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## **Plenary Session: Research and Advocacy: Partners for Systems Change**

**Janet Walker:** With us today, as always at our conference, we are very honored to have many family members in attendance. In particular we are honored to have with us the Executive Director of our local affiliate of the Federal of Families for Children's Mental Health, and that local affiliate is called the Oregon Family Support Network. We have Maureen Breckenridge, who has just taken over as the Executive Director. She would like to extend a particular welcome to family members here as well as to everyone else, and to talk a little bit about her observations and the observations of other family members so far during the conference.

**Maureen Breckenridge:** Good morning. I am happy to be here. I've only been with the Oregon Family Support Network for four weeks, but I've been listening. Just like I have been listening here. I was given this enormous task to speak on behalf of the Oregon families, welcoming you. I decided to make my job easy. I am going to ask everybody here who is a family member who doesn't live in Oregon, would you please raise your hand. Thank you. Everyone who is here who is a family member who does live in Oregon, would you please raise your hand. OK, that group there, on the count of three, say welcome. Ready, one, two, three, welcome.

**Audience:** "Welcome!"

**Maureen Breckenridge:** So we welcome all of you. I wanted to do that because there is no one voice that speaks for families. I wanted us all to remember that. That is what is good about my organization. We are full of a lot of different families who change over the years. We are ten years old and we have a great history.

I wanted to tell you just a little something. My background is a legal background, and a non-profit management background. I've sat in juvenile court and been in committees with things like that, and understand I am a family member myself, and I've been listening and I've been watching, and it is really, really, really special because I notice that if you don't really ask some questions and listen, you are not going to get too much from the families. And sometimes you are going to get too much from the other families.

Here's what I heard. I was sitting with a group for breakfast the other morning, and one of these people happens to be a person who has an ability to change systems. She was saying, "You know what you need? You need a warrior." I looked at her and I thought, oh, gosh, she doesn't even see it. Here it is in disguise, a mother from Lake Oswego [a suburb of Portland, Oregon], she is the warrior but she didn't know it. And that mother from Lake Oswego is taking on a challenge that you cannot believe. She also happens to have a couple of advanced degrees, but that is another one of the things that nobody bothered to ask about.

I also want to tell you that there are secrets. I know you clinicians don't like family secrets, but I am discovering that there are secrets. The secrets are things like, we've had two people in our agency and group, parents who have been on the radio in the past month. They are able to tell their story and able to get out there for you, the people who are providers, and tell that story. We have had this lady who is a parent, and she is here this morning. She sent me an email message that was the most powerful message of what a family member can do as a volunteer. She is a secret writer, and you don't know it unless you go find out.

So there are all these talents and this wealth. There is a woman in here named Elizabeth from Clackamas County [Oregon], and she has this hospitality sense. So when she works with families, things happen.

I want to tell you that there are secrets and there are dreams. I know that everybody I've heard here has their dreams. So listen to our secrets because we can help you do it.

And then secondly I want to say that I made about 20 phone calls in the past four weeks to some parents. And this might not be what you want to hear, but in the state of Oregon, we do have to listen to the parents. They don't want their children to be put into correctional facilities anymore because we don't have hospital beds. And we don't want our young mothers, young mothers so depressed that they can't do anything more, because we don't have clinicians in the rural counties. They can't take care of their families. They are saying, "I can't do one more thing today." Those are some of the parents that I have talked to. We have some parents who don't want you to put their children into a facility, that is a correctional facility again, with a rapist. Those are the real things that I heard in the past four weeks.

So I want you to hear that parents have secrets, we have dreams, and we are not going to sit down, and we are going to be active, and we want to work with you to make all this happen, because we know your dreams are our dreams. Thank you.

**Janet Walker:** The research panel that is about to begin is actually a very appropriate follow-on to this, because the idea is to talk about how research can inform and aid and be used in advocacy, to identify and define problems, to evaluate remedies and solutions and to evaluate and track policy changes. We are going to hear about some of the challenges of making the necessary connections between available research or research that needs to be done and advocacy. There will be some discussion, also of if we acknowledge these challenges, what can we do to increase the likelihood of productive connection between research and advocacy. So I'd like to introduce Ira Burnim, who is going to lead off the panel. Each of the panel members will be introducing themselves briefly when they begin to speak. Thank you very much and let's begin.

**Ira Burnim:** There is a timer here, but I'm not sure I can set it right. My name is Ira Burnim, and I am the Legal Director, which means I am a lawyer, at the Judge Bazelon Center for Mental Health Law, a national legal advocacy organization. With Barbara

today I am just going to introduce the topic of the panel. Then you will hear from others about specific experiences they've had in the realm of using research, doing research to inform advocacy. My own view, based on my own experience, is that research findings can be a very, very powerful tool in advocacy. But also, just as advocates depend very much on need researchers, researchers need advocates. Without advocates research often remains literally academic. In a very real way, advocates are the bridge between research and public policy. In the area of public policy debates, I find that there are essentially kind of three important audiences. One is the public at large, but since it is very difficult to communicate with the public at large, we tend to do that communication as advocates through the media. Secondly, at least in my own realm of work, judges are obviously a very important audience. And finally public officials—we have heads of state agencies, we have the governor, we had legislators. All of them, in my experience, are responsive to research findings. They are responsive to the kind of information that researchers generate and that can be brought to bear on public debate. I think for those of you who are advocates, you kind of know how it works. We, as advocates, say, "There is a problem." And they say, "We have a solution." There is a better way of doing this or some variation on that theme. And the burden of proof is really on us, not just in courts, but in the media and in the legislative process, because we are the people who are urging change, a change from the status quo.

