect and trust which recognizes that families determine their own needs; (3) to be a non-compulsory service option offered to families; (4) available to families to prevent a crisis, not as a reaction to crisis; (5) to facilitate development of comprehensive, responsive, and flexible supports; (6) to make effective use of existing resources and minimize gaps in supports to families; and (7) to encourage maximum use of existing social networks and natural sources of support through community inclusion.

A family in the project can be any of the following groups, provided that the group includes a person with a developmental disability: individuals related by blood, marriage, or adoption; individuals residing together as family; or individuals and their guardians. The term family shall not include facility-based or home-based paid providers of care, such as hospitals, nursing homes, groups homes, foster care, PCS homes or providers, residential care providers, or intermediate care facilities.

The intent of family support is to recognize that children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment, and should be afforded the opportunity to live in typical homes and communities where they can fully participate as citizens. It follows that families should receive from the communities the supports necessary to meet their children's needs.
In this model of family support, a family service coordinator helps families to locate and access the resources they need to enhance the quality of their lives. The pilot project offered a continuum of supports from information and referral to service coordination. Supports may be as simple as providing a parent with the telephone number of a local resource, or as complex as developing a plan for the entire family that includes identifying, providing, or procuring local case management.

An integral part of the family support pilot project is the participation of volunteer parents and adults with disabilities who serve on the governing committee. This group provides guidance and recommendations about implementing the best possible user-friendly service. Each member of the governing committee also participates in a coordinating committee that represents professionals in other service organizations as well as family members. Both committees work closely with the family service coordinator to implement a support system that is comprehensive, flexible, timely, and community based.

Specifically the role and responsibilities of the family committee members were to: (1) establish selection criteria for full family support; (2) establish a process for one-time emergency cash payments and determine dollar amounts the coordinator can dispense at her discretion; (3) review components of evaluation tools such as questionnaires, surveys, or interviews for appropriateness and readability; (4) monitor and evaluate progress and performance; (5) provide input, feedback, and suggestions for improvements; and (6) review all family materials.

The professional committee members’ role and responsibilities were to work on system changes incorporating family support principles and needs, and to make suggestions for a single point of entry for families into the service delivery system. Participation in the process enhanced cooperation and added critical input into system changes.

Year II goals are to: (1) establish a support structure that is based on problem-solving; (2) merge in-home assistance and respite care dollars into family support funds; (3) increase community support structure; and (4) establish educational components.

Information presented included a description of the organizational structure, eligibility, and selection criteria used in this regional family support model, demographic information about the families and family members with disabilities, a description of what families requested and what they received from the project, and a cost comparison of family support to out-of-home placements for family members with disabilities. The presentation concluded with the results of a survey covering family satisfaction, perceived
short term and long term impact of family support, and how families prioritized the need for the various support services that were offered.
In 1984, Ventura County Mental Health, Public Social Services Agency, Corrections Services Agency, and the Special Education Local Planning Area began a partnership to create a broader range of positive outcomes for a shared target population. The family is the primary nurturant and regulatory environment on which all other systems that impact the child are dependent. It is the partnership with the family that becomes the foundation on which all supports are built.

About five years ago, the head of children's mental health for Ventura County suggested the formation of a support group for parents to discuss our mutual problems and advocate for our children. In May 1990, only two couples met to talk and to cry on each other's shoulders. From that humble beginning, United Parents for Children and Adolescents with Emotional, Behavioral, and Mental Disorders was born.

Today, United Parents has a mailing list of 475 families and professionals located throughout the country, with another 500 copies of the newsletter, UPWORDS, distributed through schools and mental health clinics. United Parents also has a lending library of over 350 books, videos, and articles. We co-sponsor a Serious Emotional
Disorder (SED) one-day conference, and we have just begun a joint program with Ventura County Mental Health and Interface Children's Services to provide respite care to our families.

These accomplishments did not happen overnight, but evolved over time. Parents meet regularly and receive information through the monthly newsletter. Over the years, while the parents were receiving support and information on their rights and how to advocate effectively for their kids, strong bonds were forming with Ventura County Mental Health and the Ventura County Special Education Local Planning Area (SELP A).

Some examples of the collaboration between United Parents and the SELPA include: (1) establishment of a separate SED conference - it used to be a strand in the SH conference; (2) formation of a professional support group for SED teachers, aides, and mental health workers; (3) collaborative effort to establish an SED class in a reluctant district even though the funding was available; and (4) parents involved in the SED sub-committee on staff development for the county.

Some examples of the collaboration between United Parents and Ventura County Mental Health include: (1) parents are included on the interview committee for new staff, i.e. chief of children's services, special education supervisor; (2) parents have participated in training of new staff; and (3) parents spoke to the Board of Supervisors at budget hearings in support of the mental health department. Our biggest and most exciting endeavor is the new state and federally funded respite program which is designed by families and run by parents. It encompasses respite care and getting kids into community programs such as the YMCA, Boys and Girls Clubs, and Parks and Recreation with specially trained staff.

The Family United Network, a collaborative effort of United Parents, Ventura County Mental Health, and Interface Children and Family Services, offers respite care to Ventura County families in their home or the worker's home. Through a needs assessment, parents voiced a need for involving their kids in community activities - YMCA's, Parks and Rec., Boys and Girls Clubs, and day care facilities. In addition, a campout is planned for this summer. Respite workers or trainees will be providing child care for United Parents meetings beginning in September. Mental Health obtained the grant and administers the grant and is the fiscal agent. Interface is responsible for the recruiting, screening, hiring, and training of the respite staff and community site staff. A licensed social worker does these trainings and does consultation and support as well. United Parents is the contact for the families and has established guidelines for eligibility and participation. United Parents administers the contracts and pays the providers and maintains family records and program paperwork. United Parents and Interface work
together in matching the families and the workers. United Parents participates in the training sessions and conducts evaluations of the program.

These are some of the major accomplishments that have occurred over the past few years. There have been small steps leading up to these bigger steps, and with each step we climb higher and reach for new goals. We will continue to strive to meet the needs of our families. Positive relationships between schools, mental health and families can happen and when they do, many unique, creative and positive things happen for our kids and their families and the systems we work with.
This symposium provided an opportunity for participants to review and sample activities from a 45-hour curriculum based on national Quality Indicators for Family Support, developed by the Human Services Research Institute, the Beach Center for Children and Families, and the Institute for Integration. The curriculum consists of six modules: Philosophy of Family Support; Cultural Competence; Assessing Needs and Determining Supports; Identifying and Coordinating Resources; Skills for Working Together with Families; and Evaluating Family Support.

A number of purposes for this training initiative of the UAP of Vermont were identified by families involved in the planning. First, it is intended to produce and reinforce attitude change at the service coordination and direct support level for people supporting families. A second purpose is to build a network of experienced trainers in all regions of the state, using a mentoring or co-teaching approach. After one semester, the regional co-teacher becomes independent in subsequent offerings, and is available as a regional resource for related workshops and consultation. This local family member also acquires status and respect in the region from having served as teacher in a graduate-level course attended by professionals. A third purpose is to give potential members of the state Family Support Policy Council an opportunity to become knowledgeable and confident in family support governance issues. A fourth purpose is team-building across agency personnel in a region. As the subject of family support transcends traditional disciplinary boundaries, the course has presented an opportunity for cross-training and communication. A final purpose is to develop curriculum, materials, and methods of replication for the use of other states in strengthening their capacity to support families effectively. The curriculum incorporates information about recent federal initiatives for family support and family preservation.

This program uses techniques of experiential learning, with a minimum of lecturing. All exercises, cases and examples were developed from the real experience of families of children and adults with a range of challenges, including emotional and behavioral, as well as physical and cognitive challenges. Copies of the curriculum are available from the presenter by writing the University Affiliated Programs of Vermont.
The decade of the 1990's has witnessed exciting developments regarding the use of natural support systems/assets/resiliency, in reaching undervalued communities across the United States. These developments have highlighted the importance of human service organizations collaborating with indigenous community resources.

The Latino family residing in the United States has not only gotten more diverse in ethnic representation, but has slowly dispersed throughout all sectors of the country. However, regardless of ethnic origins and location of residence, Latino families are generally living in economically-poor urban areas. This, in combination with a tendency of the professional and popular literature to portray these families as having no strengths/resiliency, has raised many concerns about the future of this community.

Although Latino families and communities must endure the trials and tribulations of life with minimal economic resources, they are not without cultural assets of helping. These indigenous resources are deeply rooted in cultural traditions of helping and help-seeking and take on greater significance when the group has been uprooted to an alien land and culture.