What we typically do as advocates, actually there is a fairly limited number of strategies that we have available that we use. We produce "real people." We have people who have experienced the difficulty. Or people in public agencies who talk about the problems they have running their programs. We often produce experts, experts who have studied an area and can opine to the decision maker. Often, of course, their views are informed by research and evaluations. But if we really want to close the deal, often what we do is we produce a research finding. It is particularly useful if we can say that a local, reputable university has produced that research, or a national research institute

has produced that research, or the federal government or the state government has funded that research. All of that makes a difference in my experience, and can really move the public debate. I think the panelists will describe some of those specific experiences that they have had in this area.

I was thinking about the power of research, and a few examples came to my own mind of things that I believed or kind of accepted as true. I thought of how it is that I or we come to know these things. For example, that sexual abuse is very prevalent. Part of what happened is that victims came and spoke out. That self-advocacy form of advocacy, was critical in raising public awareness about sexual abuse. But it was also true that researchers began to look at that problem. Now the incidence of sexual abuse, the widespread incidence of sexual abuse, is very, very well documented. So [that is] something we have come to believe, I think through a combination of self-advocacy and research. Depression is very wide spread. How do we know that? Well, a lot of it is research findings that have recently been brought to bear by groups like the National Mental Health Association and NAMI [National Alliance for the Mentally Ill], but also published by the Surgeon General, which had an enormous impact, I think, on public discussion in the United States.

Head Start [programs] save money. I was at the Children's Defense Fund, 10 or 12 years ago. I was their legal director. We had this study that every dollar spent on Head Start saved three dollars. Actually there are some research findings now that begin to question this. But for a very long time this was just a firm part of the fabric of American public policy belief. And that came from research findings. Preventative health care saves money, another belief that was actually popularized by the Children's Defense Fund and produced the EPSDT program in the mid-'80s.

One area that I have been particularly involved in that is related, I think to children's mental health but is somewhat distinct, is the area of developmental disabilities. It is interesting because in the field of developmental disabilities, as opposed to the field of

mental health and mental illness, there is actually much more consensus about what works and what is needed.

A lot of that consensus is really research based. Some of you may remember the period of deinstitutionalization. There was a fairly early institutional closing involving the Penhurst facility in Pennsylvania. It was subject to litigation and went to the Supreme Court twice. When that facility was ultimately closed pursuant to a court order, there was a federal study done by a university in Pennsylvania, that demonstrated that deinstitutionalization was terrific for the residents of that facility. And actually the people who benefited most were those with the most severe disabilities. That research has been replicated time and again, in other institutional closings, and I think really contributed to the consensus that has not developed in that field, that no person with mental retardation should live in an institution.

Some of you may remember the Olmsted case and the Supreme Court. During the Olmsted case we marshaled all that evidence and presented it to the Supreme Court in a brief that was filed by disability advocacy organizations, and I think it had an impact on the court and helped bring the Olmsted decision to bear.

I think there are some important caveats, some important limitations. First, unfortunately, particularly in children's mental health, in my experience, there is often very little research about the things that are the most important. We have lots of research about medication and what medication works and what doesn't. We have very, very, very little research about the impact of professionals treating families with respect and as partners, and really involving them and relying on them in the service planning, implementation, and the evaluation process. I think some of that is political, but that's true. The Research and Training Center, of course, is one of the great exceptions here. Their research is very much focused on those questions that are important to us. But I think that unfortunately in the research world, that is rare.

The second limitation is that as we all know, people who are advocates, facts and evidence, while important in public policy decisions, are often not determinative. Policy makers, politicians, people in the media, and the public at large have some very strongly held beliefs that are essentially stereotypes and prejudices that are very, very hard to dispel. The one that comes most to mind in my own work is people with mental illness are violent. It doesn't matter how many studies there are and in fact that every single study done on this topic demonstrates that people with mental illness are not more violent than the population at large. But over the last ten years, polling data has shown that the belief that people with mental illness are violent has skyrocketed. And I know from my own work, it is a very deeply held belief. I think that research can have an impact on those prejudices and does over time. And here we go back to advocates, because I think advocates have a role in preparing the public and the media and the political system to hear evidence, to hear information that is not consistent with their deeply held beliefs. And advocates play a tremendous role in preparing the forums of advocacy to hear what is true and what is real.

Finally, let me just say that while I think it is true that advocates need researchers and that researchers need advocates, it is also true, and I think Barbara and others will speak some about this, that we rarely interact. This is, again, something that the Research and Training Center has done that is the exception and not the rule. Bringing researchers, bringing advocates, bringing family members and consumers together, is really quite extraordinary. And very rare, something we should cherish. But in my circles, I interact mostly with advocates. Not a lot of researchers interact with me, and that is a problem, because we both need each other so desperately. That is something we will talk about more on the panel. Thanks.

**Barbara Friesen:** My name is Barbara Friesen, and I am just going to give a two minute introduction to what is coming. Ira has just said that on the one hand we have research and evaluation and researchers and evaluators. In the other corner, often, we have advocates. What we are going to be talking about today,

the rest of the panel, is really about trying to build those bridges, and to think about how do the connections that researchers and advocates make, how do they help to create policy change. And so we are going to hear two presenters talk about the area of reform in residential treatment. That is Ann and Adjoa. They will introduce themselves. Then Mike Pullmann and Linda Reilly will be talking about the attempts to change policy in Oregon around the issue of families having to give up custody in order to get services for their children. What I would like you all to do is pay attention. At the end we would like to try to pull together some principles, some ideas, maybe to identify kind of the common elements, the things that we have to be sure are there. So as you listen to these examples, just pay attention and make some notes for yourself about what those might be. At the end we will have a chance to talk about that. Thanks.