Solutions to Latino family needs lie in individual and collective self-help/mutual aid efforts that are coordinated with and supported by formal systems; the strategies for community solutions to community needs rest on collaboration among community organizations and institutions, citizen participation, and a shared belief in the value of building individual and community problem-solving capacity. These strategies, in turn, must utilize resiliency/multi-cultural approaches as central cores in reaching all sectors of a community.

The social service literature on Latinos has also witnessed an increase in publications specifically focused on utilization of natural support systems, community development, and self-help approaches. However, not all indigenous resources can be automatically considered part of a natural support system. Consequently, it is very important for
practitioners and social service agencies to develop an in-depth understanding of how to identify and collaborate with natural support systems. Latino natural support systems can consist of any one or combination of the following types: (1) family/friends/close family neighbors; (2) religion; (3) folk healers; and (4) merchant/social clubs. However, there is very little doubt that the family, defined along extended lines (fluid boundaries allow easy membership), is the most important source of natural support.

This presentation reported on an asset assessment of a Puerto Rican community located in a medium sized city in New England. This assessment covered a broad range of indigenous institutions that have either been ignored or superficially addressed in the professional literature. This presentation provided the audience with the following: (1) overview of literature; (2) description of setting and study; (3) key findings; (4) implications for collaboration: and, (5) conclusion. Although this presentation specifically focused on one Latino sub-group (Puerto Rican), it has implications for other Latino groups in the United States.
Title: Promoting Family Involvement: Implementation of the Family Preservation and Support Programs

Presenter: Martha Matthews

Affiliation: National Center for Youth Law
114 Sansome Street, Suite 900
San Francisco, CA 94104-3820

Mental health service providers and advocates who work with children and families, parents of children who have mental health needs and/or are at risk of out-of-home placement, parent support groups, and other consumer-advocates should get involved in state and local planning, implementation, and evaluation under the new federal Family Preservation and Support Services Act (FPS).

The FPS program is governed by federal regulations requiring an inclusive, comprehensive planning process, and yearly evaluations and modifications of the state plan. The regulations require consumer and family involvement in this planning process, and also require coordination between family preservation and support service systems and children's mental health service systems.

To be effective participants in their state's FPS planning process, service providers, advocates, and consumers need to understand the overall purposes of the program, the requirements states must meet in order to receive funding, and the options left open to be decided through each state's planning and implementation process.

Parent advocates and community-based organizations in various states have already been active in developing their states' plans and overseeing implementation, and have ensured that these plans are responsive to families' needs, including the need for coordinated, comprehensive children's mental health services. The experiences of these advocates can help other parents, providers, and community-based organizations get involved in their own states' and counties' planning and implementation processes, monitor the programs over the five-year period, and advocate for any necessary 'mid-course correction' of the state plans.
This presentation focused on the Pitt-Edgecombe-Nash Public Academic Liaison (PEN-PAL) Project, established to develop a comprehensive array of individualized, accessible, community-based services for children ages 6 through 18 who have serious emotional disturbances and are at risk of out-of-home placement or who are placed out of the home with a family reunification service plan. The project is being implemented in three relatively rural communities in North Carolina, with funding from the Center for Mental Health Services (CMHS). Development of the project involved community child-serving agencies, parent advocacy groups, the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, and the North Carolina University System. The goal of the project is to develop a seamless community system of services and to empower families of children with serious emotional disturbances to access locally the services that best meet their unique needs.
The project has utilized an interagency planning process which has involved NC FAMILIES CAN, an advocacy organization for families of children with serious emotional disturbance, in a central role in planning and implementing the project. NC FAMILIES CAN has been directly involved in developing the service system, planning for services, working with children and families, problem solving as needed, and providing training for service providers from local agencies who are preparing to become case managers in the PEN-PAL project.

The project also represents a collaborative endeavor involving the public and academic sectors. A consortium of faculty members from departments at East Carolina University is providing ongoing training and consultation to service providers in the PEN-PAL Project. Faculty at the University of North Carolina at Chapel Hill have provided training for service providers on collaboration and the practice of case management.

The successful implementation of this complex project involving multiple service systems requires that service providers be well prepared for collaborative practice with families and professionals. Such preparation requires appropriate in-service training as well as on-going support. Training in case management was offered to a group of service providers in these counties using *Case Management for Children's Mental Health: A Training Curriculum for Child-Serving Agencies*, developed by faculty at the University of North Carolina at Chapel Hill under the auspices of the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, with support from the Annie E. Casey Foundation, the Robert Wood Johnson Foundation, the Fort Bragg Project, and the CASSP System. The Curriculum was used to teach case managers and other service providers the values, knowledge, and skills they need for effective practice. Family members, service providers, and university faculty were involved in providing the training to service providers in the PEN-PAL project.

The presenters included: Anne May, director of North Carolina FAMILIES CAN; Irene Nathan Zipper, faculty member at the University of North Carolina School of Social Work; Mark O'Donnell and Sandra Sherrill, Research Associates with the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services working with the PEN-PAL project; and Evelyn Williams, faculty member at the University of North Carolina. They described the PEN-PAL project and reviewed the history of project planning and implementation. The training provided to local service providers around case management was described, with discussion of the role of NC FAMILIES CAN in planning and implementing the training.
SECTION III
Conference Agenda
SPONSORED BY

- Research and Training Center on Family Support and Children’s Mental Health
- National Institute on Disability and Rehabilitation Research, U.S. Department of Education
- Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services
- Annie E. Casey Foundation’s Urban Children’s Mental Health Initiative
- Department of Mental Hygiene, The Johns Hopkins University
- Federation of Families for Children’s Mental Health
- Oregon Family Support Network
Welcome to Portland!

This conference is designed to respond both to informal feedback and to formal recommendations about research regarding families whose children have emotional, behavioral, or mental disorders. In November, 1992, we sponsored a meeting of family members, service providers, researchers, and representatives of research funding sources to: (1) identify the current state of knowledge about family issues in children’s mental health, (2) develop recommendations about promising areas of investigation in family research; and, (3) identify ways to encourage research about family issues in children’s mental health. At that time we wrote:

In less than a decade we have witnessed perceptible changes in theories, beliefs, and practices regarding appropriate roles and services for families whose children have serious emotional, behavioral, or mental disorders. Stimulated in part by programs supported by the Child and Adolescent Service System Program (CASSP), formerly of the National Institute of Mental Health, now in the Center for Mental Health Services, these changes represent an overall movement toward community-based, family-centered services and family participation in all aspects of the planning, implementation, and evaluation of services. In particular, there is renewed interest in preserving families, increased understanding that families need resources and support in order to deal with their difficult children at home, and a growing appreciation of the positive contribution that families can make to improving services and shaping public policy.

Symposium participants identified the need for better information exchange among researchers and for broader and more effective dissemination of promising research methods and findings. Because the relationship between applied research and good practice must be interactive, we have designed this conference to include the latest research and program innovations, and to actively include family members -- the ultimate beneficiaries of research and program activities.

Thus, the goals of the conference are to:

- Provide a forum for the examination and dissemination of state-of-the-art research findings and issues in the areas of family support and family-centered services;
- create a forum for participants to interact and exchange information about a wide range of family research issues; and
- highlight family participation in the research process and the usefulness of research for families.

We welcome your feedback about how well we address these goals, and your ideas about improvements and innovations for future conferences. Thank you for your participation.

Barbara J. Friesen, Ph.D.
Director, Research and Training Center on Family Support and Children’s Mental Health, Regional Research Institute for Human Services, Graduate School of Social Work, Portland State University