**Ann Capoccia:** Good morning. Thank you Barbara for inviting me to Portland's Building on Family Strengths Conference this year to talk about research, evaluation and advocacy efforts underway in the Massachusetts Department of Mental Health [DMH] residential treatment system. My name is Ann Capoccia. I work for the Department and have worked for children's services in the Commonwealth for over a hundred years probably. We are really very excited about the directions occurring throughout our statewide residential program in three particular areas: family involvement and participation; the reduction of seclusion and restraint; and child and adolescent human rights. DMH's Commissioner, Mary Lou Sutters, has strongly supported these areas and endorses the activities of the Parent Professional Advocacy League, the restraint reduction program built on best practices in the state of New York, and the creation of the position of a new Director of Child/Adolescent Human Rights, now filled by a lawyer/nurse, Bernadette Drum. I might add that Commissioner Sutters has also strongly supported cultural competence, and in the Department created a senior-level director position, and revised the Department's mission statement last year to include the wording cultural competence. We were also proud

to have Terry Cross as our keynote speaker at the Second Annual Cultural Competence Conference in Boston last year.

Today I would just like to tell you that the context for understanding the Department's residential system, the residential system that I am going to talk about, really exists within the Child Adolescent Services Division. The Division is led by Assistant Commissioner Joan McCullough, who manages a budget of \$20,000,000; \$12,000,000 is in the residential services system. The Division serves children 0 to 18, coordinates planning across Massachusetts, sets and monitors broad policy and standards, and performs fiscal, personnel and legal functions. The Child/Adolescent Division itself manages two program models—continuing care inpatient and intensive residential treatment. Today I am focusing most of my remarks on the intensive residential treatment programs. These service children 6 to 13 and 13 to 18. They are in facilities across the Commonwealth, located in state hospitals. These are children who have a serious mental illness and require rigorous bio-psycho-social treatment in a locked setting.

With a federal block grant funded by the National Institute of Mental Health, the Parent Professional Advocacy League [PPAL] was founded, the Massachusetts state chapter of the Federation of Families for Children's Mental Health, now on its own web site, PPAL.net. We are honored to have PPAL members in the audience today: Pauline Curry, Margery Jess-Reid, and Evelyn Montanez, over on that right corner. PPAL provides support, education and advocacy around issues related to children's mental health and works in partnership with the families and with professionals who develop policy and provide services to children and their families. Family collaboration has been informed by a former Portland professional, now at Salem State School of Social Work, Neil DeChillo, in his work, "From Paternalism to Partnership: Family and Professional Collaboration in Children's Mental Health," and in the department's core curriculum, authored by Donna Well, the Executive Director of PPAL, "Promoting Family Collaboration in the Child and Adolescent Health

System.” Please note on the reading list, “Parent and Evaluators as Research Team Partners.”

Throughout the last ten years, PPAL has successfully promoted the voice of the advocate, facilitated over 30 support groups each month, and has affiliations with 23 family advocates across Massachusetts. PA joined the Division, the Department’s Division, to help a procurement process that would include family collaboration principles and standards, and involve family members in the review of the intensive residential treatment programs.

Family collaboration principles and standards are as follows:

- ◆ Parents and guardians should be viewed as partners of professionals in the treatment of children with mental health programs.
- ◆ Parents have the right to full information about their child.
- ◆ Parents bring different perspectives. Policies need to be designed and evaluated with significant input from parents as well as professionals.
- ◆ Parents have valuable information to share and can be a source of emotional support to each other.
- ◆ Parents have the right and the responsibility to advocate.

Today the request for response process does not proceed in Massachusetts without a family member as a participant on the proposal review committee. The evaluation for these treatment programs includes the following questions:

- ◆ Describe how access to the program will be ensured for all families.
- ◆ Describe the transportation alternatives.
- ◆ Does the bidder’s response promote regular, frequent contact between the family and the adolescent?
- ◆ Is there a plan for orienting adolescents?
- ◆ Describe your family visitation policy.

Family members are now participants in the development and design of intensive residential treatment programs in the creation of monitoring and evaluation activities.

Moving to restraint reduction, this initiative under the leadership of Janice LaBelle of the Child and Adolescent Division and Nan Stromberg of Clinical and Professional Services, started with a review that was conducted of the increase in incidents both within inpatient and residential treatment programs. In studying best practices in Bellevue and Sagamore, New York, and with the hiring of consultant Beth Caldwell, an expert in this work, the decision was made to begin to reduce restraint and seclusion:

“There is not research to support a theoretical foundation for the use of seclusion with children. Evidence has been building for more than 30 years that the practice of seclusion does not add to therapeutic goals and is in fact a method to control the environment instead of a therapeutic intervention.”—Linda Fink from Indianapolis, Indiana.

A strengths-based, family-involved, skill-replacement culture change was instituted through the systems beginning September 2000, through February 2002.

How are we doing? We have reduced restraint and seclusion in the child system 80%. We have reduced seclusion and restraint with mixed child and adolescent programs 73%. We have reduced seclusion and restraint in the adolescent system 25%. Every provider throughout the inpatient and residential system has developed their own strategic plan in partnership with family members and consistent with their own model and philosophy. There are some examples of providers who have done this:

- ◆ The Boston University Medical Center is the provider for one of our residential treatment programs. This is also a child trauma treatment center and one of five SAMSA grants in the county. Their work will be informing the future direction of the seclusion and restraint intervention, which will be including a trauma

paradigm. And 85% of the children and adolescents we have in our program have documented trauma history.