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**THURSDAY, JUNE 1**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>11:00 am</td>
<td>Registration in Foyer</td>
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<tr>
<td>1:00 pm</td>
<td>Welcome and Keynote Address in State Ballroom</td>
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<tr>
<td></td>
<td>Welcome: Barbara Friesen, William Feyerherm, James Ward &amp; Barbara Huff</td>
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<td>Introduction: Terry Cross</td>
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<td>Keynote: Karl Dennis -- Implications of Wraparound Services</td>
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<tr>
<td>3:00 pm</td>
<td>Break</td>
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<tr>
<td>3:15 - 4:45 pm</td>
<td>Concurrent Sessions (Listed Below)</td>
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<td>(P)=Innovative Program</td>
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<td>(R)=Research</td>
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<tr>
<td>Session 1</td>
<td>Including Families in Program Evaluation (P,R)</td>
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<tr>
<td></td>
<td>Cross, Sullivan, Riseberg, Flint &amp; McKenzie</td>
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<tr>
<td>Session 2a</td>
<td>Serving Children with SED in Community-Based-Programs: Measuring the Impact on Families (R)</td>
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<td>Kutash &amp; Duchnowski</td>
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<td>Session 2b</td>
<td>Access Vermont: A Statewide Evaluation of Non-Categorical Service Delivery to Children and Families (R)</td>
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<tr>
<td>Session 3</td>
<td>Strategies for Involving Families of Color (P)</td>
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<td>Mason &amp; Telesford</td>
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<td>Session 4</td>
<td>Straight from the Horse’s Mouth: Family Members as Providers of Training and Technical Assistance (P)</td>
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<td>Osher, Pola, Deck &amp; Hyatt</td>
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<tr>
<td>Session 5a</td>
<td>Comparing Family Involvement During Brief Psychiatric Hospitalization with Post-Discharge Adjustment (P,R)</td>
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<td>Leinbach, Pelts &amp; Katz</td>
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<tr>
<td>Session 5b</td>
<td>Families’ Perceptions of Change (R)</td>
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<td>Nelson, Pace, Wright &amp; Arndorfer</td>
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<tr>
<td>Session 6a</td>
<td>Latino Natural Support Systems: A Collaborative Resource for Helping Families (P)</td>
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<td>Session 6b</td>
<td>Parent Perceptions of the Effectiveness of Support Families Receive (R)</td>
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<tr>
<td>Session 7</td>
<td>Building Family, Neighborhood and Community (P)</td>
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<td>Garcia</td>
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<td>Session 8</td>
<td>Family Matters: Getting Families Involved in Care (P)</td>
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<td>Dal Pra, Davis, Taylor &amp; Holmes</td>
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<td>5:00-6:00 pm</td>
<td>Parent Welcome in Galleria I</td>
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<td>6:00-7:30 pm</td>
<td>Special Interest Group Meetings (Listed Below)</td>
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<tr>
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<tr>
<td>Session 7</td>
<td>Review and Discussion of a Planned Study of Parent Participation in Treatment Foster Care</td>
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<td>Pauline Jivanjee</td>
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<td>Session 8</td>
<td>Programmatic Discussion and Networking Regarding Providing Intensive In-home Family-Based Treatment for Children with Emotional Disturbances and Their Families</td>
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<td>Paula Fortier &amp; Mary Terrio</td>
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Please see the Message Boards by the Registration Desk in the Ballroom Foyer for announcements of additional special interest meetings.
### Friday, June 2

**7:30 am**
Continental Breakfast in South Ballroom Foyer

**9:00 am**
Plenary Session in State Ballroom
- **Greetings:** Carolyn Sanger
- **Introduction:** Barry Kast
- **Speaker:** Peter Jensen -- Implications of Research Advances in Children’s Mental Health

**10:30 am**
Break

**10:45 am - 12:15 pm**
Concurrent Sessions
- **Room:** Galleria I, Galleria II, Galleria III, Parlor A

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<tr>
<th>Room</th>
<th>Galleria I</th>
<th>Galleria II</th>
<th>Galleria III</th>
<th>Parlor A</th>
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<tr>
<td><strong>Session 9</strong></td>
<td>Making the Dream Come True: Putting it all Together for Family Leadership in Children’s Mental Health (P)</td>
<td>Parents Provide Power to the Partnership (P)</td>
<td>Collaborative Research: A Pilot Study of Parents as Researchers (P, R)</td>
<td>Building Strengths Through Family Diversity (P)</td>
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<td></td>
<td>Telesford, Osher &amp; Huff</td>
<td>Argoitia, Benson, Johns &amp; Velez</td>
<td>Werrbach &amp; Harrod</td>
<td>Werner &amp; Price</td>
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<tr>
<td><strong>Session 10a</strong></td>
<td>The Belle Glade Project: Working from the Inside Out (P)</td>
<td>The Belle Glade Project: Working from the Inside Out (P)</td>
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<td>Logan, Akers, Anderson &amp; Ferguson</td>
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<tr>
<td><strong>Session 10b</strong></td>
<td>The Belle Glade Project: Working from the Inside Out (P)</td>
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<tr>
<td><strong>Session 11</strong></td>
<td>The Belle Glade Project: Working from the Inside Out (P)</td>
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12:15 pm Break

**12:30 pm**
Plenary Luncheon in State Ballroom
- **Introductions:** Linda Reilly, James Mason
- **Speakers:** Velva Spriggs, Janice Hutchinson -- Family-Centered Culturally Competent Systems of Care

**2:30 - 4:00 pm**
Concurrent Sessions
- **Room:** Galleria I, Galleria II, Galleria III, Parlor A

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<th>Room</th>
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<tbody>
<tr>
<td></td>
<td>Beale, Bell, Burt &amp; Moody</td>
<td>Mason &amp; Williams-Murphy</td>
<td>Anderson &amp; McHenry</td>
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**Session 18**
Family Research and Diversity (R, P)

**Session 19**
Changes from the Inside: Helping the System of Care for Children and Families Become Responsive to Their Needs Through Collaboration and Family Support (R)

**Session 20**
Family Support - Making it Work: The West Virginia Story (P)

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**Friday, June 2**
Continued Next Page
**F R I D A Y ,  J U N E  2 (Continued)**

<table>
<thead>
<tr>
<th>2:30 - 4:00 pm</th>
<th>Concurrent Sessions (Continued)</th>
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<td><strong>Room:</strong></td>
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<td><strong>Parlor C</strong></td>
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<tr>
<td><strong>Session 21a</strong></td>
<td>Incorporating Values Into</td>
<td>Evaluation: A Family Support Model (R,P) Green</td>
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<tr>
<td><strong>Session 21b</strong></td>
<td>The Family-Centered Service</td>
<td>Delivery Scale: A Report on the Validation Study (R) Allen &amp; Ramos</td>
</tr>
<tr>
<td><strong>Session 22</strong></td>
<td>Oregon Partners Project: Process and Outcome Report (R,P) Gratton, Paulson, Stuntzner-Gibson &amp; Summers</td>
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<tr>
<td><strong>Session 23</strong></td>
<td>Improving Child Outcomes Through Parent Participation: CASSP, School Restructuring, and University Collaboration (R,P) Rudo, Duchnowski, Malysiak &amp; Berg</td>
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<tr>
<td><strong>Session 24</strong></td>
<td>Role of Families in Determining Evaluation Design and Influencing Family Policy (P,R) Lawer, Kimmich, Melda &amp; Mullens</td>
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<tr>
<th>4:30 - 6:30 pm</th>
<th>Poster Session in State Ballroom</th>
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<tr>
<td>6:30 - 8:30 pm</td>
<td>Special Interest Group Meetings (Listed Below)</td>
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<tr>
<th><strong>Room:</strong></th>
<th><strong>Galleria I</strong></th>
<th><strong>Galleria II &amp; III</strong></th>
<th>Please see the Message Boards by the Registration Desk in the Ballroom Foyer for announcements of additional special interest meetings.</th>
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<tr>
<td><strong>Session 25</strong></td>
<td>Parents as Members of the Team (P,R) Hyde &amp; Lloyd</td>
<td><strong>Session 26</strong></td>
<td>Helping to Build Parent-Researcher Collaborations (P) Leaf &amp; Tager</td>
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<tr>
<td><strong>Session 27a</strong></td>
<td>Wraparound and Education: Building Partnerships Between Families and Schools (P) Kaplan &amp; Lezak</td>
<td><strong>Session 27b</strong></td>
<td>Inreach and Outreach to Ensure Family Involvement (P) Moonrider &amp; Newbury</td>
</tr>
<tr>
<td><strong>Session 28a</strong></td>
<td>An Innovative, Community-Based Model for Adolescent Crisis Intervention: An Examination of Family and Substitute Care Treatment Success (P,R) Boyer, Matthews &amp; Stewart</td>
<td><strong>Session 28b</strong></td>
<td>The Impact of Unmet Parental Expectations on Continuance in Children’s Mental Health Services (R) Elliott</td>
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**S A T U R D A Y ,  J U N E  3**

<table>
<thead>
<tr>
<th>7:30 am</th>
<th>Continental Breakfast in South Ballroom Foyer</th>
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<tr>
<td>9:00 - 10:30 am</td>
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**Saturday, June 3 Continued Next Page**
9:00 - 10:30 am  Concurrent Sessions (Continued) (Listed Below)

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<th>Council Suite</th>
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<tbody>
<tr>
<td>Session 29</td>
<td>Wraparound Training for Parents as Implementors (P)</td>
<td>Session 30a Balancing Work and Family Responsibilities: Results of the Family Caregiving Survey (R) Brennan &amp; Poertner</td>
<td>Session 31a Interprofessional Education Project Findings (P,R) Jivanjee, Friesen &amp; Schultze</td>
<td>Session 32a The Efficacy of Family Support in a Regional Model (P,R) Fodor-Davis, Cloud &amp; Curry</td>
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<td></td>
<td>Critchlow, Hebdom &amp; Stieper</td>
<td>Session 30b Exploring the Reliability and Validity of the Burden of Care Questionnaire (R) Brannan &amp; Heflinger</td>
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<td>Session 32b Head Start Family Service Center: A Critical Family Support Initiative (P) Lightburn &amp; Kemp</td>
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10:30 am  Break

10:45 am  Plenary Panel Session in Rose Ballroom
Positive Examples of Researcher-Family Collaboration
Moderator: James Mason
Panelists: Mary Telesford, Philip Leaf, Susan Tager, Charles Sullivan & I.V McKenzie

12:00 pm  Break

12:15 pm  Lunch in State Ballroom

1:30 - 3:00 pm  Concurrent Sessions  (Listed Below)

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<tr>
<th>Room:</th>
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<td>Session 35b Family Support Services in One Rural Area of New Hampshire (P) Seaward-Salvati &amp; Santaniello Long</td>
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<td>Strength in American Indian Families and Traditions (P) Matheson</td>
<td>Session 38b Showing the Efficacy of an Individualized Service Model (P,R) Hyde &amp; Woodworth</td>
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<td>Session 39b Promoting Family Involvement in Implementing the Family Preservation and Support (P) Matthews</td>
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3:00 pm  Conference Wrap-Up in Rose Ballroom
THURSDAY, JUNE 1

South Ballroom Foyer

11:00 am - 1:00 pm

Registration

Welcome/Plenary

Rose Ballroom

1:00 pm - 3:00 pm

Welcome

Barbara J. Friesen, Research and Training Center on Family Support and Children’s Mental Health, Portland State University; William H. Feyerherm, Regional Research Institute for Human Services, Portland State University; James H. Ward, Graduate School of Social Work, Portland State University; and Barbara Huff, Federation of Families for Children’s Mental Health

Implications of Wraparound Services for Families, Professionals and Researchers

Introduction: Terry Cross, National Indian Child Welfare Association, Portland, OR

Speaker: Karl Dennis, Kaleidoscope, Inc., Chicago, IL

Session 1

Galleria I

3:15 pm - 4:45 pm

Including Families in Program Evaluation -- Symposium (P,R)

Theodore Cross, Brandeis University; Charles Sullivan, Project Connect, Massachusetts Society for Prevention of Cruelty to Children; Jocelyn Riseberg, Brandeis University; Susan Flint, Judge Baker Children’s Center, Boston, MA; and I.V. McKenzie, Project Connect, Family Member

Project Connect, a family-centered program encouraging family involvement in evaluating program processes, is designed to develop, implement and monitor interagency treatment plans for children and adolescents with serious emotional disturbance. The presentation will demonstrate how this project includes families in program evaluation. Presenters analyze focus group and questionnaire response data and recommend strategies for involving families in the program evaluation process by focusing on families' strengths.

Session 2a

Galleria II

3:15 pm - 4:00 pm

Serving Children with Serious Emotional Disabilities in Community-Based Programs: Measuring the Impact on Families -- Paper (R)

Krista Kutash and Albert Duchnowski, Research and Training Center for Children's Mental Health, University of South Florida

Utilizing an "impact on family" scale, presenters of this paper will detail a method for learning more about the perceptions, functioning, and impact on families of children with serious emotional disturbance. A study based on data collected from Alternatives to Residential Treatment (ARTS) which examined five community-based programs is described. Presenters will discuss point of entry and one-year follow up data on families participating in the ARTS study. A part of the presentation will be devoted to understanding the limitations of existing family impact and family functioning scales. Methodologies for explicating family strengths variables will be examined.
Session 2b

Galleria II
4:00 pm - 4:45 pm
Access Vermont: A Statewide Evaluation of Non-Categorical Service Delivery to Children and Families -- Paper (P)
Lori Farnsworth, University of Vermont, Department of Psychology, Burlington, VT

Access Vermont is a part of the Comprehensive Community Mental Health Services Program funded through CMHS to help provide non-categorical mental health programs in 22 sites across the country. This paper presentation will provide an overview of Access Vermont's implementation and evaluation process. The presenter will also provide early family empowerment, satisfaction and involvement data collected in three self-report measures from a randomly selected group of parents involved in Access Vermont. The self-report measures used with these families were: The Family Empowerment Scale (Koren & DeChillo), The Family Satisfaction Questionnaire, and the Youth Satisfaction Questionnaire (Froelich & Burchard).

Session 3

Galleria III
3:15 pm - 4:45 pm
Strategies for Involving Families of Color -- Symposium (P)
James Mason, Research and Training Center on Family Support and Children's Mental Health, Portland State University; and Mary Telesford, Federation of Families For Children's Mental Health

This session will cover some of the theoretical issues and practical applications associated with involving families of color in roles to enhance children's mental health services and service delivery systems. There will be a blend of theory and how-to's designed to help those who want to place parents and family in key roles that can positively impact services to culturally diverse children and youth and their families.

Session 4

Parlor A
3:15 pm - 4:45 pm
Straight from the Horse's Mouth: Family Members as Providers of Training and Technical Assistance -- Symposium (P)
Trina Osher, Federation of Families for Children's Mental Health; Carmen Pola, Black and Latina Together, Roxbury, MA; Ellen Deck, Washington Business Group on Health; and Debbie Hyatt, New Hampshire Alliance for the Mentally Ill

This presentation includes a description of strategies developed by the Family Leadership Initiative: to recruit and train family members to be technical assistance providers; to build and support links with family trainers, leaders and networks; to conduct a culturally competent and family-centered training and technical assistance needs assessment process; and, to design an evaluation format for the training and technical assistance provided by family leaders.

Session 5a

Parlor B
3:15 pm - 4:00 pm
Comparing Family Involvement During Brief Psychiatric Hospitalization with Post-Discharge Adjustment -- Paper (P,R)
Nancy Leinbach, *Southeast Louisiana Hospital*; Paul Pelts, *Southeast Louisiana Hospital*; and Cassandra Katz, *Graduate Student, Louisiana State University School of Social Work*

This presentation describes the family-centered treatment approach of an adolescent inpatient program at Southeast Louisiana Hospital and outlines the design and preliminary findings from a study comparing degree of family involvement, outpatient symptom remission, and aftercare follow-through.

**Session 5b**

Parlor B
4:00 pm - 4:45 pm  
**Families’ Perceptions of Change** -- Paper (R)
Kristine Nelson, *Graduate School of Social Work, Portland State University*; Laurie Arndorfer, Thomas J. Wright, *Intensive Family Services, Portland, OR*; and Marjorie Pace, *Family Member*

The evaluation of family preservation services may be different based on the perspective of the evaluator. Often family intervention program outcomes are measured only from the perspective of the service system or the service provider. In this presentation, an assessment of family functioning and case outcome is examined from the perspective of the family. Information gained utilizing three distinct survey instruments with 21 families who received crisis intervention services will be discussed. Presenters will also discuss reasons why families rated themselves lower in family functioning than did their workers after six weeks of intervention.

**Session 6a**

Parlor C
3:15 pm - 4:00 pm  
**Latino Natural Support Systems: A Collaborative Resource for Helping Families** -- Paper (P)
Melvin Delgado, *School of Social Work, Boston University*

This presentation includes a description of the presence and role of natural support systems in helping Latino families address their social needs. Presenters will include a series of recommendations to help agencies work with natural support systems based on results gathered from a community asset assessment of a Puerto Rican community located in New England.

**THURSDAY, JUNE 1**

**Session 6b**

Parlor C
4:00 pm - 4:45 pm  
**Families who have Children with Emotional or Behavioral Disabilities: Parent Perceptions of the Effectiveness of the Support Their Families Receive** -- Paper (R)
Constance Lehman, *Western Oregon State College, Monmouth, OR*

Families who have children with serious emotional or behavioral disabilities face multiple and complex challenges in their daily lives. Even though parents shoulder the ultimate responsibility for assuring that the needs of both their child with a disability and their entire family are met, only recently has the professional establishment asked for their input about what types of support are effective in making life better for their child and family. This presentation reports the results of a survey of parents in Oregon which explored parent perceptions of the effectiveness of both formal and informal support families receive.
Session 7

Forum Suite
3:15 pm - 4:45 pm
Building Family, Neighborhood and Community -- Symposium (P)
Joseph Garcia, Touchstones, Seattle, WA

In a highly publicized report, the Institute for Educational Leadership (1987) declared that no single institution can effectively address the complex issues of families with children with special needs. The Parent Rights Initiatives on Disabilities & Equality (PRIDE) project was designed to address this piecemeal approach to service delivery by developing and strengthening connections between the naturally-occurring triad of family, neighborhood and community. Three elements of PRIDE, the Family Enabling Team (FET), the Neighborhood Enabling Team (NET), and the Community Enabling Team (CET) will be the focus of this presentation.