- ◆ At the Cambridge Hospital inpatient program, the family is the seclusion and restraint intervention. A 24-hour, open-door policy has been established with families who now assist staff in creating a nurturing environment on the unit. Families chair treatment team meetings and are seen as integral to the success of the seclusion and restraint reduction program. Partnering with Cambridge Hospital, we have in the audience today Susan Ayres and Peggy Worrell from the Cambridge youth Guidance Center, and we are pleased to have them with us. Without human rights advocates and licensing staff, the restraint and seclusion reduction program could not have gone forward.

Family members are now participants in the development and design of intensive residential treatment [IRTP] programs and in the creation of monitoring and evaluation programs. A report to the Commission of Mental Health, entitled *Human Rights Program in State Hospitals*, authored by Clarence Sundrum, Esq., consultant from New York State, put forth a recommendation regarding human rights for children and adolescents that reads as follows. “The Human Rights Advisory Committee should examine the human rights policies as they apply to children and adolescents, and advise the commissioner on the need for any modifications and on the need for further staff training on the implementation of human rights policies in facilities for children and adolescents.”

In order to respond to the need for staff training described in the Sundrum report and recommended by families members and advocates on the IRTP Human Rights Advisory Committee, the Child Adolescent Division hired a consultant, Hillary Zivin, from First Life Consulting, and a former IRTP director. In June of 2000, a training program was initiated for the human rights offices and Human Rights Committee members. Meetings were held on a monthly basis, with agenda items such as: behavior plans and human rights, dealing with complaints,

attacks against staff, and conflicts between individual and group rights. The Human Rights Committee consists of advocates, parents, and program residents. Program graduates have been added to the membership and agenda items from residents are the major priority. Issues discussed at the Committee include mail, telephone, visits, conflict resolution, dress codes, food availability, restraint data, and the “five fundamental rights.”

Out of these meetings grew the idea for an orientation video on child and adolescent human rights that would be written and performed by residents for newcomers entering resident treatment programs. I’d like to show you as much of the video as time will allow and thank you for your interest in residential reforms in Massachusetts.

[Video]

**Adjoa Robinson:** I am a project manager at the Research and Training Center. What I am going to talk about I think fits very well into what we have seen. I’m going to talk about telephone calls and visits that we asked about in a national survey. You will find out that it is not a right everywhere that is guaranteed. I think also from what I am going to share with you today, you will see that sometimes linking research with advocacy is as much about serendipity as it is about hard work and planning.

We have been looking at data from the Family Participation Survey. The Family Participation Survey was a national survey of families whose children received mental health treatment between 1996 and 1998. The purpose of the study was to systematically gather information about parent participation in their child’s educational and treatment planning. In 1999, data were collected using a sample recruited through randomly selected chapters of the Federation of Families, other family organizations, and the Research and Training Center’s mailing list. We asked caregivers to fill out a survey, which among other things, asked about parent empowerment, involvement in decisions about the child’s daily life, and contact between parents and children when the children were receiving out-of-home treatment. These conversations revealed that

at many residential treatment centers, group homes and psychiatric hospitals, parent-child contact was limited by program policies and staff practices.

This concerned us for several reasons. First, family involvement is a core System of Care value. Second, previous research and child welfare literature suggests that maintaining parent-child contact contributes to the child's well-being and also is associated with more rapid reunification when the child is placed outside of the home. In the field of children's medical care, there is an assumption that parents have the right to be with their children during all but the most complex procedures, and that there is evidence that children's recovery from medical treatment is facilitated by a parent being present and actively involved in the treatment. And finally, unless a parent does not have legal custody, they retain all rights to be consulted for major decisions involving their child.

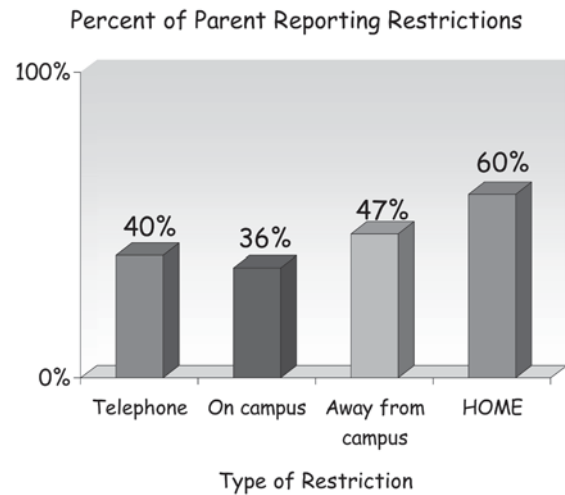
The present analysis is based on responses from 102 families whose children either received treatment in a residential treatment facility, a psychiatric hospital or unit or group home. We wanted to know about the experiences of families regarding parent-child contact, and to see if and how those experiences varied. This is what we found:

We asked parents this question: "When your child first entered the out-of-home placement, was contact between your child and family limited for a period of adjustment?" Nearly 60% of caregivers said "yes," their contact was restricted for an initial period of adjustment. They also reported that that adjustment period could last from anywhere from one to eight weeks. This was true regardless of the child's age and regardless of the type of placement.

We also asked parents if after that initial adjustment period were there restrictions on contact, whether it be telephone calls or visits. And 79% of parents reported "yes" to some type of restriction whether it be telephone or on-campus day visits, day visits away from campus or home visits. This graph shows the percentages of folks who answered in the affirmative.