Session 8

Council Suite
3:15 pm - 4:45 pm
Family Matters: Getting Families Involved in Care -- Symposium (P)
Christopher Dal Pra, Tim Davis, Ann Taylor and Mark Holmes, Tamarack Center, Spokane, WA

A description of Family Matters, an innovative family program utilized in a residential treatment facility for adolescents, will be the focus of this presentation. Presenters will provide an overview of the program and discuss how the program utilizes various treatment modalities in unique approach to family skills development.

Parent Welcome

Galleria I
5:00 pm - 6:00 pm

THURSDAY, JUNE 1

Galleria II
6:00 pm - 7:30 pm
From Family Support to Family Friendly to Collaborating with Families: Metaphors, Change and Service Provision
David Osher, Senior Research Analyst, The Chesapeake Institute, and the parent of two children with disabilities

Collaborating with families is critical to: (1) implementing the National Agenda to Improve Results for Children and Youth with Serious Emotional Disturbance and (2) developing effective systems of care. This session will use the evolution of Target 4 of the National Agenda—From Support families (1991) to Family Friendly Services (1992) to Collaborate with Families (1993) to suggest how metaphors structure family-professional interactions. Metaphors to be discussed will include “help,” “service,” “support,” “allies,” “partners,” “system of care,” “wrap-around service,” “case manager,” “coordinator,” “facilitator” and others generated by participants.

Galleria III
6:00 pm - 7:30 pm
Review and Discussion of a Planned Study of Parent Participation in Treatment Foster Care
Pauline Jivanjee, Graduate School of Social Work, Portland State University

Parlor A
6:00 pm - 7:30 pm
Programmatic Discussion and Networking Regarding Providing Intensive In-home Family-based Treatment for Children with Emotional Disturbances and Their Families -- Everyone Welcome
Paula Fortier, Community Services Council of Nashua, NH; and Mary Terrio, New Hampshire Division of Mental Health

Please see the Message Boards by the Registration Desk in the Ballroom Foyer for announcements of additional special interest meetings.

FRIDAY, JUNE 2

South Ballroom Foyer
7:30 am - 9:00 am
Continental Breakfast

Plenary
State Ballroom
9:00 am - 10:30 am
Implications of Research Advances in Children's Mental Health
Greetings: Carolyn Sanger, National Alliance for the Mentally Ill Child and Adolescent Network (NAMI-CAN)
Introduction: Barry Kast, Administrator, Oregon Mental Health and Developmental Disability Services Division
Speaker: Peter Jensen, Chief of the Child and Adolescent Disorders Research Branch, Division of Clinical and Treatment Research, National Institute of Mental Health, Washington, DC

Session 9
Galleria I
10:45 am - 12:15 pm
Making the Dream Come True: Putting it all Together for Family Leadership in Children’s Mental Health -- Symposium (P)
Mary Telesford, Trina Osher and Barbara Huff, Federation of Families for Children’s Mental Health

The CASSP model for comprehensive, community-based, family-centered, interagency systems of care encourages professionals working in children’s mental health to recognize and value family members as fully collaborating partners in developing, providing, and evaluating services. Family members who comprise the professional staff of The Federation of Families for Children’s Mental Health, a national network of family support and advocacy organizations, will present evidence that family leadership can play a role in systems reform to improve the way children’s mental health needs are addressed.

Session 10a
Galleria II
10:45 am - 11:30 am
Parents Provide Power to the Partnership -- Paper (P)
Stephanie Argoitia, Baby Watch Early Intervention Program, Division of Family Health Services,
This symposium will present Utah’s parental involvement model in developing a statewide, comprehensive, coordinated, multidisciplinary system of early intervention services for infants and toddlers with disabilities and their families. Focusing on strategies and products developed through input of families, presenters will explore advocacy efforts, from promoting family participation in all aspects of state family policy development to procuring state funds to support early intervention, preschool special education, and family support services. The presentation will also examine implications for future family involvement ideals and partnership opportunities.

**F R I D A Y , J U N E 2**

**Session 10b**

**Galleria II**

11:30 am - 12:15 pm

*The Belle Glade Project: Working from the Inside Out -- Paper (R)*

Hyacinth Logan, Shirley Anderson and Mike Ferguson, *United Families for Children’s Mental Health*; Nancy Akers, *Belle Glade CASSP Project*

The CASSP-funded Belle Glade project was initiated in 1992 to promote family/professional collaboration, encourage family support options, address culturally-defined needs, advocate for family preservation services, and promote family’s expertise in planning, implementing, monitoring and evaluating the quality of services and supports in a culturally-diverse, agriculturally-based community in Florida. The presenters will describe this project which focused on innovative ways to enhance minority outreach in rural areas.

**Session 11**

**Galleria III**

10:45 am - 12:15 pm

*Collaborative Research: A Pilot Study of Parents as Researchers -- Symposium (P,R)*

Gail Werrbach and James Harrod, *Bureau of Children with Special Needs, State of Maine*

This presentation will focus on one rural state’s efforts to expand parent participation in all aspects of development, implementation and evaluation of a new family strengths based system of care for families with children with severe emotional and behavioral problems. Organized in three parts, this presentation will first provide a description of the development and implementation of the family strengths model, followed by an overview of efforts to expand family involvement in research activities and concluding with a presentation of findings from a preliminary study designed to develop and refine family strengths based research methodology.

**Session 12**

**Parlor A**

10:45 am - 12:15 pm

*Building Strengths Through Family Diversity -- Symposium (P)*

Sarah Jane Werner and Karen Price, *Pennsylvania CASSP Minority Initiative Parent and Grandparent Advocates*

Despite the fact that children of color are at a higher risk for developing mental disorders, based...
on a number of social indicators such as poverty, low income, and exposure to traumatic events, they are often underrepresented in child mental health services, especially those that are in non-institutional community-based settings. This symposium presents a training module that attempts to train professionals to identify and recognize the strengths of families from diverse backgrounds and to incorporate that knowledge into a plan for culturally competent service delivery.

F R I D A Y , J U N E 2

Session 13
Parlor B
10:45 am - 12:15 pm
Reinventing Human Services: Building Family-Centered Systems -- Symposium (P)
Paul Adams and Kristine Nelson, Graduate School of Social Work, Portland State University; and Robert Cohen, Virginia Commonwealth University

Individual professionals, projects and programs often find their efforts to build partnerships with families constrained by the disempowering systems of which they are a part. This panel will discuss efforts to translate empowerment-based, family-supportive principles from the margins of larger health and human services to their center.

Session 14a
Parlor C
10:45 am - 11:30 am
The Viewpoint of Parents and Youth: Issues Concerning Lengths of Stay for Children in Psychiatric and Residential Facilities in New York City -- Paper (R)
Valerie King, Citizens’ Committee for Children of New York

The Citizens Committee for Children is engaged in a two year grant funded study to examine the related issues of length of stay for children in psychiatric and residential facilities. The viewpoint of participating parents and youth is represented, in addition to the views of policy makers, facility administrators, clinicians and child care providers. Preliminary findings of an extensive study indicate that there are limited options for children and youth with serious emotional disturbance. These findings and their implications will be examined in this presentation.

Session 14b
Parlor C
11:30 am - 12:15 pm
Respite for Children Receiving Short-Term In-Home Psychiatric Emergency Services: Lessons from the Data -- Paper (R,P)
Mary E. Evans and Roger A. Boothroyd, Bureau of Evaluation and Services, New York State Office of Mental Health

The New York State Office of Mental Health received a research grant to study the outcomes of three intensive in-home program models for children in psychiatric crisis. Respite care was available in two of the models. Researchers found that, early in the study, respite care fell below expected utilization which necessitated a focus group review of issues related to respite care. Data from the focus group, comprised of providers, respite workers, parents, and program managers who convened to discuss barriers, remedies and respite utilization issues will be presented along with descriptions of the project and respite programs.
Session 15a
Forum Suite
10:45 am - 11:30 am
Major Events in the Lives of Family Caregivers -- Paper (R)
Tom McDonald, Graciela Couchónnal, and Theresa Early, School of Social Welfare, University of Kansas

This presentation reports the results of a survey of family caregivers of children with serious emotional disorders who were asked to identify major pleasant and stressful events which had occurred to them and their families within a twelve month period. Descriptions of these events and their relationship to the caregivers’ perceived well-being are presented.

Session 15b
Forum Suite
11:30 am - 12:15 pm
Challenges Faced by Working Caregivers of Children with Serious Emotional Disorders -- Paper (R)
Eileen Brennan and Julie Rosenzweig, Research and Training Center on Family Support and Children’s Mental Health, Portland State University

For working parents whose children have serious emotional disorders, a lack of support for their caregiving can make meeting the demands of home and employment very stressful. The focus of this presentation will be a preliminary conceptualization of the major challenges faced by families with workers caring for children with serious emotional disorders, a description of the Family Support Research project which will gather data from families concerning the nature of their employment situation and family responsibilities and an examination of major questions which must be answered to design effective family support programs for working family caregivers.