We also asked parents if there was a level system in place by which the child had to earn points in order

to have contact with their family. And 51% of the parents said yes. A level system is a behavior management technique for which a child earns points for good behavior and they get to use that for treats or special activities and parent-child contact. They lose points and privileges for bad behavior.



We also asked parents if the placement or program made contact dependent on someone's behavior, whether it be the child's behavior, the parent's behavior or group behavior. Over 59% of parents reported that contact depended on the child's behavior. Almost 12% of parents reported being required to participate in either an education or therapeutic service as a condition for contact with their child. And 16% reported that contact was dependent on group behavior, so if one child in the treatment unit had a problem that day, they locked down the whole unit, and so any visits or telephone contact was suspended for everyone.

Those were our findings. Now I would like to tell you how those have been used in our advocacy efforts. This is serendipitous moment number one. One day, Mary Giliberti, a legal advocate at the Bazelon Center for Mental Health Law, called us and asked us if we had any data on parent-child contact. Her interest in this issue arose out of complaints that she had received from parents about policies and practices restricting contact. She asked if we had any data related to this issue. So we sent her some preliminary analysis data and she was very excited about it. She found it very compelling. So then she asked us, "What are you

planning to do with this information?” We are like, “Do?” More sophisticated analysis, writing research articles. Those are things that came to mind. But that is not what Mary had in mind. She meant “do,” as in using the data as a tool, a tool for advocacy, a tool to better the lives of families and children. So Mary encouraged us to think creatively and broadly about the research impact on systems. So we then focused our analysis effort on this issue of parent-child contact. We published an article in *Focal Point*, which we put out, and we’re also working on another article right now. Together, we worked to develop a strategy to address our concerns to accrediting organizations.

This is serendipitous moment number two. One such organization is the Joint Commission on Accreditation of Healthcare Organizations, otherwise known as JCAHO. It is an organization that accredits hospitals and residential treatment facilities. We presented our findings during a teleconference with representatives of the Research and training Center, the Bazelon Center and JCAHO. During that call JCAHO asked for more: more evidence about the benefits of parent-child contact, more findings from our own work documenting restrictive practices. Why? Because it just so happened that JCAHO was going to be receiving their behavioral health care standards that year, and would decide on whether or not to propose new changes to their standards.

We found out in February that they put out some proposed standards for review. These are examples of some of the elements of those proposed changes:

- ◆ The first one is basically requiring disclosure about the use of the level system. At the time of admission the organization’s use of behavioral support interventions, including level systems, are made known to the individuals served and as appropriate, to the family.
- ◆ A second set of statements effectively prohibits the use of group punishment. Conditions under which an individual moves through the level systems are individualized. Group contingencies are not based on a single individual’s behavior.

Group consequences may not impact an individual’s right.

We are encouraged by the progress that has happened so quickly, but we are aware that we must remain vigilant to see some of these proposed changes actually become enacted. And if and when they are enacted, vigilant to make sure that they are followed. I encourage you all to go to the JCAHO web site and check out the language of those proposed changes for yourself. There is the link and you can also just go to [<http://www.jcaho.org/>] and look around and you can find it. And call and write letters expressing your opinions on their proposed changes.

Last year when we presented some of this information, we let our audience know that we were looking at standards and laws and guidelines that we could refer to in our analysis to sort of compare parent’s experiences with what is said as best practice. So we solicited suggestions from the audience. And wouldn’t you know it, our own Ann Capoccia stood up and said, “Isn’t that just a human rights issue?” From that we were spurred on to look at international documents like the UN Rights of the Child treaty.

Just to conclude, I’d like to suggest these questions to parents, advocates, or caseworkers, anyone who is involved in making a decision about a child going into residential treatment. You might consider asking some questions like these:

- ◆ Are there any restrictions on contact with my child while he or she is staying at the program. If so, what are they?
- ◆ How are the restrictions determined?
- ◆ What support or concrete assistance does the program provide to family members to maintain regular contact with our children?
- ◆ Who should I talk to about parent-child contact?
- ◆ Is there a parent support group or other opportunity to meet other parents of children at the facility?

Thank you.

**Linda Reilly:** Good morning, my name is Linda Reilly. I am from here in Portland, Oregon, and have been a parent and family advocate for something like 11 or 12 years. Mike is going to introduce himself first, because we are going to trade off.

**Mike Pullmann:** I work at the Research and Training Center. I have been here about three years now and I have been working on and off with Linda for basically that whole time.

**Linda Reilly:** Mike and I are going to tell you about how collaboration between researchers and advocates has led to Oregon's solution to the custody problem. Some of you may ask, "What is this custody problem, anyway?" I will tell you briefly about our family's experience. My husband and I have a daughter who was diagnosed with schizophrenia back in 1990, when she was 15. Her symptoms became so intense that her father and I could not keep her safe in our home. The only option at that time was to have her live in our community in a mental health group home. We knew we would have to use the state child welfare agency to gain access to a bed in the group home, but we were surprised and dismayed to learn that we would also have to transfer custody of our child to the state in order to access the residential bed.

Now this custody relinquishment was particularly significant to us, because we had adopted our daughter at the age of three weeks, and did not have a genetic bond with her. Severing the legal custody bond was very painful for us and also for our ill daughter.

There is that old saying, don't get mad, get even. So another mother who had a child with an emotional disability and I made an appointment with our state representative, who is now a state senator, Kate Brown. We told her about a number of problems facing families who had children with mental disorders, and gave her a packet of written information explaining children's mental health issues. In that packet we included copies of the Research and Training Center on Family Support and Children's Mental Health's bulletin, *Focal Point*, which described the problems of families throughout the United States

having to relinquish custody to access out-of-home treatment services.