Session 16a
Council Suite
10:45 am - 11:30 am
System Barriers to Successful Services to Foster Children at Risk of Severe Emotional/Behavioral Disturbances: Findings from a Controlled Wraparound Study -- Paper (R)
L. Adlai Boyd, Hewitt Clark, Beth McDonald, and Rosalyn Malysiak, Department of Child and Family Studies, Florida Mental Health Institute, University of South Florida

Family-centered, wraparound case management is proving significantly more successful than standard practice in effecting client placement stability, development and implementation of permanency plans, and emotional/behavioral adjustment of children in foster care who have severe emotional and behavioral disturbances. System barriers to even greater success are discussed and remedies recommended.

Session 16b
Council Suite
11:30 am - 12:15 pm
Same As It Ever Was? The Promise and Danger for Wraparound Services -- Paper (P)
Carol Croft, Department of Child and Family Studies, Florida Mental Health Institute, University of South Florida
Engaging parents as partners in strengths-based, individualized assessment and planning through the wrap-around model helps professionals relinquish confusing deficit theories of human experience and facilitates integrating categorical services. This presentation delineates the theoretical differences between wraparound and traditional services and heightens the contradiction of approaching wrap-around services as simply a new method of service delivery. The presentation will explore what models of training, supervision, and management may be more congruent with this distinctly different approach to working with families and suggests the critical role families must play as consultants to wrap-around application and development.

State Ballroom
12:30 pm - 2:15 pm
Family-Centered Culturally Competent Systems of Care

**Introductions:** Linda Reilly, Oregon Family Support Network; James Mason, Research and Training Center on Family Support and Children’s Mental Health

**Speakers:** Velva Spriggs, Director of Planning and System Development Programs in the Child, Adolescent and Family Branch of the Center for Mental Health Services, Washington, DC; Janice Hutchinson, Acting Administrator, Child and Youth Services Administration, Commission on Mental Health Services, District of Columbia Department of Human Services

Session 17

Galleria I
2:30 pm - 4:00 pm


Bobbi Beale, Child and Adolescent Service Center; Jane Burt, Stark County Department of Human Services; and Doris Moody, Family Member, Canton, OH

Successful service delivery generally relies on effective collaboration between agencies. This presentation will describe a successful collaborative relationship between child welfare and mental health agencies as an example of the seamless system of care for family-driven services in Stark County, Ohio. Presenters will provide an overview of the integrated system of care and this county’s infrastructure mechanism that allows this integration to take place. Finally, a discussion of how this county received federal funding to expand collaborative and family preservation principles will be provided.

**F R I D A Y ,   J U N E   2**

Session 18

Parlor C
2:30 pm - 4:00 pm

**Family Research and Diversity -- Symposium (R,P)**

James Mason and Tracy Williams-Murphy, Research and Training Center on Family Support and Children’s Mental Health, Portland State University

The presenters will identify some of the gaps in the knowledge base as it concerns services to culturally diverse children with serious emotional disabilities and their families. These gaps will be expressed in terms of research frontiers and be briefly discussed in terms of the potential knowledge such research can yield. The presentation will highlight some historical and
contemporary barriers to conducting culturally competent research. A part of the presentation will be geared toward engaging presentation participants in a discussion to prioritize research and describe its potential benefit to children, families, professionals, and systems.

**Session 19**  
Parlor A -- **CANCELLED**  
2:30 pm - 4:00 pm  
Changes from the Inside: Helping the System of Care for Children and Families Become Responsive to Their Needs Through Collaboration and Family Support -- Symposium

**Session 20**  
Galleria II  
2:30 pm - 4:00 pm  
Family Support - Making it Work: The West Virginia Story -- Symposium (P)  
Terri Toothman, Mountain State Parents, Children and Adolescent Network; Susan Nally, Family Member; Tom Toothman Sr., Family Member

This symposium will provide an overview of how a group of West Virginia parents developed and implemented a program that not only offers support, education and advocacy but also family support in ways that assist parents in obtaining services for their mentally/emotionally and behaviorally challenged child. Importance of parent and family involvement will be discussed along with ways to enable parents and families to become involved.

**Session 21a**  
Parlor B  
2:30 pm - 3:15 pm  
Beth Green, University of Pittsburgh

Evaluators who face the challenge of evaluating family support centers have little to work with in terms of appropriate methodologies. Presented in this workshop is an evaluation framework that is based on the assumption that in order to be effective and useful, family support evaluations must themselves be rooted in family support principles. Presenters will focus on how these principles can form the basis for designing and implementing family support evaluations.

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**FRIDAY, JUNE 2**

**Session 21b**  
Parlor B  
3:15 pm - 4:00 pm  
The Family-Centered Service Delivery Scale: A Report on the Validation Study -- Paper (R)  
Reva Allen and Kari Ramos, Beach Center on Families & Disability, University of Kansas

The concept of family-centered care is not newly-developed. In some disciplines, the term and concept have been used for nearly four decades. Despite this history, there are difficulties operationalizing the concept. One difficulty seems to be that there is no single, concise definition of "family-centered." A lack of consensus about how to operationalize a family-centered model is another problem. It is also difficult to differentiate the concept of family-centered service delivery from related concepts such as family empowerment, case management, and home-based services. This presentation will introduce the Family-Centered
Session 22

Galleria III
2:30 pm - 4:00 pm
Oregon Partners Project: Process and Outcome Report -- Symposium (R,P)
Janice Gratton, Oregon Partners Project; Robert Paulson and Denise Stuntzner-Gibson, Regional Research Institute on Human Development, Portland State University; Ralph Summers, Oregon Mental Health and Developmental Disability Services Division

The Oregon Partners project is an innovative program including case management and flexible funding for children with serious emotional disabilities. The presenters will describe the program design, its implementation and outcomes for children and families after one year in the program.

Session 23

Forum Suite
2:30 pm - 4:00 pm
Zena Rudo, Rosalyn Malysiak and Albert Duchnowski, Department of Special Education, University of South Florida; and Kathy Berg, Family Advocacy Project, Idaho Parents Unlimited

The developmental and complementary relationship between increasing parent participation and transforming professional beliefs, roles, and processes will be explored through the collaborative experiences of a university, school, and community partnership developed in response to the school restructuring and service integration movements.

Friday, June 2

Session 24

Council Suite
2:30 pm - 4:00 pm
Role of Families in Determining Evaluation Design and in Influencing Family Policy -- Symposium (P,R)
JoAnn Lawer, Center for Schools and Communities of the Pennsylvania Department of Education; Madeleine Kimmich and Kerri Melda, Human Services Research Institute, Monmouth, OR; and Laural Mullens, Family Member, Pittsburgh, PA

The panel will discuss: (1) innovative, family-guided evaluation of Pennsylvania’s statewide family support initiative, uniting foundation, public sector, and nonprofit research entities; (2) development and use of a family survey tool to assess quality in family support; and (3) integration of such family-centered evaluation with states’ family policy formulation.

Poster Session

State Ballroom
4:30 pm - 6:30 pm
(See Next Page for List of Poster Presentations)
Interest Group Meetings

Galleria I
6:30 pm - 8:30 pm
Discussion of Success Story of Florida NAMI-CAN and its State Affiliates as Well as Progress with Services to Be Given Through Their Families

Galleria II & III
6:30 pm - 8:30 pm
Family/Professional Information Exchange and Reception
Sponsored by Oregon Family Support Network, Federation of Families for Children’s Mental Health, Research & Training Center on Family Support & Children's Mental Health, and Department of Mental Hygiene, John Hopkins University

A forum for parents, family members, caregivers, advocates and professionals to meet and exchange ideas and information. A short program will include introductions of professionals and family members from the 22 Service Initiative Sites and leaders of the 28 Family Network Grants.

Please see the Message Boards by the Registration Desk in the Ballroom Foyer for announcements of additional special interest meetings.

FRIDAY, JUNE 2

POSTER SESSION
Friday, June 2
State Ballroom
4:30 pm - 6:30 pm

List of Posters
1. The Effectiveness of School-based Therapy for Inner-City Hispanic Youth
   Matthew Carlson, Hogg Foundation for Mental Health, University of Texas

2. Factors Predicting Competence in Children with Chronic Illness and Disability: A Longitudinal Study
   Traci Colvin and Nancy A. Carlson, LaRabida, University of Chicago Research and Policy Center

3. King County Parent Advocacy Network
   David Duché, Seattle Children’s Home

4. MEGASKILLS
   Juanita Fortier, Patricia Dixon and Marcia Smith, Portland Public Schools, Chapter 1 District Parent Advisory Council

5. Affirming Every Person: A Family-Centered, Community-Based, Collaborative Program for Children with Serious Emotional Disturbances
   Paula Fortier and Mary P. Terrio, Community Council of Nashua, Nashua, NH
6. The Parent Satisfaction Scale and the Parent-Staff Interaction Scale: Development, Validity and Reliability
   Janis Gerkensmeyer, Joan Austin, Angela Barron McBride and Linda Finke, Indiana University School of Nursing

7. Evaluating Oregon’s Health Start/Family Support Projects
   Aphra Katzev, Clara Pratt, Pat Moran, Linda Eddy, Oregon State University--Family Study Center

8. Utilization of Client Perception of Services in Family Preservation Research
   Marlys Staudt, Bev Bates, Sara Friesen-Guhr, Washington University and Edgewood Children’s Center, St. Louis

   Cathryne L. Schmitz, Greg Echele, Katherine Kennedy and Holly Ingraham, School of Social Service, Saint Louis University and Family Resource Center, St. Louis City Public Schools

F R I D A Y, J U N E 2

10. The Temperament Program: Honoring Each Child’s Individuality
    Barb Zukin, Donise Warsaw and Kathy Goodman, Center for Human Development, LaGrande, Oregon

11. The Family-Centered Service Delivery Scale: A Report on the Validation Study
    Reva Allen and Kari Ramos, Beach Center on Families and Disability, School of Social Welfare, University of Kansas

12. Wraparound Training for Parents as Implementors
    Marge Critchlow, Family Member, Tacoma, WA; Heath Hebdom, PAVE, Tacoma, WA; and Carol Stieper, The Community Partnership Group, Seattle

13. Respite for Children Receiving Short-term In-home Psychiatric Emergency Services: Lessons from the Data
    Mary Evans and Roger Boothroyd, New York State Office of Mental Health

14. The Role of Families in Determining Evaluation Design and in Influencing Family Policy
    Joann Lawer, Center for Schools and Communities, Lemoyne, PA; Madeleine Kimmich and John Agosta, Human Services Research Institute, Salem, OR; and Laurel Mullins, Family Member, Homewood Family Center, Pittsburgh

15. Parents and Professionals--Combining Our Strengths to Build Stronger Families
    Ellen-Linder, United Parents, Moorpark, CA; Don Kingdon, Ventura County Mental Health; and Fran Arner Costello, Ventura County SGLPA

16. Inreach and Outreach to Ensure Family Involvement
    Delia Moonrider and Jennifer Newbury, San Mateo County Mental Health

17. Building Strengths through Family Diversity
Sarah Jane Werner and Karen Price, Minority Initiative Subcommittee, Pennsylvania CASSP Advisory Board

   Susan Yuan, UAP of Vermont

19. Identified Systems of Care: Needs and Responses in Southeast Kansas
   Ed Glenn, Michael Ehling, Jim Rast, Virginia Standley, KAN FOCUS

S A T U R D A Y , J U N E 3

South Ballroom Foyer
7:30 am - 9:00 am
Continental Breakfast

Session 25
Galleria I
9:00 am - 10:30 am
Parents as Members of the Team -- Symposium (P,R)
Kelly Hyde and Angela Lloyd, The Family Preservation Initiative, Baltimore

This symposium will provide an overview of wrap-around research and evaluation efforts of the Family Preservation Initiative (FPI) of Baltimore City, with a specific focus on the powerful role of parents as part of the research and evaluation team. The FPI Parent Liaison Information Assistant will also present a perspective on the values of parental roles in general and her own experience specifically.

Session 26
Galleria II
9:00 am - 10:30 am
Helping to Build Parent-Researcher Collaborations -- Symposium (P)
Philip Leaf, Department of Mental Health Hygiene, The Johns Hopkins University; and Susan Tager, Families Involved Together, East Baltimore Mental Health University

Changes in federal and state policies could result in substantial improvements in services for children with serious emotional disturbances or a substantial dismantling of services, especially those most useful to parents and their children. This workshop will bring together researchers and parents to discuss ways in which the perspectives of parents can have a greater influence on services, research and public policy.

Session 27a
Galleria III
9:00 am - 9:45 am
Wraparound and Education: Building Partnerships Between Families and Schools -- Paper (P)
Barbara Kaplan, Illinois State Board of Education; and Laurie Lezak, Family Member

This presentation will provide information from two project sites in Illinois that have chosen to integrate the wrap-around philosophy into special education settings. Project directors will
discuss the efforts at systems change and strategies utilized for successful outcomes. Specific examples will be given relating to service planning, the changing role of parents, and collaborating with other child-serving systems in the effort to produce a more coordinated system of care.

S A T U R D A Y , J U N E 3

Session 27b
Galleria III
9:45 am - 10:30 am
Inreach and Outreach to Ensure Family Involvement -- Paper (P)
Delia Moonrider and Jennifer Newbury, San Mateo County Mental Health

The Family Partnership Team in San Mateo County, California, in its second year of a five year grant cycle, continues to develop a family-centered collaborative approach in its program design and interactions with stakeholders such as the juvenile probation division, the child welfare system and families. In order to stimulate discussion, presenters, including one parent, will highlight: (1) a proactive approach to win “buy-in” from all stakeholders; (2) the impact parents have on their county co-workers; (3) the challenges to effective radical change from within the system; (4) the importance of a common vision shared by the Family Partnership team; and (5) the conflict resolution skills needed.

Session 28a
Parlor A
9:00 am - 9:45 am
An Innovative, Community-Based Model for Adolescent Crisis Intervention: An Examination of Family and Substitute Care Treatment Success -- Paper (P,R)
David Boyer, Ohio State University, David Matthews, Delaware Morrow Mental Health and Recovery Services Board, and Erik Stewart, Paint Valley Alcohol, Drug Addiction and Mental Health Services Board

Until 1986, Ohio’s public mental health system was heavily dependent on state institutions for care for youths in crisis or with severe mental disturbances. This paper presentation describes the impact on families, youth and the mental health system, and the conversion of the system from institutional to a family-oriented model. An evaluation of the new service system is presented along with the youth characteristics and services they received. The presentation will also explore the likelihood of treatment success for those youth in home-like settings versus those in substitute care. Program policy recommendations will also be offered.

Session 28b
Parlor A
9:45 am - 10:30 am
The Impact of Unmet Parental Expectations on Continuance in Children’s Mental Health Services -- Paper (R)
Debi Elliott, Regional Research Institute on Human Development, Portland State University

The relative impact of unmet parental expectations for child therapy and therapist personality characteristics on treatment continuance was evaluated for 120 low income families. Unmet expectations for therapy events were significantly greater for parents who dropped out of treatment (16%). Unmet expectations for therapist characteristics also negatively affected treatment continuance, with the parents who dropped out perceiving the therapist as significantly less caring and involved. Data from this study will be presented.
Session 29
Parlor B
9:00 am - 10:30 am
Wraparound Training for Parents as Implementors -- Symposium (P)
Marge Critchlow, Family Member; Heather Hebdom, PAVE; and Carol Stieper, The Community Partnerships Group

Washington piloted the first wraparound training for parents as implementors in the country. These trainings have helped move parent involvement and interagency collaboration to a level of true partnerships between families and systems. By agency request, parents provided twelve workshops in Building More Effective Parent-Professional Partnerships. This presentation will explore data gathered from the Pierce County Parent Partners Project, an institute which trained parents as implementors of the wraparound model.

Session 30a
Parlor C
9:00 am - 10:30 am
Balancing Work and Family Responsibilities: Results of the Family Caregiving Survey -- Paper (R)
Eileen Brennan, Portland State University; and John Poertner, University of Kansas

The employment conditions of family members who are caregivers of children with serious emotional disorders are explored in this research analysis. Employment situations most identified with positive appraisals of work, highly satisfactory family relationships, satisfaction with caregiving, and lower levels of stress in areas of family life are discussed.

Session 30b
Parlor C
9:00 am - 10:30 am
Balancing Work and Family Responsibilities: Results of the Family Caregiving Survey -- Paper (R)
Ana Maria Brannan and Craig Anne Heflinger, Center for Mental Health Policy, Vanderbilt University

Presenters of this paper will report findings on the validity and reliability of the Burden of Care Questionnaire (BCQ) for measuring caregiver burden among parents of children and adolescents with emotional or behavioral disorders. In addition, the relationship between caregiver burden and other family and child variables will be explored. Finally, the implications of these findings for service providers and policy makers will be discussed.

Session 31a
Forum Suite
9:00 am - 9:45 am
Interprofessional Education Project Findings -- Paper (P,R)
Pauline Jivanjee, Barbara Friesen and Katie Schultze, Research and Training Center on Family Support and Children’s Mental Health, Portland State University
This paper will present findings from a survey of 51 family-centered interprofessional/interdisciplinary education programs around the country. The presentation will describe the challenges of developing interprofessional training and the content and training methods used to prepare professionals to collaborate. A particular focus will be on the roles of family members in developing, implementing and evaluating training.