Using materials from the Research and Training Center helped us to enlist Representative Brown as our ally. Meanwhile, back at the Research and Training Center...

**Mike Pullmann:** Actually the Research and Training Center first became aware of what we began to call "the custody problem" in the mid-1980s. This is the issue, as Linda said, of families being forced to relinquish custody of their children in order to obtain needed services. These are families who are not abusive, who are not neglectful. They are simply not able to provide the services that their children need and they can't afford these services.

In 1989 we conducted a national survey of family members of children with serious emotional disturbances. Out of 966 responses that we received from around the nation, 25% of the families reported that somebody had suggested to them that they relinquish custody of their child in order to obtain services. Of that 25%, 35% actually did relinquish custody. We wrote some *Focal Point* articles around this, and these are the articles that Linda brought to her state representative.

Also, at the same time, some other researchers were looking at this issue. Robert Cohen, in 1991, and his colleagues found that more than 60% of the states had at least one agency that required custody transfer in order to receive services. So this was definitely a prevalent problem throughout the nation.

**Linda Reilly:** With the support of Representative Brown, the next step in addressing the custody problem was to approach child welfare and see what could be done to change current practice. We formed a group called the Care and Placement Committee, which included family members from Oregon Family Support Network, our statewide family support group that you heard about this morning, an attorney/social worker from Legal Aid, two family advocates from the Developmental Disabilities Council, and representatives from the PSU Research and Training

Center, the Oregon Mental Health Association, and the child welfare office.

We first explored the idea of solving the custody problem administratively, but it soon became apparent that we would need some sort of legislative incentive to make significant and timely progress. With the sponsorship of Representative Brown and collaboration among parents, Legal Aid, and the Research and Training Center attorneys and other advocates, we drafted a bill, HB 3577, which would abolish the custody transfer requirement. We submitted the bill to the 1993 Oregon Legislative Assembly.

During this same period, the researchers at PSU were not idle:

**Mike Pullmann:** So in 1992, in collaboration with the Oregon Family Support Network (OFSN), we invited every family on the OFSN and the Research and Training Center mailing lists to participate in a study of their experiences with custody transfer. From that questionnaire we identified and learned about the often tragic experiences of 41 families in Oregon. We identified 20 of those families who had actually relinquished custody to the state. We additionally identified several families that were willing to go public with their story and willing to testify before the state legislature.

**Linda Reilly:** During the complex legislative project of working with our Bill, families worked diligently explaining HB 3577 to their legislators and testifying about their personal experiences during committee hearings. Many letters were written and many phone calls made. Advocates and parents worked together to clarify fiscal consequences of the bill so that the child welfare agency could lend its support.

The Bill passed 58 to 0 in the House, 29 to 0 in the Senate, and became law on November 4, 1993. The statute states that families cannot be forced to relinquish legal custody of their children in order to have the child placed out of the home for treatment of an emotional, behavioral, or mental disorder, or developmental disability or physical disability. In all

such cases, the children will be placed by using a voluntary child placement agreement. So we had a party to celebrate.

The next step was to follow the implementation of the law, using some of the Care and Placement Committee members. We formed a new group, the Implementation Committee, and started having meetings. Researchers, advocates, and child welfare staff worked together on drafting the voluntary child placement agreement forms, and editing the language of the administrative rules. Families helped conduct trainings for the child welfare branch managers and the staff. We thought we were done. We had another party.

But it wasn't over yet. At Oregon Family Support Network, we still kept hearing from families who were being told that they had to give up custody to get services for their children. It was clear that there were many child welfare workers and other providers who did not understand the voluntary child placement agreement and how and when to use it. What we needed was the researchers.

**Mike Pullmann:** So in 1998, here is where serendipity again steps in. In 1998, we were contracted by the Bazelon Center for Mental Health Law to be part of a national study of state's approaches to implementing solutions to the custody problem. This is five years after the passage of the Oregon bill, which was intended to abolish the custody relinquishment requirement.

Actually, in case you are wondering if any of this is happening in your state, it probably is. If you want to know about it, you can go to the Bazelon Center's web site [<http://www.bazelon.org/>] and order their report. I also have a bibliography sheet, so after the presentation, if you are interested in it, I can give you that. It has a list of articles that discuss this issue.

Again in collaboration with the Oregon Family Support Network, and in collaboration with Legal Aid, and now for the first time in collaboration with the child welfare agency, as far as our research part was concerned, we developed a study to examine the

implementation of Oregon's solution. We developed telephone interviews for families and for child welfare line workers. Before I tell you about the interviews, I should tell you that in child welfare's defense, it is important to keep in mind that their principal focus is child protection. And the families that need voluntary placements are a very small percentage of their caseloads...

[changing tapes]

...encountering a family that is appropriate for voluntary placement. So they don't have a lot of chances to hone their skills in this area. However, we developed a pop quiz questionnaire for them, and we called them on the phone and presented them with different hypothetical situations.

We found a very, very low level of understanding of the voluntary placement agreements and the custody relinquishment requirements. It appeared that the majority of caseworkers did not know the appropriate use of these agreements. It appeared that families were still relinquishing custody unnecessarily five years after the passage of the law to abolish this practice.

So in 1999, we wrote a report of our findings. With the help of our collaborators, we presented our report and our recommendations for action to the child welfare agency. During this meeting we discussed the possibility of co-releasing the report with Child Welfare. After the meeting we had a party. Then nothing happened for several months, until Barbara [Friesen] received a voice mail from a human rights organization that had an inquiry. They had somehow found a copy of our report and they had some inquiries for us. That sort of started the process again. We eventually co-released the report along with a promise statement from Child Welfare to implement many of the recommendations that we made in our report.