Session 31b

Forum Suite
9:45 am - 10:30 am
Beliefs of Social Workers, Psychiatrists and Psychologists about Parents of Children with Emotional and Mental Disabilities -- Paper (R)
Harriette Johnson, School of Social Work, University of Connecticut

This paper will report results of a nationwide study of the views of three groups of mental health professionals—social workers, psychiatrists, and psychologists—about parents of children with emotional and mental disabilities. Among the questions explored during this presentation are: (1) do professional disciplines differ in their belief system about parents?; (2) are ethnicity, gender, age, partnership status, parental status, or other demographic variables associated with differences in professional beliefs?; and (3) do preferred approaches to practice with parents correspond with preferred theoretical orientations?

Session 32a

Council Suite
9:00 am - 9:45 am
The Efficacy of Family Support in a Regional Model -- Paper (P,R)
Julie Fodor-Davis, Idaho Center on Developmental Disabilities, University of Idaho; Carol Cloud, Family Support Pilot Project, Idaho Center on Developmental Disabilities, University of Idaho; and Chris Curry, Families Together Program

Summary data on a 12-month Family Support Pilot Project conducted in a five county region of Idaho will be presented. The models’ structure, demographics of participating families, supports requested, cost analysis, community teaming, family satisfaction, perceived impact of supports received and families prioritization of those supports will be discussed.

SATURDAY, JUNE 3

Session 32b

Council Suite
9:45 am - 10:30 am
Anita Lightburn, Smith College School of Social Work, Smith College; and Susan Kemp, University of Washington School of Social Work

Transformation of traditional approaches to program and service delivery is described based on a three-year evaluation of a successful Head Start family support demonstration program. Attention will be given to the process of building agency capacity, and the creation of new service delivery cultures in Head Start to benefit poor families.

Plenary Panel Session

Rose Ballroom
10:45 am - 12:00 pm
Positive Examples of Researcher/Family Collaboration

**Moderator:** James Mason, Research and Training Center, Portland State University

**Panelists:** Mary Telesford, Annie E. Casey Foundation Site Advisor, Federation of Families for Children’s Mental Health; Philip Leaf, Department of Mental Hygiene, The Johns Hopkins University; Susan Tager, Families Involved Together, Baltimore; Charles Sullivan, Project Connect; and Ivy McKenzie, Project Connect, Family Member

State Ballroom
12:15 pm - 1:15 pm
Lunch

**Session 33**

Galleria I
1:30 pm - 3:00 pm

*Parents and Professionals: Combining our Strengths to Build Stronger Families* -- Symposium (P)

**Ellen Linder,** *United Parents,* **Fran Arner-Costello,** *Ventura County Special Education Local Planning Area,* and **Don Kingdon,** *Children’s Mental Health*

This presentation will describe the growth and development of United Parents, a parent advocacy and support organization that has been a facilitator in implementing successful collaborative relationships between mental health, corrections, special education and families. The presentation will focus on the influence families have had on policy change, advocacy efforts and program development as a result of the collaborative relationships fostered by United Parents.

**Saturday, June 3**

**Session 34**

Galleria II
1:30 pm - 3:00 pm

*Family Participation in Residential Treatment Programs* -- Symposium (R,P)

**Barbara Friesen,** **Jean Kruzich,** and **Katie Schultze,** Research and Training Center, Portland State University

This workshop features preliminary findings from focus groups about the participation of family members whose children are in residential treatment. Topics include types of family involvement, barriers to participation, organizational and staff supports, and recommendations for improving and supporting family involvement in residential treatment.

**Session 35a**

Galleria III
1:30 pm - 2:15 pm

*Implementing a Family-Centered Approach* -- Paper (P)

**Stan Kuperis,** **Sandra Fellowes,** D’Anne Epp, and Ernie Klassen, Fraser Valley Child Development Center

Family support services are provided in a unique way in rural New Hampshire. Throughout this presentation, the presenters will detail how they work with families and look toward community solutions to solve problems with families. They will also discuss how services have grown over
the years to meet the ever-changing needs that families present.

**Galleria III**  
**2:15 pm - 3:00 pm**  
*Family Support Services in One Rural Area of New Hampshire -- Paper (P)*  
*Cindy Seaward-Salvati and Christine Santaniello Long, Lakes Region Community Services Council, Laconia, NH*

The Fraser Valley Child Development Centre is a non-profit organization funded by several sources. This center has moved from a client oriented intervention model to a family-centered model. Presenters will share the process of change for the intervention programs provided for children with special needs. Professionals from physiotherapy, occupational therapy, speech therapy, social services, early childhood education and caregivers are all presented as integral components of the team and process.

**Session 36**  
**Parlor A**  
**1:30 pm - 3:00 pm**  
*Susan Yuan, UAP of Vermont*

This symposium provides an opportunity for participants to review and sample activities from a 45-hour curriculum developed for people who work in a variety of positions supporting families. Based on national quality indicators, this hands-on program involves people who work in positions supporting families.

**Session 37a**  
**Parlor B**  
**1:30 pm - 2:15 pm**  
*The Lifecycles of Statewide Family Organizations -- Paper (P,R)*  
*Harold Briggs, Research and Training Center, Portland State University*

Based on case studies of 17 family advocacy organizations, several key life cycle dimensions will be explored.

**Session 37b**  
**Parlor B**  
**2:15 pm - 3:00 pm**  
*Strength in American Indian Families and Traditions -- Paper (P)*  
*Lou Matheson, Private Practice, Spokane, WA*

In this presentation, advocating for the recognition of traditional American Indian family systems and the application of inherent empowering factors will be examined. Current intervention and treatment practices have not been effective, in part, because the Euro-American concept of family and relationship patterns are not culturally adaptable. These and other issues will be the focus of this presentation.
Parlor C  
1:30 pm - 2:15 pm  
**CAPPS: Community Activities for Positive Peer Socialization** -- Paper (P,R)  
Bobbi Beale and Sheryl Bell, *Child and Adolescent Service Center*; and Doris Moody, *Family Member*  

The Wraparound Department of the Child and Adolescent Service Center has developed an innovative program involving consumers, families and the community. The focus of this presentation is based on this innovative program entitled Community Activities for Positive Peer Socialization (CAPPS). CAPPS is an array of groups, structured to provide a variety of activities that will allow positive, supervised peer interactions.

Parlor C  
2:15 pm - 3:00 pm  
**Showing the Efficacy of an Individualized Service Model** -- Paper (P,R)  
Kelly Hyde and Katy Woodworth, *The Family Preservation Initiative, Baltimore*  

Presenters of this paper will provide an overview of the wrap-around research and evaluation efforts conducted by the Family Presentation Initiative (FPI) of Baltimore City. A specific focus will be the outcomes of youth who have been returned or diverted from residential treatment outside the state of Maryland. The presentation will provide participants with an explanation of data collected over a three-year period and the dissemination process.

**Saturday, June 3**

Forum Suite  
1:30 pm - 2:15 pm  
**Developing a Family-Centered Approach to Research and Evaluation** -- Paper (P,R)  
Stanley Witkin, *Department of Social Work, University of Vermont*  

The values and principles that underlie a family-centered approach have the potential to transform the service delivery system for children and families. The presenter contends that in order for this potential to be realized, research and evaluation must adhere to similar values and principle. Key values and principles of family-support are identified and contrasted with those underlying conventional research and evaluation. The implications of these differences are discussed and alternative strategies outlined.

Forum Suite  
2:15 pm - 3:00 pm  
**Promoting Family Involvement in Implementing the Family Preservation and Support Program** -- Paper (P)  
Martha Matthews, *National Center For Youth Law, San Francisco*  

This session describes how service providers and advocates can help parents of children who have mental health needs and/or are at risk of out of home placement. Presenters will explore how parent support groups and other consumer-advocate groups get involved in state and local implementation of the federal legislation to preserve and support families.
Council Suite
1:30 pm - 3:00 pm
PEN-PAL: Family Involvement in the Development of A Community-Based System -- Symposium (P)
Ann May, North Carolina Families Can; Martha Kaufman, PEN-PAL; Irene Zipper and Evelyn Williams, School of Social Work, University of North Carolina

This presentation will focus on the Pitt-Edgecombe-Nash Public Academic Liaison (PEN-PAL) project, established to develop a comprehensive array of individualized, accessible, community-based services. The project has utilized an interagency planning process in which family advocates play a central role in developing the service system, implementing the project and providing training for service providers.

State Ballroom
3:00 pm
Conference Wrap-Up
Barbara J. Friesen, Research and Training Center, Portland State University