**Linda Reilly:** So here we are with child welfare's implementation of the Research and Training Center's study recommendations moving forward. We would like to think it is time for another party. But there are still many challenges out there that need attention.

We will need to carefully monitor the progress of trainings at child welfare and remain vigilant as new issues crop up that can affect our custody law. But what we can celebrate now is that we have learned hands-on the importance of collaboration between researchers and advocates. The whole is truly greater than the sum of its parts, and together we can actually improve the lives of children and their families.

Thank you.

**Barbara Friesen:** I wanted to acknowledge that Jane Adams' name is on the program and Jane is unable to be with us. There is no way that I can stand in for Jane, but I just want to alert you, for those of you who are interested in the content of the custody problem, especially, Jane was going to come and talk about the approach that Kansas took, which was a different approach. Here we passed a law saying you can't do that, you can't require this. The main approach that Kansas took was to work toward getting a waiver so that Medicaid dollars could be used to support community-based services so that children wouldn't have to leave home. We think that probably both things are needed. You may need a law and you have to have the services or all we are doing is just kind of putting out fires in the wrong place.

I know that in Kansas one of the things that Jane did in the Keys for Networking, which is the statewide family organization, she developed a database and kept very careful information about what families had to say when they called. So over a number of years, they could then pull out the information about how many families had expressed concern about a number of issues, including the custody problem. Also I know that Jane and her colleagues used information from the evaluations of the federally funded comprehensive child and family community mental health programs. There are two in Kansas that have evaluations and so they used information both from the Macro, the national evaluation, and from their local evaluations.

Jane sends her regrets and said she is really willing to talk to anybody who has an interest and wants to know more about Kansas' approach. The information about

the Bazelon report that talks about the Kansas approach is on the bibliography that Mike has.

I promised a little summary and I hope you have all been paying attention and taking notes. When we last left this bridge—I'm the world's worst artist, but I love PowerPoint because I can make things that look regular—we were talking about researchers and evaluators on the one hand and advocacy and advocates on the other, and how to build a bridge and how to come together to make policy change. It seemed to me—and this is stuff I just made up, so when we get into the discussion I want you to say what you think—part of the bridge that people have talked about is information. You have to have a way that the researchers can find out from advocates what are hot topics, and advocates can find out what research the researchers are doing. It is a little alarming the serendipity we have talked to you about, and the point is that Linda and Mike, I think, illustrated so well, is the relationship that is necessary.

The next thing, though, is I think you have to have goals. These things that are serendipity, in a way they are unexpected. But if you have a goal and if you know where you want to go, it is only then that you can see an opportunity when it presents itself. I do think it is really important to have an idea about what you want, and then these things that seem serendipitous, you will say, "Ah, here is an opportunity to do what we want to do." The next thing is you have to have some leadership. And frankly the leadership almost always comes from the advocate side, and influence. Linda and I have this sort of ongoing discussion about this. I think mostly, again, the influence and the ability to dig up influence comes from the advocate side. There is some influence that may be contained in fact and in research findings, but it is advocates who have constituencies and the ability to create public awareness and to do things that I think researchers can't ever do.

So now we are going to move into a period of discussion and I hope you will give us your reflections as well.

**Ira Burnim:** Let me encourage you to make comments, have questions, share your own experiences. We have 15 or 20 minutes left and we would really like to hear from you.

**Audience member:** Barbara, I would like for you to comment about how you feel that you have inspired your research team to seize the opportunity for advocacy.

My experience is that often university-based researchers see themselves as just that, and either are not willing to put themselves out there with the information, the facts, or don't know how to do it. Consequently, the factual information that can be so vital in really bringing attention to particular issues is not utilized. The advocate organizations, normally, don't know how to go about accessing that factual information. I feel like the leadership on putting the factual information out there or making it available or making yourselves receptive to entrees from advocates is an important ingredient here.

I wonder if you could speak to how you have been able to create that atmosphere or sense of responsibility?

**Barbara Friesen:** I don't think I've inspired anybody, but I guess the first thing I would say is that at one level we have to give credit to our funding organizations: the Center for Mental Health Services, the Child and Family Branch, and our other funder is something called the National Institute for Disability and Rehabilitation Research. Both of these organizations are not typical research funding organizations in the sense that they really fund research that is supposed to be connected to something, to improving the lives of people or to improving systems. I would say that a part of what has made it possible for us to do what we have done over the years, for example, to track the custody issue when we were really never funded specifically to do that, is because we have the kind of support and funding from the federal government that we've had.

I think a second thing is that it has been really important for us to have relationships with advocates

and especially families and family organizations, because if we didn't have those relationships we wouldn't know what the issues were. The first time I got a phone call in 1984 from a parent in Virginia who said, "You know, we've got to do something about this custody problem," I had no idea what she was talking about. So then we got interested and began to track it. Don't think we don't get criticized for our approach. We really have a kind of, what I call, research in the service of a goal. You know where you want to go and you undertake research that you hope will have some relevance to that reform or that change.

You are right, that is really quite different from much research that is funded to hopefully be useful, but the focus is really on gathering facts. We have had many conversations over the years about this, and we do get criticized for our lack of objectivity. Not in the doing of the research, but sometimes in our close connection with advocates.

**Audience member:** I actually have two questions in connection with part of what we heard this morning. One is around the parent-child connectedness, and the research that you have done and the results. Is there any plan to present that information to the Medicaid agency, since they are one of the first funders of services for kids when they are in residential care? If they can see that research, it may also influence some of how they perceive important pieces of how parents and kids stay connected. So I wonder if there is any plan for presenting it to them.

My other question is, with the research that you have been doing around the custody relinquishment issues, is there a portion of your curriculum with your master's level social workers that you train here, that you present that information to them, so we are not always having to retrain social workers once they get into the field? But that there is some pre-service training that is done with that information in your own program.

**Barbara Friesen:** The first answer is, no, but that is a good idea, and I'll talk to you, Liz, about whether you are talking about state level, federal level, Medicaid and so on. We had a recent conversation here in

Oregon about why can't Oregon have a Medicaid waiver, and apparently the rules are and the structure of the waiver requirements are such that you have to either have a whole bunch of kids that are in residential that are going to come out or who are out-of-state. I'd like to talk to you more about how Medicaid might be directly involved.

The second question—there is much giggling and laughing down here at the table of our faculty members at the School of Social Work. The answer is yes, we do talk about custody relinquishment. I have been in classes where we have talked about the changes in the law. We have been very polite this morning, and we haven't talked about what I think are really some of the underlying attitudes that keep this going. In Oregon we had a law that was already on the books that said you didn't have to do this, except in the judgment of residential providers and clinicians and other people that it was in the best interest of the child that the parents not have custody. Parents always lost custody. That was practice. So I think the challenge is yes, we do talk, and we have much controversy.

We have a wide range of students and we have a wide range of opinions. We have some very promising reform efforts going on in Oregon. But there are still lots of attitudes and stereotypes about who those parents are and what has caused their children's problem that serve as a kind of invisible web to support the ongoing lack of implementation and ongoing attitudes about families.

**Audience member:** It would seem that to keep with the metaphor of bridge-building, that one natural bridge builder in the relationship piece would be to have advocates who are also researchers. I don't know if there are examples on any of the teams in which the advocates, the family members are also researchers themselves. Or whether there are any promising practices that would support initiatives for family members to get advanced degrees so that ultimately they could be part of research teams themselves.

**Ira Burnim:** Researchers often work with advocates. I don't know if I am directly answering your question. Of course, in litigation, they are presented to the judge

as expert witnesses. I'm not the person to answer the question about family members getting advanced degrees, although we have heard earlier today that many family members do have advanced degrees. I think it is also true that just as people's personal experiences often encourage them to become lawyers, I'm sure it is also true in the research field. One interesting link that should be mentioned is that on the Bazelon Center board we have researchers. On the Research and Training Center National Advisory Committee, I sit, as do other advocates. So there have been some attempts to make sort of institutional links, to make sure information is shared. I don't know if that is really responsive.

**Audience member:** I think that makes sense. There may just be, maybe, as you say, many people come in as family members and go on to get degrees and information and do things. Some of us come in as professors of special education and then have a child with a disability and get in a different way. So there is certainly one way to bridge a relationship, and that is the same person wears both hats and very often advocates and research can be the same. But as we know in special education, there was a massive time, a couple of decades ago, where the federal government put lots of money into leadership training in special education. Then we had a whole generation of special education leaders out there. That money has kind of dried up. If there was a funding source that could put money into a particular priority like family members getting advanced degrees to go on to advocate and research, that I think would certainly prime the pump. So it is just another good funding idea. I didn't know if there was anything out there already, or whether we could start the charge.

**Ira Burnim:** Sounds like another job for advocacy.

**Audience member:** I am speaking as a parent, as someone who has gone through this issue. I am wondering if there has ever been any research done in regards to the children and what the effect of custody relinquishment has on them. I know that was a big issue with us and our son, and him trying to understand, and him thinking that he wasn't ours

anymore, and this having a big piece in his recovery, as far as the anxieties that he had regarding the fact of was he still a member of our family or was he ever going to get to come home again and these kinds of things. Maybe some information and feedback from the children could have a lot of impact on how this issue is looked at by systems of care.

**Barbara Friesen:** The answer is no. We have certainly proposed, we have certainly heard from families the kinds of things that you are talking about. But we haven't done, and I don't know of anybody who has done, a formal study of the impact on the children and the impact on the families.

**Ira Burnim:** I was going to say that there has been some analogous work. In the child welfare system there has been over time investigations of the impact on kids of being removed from their homes, the effect of sort of separation and loss. It is not the same thing, but I think it is very much related. That is something that advocates often us in promoting family preservation and family-based services in the child welfare context.

**Nancy Koroloff:** I wanted to add to the comment made by the gentleman about family members getting advanced degrees and becoming researchers themselves, and there are some that have done that. But I also want to remind people that the Federation of Families does have a training sequence that we have talked about in a number of sessions already here, so I hope I am not being too repetitive, but they do have a series of courses. The third course is focused on training families and family organizations to carry out research and use researchers as their technical assistants. So it is a little bit shorter than actually going on and getting your advanced degree. I just want to make sure people know that that is an alternative. Elaine Slaton is sitting over there in the spotlight in the white shirt, and if you have an interest in knowing more about this, she would be the person to connect with.

**Janet Walker:** I hope you all found that informative. I would like you to join me in thanking the members of the Research and Advocacy panel.

Finally, just to alert you to the *Focal Point* that everybody has been mentioning. You have one in your packet, the most recent edition. The previous one, which includes an article by Barbara and other members of our staff about the level systems and contingencies and all that is in the previous *Focal Point*, which is out on the table across from the registration. Focal Point is free, so if you want to subscribe, there is information on the back flap about how to do that.

Thank you and enjoy the rest of the day.